# HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.

**NATIONAL** 

FORM 990 COPY FOR PUBLIC INSPECTION

YEAR ENDED DECEMBER 31, 2020



# **EXTENSION ATTACHED**

# **Return of Organization Exempt From Income Tax**

Form **990** 

Department of the Treasury Internal Revenue Service Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

► Do not enter Social Security numbers on this form as it may be made public.

▶ Information about Form 990 and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2020

Open to Public

| A F                            | or th      | ne 2020 calendar year, or tax year beginning , 2020, an  | d ending          |   |                 | , 20            |              |  |
|--------------------------------|------------|--|-------------------|---|-----------------|-----------------|--------------|--|
| <b>B</b> c                     | neck if ap | C Name of organization HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.   |                   | D Employer id                           | entification    | n number        |              |  |
|                                | Addre      |  |                   | 13-334                                  | 9872            |                 |              |  |
|                                | 7          |  | m/suite           | E Telephone number                      |                 |                 |              |  |
|                                | Initial    | 1 return 505 EIGHTH AVENUE, SUITE 902  | (212) 24          | 2-1968                                  | 8               |                 |              |  |
|                                | Term       | City or town, state or province, country, and ZIP or foreign postal code   |                   |   |                 |                 |              |  |
|                                | Amer       |  |                   | G Gross receip                          | ots \$          | 8,901           | ,197.        |  |
|                                |            | F Name and address of principal officer: LOUILSE VETTER  |                   | H(a) Is this a gro                      |                 | Yes             | X No         |  |
|                                | _ perior   | 505 EIGHTH AVENUE, SUITE 902, NEW YORK, NY 100   | 18                | subordinates <b>H(b)</b> Are all subore |                 | ? Yes           | ∏ No         |  |
| 1                              | Tax-ex     | xempt status: X 501(c)(3) 501(c) ( ) ◀ (insert no.) 4947(a)(1) or  | 527               | If "No," atta                           | ch a list. (see | instructions)   |              |  |
|                                |            | ite: WWW.HDSA.ORG  | 1 10-1            | H(c) Group exem                         | notion numbe    | r <b>&gt;</b> 9 | 201          |  |
| K                              | Form       | of organization: X Corporation Trust Association Other   | L Year of forma   | tion: 1986 <b>M</b>                     | •               |                 | NY           |  |
|                                | art I      | Summary  |                   |   |                 | <u> </u>        |              |  |
|                                |            | Briefly describe the organization's mission or most significant activities: HUNTINGT   | ON'S DISE         | CASE SOCIE                              | TY OF           | AMERIC          | Ā,           |  |
| Governance                     | -          | INC. IS A HEALTH AND WELFARE ORGANIZATION DEDICATED THE LIVES OF PEOPLE WITH HUNTINGTON'S DISEASE AND T  | TO IMPRO          | VING                                    |                 |                 |              |  |
| ırı                            | 2          | Check this box if the organization discontinued its operations or disposed of  |                   |   |                 |                 |              |  |
| ò                              |            | Number of voting members of the governing body (Part VI, line 1a)  |                   |   | 3               |                 | 15.          |  |
| 8                              |            | Number of independent voting members of the governing body (Part VI, line 1b)  |                   |   | 4               |                 | 15.          |  |
| Activities                     |            | Total number of individuals employed in calendar year 2020 (Part V, line 15)   |                   |   | 5               |                 | 36.          |  |
| ivi                            |            |  |                   |   | 6               |                 | 500.         |  |
| Act                            |            | Total number of volunteers (estimate if necessary)  Total unrelated business revenue from Part VIII, column (C), line 12   |                   |   | 7a              |                 | 0            |  |
|                                |            | Net unrelated business taxable income from Form 990-T, line 34   |                   |   | 7b              |                 | 0            |  |
|                                |            | The unrelated business taxable income norm of one of the office of the o |                   | Prior Year                              | 1,0             | Current Y       | ear          |  |
|                                | 8          | Contributions and grants (Part VIII, line 1h)  |                   | 10,888,66                               | 58.             |                 | 0,494        |  |
| Revenue                        |            | Program service revenue (Part VIII, line 2g)   | DR                | 20,000,00                               | 0.              | 0,10            | 0            |  |
| ) ve                           | 10         | Investment income (Part VIII, column (A), lines 3, 4, and 7d)  | ECTION            | 27,42                                   | 26.             | 2               | 4,533        |  |
| Re                             | 11         | Other revenue (Part VIII, column (A), lines 5, 4, and 70)  Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)  | ————              | 101,28                                  |                 |                 | 1,919        |  |
|                                | 12         | Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)   |                   | 11,017,38                               |                 |                 | 6,946        |  |
| _                              | 13         | Grants and similar amounts paid (Part IX, column (A), lines 1-3)   |                   | 2,129,50                                |                 |                 | 2,868        |  |
|                                | 14         | Benefits paid to or for members (Part IX, column (A), line 4)  |                   | 2,125,6                                 | 0.              |                 | 0            |  |
|                                | 15         | Salarios other componentian ampleyee benefits (Part IV column (A) lines 5.10)  |                   | 3,985,76                                |                 | 3.96            | 4,488        |  |
| Expenses                       | 162        | Professional fundraising fees (Part IX, column (A), line 11e)  Total fundraising expenses (Part IX, column (D), line 25)   1,084,333.  | • • • • •         | 3,7500,7                                | 0.              | 373017130       |              |  |
| ben                            | 10a        | Total fundraising expanses (Part IV, column (A), line 116)   |                   |   |                 |                 |              |  |
| Ĕ                              | 17         | Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)   |                   | 3,077,90                                | 16              | 1.65            | 4,839        |  |
|                                |            | Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)  |                   | 9,193,1                                 |                 |                 | 2,195        |  |
|                                | 19         | Revenue less expenses. Subtract line 18 from line 12   |                   | 1,824,23                                |                 |                 | 4,751        |  |
| es                             | 13         | revenue less expenses. Subtract line 10 Horn line 12   |                   | nning of Current                        |                 | End of Ye       |              |  |
| Net Assets or<br>Fund Balances | 20         | Total assets (Part X, line 16)   | 209               | 10,968,66                               |                 | 12,18           |              |  |
| 4ss<br>Bal                     | 21         | Total liabilities (Part X, line 26)  | • • • •           | 1,616,44                                |                 |                 | 6,092        |  |
| und                            | 22         | Net assets or fund balances. Subtract line 21 from line 20.  |                   | 9,352,23                                |                 |                 | 2,376        |  |
| Pa                             | rt II      | Signature Block  |                   | -,,                                     |                 | , , , , , ,     |              |  |
|                                |            | <u> </u>   | and statements.   | and to the best o                       | f mv know       | ledge and b     | elief. it is |  |
| true                           | , corre    | nalties of perjury, I declare that I have examined this return, including accompanying schedules a<br>act, and complete. Declaration of preparer (other than officer) is based on all information of which pr  | reparer has any k | nowledge.                               |                 |                 |              |  |
|                                |            |  |                   | 07/1                                    | 6/2021          | L               |              |  |
| Sig                            | n          | Signature of officer   |                   | Date                                    |                 |                 |              |  |
| Her                            | e          | LOUISE VETTER ELECTRONICALLY FILE  | TIVAL C           | 4                                       |                 |                 |              |  |
|                                |            | Type or print name and title   | JVVIII            |   |                 |                 |              |  |
|                                |            | Print/Type preparer's name   | Pate // CI        | Check                                   | if PTIN         |                 |              |  |
| Paid                           |            | Print/Type preparer's name WILLIAM EPSTEIN  INTERNAL GREVENUE \$   | CKVIC             | self-employ                             | _               | 1307171         | L            |  |
|                                | oarer      | Firm's name EISNERAMPER LLP  | , ,               | Firm's EIN ▶                            | 13-163          |                 |              |  |
| Use                            | Only       | Firm's address > 733 THIRD AVENUE NEW YORK, NY 10017-2703  |                   | Phone no.                               |                 | 49-8700         |              |  |
| Mav                            | the I      | RS discuss this return with the preparer shown above? (see instructions)   |                   | i none no.                              |                 | X Yes           | No           |  |
| <u> </u>                       |            | rwork Reduction Act Notice, see the separate instructions.   |                   |   | [               | Form <b>99</b>  |              |  |

# Form **8868**

(Rev. January 2020)

Department of the Treasury Internal Revenue Service

# Application for Automatic Extension of Time To File an **Exempt Organization Return**

File a separate application for each return. Go to www.irs.gov/Form8868 for the latest information. OMB No. 1545-0047

Electronic filing (e-file). You can electronically file Form 8868 to request a 6-month automatic extension of time to file any of the forms listed below with the exception of Form 8870, Information Return for Transfers Associated With Certain Personal Benefit Contracts, for which an extension request must be sent to the IRS in paper format (see instructions). For more details on the electronic

| iling of this f   | form, visit www.irs.gov/e-file-providers/e-file-f  | for-charities  | -and-non-profits.   |                             |        |                   |                |                  |  |  |
|---|--|--|---|-----------------------------|--------|-------------------|----------------|------------------|--|--|
| Automatic   | 6-Month Extension of Time. Only subm   | it original  | (no copies needed).   |                             |        |                   |                |                  |  |  |
| •   | ons required to file an income tax return other rm 7004 to request an extension of time to f   |  | , •   | O-C filers), partnerships,  | REI    | ИICs, а           | and trust      | (S               |  |  |
| Гуре or   | Name of exempt organization or other filer, see in   | structions.  |   | Taxpayer identification nul | mber   | (TIN)             |                |                  |  |  |
| orint   | HUNTINGTON'S DISEASE SOCIETY   | OF AMERI   | ICA, INC.   | 13-3349872                  | 2      |                   |                |                  |  |  |
| ile by the  | Number, street, and room or suite no. If a P.O. bo   |  |   |                             |        |                   |                |                  |  |  |
| lue date for<br>iling your                                    | 505 EIGHTH AVENUE, SUITE 902   |  |   |                             |        |                   |                |                  |  |  |
| eturn. See<br>nstructions.                                    | City, town or post office, state, and ZIP code. For a foreign address, see instructions.  NEW YORK, NY 10018   |  |   |                             |        |                   |                |                  |  |  |
| Enter the Re  | eturn Code for the return that this application  | is for (file   | a separate application fo   | or each return)             |        |                   | 0              | 1                |  |  |
| Application   |  | Return   | Application   |                             |        |                   | Retu           | rn               |  |  |
| s For   |  | Code   | Is For  |                             |        |                   | Cod            |                  |  |  |
|   | Form 990-EZ  | 01   | Form 990-T (corporat  | ion)                        | C (    |                   |                |                  |  |  |
| Form 990-BL   |  | 02   | Form 1041-A   |                             |        |                   | 08             |                  |  |  |
| Form 4720 (   | ,  | 03   | Form 4720 (other tha  | n individual)               | —      |                   | 09             |                  |  |  |
| Form 990-PF   | (sec. 401(a) or 408(a) trust)  | 04<br>05   | Form 5227<br>Form 6069  |                             |        |                   | 10             |                  |  |  |
|   | (trust other than above)   | 06   | Form 8870   |                             |        |                   | 12             |                  |  |  |
| Telephone If the orga If this is foor the whole Itst with the | s are in the care of ► 505 EIGHTH AVEN  e No. ► 212 242-1968  anization does not have an office or place of or a Group Return, enter the organization's for e group, check this box ► . I e names and TINs of all members the extens | business in<br>ur digit Gro<br>f it is for pa<br>ion is for. | Fax No.  the United States, checoup Exemption Number (art of the group, check the process of the control of the group, check the group the group, check the group the | ck this box                 | ;      | If that<br>and at | his is<br>tach | <u> </u>         |  |  |
|   | st an automatic 6-month extension of time u  |  |   | 21, to file the exempt      | org    | anizat            | ion retui      | rn               |  |  |
| ► X<br>►  | organization named above. The extension is calendar year 20 20 or tax year beginning   | , 20   | , and ending  | eturn Final return          |        |                   |                |                  |  |  |
| c   | ax year entered in line 1 is for less than 12 m<br>hange in accounting period  |  |   |                             | ı<br>— |                   |                |                  |  |  |
|   | application is for Forms 990-BL, 990-PF, 9   | 90-T, 4720   | ), or 6069, enter the   | -                           |        |                   |                | 0                |  |  |
|   | undable credits. See instructions.   | 4700   |   |                             | 3a     | \$                |                | 0.               |  |  |
|   | application is for Forms 990-PF, 990-T, ted tax payments made. Include any prior yea   |  | •   |                             | 26     | <b>.</b>          |                | 0.               |  |  |
|   | e due. Subtract line 3b from line 3a. Include  |  |   |                             | 3b     | <u> </u>          |                | <del>- 0 .</del> |  |  |
|   | onic Federal Tax Payment System). See instru   |  | one with this form, if for  | ·                           | 3с     | \$                |                | 0.               |  |  |
|   | are going to make an electronic funds withdrawa  |  | it) with this Form 8868, se   |                             | _      |                   | or pavme       |                  |  |  |
| nstructions.  |  | ,  | ,   |                             | -01    | 0 .               |                |                  |  |  |
|   | ct and Paperwork Reduction Act Notice, see insti   | ructions.  |   |                             | Form   | 8868              | Rev. 1-2       | 2020)            |  |  |

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| Pa     | Statement of Program Service Accomplishments  Check if Schedule O contains a response or note to any line in this Part III | X     |
|--------|--|-------|
| 1      | Briefly describe the organization's mission:   | Λ     |
| •      | HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. IS A NATIONAL VOLUNTARY  |       |
|        | HEALTH AND WELFARE ORGANIZATION DEDICATED TO IMPROVING THE LIVES OF  |       |
|        | PEOPLE WITH HUNTINGTON'S DISEASE AND THEIR FAMILIES.   |       |
|        |  |       |
| 2      | Did the organization undertake any significant program services during the year which were not listed on the               |       |
| _      | prior Form 990 or 990-EZ?  | X No  |
|        | If "Yes," describe these new services on Schedule O.   |       |
| 3      | Did the organization cease conducting, or make significant changes in how it conducts, any program                         |       |
| •      | services?  | X No  |
|        | If "Yes," describe these changes on Schedule O.  |       |
| 4      | Describe the organization's program service accomplishments for each of its three largest program services, as measu       | red b |
|        | expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to     |       |
|        | the total expenses, and revenue, if any, for each program service reported.  |       |
|        |  |       |
| <br>4а | (Code: ) (Expenses \$ 2,102,371. including grants of \$ 1,103,059. ) (Revenue \$ )   |       |
|        | RESEARCH - SUPPORTS RESEARCH AS ADVISED BY ITS SCIENTIFIC ADVISORY   |       |
|        | BOARD. THE RESEARCH PROJECTS ARE INVOLVED IN FINDING CURES AND   |       |
|        | TREATMENTS FOR HUNTINGTON'S DISEASE.   |       |
|        | THE TOTAL MONITOR & PICE NO.   |       |
|        |  |       |
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|        |  |       |
|        |  |       |
| 4b     | (Code: ) (Expenses \$ 2,794,287. including grants of \$ 1,509,809. ) (Revenue \$ )   |       |
|        | PATIENT AND FAMILY SERVICES - PROVIDES COUNSELING AND REFERRAL   |       |
|        | SERVICES TO PATIENTS WITH HUNTINGTON'S DISEASE AND THEIR FAMILIES.   |       |
|        |  |       |
|        |  |       |
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|        |  |       |
|        |  |       |
| 4c     | (Code: ) (Expenses \$ 974,649. including grants of \$ ) (Revenue \$ )  |       |
|        | COMMUNITY OUTREACH - PROVIDES WORKSHOPS, SEMINARS, AND SYMPOSIUMS  |       |
|        | ON HUNTINGTON'S DISEASE THROUGH A NETWORK OF CHAPTER AFFILIATES  |       |
|        | AND BRANCHES THROUGHOUT THE UNITED STATES.   |       |
|        |  |       |
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|        |  |       |
|        |  |       |
|        |  |       |
|        |  |       |
| 4d     | Other program services (Describe on Schedule O.) ATTACHMENT 1  |       |
|        | (Expenses \$ 757,658. including grants of \$ ) (Revenue \$ )   |       |
| 46     | Total program service expenses ► 6,628,965.  |       |

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| Par  | t IV Checklist of Required Schedules  |     |     |    |
|------|---|-----|-----|----|
|      |   |     | Yes | No |
| 1    | Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes,"   |     |     |    |
|      | complete Schedule A   | 1   | X   |    |
| 2    | Is the organization required to complete Schedule B, Schedule of Contributors See instructions?   | 2   | X   |    |
| 3    | Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to  |     |     | v  |
|      | candidates for public office? If "Yes," complete Schedule C, Part I   | 3   |     | X  |
| 4    | Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h)   |     |     | Х  |
| _    | election in effect during the tax year? If "Yes," complete Schedule C, Part II  | 4   |     | Λ  |
| 5    | Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III | 5   |     | Х  |
| 6    | Did the organization maintain any donor advised funds or any similar funds or accounts for which donors   | 3   |     | 21 |
| U    | have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If   |     |     |    |
|      | "Yes," complete Schedule D, Part I  | 6   |     | Х  |
| 7    | Did the organization receive or hold a conservation easement, including easements to preserve open space,   |     |     |    |
|      | the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II  | 7   |     | Х  |
| 8    | Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes,"   |     |     |    |
|      | complete Schedule D, Part III   | 8   |     | Х  |
| 9    | Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a   |     |     |    |
|      | custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or  |     |     |    |
|      | debt negotiation services? If "Yes," complete Schedule D, Part IV   | 9   |     | Х  |
| 10   | Did the organization, directly or through a related organization, hold assets in donor-restricted endowments  |     |     |    |
|      | or in quasi endowments? If "Yes," complete Schedule D, Part V   | 10  | X   |    |
| 11   | If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI,  |     |     |    |
|      | VII, VIII, IX, or X as applicable.  |     |     |    |
| a    | a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes,"  |     | Х   |    |
|      | complete Schedule D, Part VI  | 11a | Λ   |    |
| K    | Did the organization report an amount for investments-other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII                      | 11b |     | Х  |
| ,    | Did the organization report an amount for investments-program related in Part X, line 13, that is 5% or more  | 110 |     | 21 |
| •    | of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII   | 11c |     | Х  |
| ,    | Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets   | 1.0 |     |    |
|      | reported in Part X, line 16? If "Yes," complete Schedule D, Part IX   | 11d |     | Х  |
| 6    | Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X   | 11e | Х   |    |
|      | Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses   |     |     |    |
|      | the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X  | 11f | Х   |    |
| 12 a | a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete   |     |     |    |
|      | Schedule D, Parts XI and XII.   | 12a | X   |    |
| k    | Was the organization included in consolidated, independent audited financial statements for the tax year? If  |     |     |    |
|      | "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional  | 12b |     | X  |
| 13   | Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E   | 13  |     | X  |
|      | a Did the organization maintain an office, employees, or agents outside of the United States?   | 14a |     | Х  |
| K    | Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate                  |     |     |    |
|      | foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV  | 14b |     | Х  |
| 15   | Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or   | 145 |     |    |
|      | for any foreign organization? If "Yes," complete Schedule F, Parts II and IV  | 15  | Х   |    |
| 16   | Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other  |     |     |    |
|      | assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV   | 16  |     | Х  |
| 17   | Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on  |     |     |    |
|      | Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I See instructions  | 17  |     | Х  |
| 18   | Did the organization report more than \$15,000 total of fundraising event gross income and contributions on   |     |     |    |
|      | Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II  | 18  | X   |    |
| 19   | Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a?  |     |     |    |
|      | If "Yes," complete Schedule G, Part III   | 19  |     | X  |
|      | a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H   | 20a |     | Х  |
|      | o If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?  | 20b |     |    |
| 21   | Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or   |     | Х   |    |
|      | domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II   | 21  | 41  | 1  |

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| Part          | Checklist of Required Schedules (continued)  |           |     |       |
|---------------|--|-----------|-----|-------|
|               |  |           | Yes | No    |
| 22            | Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on  |           |     | 37    |
|               | Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III  | 22        |     | X     |
| 23            | Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the  |           |     |       |
|               | organization's current and former officers, directors, trustees, key employees, and highest compensated  |           | 3.7 |       |
|               | employees? If "Yes," complete Schedule J   | 23        | X   |       |
| 24 a          | Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than  |           |     |       |
|               | \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b  |           |     | 3.7   |
|               | through 24d and complete Schedule K. If "No," go to line 25a   | 24a       |     | X     |
|               | Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?  | 24b       |     |       |
| С             | Did the organization maintain an escrow account other than a refunding escrow at any time during the year  |           |     |       |
|               | to defease any tax-exempt bonds?   | 24c       |     |       |
|               | Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?  | 24d       |     |       |
| 25 a          | Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit   |           |     |       |
|               | transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I  | 25a       |     | X     |
| b             | Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior   |           |     |       |
|               | year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ?   |           |     |       |
|               | If "Yes," complete Schedule L, Part I  | 25b       |     | X     |
| 26            | Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current  |           |     |       |
|               | or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35%  |           |     | 3.7   |
|               | controlled entity or family member of any of these persons? If "Yes," complete Schedule L, Part II.  | 26        |     | X     |
| 27            | Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key  |           |     |       |
|               | employee, creator or founder, substantial contributor or employee thereof, a grant selection committee   |           |     |       |
|               | member, or to a 35% controlled entity (including an employee thereof) or family member of any of these   |           |     | v     |
|               | persons? If "Yes," complete Schedule L, Part III   | 27        |     | X     |
| 28            | Was the organization a party to a business transaction with one of the following parties (see Schedule L,  |           |     |       |
| _             | Part IV instructions, for applicable filing thresholds, conditions, and exceptions):   |           |     |       |
| а             | A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If   | 202       |     | Х     |
| L             | "Yes," complete Schedule L, Part IV  | 28a       |     | X     |
|               | A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV.   | 28b       |     |       |
| C             | A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? If  | 200       |     | Х     |
| 20            | "Yes," complete Schedule L, Part IV  | 28c<br>29 | Х   | 21    |
| 29            | Did the organization receive more than \$25,000 in non-cash contributions? If res, complete scriedule in   | 29        | 21  |       |
| 30            | conservation contributions? If "Yes," complete Schedule M  | 20        |     | Х     |
| 31            | Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>  | 30        |     | X     |
| 32            | Did the organization inquidate, terminate, or dissolve and cease operations? If res, complete scriedule N, Fart r  Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," | 31        |     | - 21  |
| 32            |  | 32        |     | Х     |
| 33            | complete Schedule N, Part II   | 32        |     | 21    |
| 33            | sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I  | 33        |     | Х     |
| 34            | Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III,   | 33        |     |       |
| <b>5</b> 4    | or IV, and Part V, line 1  | 34        | X   |       |
| 35 a          | Did the organization have a controlled entity within the meaning of section 512(b)(13)?  | 35a       |     | X     |
|               | If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a  | 000       |     |       |
| ~             | controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2  | 35b       |     |       |
| 36            | Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable   |           |     |       |
|               | related organization? If "Yes," complete Schedule R, Part V, line 2  | 36        |     | Х     |
| 37            | Did the organization conduct more than 5% of its activities through an entity that is not a related organization   | "         |     |       |
| •             | and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI   | 37        |     | Х     |
| 38            | Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and   |           |     |       |
|               | 19? <b>Note:</b> All Form 990 filers are required to complete Schedule O.  | 38        | Х   |       |
| Part          |  |           |     |       |
|               | Check if Schedule O contains a response or note to any line in this Part V   |           |     | _ X   |
|               | •  |           | Yes | No    |
| 1a            | Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable   |           |     |       |
|               | Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable  |           |     |       |
| С             | Did the organization comply with backup withholding rules for reportable payments to vendors and   |           |     |       |
|               | reportable gaming (gambling) winnings to prize winners?  | 1c        |     |       |
| JSA<br>0E1030 | 1.000  | Form      | 990 | (2020 |
|               | 2025CU L161 7/16/2021 11:01:58 AM V 20-5.7F 305881 NAT'L RTRN  |           |     |       |
|               |  |           |     |       |

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| Par        | t V Statements Regarding Other IRS Filings and Tax Compliance (continued)  |     |     |     |
|------------|--|-----|-----|-----|
|            |  |     | Yes | No  |
| 2a         | Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax  |     |     |     |
|            | Statements, filed for the calendar year ending with or within the year covered by this return. 2a 36                               |     |     |     |
| b          | If at least one is reported on line 2a, did the organization file all required federal employment tax returns?                     | 2b  | X   |     |
|            | <b>Note:</b> If the sum of lines 1a and 2a is greater than 250, you may be required to <i>e-file</i> (see instructions)            |     |     |     |
| 3a         | Did the organization have unrelated business gross income of \$1,000 or more during the year?                                      | 3a  |     | Х   |
|            | If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation on Schedule O</i>                 | 3b  |     |     |
|            | At any time during the calendar year, did the organization have an interest in, or a signature or other authority over,            |     |     |     |
| τu         | a financial account in a foreign country (such as a bank account, securities account, or other financial account)?                 | 4a  |     | Х   |
| h          | If "Yes," enter the name of the foreign country $\blacktriangleright$  |     |     |     |
| b          | See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).                |     |     |     |
| <b>5</b> ~ | Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?                              | 5a  |     | Х   |
|            |  | 5b  |     | X   |
|            | Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?                   | 5c  |     |     |
|            | If "Yes" to line 5a or 5b, did the organization file Form 8886-T?  | 30  |     |     |
| ьа         | Does the organization have annual gross receipts that are normally greater than \$100,000, and did the                             | 60  |     | Х   |
|            | organization solicit any contributions that were not tax deductible as charitable contributions?                                   | 6a  |     | 21  |
| b          | If "Yes," did the organization include with every solicitation an express statement that such contributions or                     | C L |     |     |
| _          | gifts were not tax deductible?   | 6b  |     |     |
| 7          | Organizations that may receive deductible contributions under section 170(c).  |     |     |     |
| а          | Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods                        | _   | v   |     |
|            | and services provided to the payor?  | 7a  | X   |     |
|            | If "Yes," did the organization notify the donor of the value of the goods or services provided?                                    | 7b  | X   |     |
| С          | Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was                           |     |     | 3.7 |
|            | required to file Form 8282?  | 7c  |     | X   |
| d          | If "Yes," indicate the number of Forms 8282 filed during the year  |     |     |     |
| е          | Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?                    | 7e  |     | X   |
| f          | Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?                       | 7f  |     | Х   |
| g          | If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?   | 7g  |     |     |
| h          | If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C? | 7h  | X   |     |
| 8          | Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the                               |     |     |     |
|            | sponsoring organization have excess business holdings at any time during the year?   | 8   |     |     |
| 9          | Sponsoring organizations maintaining donor advised funds.  |     |     |     |
| а          | Did the sponsoring organization make any taxable distributions under section 4966?   | 9a  |     |     |
| b          | Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?                                  | 9b  |     |     |
| 10         | Section 501(c)(7) organizations. Enter:  |     |     |     |
| а          | Initiation fees and capital contributions included on Part VIII, line 12   |     |     |     |
| b          | Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10b                                    |     |     |     |
| 11         | Section 501(c)(12) organizations. Enter:   |     |     |     |
| а          | Gross income from members or shareholders  |     |     |     |
| b          | Gross income from other sources (Do not net amounts due or paid to other sources   |     |     |     |
|            | against amounts due or received from them.)  |     |     |     |
| 12 a       | Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?                         | 12a |     |     |
| b          | If "Yes," enter the amount of tax-exempt interest received or accrued during the year  |     |     |     |
| 13         | Section 501(c)(29) qualified nonprofit health insurance issuers.   |     |     |     |
| а          | Is the organization licensed to issue qualified health plans in more than one state?   | 13a |     |     |
|            | Note: See the instructions for additional information the organization must report on Schedule O.                                  |     |     |     |
| b          | Enter the amount of reserves the organization is required to maintain by the states in which                                       |     |     |     |
|            | the organization is licensed to issue qualified health plans   |     |     |     |
| С          | Enter the amount of reserves on hand   |     |     |     |
|            | Did the organization receive any payments for indoor tanning services during the tax year?   | 14a |     | X   |
|            | If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation on Schedule</i> O · · · · · ·       | 14b |     |     |
| 15         | Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or                      |     |     |     |
|            | excess parachute payment(s) during the year?   | 15  |     | Х   |
|            | If "Yes," see instructions and file Form 4720, Schedule N.   |     |     |     |
| 16         | Is the organization an educational institution subject to the section 4968 excise tax on net investment income?                    | 16  |     | Х   |
|            | If "Yes," complete Form 4720, Schedule O.  |     |     |     |
|            |  |     |     |     |

Form 990 (2020) Part VI

Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions. Check if Schedule O contains a response or note to any line in this Part VI

| Sect  | ion A. Governing Body and Management   |         |             |               | •      |        |
|-------|--|---------|-------------|---------------|--------|--------|
|       | ion / ii oo rommig boay ana managomoni   |         |             |               | Yes    | No     |
| 10    | Enter the number of voting members of the governing hady at the and of the tay year  | 1a      | 15          |               |        |        |
| ıa    | Enter the number of voting members of the governing body at the end of the tax year  If there are material differences in voting rights among members of the governing body, or                    |         |             |               |        |        |
|       | if the governing body delegated broad authority to an executive committee or similar   |         |             |               |        |        |
|       | committee, explain on Schedule O.  | 1b      | 15          |               |        |        |
| a     | Enter the number of voting members included on line 1a, above, who are independent   |         |             |               |        |        |
| 2     | Did any officer, director, trustee, or key employee have a family relationship or a business rel   |         | -           | 2             |        | X      |
| •     | any other officer, director, trustee, or key employee?   |         |             |               |        |        |
| 3     | Did the organization delegate control over management duties customarily performed by or ur  |         |             | 3             |        | Х      |
|       | supervision of officers, directors, trustees, or key employees to a management company or other p  |         |             | 4             |        | X      |
| 4     | Did the organization make any significant changes to its governing documents since the prior Form 990 was fi   |         |             | 5             |        | X      |
| 5     | Did the organization become aware during the year of a significant diversion of the organization's a   |         |             | 6             |        | X      |
| 6     | Did the organization have members or stockholders?   |         |             | _             |        |        |
| 7a    | Did the organization have members, stockholders, or other persons who had the power to el  |         |             | 7a            |        | X      |
|       | one or more members of the governing body?   |         |             | 7 a           |        |        |
| b     | Are any governance decisions of the organization reserved to (or subject to approval   |         |             | 7b            |        | X      |
| •     | stockholders, or persons other than the governing body?  |         |             | 7.5           |        |        |
| 8     | Did the organization contemporaneously document the meetings held or written actions under   | ertake  | n auring    |               |        |        |
|       | the year by the following:   |         |             | 8a            | Х      |        |
| a     | The governing body?  |         |             | 8b            | X      |        |
| b     | Each committee with authority to act on behalf of the governing body?  |         |             | 0.0           |        |        |
| 9     | Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot the organization's mailing address? If "Yes," provide the names and addresses on Schedule O     |         |             | 9             |        | X      |
| Secti | on B. Policies (This Section B requests information about policies not required by the Inte  |         |             | _             | )      |        |
| 0001  | on Bit Gildios (17110 Goodon Broqueste illionnadon about policios notroquiros by the line  | mari    | 10101140    | Oodo          | Yes    | No     |
| 40-   | Did the agreemination have local chanters branches as affiliates?  |         |             | 10a           | X      |        |
|       | Did the organization have local chapters, branches, or affiliates?   |         |             | - Tu          |        |        |
| D     | If "Yes," did the organization have written policies and procedures governing the activities of  |         | -           | 10b           | Х      |        |
| 44.   | affiliates, and branches to ensure their operations are consistent with the organization's exempt po   | •       |             | 11a           | X      |        |
| 11a   | Has the organization provided a complete copy of this Form 990 to all members of its governing body before fi  | iing th | e iomir .   | - 1 4         |        |        |
| b     | Describe in Schedule O the process, if any, used by the organization to review this Form 990.  |         |             | 12a           | Х      |        |
| 12a   | Did the organization have a written conflict of interest policy? <i>If "No," go to line 13</i> Were officers, directors, or trustees, and key employees required to disclose annually interests to |         |             |               |        |        |
| b     | rise to conflicts?   |         |             | 12b           | Х      |        |
| •     | Did the organization regularly and consistently monitor and enforce compliance with the p  |         |             |               |        |        |
| С     | describe in Schedule O how this was done   | -       |             | 12c           | Х      |        |
| 13    | Did the organization have a written whistleblower policy?  |         |             | 13            | Х      |        |
| 14    | Did the organization have a written document retention and destruction policy?   |         |             | 14            | Х      |        |
| 15    | Did the process for determining compensation of the following persons include a review ar  |         |             |               |        |        |
| 13    | independent persons, comparability data, and contemporaneous substantiation of the deliberation  |         | ,           |               |        |        |
| а     | The organization's CEO, Executive Director, or top management official   |         |             | 15a           | Х      |        |
| b     | Other officers or key employees of the organization  |         |             | 15b           | Х      |        |
| D     | If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions).  |         |             |               |        |        |
| 162   | Did the organization invest in, contribute assets to, or participate in a joint venture or similar   | r arra  | ngement     |               |        |        |
| 104   | with a taxable entity during the year?   | ı ana   | ngemen      | 16a           |        | Х      |
| h     | If "Yes," did the organization follow a written policy or procedure requiring the organization   | to ev   | عti معديياد |               |        |        |
|       | participation in joint venture arrangements under applicable federal tax law, and take steps to  |         |             |               |        |        |
|       | organization's exempt status with respect to such arrangements?  |         |             | 16b           |        |        |
| Sect  | on C. Disclosure   |         |             |               |        |        |
| 17    | List the states with which a copy of this Form 990 is required to be filed ▶ ATTACHMENT 2  | 2       |             |               |        |        |
| 18    | Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable),  | 990     | and 990-T   | (Sec          | tion 5 | (01(c) |
|       | (3)s only) available for public inspection. Indicate how you made these available. Check all that ap   |         | JUU 1       | ,500          |        | 3.(0)  |
|       | Own website Another's website X Upon request Other (explain on Sc  | -       | e O)        |               |        |        |
| 19    | Describe on Schedule O whether (and if so, how) the organization made its governing docum  |         | ,           | f inter       | est r  | olicy  |
|       | and financial statements available to the public during the tax year.  | ,       |             |               |        | ,      |
| 20    | State the name, address, and telephone number of the person who possesses the organization's become many coluccio 505 Eighth Avenue, Suite 902 New York, NY 10018 212-242-1968                     | ooks    | and record  | s <b>&gt;</b> |        |        |
|       | ROSEMARY COLUCCIO 505 EIGHTH AVENUE, SUITE 902 NEW YORK, NY 10018 . 212-242-1968   |         |             |               |        |        |

## Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, **Independent Contractors**

### Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's current officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
  - List all of the organization's current key employees, if any. See instructions for definition of "key employee."
- List the organization's five current highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's former officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's former directors or trustees that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations. See instructions for the order in which to list the persons above.

Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

| (A) Name and title             | (B) Average hours per week  | box,                           | unles                 | Pos<br>heck<br>ss pe | rson         | e than o<br>is both<br>or/trust | an     | (D) Reportable compensation from the | (E) Reportable compensation from related | (F) Estimated amount of other compensation      |
|--------------------------------|---|--------------------------------|-----------------------|----------------------|--------------|---------------------------------|--------|--------------------------------------|--|---|
|                                | (list any<br>hours for<br>related<br>organizations<br>below<br>dotted line) | Individual trustee or director | Institutional trustee | Officer              | Key employee | Highest compensated employee    | Former | organization<br>(W-2/1099-MISC)      | organizations<br>(W-2/1099-MISC)         | from the organization and related organizations |
| (1)LOUISE VETTER               | 35.00   |                                |                       |                      |              |                                 |        |                                      |  |   |
| CHIEF EXECUTIVE OFFICER        | 3.00  |                                |                       | Х                    |              |                                 |        | 274,376.                             | 0.                                       | 56,267.   |
| (2)GEORGE YOHRLING             | 35.00   |                                |                       |                      |              |                                 |        |                                      |  |   |
| SR. DIR. MISSION & SCI AFFAIRS | 3.00  |                                |                       |                      |              | Х                               |        | 233,994.                             | 0.                                       | 13,117.   |
| (3) ROSEMARY COLUCCIO          | 35.00   |                                |                       |                      |              |                                 |        |                                      |  |   |
| CHIEF OPERATING OFFICER        | 3.00  |                                |                       | Х                    |              |                                 |        | 220,662.                             | 0.                                       | 22,220.   |
| (4) CHRISTOPHER COSENTINO      | 35.00   |                                |                       |                      |              |                                 |        |                                      |  |   |
| DIRECTOR OF MARKETING & COMM.  | 3.00  |                                |                       |                      |              | Х                               |        | 126,438.                             | 0.                                       | 48,872.   |
| (5) DEBRA LOVECKY              | 35.00   |                                |                       |                      |              |                                 |        |                                      |  |   |
| DIR OF PROGRAM SERV & ADVOCACY | 3.00  |                                |                       |                      |              | X                               |        | 151,476.                             | 0.                                       | 23,518.   |
| (6) NANCY RHODES               | 35.00   |                                |                       |                      |              |                                 |        |                                      |  |   |
| DIRECTOR OF FIELD DEV & OPER.  | 3.00  |                                |                       |                      |              | X                               |        | 151,999.                             | 0.                                       | 4,079.  |
| (7) JAMISON SKALA              | 35.00   |                                |                       |                      |              |                                 |        |                                      |  |   |
| DIRECTOR, NATIONAL DEVELOPMENT | 3.00  |                                |                       |                      |              | Х                               |        | 127,511.                             | 0.                                       | 9,760.  |
| (8) ARIK JOHNSON, PSYD         | 6.00  |                                |                       |                      |              |                                 |        |                                      |  |   |
| PAST CHAIR                     | 3.00  | Х                              |                       | Х                    |              |                                 |        | 0.                                   | 0.                                       | 0.  |
| (9) KAMRAN ALAM                | 6.00  |                                |                       |                      |              |                                 |        |                                      |  |   |
| TREASURER                      | 3.00  | X                              |                       | Х                    |              |                                 |        | 0.                                   | 0.                                       | 0.  |
| (10) VICTOR SUNG, MD           | 6.00  |                                |                       |                      |              |                                 |        |                                      |  |   |
| CHAIR-ELECT                    | 3.00  | X                              |                       | Х                    |              |                                 |        | 0.                                   | 0.                                       | 0.  |
| (11) EJ GARNER                 | 6.00  |                                |                       |                      |              |                                 |        |                                      |  |   |
| CHAIR                          | 3.00  | X                              |                       | Х                    |              |                                 |        | 0.                                   | 0.                                       | 0.  |
| (12) JENNE COLER-DARK          | 6.00  |                                |                       |                      |              |                                 |        |                                      |  |   |
| SECRETARY                      | 3.00  | X                              |                       | Х                    |              |                                 |        | 0.                                   | 0.                                       | 0.  |
| (13) JAY HUGHES                | 6.00  |                                |                       |                      |              |                                 |        |                                      |  |   |
| TRUSTEE                        | 3.00  | X                              |                       |                      |              |                                 |        | 0.                                   | 0.                                       | 0.  |
| (14) DANIEL BRENNAN            | 6.00  |                                |                       |                      |              |                                 |        |                                      |  | _   |
| TRUSTEE                        | 3.00  | X                              |                       |                      |              |                                 |        | 0.                                   | 0.                                       | 0.  |

| (A)  | (B)   |                                |                       | (C                               | <b>(</b> 2       |                              |                       | (D)                              | (E)  | (F)  |
|--|---|--------------------------------|-----------------------|----------------------------------|------------------|------------------------------|-----------------------|----------------------------------|--|--|
| Name and title   | Average<br>hours per<br>week (list any<br>hours for | box,                           | unles<br>er and       | Posi<br>neck<br>ss per<br>d a di | ition<br>more    | e than o                     | an<br>ee)             | Reportable compensation from the | Reportable compensation from related organizations | Estimated amount of other compensation                   |
|  | related<br>organizations<br>below dotted<br>line)   | Individual trustee or director | Institutional trustee | Officer                          | Key employee     | Highest compensated employee | Former                | organization<br>(W-2/1099-MISC)  | (W-2/1099-MISC)                                    | from the<br>organization<br>and related<br>organizations |
| 5) STACY COEN  | 6.00  |                                |                       |                                  |                  |                              |                       |                                  |  |  |
| TRUSTEE  | 3.00  | Х                              |                       |                                  |                  |                              |                       | 0                                | 0.   |  |
| .6) DANIEL VANDIVORT   | 6.00  |                                |                       |                                  |                  |                              |                       |                                  | _  |  |
| TRUSTEE  | 3.00  | X                              |                       |                                  |                  |                              |                       | 0                                | 0.   |  |
| .7) TERESA SRAJER<br>TRUSTEE   | 6.00  | 37                             |                       |                                  |                  |                              |                       |                                  | 0  |  |
| .8) WENDY ERLER  | 3.00  | X                              |                       |                                  |                  |                              |                       | 0                                | 0.   |  |
| TRUSTEE  | 3.00  | X                              |                       |                                  |                  |                              |                       | 0                                | 0.   |  |
| .9) JONATHAN KLEIN   | 6.00  |                                |                       |                                  |                  |                              |                       | 0                                |  |  |
| TRUSTEE  | 3.00  | X                              |                       |                                  |                  |                              |                       | 0                                | 0.   |  |
| 20) LESLIE M THOMPSON, PHD   | 6.00  |                                |                       |                                  |                  |                              |                       | 0                                | ·  |  |
| TRUSTEE  | 3.00  | Х                              |                       |                                  |                  |                              |                       | 0                                | 0.   |  |
| 21) DONALD HIGGINS, MD   | 6.00  |                                |                       |                                  |                  |                              |                       |                                  |  |  |
| TRUSTEE  | 3.00  | Х                              |                       |                                  |                  |                              |                       | 0                                | 0.   |  |
| 22) VICKY WHEELOCK, MD   | 6.00  |                                |                       |                                  |                  |                              |                       |                                  |  |  |
| TRUSTEE  | 3.00  | Х                              |                       |                                  |                  |                              |                       | 0                                | 0.   |  |
|  |   | -                              |                       |                                  |                  |                              |                       |                                  |  |  |
|  |   |                                |                       |                                  |                  |                              |                       |                                  |  |  |
|  |   |                                |                       |                                  |                  |                              |                       |                                  |  |  |
| 1b Sub-total   |   |                                |                       |                                  |                  |                              | <b></b>               | 1,286,456.                       | 0.   | 177,833  |
| c Total from continuation sheets to Part VII, S  | Section A   |                                |                       |                                  |                  |                              | $\blacktriangleright$ | 0.                               | 0.   | ı  |
| d Total (add lines 1b and 1c)  |   |                                |                       |                                  |                  |                              | <b>&gt;</b>           | 1,286,456.                       | 0.   | 177,833  |
| 2 Total number of individuals (including but not<br>reportable compensation from the organization  |   | hose<br>{                      |                       | d ab                             | OOV              | e) who                       | o re                  | ceived more than                 | \$100,000 of                                       |  |
|  |   |                                |                       |                                  |                  |                              |                       |                                  |  | Yes N  |
| 3 Did the organization list any <b>former</b> office employee on line 1a? If "Yes," complete Sched |   |                                |                       |                                  |                  |                              |                       |                                  |  | 3 2  |
| 4 For any individual listed on line 1a, is the organization and related organizations grindividual | sum of repeater than                                | ortab<br>\$15                  | le c                  | omı<br>00?                       | pen<br><i>If</i> | sation                       | n ai                  | nd other compens                 | sation from the le J for such                      | 4 X  |
|  |   |                                |                       |                                  |                  |                              |                       | related organization             |  |  |

compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax

| (A) Name and business address | (B) Description of services | (C)<br>Compensation |
|-------------------------------|-----------------------------|---------------------|
| ATTACHMENT 3                  |                             |                     |
|                               |                             |                     |
|                               |                             |                     |
|                               |                             |                     |
|                               |                             |                     |

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 in compensation from the organization ▶ 3

# Form 990 (2020) HUN Part VIII Statement of Revenue

| rai  | τνιιι  | Check if Schedule O contains a respon         | nse or note to ar                       | nv line in this Part V | /III                                   |                                      |  |
|--|--------|---|---|------------------------|--|--------------------------------------|--|
|  |        | ·   |   | (A)<br>Total revenue   | (B) Related or exempt function revenue | (C)<br>Unrelated<br>business revenue | (D) Revenue excluded from tax under sections 512-514 |
| ts   | 1a     | Federated campaigns 1a                        | 179,903.                                |                        |  |                                      |  |
| and and  | b      | Membership dues                               |   |                        |  |                                      |  |
| عَ ق   | c      | Fundraising events 1c                         | 978,304.                                |                        |  |                                      |  |
| Contributions, Gifts, Grants and Other Similar Amounts | d      | Related organizations 1d                      | 1,577,568.                              |                        |  |                                      |  |
|  | e      | Government grants (contributions) 1e          | , |                        |  |                                      |  |
| Sin  | f      | All other contributions, gifts, grants,       |   |                        |  |                                      |  |
| er S   | _      | and similar amounts not included above . 1f   | 5,744,719.                              |                        |  |                                      |  |
| 혈  | g      | Noncash contributions included in             | 2,122,122                               |                        |  |                                      |  |
| a t  | 9      | lines 1a-1f                                   | <b>3</b> 295,757.                       |                        |  |                                      |  |
| ಕ್ಷ ಬ  | h      | Total. Add lines 1a-1f                        |   | 8,480,494.             |  |                                      |  |
|  |        |   | Business Code                           |                        |  |                                      |  |
| ë  | 20     |   |   |                        |  |                                      |  |
| Program Service<br>Revenue                             | 2a     |   |   |                        |  |                                      |  |
| Se   | b      |   |   |                        |  |                                      |  |
| E S  | C      |   |   |                        |  |                                      |  |
| Re   | d      |   |   |                        |  |                                      |  |
| ဥ  | e      |   |   |                        |  |                                      |  |
| _  | f a    | All other program service revenue             |   | 0.                     |  |                                      |  |
|  | g      |   |   | 0.                     |  |                                      |  |
|  | 3      | Investment income (including dividends,       | _                                       | 23,523.                |  |                                      | 23,523.  |
|  |        | other similar amounts)                        |   | 0.                     |  |                                      | 23,323.  |
|  | 4<br>5 | Income from investment of tax-exempt bond     |   | 0.                     |  |                                      |  |
|  | "      | Royalties                                     | (ii) Personal                           | 0.                     |  |                                      |  |
|  |        |   | (ii) i diddiidi                         |                        |  |                                      |  |
|  | 6a     | Gross rents 6a                                |   |                        |  |                                      |  |
|  | b      | Less: rental expenses 6b                      |   |                        |  |                                      |  |
|  | C      | Rental income or (loss) 6c                    |   | 0                      |  |                                      |  |
|  | d _d   | Net rental income or (loss)                   |   | 0.                     |  |                                      |  |
|  | 7a     | Gross amount from (i) Securities              | (ii) Other                              |                        |  |                                      |  |
|  |        | sales of assets                               |   |                        |  |                                      |  |
|  |        | other than inventory <b>7a</b> 222,649.       |   |                        |  |                                      |  |
| ne   | b      | Less: cost or other basis                     |   |                        |  |                                      |  |
| evenue   |        | and sales expenses <b>7b</b> 221,639.         |   |                        |  |                                      |  |
|  | С      | Gain or (loss)                                |   |                        |  |                                      |  |
| Other R  | d      | Net gain or (loss)                            | <u></u>                                 | 1,010.                 |  |                                      | 1,010.   |
| ÷  | 8a     | Gross income from fundraising                 |   |                        |  |                                      |  |
| J  |        | events (not including \$978,304.              |   |                        |  |                                      |  |
|  |        | of contributions reported on line             |   |                        |  |                                      |  |
|  |        | 1c). See Part IV, line 18 8a                  | 92,612.                                 |                        |  |                                      |  |
|  | b      | Less: direct expenses 8b                      | 92,612.                                 |                        |  |                                      |  |
|  | С      | Net income or (loss) from fundraising events. | <u></u> ▶                               | 0.                     |  |                                      |  |
|  | 9a     | Gross income from gaming                      |   |                        |  |                                      |  |
|  |        | activities. See Part IV, line 19 9a           | 0.                                      |                        |  |                                      |  |
|  | b      | Less: direct expenses 9b                      | 0.                                      |                        |  |                                      |  |
|  | С      | Net income or (loss) from gaming activities.  |   | 0.                     |  |                                      |  |
|  | 10a    | Gross sales of inventory, less                |   |                        |  |                                      |  |
|  |        | returns and allowances                        | 0.                                      |                        |  |                                      |  |
|  | b      | Less: cost of goods sold 10b                  | 0.                                      |                        |  |                                      |  |
|  | С      | Net income or (loss) from sales of inventory. | ▶                                       | 0.                     |  |                                      |  |
| <u>s</u>   |        |   | Business Code                           |                        |  |                                      |  |
| eo e   | 11a    | MISCELLANEOUS                                 | 900099                                  | 81,919.                | 81,919.                                |                                      |  |
| lan  | b      |   |   |                        |  |                                      |  |
| e Ke   | C      |   |   |                        |  |                                      |  |
| Miscellaneous<br>Revenue                               | d      | All other revenue                             |   |                        |  |                                      |  |
|  | е      | Total. Add lines 11a-11d                      |   | 81,919.                |  |                                      |  |
|  | 12     | Total revenue. See instructions               |   | 8,586,946.             | 81,919.                                |                                      | 24,533.  |

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Form 990 (2020)

### HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. 13-3349872

# Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

|     | Check if Schedule O contains a response or note to any line in this Part IX              |                       |                        |                       |                           |  |  |  |  |  |  |
|-----|--|-----------------------|------------------------|-----------------------|---------------------------|--|--|--|--|--|--|
| Do  | not include amounts reported on lines 6b, 7b,  | (A)<br>Total expenses | (B)<br>Program service | (C)<br>Management and | <b>(D)</b><br>Fundraising |  |  |  |  |  |  |
| 8b, | 9b, and 10b of Part VIII.  | rotal expenses        | expenses               | general expenses      | expenses                  |  |  |  |  |  |  |
| 1   | Grants and other assistance to domestic organizations                                    |                       |                        |                       |                           |  |  |  |  |  |  |
|     | and domestic governments. See Part IV, line 21   | 2,101,403.            | 2,101,403.             |                       |                           |  |  |  |  |  |  |
| 2   | Grants and other assistance to domestic  |                       |                        |                       |                           |  |  |  |  |  |  |
|     | individuals. See Part IV, line 22  | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| 3   | Grants and other assistance to foreign   |                       |                        |                       |                           |  |  |  |  |  |  |
|     | organizations, foreign governments, and  |                       |                        |                       |                           |  |  |  |  |  |  |
|     | foreign individuals. See Part IV, lines 15 and 16  | 511,465.              | 511,465.               |                       |                           |  |  |  |  |  |  |
| 4   | Benefits paid to or for members  | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| 5   | Compensation of current officers, directors,   |                       |                        |                       |                           |  |  |  |  |  |  |
|     | trustees, and key employees  | 573,526.              | 414,405.               | 51,789.               | 107,332.                  |  |  |  |  |  |  |
| 6   | Compensation not included above to disqualified  |                       |                        |                       |                           |  |  |  |  |  |  |
|     | persons (as defined under section 4958(f)(1)) and  |                       |                        |                       |                           |  |  |  |  |  |  |
|     | persons described in section 4958(c)(3)(B)   | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| 7   | Other salaries and wages   | 2,556,241.            | 1,847,029.             | 230,826.              | 478,386.                  |  |  |  |  |  |  |
| 8   | Pension plan accruals and contributions (include   |                       |                        |                       |                           |  |  |  |  |  |  |
|     | section 401(k) and 403(b) employer contributions)  | 102,599.              | 74,133.                | 9,265.                | 19,201.                   |  |  |  |  |  |  |
| 9   | Other employee benefits  | 472,567.              | 341,457.               | 42,672.               | 88,438.                   |  |  |  |  |  |  |
| 10  | Payroll taxes  | 259,555.              | 187,543.               | 23,438.               | 48,574.                   |  |  |  |  |  |  |
| 11  | Fees for services (nonemployees):  |                       |                        |                       |                           |  |  |  |  |  |  |
| а   | Management   | 0.                    |                        |                       |                           |  |  |  |  |  |  |
|     | Legal  | 406.                  |                        | 406.                  |                           |  |  |  |  |  |  |
| c   | Accounting   | 62,948.               |                        | 62,948.               |                           |  |  |  |  |  |  |
| d   | Lobbying   | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| е   | Professional fundraising services. See Part IV, line 17.                                 | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| f   | Investment management fees   | 1,593.                |                        | 1,593.                |                           |  |  |  |  |  |  |
| g   | Other. (If line 11g amount exceeds 10% of line 25, column                                |                       |                        |                       |                           |  |  |  |  |  |  |
|     | (A) amount, list line 11g expenses on Schedule O.)                                       | 604,125.              | 547,648.               | 30,799.               | 25,678.                   |  |  |  |  |  |  |
| 12  | Advertising and promotion  | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| 13  | Office expenses  | 106,793.              | 70,539.                | 17,739.               | 18,515.                   |  |  |  |  |  |  |
| 14  | Information technology   | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| 15  | Royalties  | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| 16  | Occupancy  | 287,203.              | 222,338.               | 18,780.               | 46,085.                   |  |  |  |  |  |  |
| 17  | Travel   | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| 18  | Payments of travel or entertainment expenses   |                       |                        |                       |                           |  |  |  |  |  |  |
|     | for any federal, state, or local public officials  | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| 19  | Conferences, conventions, and meetings   | 43,258.               | 39,396.                | 806.                  | 3,056.                    |  |  |  |  |  |  |
| 20  | Interest   | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| 21  | Payments to affiliates   | 0.                    |                        |                       |                           |  |  |  |  |  |  |
| 22  | Depreciation, depletion, and amortization  | 44,167.               | 34,700.                | 2,849.                | 6,618.                    |  |  |  |  |  |  |
| 23  | Insurance  | 48,159.               | 31,145.                | 10,940.               | 6,074.                    |  |  |  |  |  |  |
| 24  |  |                       |                        |                       |                           |  |  |  |  |  |  |
|     | above (List miscellaneous expenses on line 24e. If                                       |                       |                        |                       |                           |  |  |  |  |  |  |
|     | line 24e amount exceeds 10% of line 25, column   |                       |                        |                       |                           |  |  |  |  |  |  |
|     | (A) amount, list line 24e expenses on Schedule O.)                                       |                       |                        |                       |                           |  |  |  |  |  |  |
| а   | PRINTING AND PUBLICATIONS  | 135,180.              | 90,029.                | 227.                  | 44,924.                   |  |  |  |  |  |  |
|     | PRIZES, GIFTS & AWARDS   | 34,246.               | 15,820.                | 340.                  | 18,086.                   |  |  |  |  |  |  |
| _   | EQUIPMENT RENTAL   | 17,295.               | 14,458.                |                       | 2,837.                    |  |  |  |  |  |  |
| d   | TELEPHONE  | 64,056.               | 45,101.                | 3,848.                | 15,107.                   |  |  |  |  |  |  |
| е   | All other expenses   | 205,410.              | 40,356.                | 9,632.                | 155,422.                  |  |  |  |  |  |  |
| 25  | Total functional expenses. Add lines 1 through 24e                                       | 8,232,195.            | 6,628,965.             | 518,897.              | 1,084,333.                |  |  |  |  |  |  |
| 26  | Joint costs. Complete this line only if the  |                       |                        |                       |                           |  |  |  |  |  |  |
|     | organization reported in column (B) joint costs from a combined educational campaign and |                       |                        |                       |                           |  |  |  |  |  |  |
|     | fundraising solicitation. Check here if  |                       |                        |                       |                           |  |  |  |  |  |  |
|     | following SOP 98-2 (ASC 958-720)   | 0.                    |                        |                       |                           |  |  |  |  |  |  |
|     |  |                       |                        |                       | Form <b>990</b> (2020)    |  |  |  |  |  |  |

Form 990 (2020) Page **11** 

# Part X Balance Sheet

|               |      | Check if Schedule O contains a response or note to any line in this P        | art X                                   |     |                        |
|---------------|------|--|---|-----|------------------------|
|               |      |  | (A)<br>Beginning of year                |     | (B)<br>End of year     |
|               | 1    | Cash - non-interest-bearing  | 0.                                      | 1   | 0.                     |
|               | 2    | Savings and temporary cash investments                                       | 7,443,343.                              | 2   | 8,527,019.             |
|               | 3    | Pledges and grants receivable, net   | 1,187,716.                              | 3   | 1,130,598.             |
|               | 4    | Accounts receivable, net   | 0.                                      | 4   | 0.                     |
|               | 5    | Loans and other receivables from any current or former officer, director,    |   |     |                        |
|               |      | trustee, key employee, creator or founder, substantial contributor, or 35%   |   |     |                        |
|               |      | controlled entity or family member of any of these persons                   | 0.                                      | 5   | 0.                     |
|               | 6    | Loans and other receivables from other disqualified persons (as defined      |   |     |                        |
|               |      | under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)    | 0.                                      | 6   | 0.                     |
| ts            | 7    | Notes and loans receivable, net  | 0.                                      | 7   | 0.                     |
| Assets        | 8    | Inventories for sale or use  | 0.                                      | 8   | 0.                     |
| Ä             | 9    | Prepaid expenses and deferred charges  | 159,116.                                | 9   | 151,279.               |
|               | 10 a | Land, buildings, and equipment: cost or other                                |   |     |                        |
|               |      | basis. Complete Part VI of Schedule D 10a 415,470.                           |   |     |                        |
|               | b    | Less: accumulated depreciation   | 47,177.                                 | 10c | 29,946.                |
|               | 11   | Investments - publicly traded securities                                     | 2,069,844.                              | 11  | 2,310,097.             |
|               | 12   | Investments - other securities. See Part IV, line 11                         | 0.                                      | 12  | 0.                     |
|               | 13   | Investments - program-related. See Part IV, line 11.                         | 0.                                      | 13  | 0.                     |
|               | 14   | Intangible assets  | 0.                                      | 14  | 0.                     |
|               | 15   | Other assets. See Part IV, line 11   | 61,469.                                 | 15  | 39,529.                |
|               | 16   | <b>Total assets.</b> Add lines 1 through 15 (must equal line 33)             | 10,968,665.                             | 16  | 12,188,468.            |
| _             | 17   | Accounts payable and accrued expenses  | 366,588.                                | 17  | 489,890.               |
|               | 18   | Grants payable   | 1,088,162.                              | 18  | 1,283,055.             |
|               | 19   | Deferred revenue.  | 34,167.                                 | 19  | 0.                     |
|               | 20   | Tax-exempt bond liabilities.   | 0.                                      | 20  | 0.                     |
|               | 21   | Escrow or custodial account liability. Complete Part IV of Schedule D.       | 0.                                      | 21  | 0.                     |
| s             | 22   | Loans and other payables to any current or former officer, director,         |   |     |                        |
| Liabilities   |      | trustee, key employee, creator or founder, substantial contributor, or 35%   |   |     |                        |
| ig            |      | controlled entity or family member of any of these persons                   | 0.                                      | 22  | 0.                     |
| Ë             | 23   | Secured mortgages and notes payable to unrelated third parties               | 0.                                      | 23  | 0.                     |
|               | 24   | Unsecured notes and loans payable to unrelated third parties                 | 0.                                      | 24  | 634,692.               |
|               | 25   | Other liabilities (including federal income tax, payables to related third   |   | 27  | 332,372                |
|               | -0   | parties, and other liabilities not included on lines 17-24). Complete Part X |   |     |                        |
|               |      | of Schedule D  | 127,529.                                | 25  | 118,455.               |
|               | 26   | Total liabilities. Add lines 17 through 25                                   | 1,616,446.                              | 26  | 2,526,092.             |
|               |      | Organizations that follow FASB ASC 958, check here ► X                       | , |     |                        |
| Fund Balances |      | and complete lines 27, 28, 32, and 33.                                       |   |     |                        |
| lan           | 27   | Net assets without donor restrictions  | 3,953,703.                              | 27  | 5,361,276.             |
| Ва            | 28   | Net assets with donor restrictions.  | 5,398,516.                              | 28  | 4,301,100.             |
| pu            |      | Organizations that do not follow FASB ASC 958, check here ▶                  |   | 20  | 1,002,200              |
| 교             |      | and complete lines 29 through 33.  |   |     |                        |
| Assets or     | 29   | Capital stock or trust principal, or current funds                           |   | 29  |                        |
| ets           | 30   | Paid-in or capital surplus, or land, building, or equipment fund.            |   | 30  |                        |
| SS            | 31   | Retained earnings, endowment, accumulated income, or other funds.            |   | 31  |                        |
| Net A         | 32   | Total net assets or fund balances  | 9,352,219.                              | 32  | 9,662,376.             |
| ž             | 33   | Total liabilities and net assets/fund balances                               | 10,968,665.                             | 33  | 12,188,468.            |
| _             | 1    |  | .,,                                     | 55  | Form <b>990</b> (2020) |

| orm 9 | 30 (2020)  |           |      |     | Pa   | ge IZ |
|-------|--|-----------|------|-----|------|-------|
| Part  | XI Reconciliation of Net Assets  |           |      |     |      |       |
|       | Check if Schedule O contains a response or note to any line in this Part XI  | <u></u> . |      |     |      | _ X   |
| 1     | Total revenue (must equal Part VIII, column (A), line 12)  | 1         |      |     | 86,9 | 946.  |
| 2     | 9.2  |           |      |     |      |       |
| 3     | 254.5  |           |      |     |      |       |
| 4     | Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))  | 4         |      | 9,3 | 52,2 | 219.  |
| 5     | The dissels of fund balances at beginning of year (must equal fair X, into 52, column (77) 1.1.1.  |           |      |     |      | )94.  |
| 6     | game (issue) and issued in the control of the contr |           |      |     |      |       |
| 7     | Investment expenses  | 7         |      |     |      | 0.    |
| 8     | Prior period adjustments   | 8         |      |     |      | 0.    |
| 9     | Other changes in net assets or fund balances (explain on Schedule O)   | 9         |      | _   | 43,5 | 500.  |
| 10    | Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line   |           |      |     |      |       |
|       | 32, column (B))  | 10        |      | 9,6 | 62,3 | 376.  |
| Part  | XII Financial Statements and Reporting   |           |      |     |      |       |
|       | Check if Schedule O contains a response or note to any line in this Part XII   |           |      |     |      |       |
|       |  |           |      |     | Yes  | No    |
| 1     | Accounting method used to prepare the Form 990: Cash X Accrual Other   |           |      |     |      |       |
|       | If the organization changed its method of accounting from a prior year or checked "Other," e   | xplair    | n in |     |      |       |
|       | Schedule O.  |           |      |     |      |       |
| 2a    | Were the organization's financial statements compiled or reviewed by an independent accountant?.   |           |      | 2a  |      | X     |
|       | If "Yes," check a box below to indicate whether the financial statements for the year were con   | npiled    | lor  |     |      |       |
|       | reviewed on a separate basis, consolidated basis, or both:   |           |      |     |      |       |
|       | Separate basis Consolidated basis Both consolidated and separate basis   |           |      |     |      |       |
| b     | Were the organization's financial statements audited by an independent accountant?   |           |      | 2b  | X    |       |
|       | If "Yes," check a box below to indicate whether the financial statements for the year were audi  | ted o     | n a  |     |      |       |
|       | separate basis, consolidated basis, or both:   |           |      |     |      |       |
|       | Separate basis   |           |      |     |      |       |
| С     | If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for over   | ersigh    | t of |     |      |       |
|       | the audit, review, or compilation of its financial statements and selection of an independent accounta   | nt?.      |      | 2c  | X    |       |
|       | If the organization changed either its oversight process or selection process during the tax year, ex  | xplain    | on   |     |      |       |
|       | Schedule O.  |           |      |     |      |       |
| 3a    | As a result of a federal award, was the organization required to undergo an audit or audits as set for   | rth in    | the  |     |      |       |
|       | Single Audit Act and OMB Circular A-133?   |           |      | 3a  |      | X     |
| b     | If "Yes," did the organization undergo the required audit or audits? If the organization did not und   | ergo      | the  |     |      |       |
|       | required audit or audits, explain why on Schedule O and describe any steps taken to undergo such a   | ıdits     |      | 3b  |      |       |

### **SCHEDULE A** (Form 990 or 990-EZ)

# **Public Charity Status and Public Support**

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable

► Attach to Form 990 or Form 990-EZ.

OMB No. 1545-0047 2M2N

Department of the Treasury Internal Revenue Service

► Go to www.irs.gov/Form990 for instructions and the latest information.

| tempt charitable trust. |                |
|-------------------------|----------------|
|                         | Open to Public |
| ion.                    | Inspection     |
| Employer identification | n number       |

|         |        | ne organization  |                      |   |  |             |                              | Employer identif                    |                                       |  |
|---------|--------|--|----------------------|---|--|-------------|------------------------------|-------------------------------------|---------------------------------------|--|
| _       |        |  |                      | IETY OF AMERI                             |  |             |                              | 13-33498                            |                                       |  |
|         | rt I   |  |                      | <u> </u>                                  | organizations must                                   |             |                              |                                     | S.                                    |  |
| The     | orga   |  | •                    |   | is: (For lines 1 through                             | •           | -                            | •                                   |                                       |  |
| 1       | Щ      | A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i). |                      |   |  |             |                              |                                     |                                       |  |
| 2       | Щ      |  |                      |   | . (Attach Schedule E                                 | -           |                              |                                     |                                       |  |
| 3       | Н      | •  | •                    | •   | rganization described                                |             |                              |                                     | · · · · · · · · · · · · · · · · · · · |  |
| 4       |        |  | =                    |   | conjunction with a ho                                | spital de   | scribed in                   | n section 170(b)(1)(A               | )(III). Enter the                     |  |
| _       |        | -  | name, city, and st   |   | !!   |             |                              |                                     |                                       |  |
| 5       |        | _  |                      |   | a college or universit                               | ty owne     | a or ope                     | erated by a governme                | ental unit described ir               |  |
| 6       |        |  | 70(b)(1)(A)(iv). (C  | •   | rnmental unit describe                               | d in soot   | ion 170/                     | h)/1)/A)/y)                         |                                       |  |
| 6<br>7  | X      |  |                      | •   |  |             |                              | , , , , , , ,                       | om the general public                 |  |
| '       | 21     | _  |                      | any receives a suc<br>)(1)(A)(vi). (Compl | •  | ipport in   | oni a go                     | verninental unit of it              | oni the general public                |  |
| 8       |        |  |                      |   | o)(1)(A)(vi). (Complete                              | e Part II ) |                              |                                     |                                       |  |
| 9       |        |  |                      |   | ed in <b>section 170(b)(1</b>                        |             |                              | I in conjunction with a             | land-grant college                    |  |
| •       |        | _  |                      | -   | griculture (see instruct                             |             | -                            |                                     |                                       |  |
|         |        | university   | •                    | J   | , (  | ,           |                              | ., . <b>,</b> ,                     | <b></b>                               |  |
| 10      |        | An organi  | zation that norma    | Illy receives (1) mo                      | ore than 331/3 % of its                              | support     | from cor                     | ntributions, membersh               | nip fees, and gross                   |  |
|         |        | receipts f   | rom activities rela  | ited to its exempt f                      | unctions, subject to conrelated business tax         | ertain ex   | xceptions                    | s; and (2) no more tha              | n 331/3 % of its                      |  |
|         |        |  |                      |   | 975. See <b>section 509</b>                          |             |                              |                                     | i businesses                          |  |
| 11      |        | An organi  | zation organized     | and operated excl                         | usively to test for publi                            | ic safety.  | See sec                      | tion 509(a)(4).                     |                                       |  |
| 12      |        | An organi  | ization organized    | and operated exclu                        | usively for the benefit                              | of, to pe   | erform th                    | e functions of, or to               | carry out the purposes                |  |
|         |        |  |                      |   |  |             |                              |                                     | See section 509(a)(3).                |  |
|         |        | Check the  | box in lines 12a t   | through 12d that d                        | escribes the type of s                               | upporting   | g organiz                    | zation and complete li              | nes 12e, 12f, and 12g                 |  |
| а       |        |  |                      | •   | , supervised, or contr                               | -           |                              | • , ,                               |                                       |  |
|         |        |  | _                    |   | regularly appoint or e                               |             | ajority of                   | the directors or truste             | ees of the                            |  |
|         |        | ¬ ··   |                      | •   | e Part IV, Sections A                                |             |                              |                                     |                                       |  |
| b       |        |  |                      | •   | ed or controlled in co                               |             |                              |                                     |                                       |  |
|         |        |  |                      |   | organization vested in                               | tne sam     | ie persor                    | is that control or mai              | nage the supported                    |  |
| •       |        |  |                      |   | , Sections A and C.                                  | atod in a   | onnoctio                     | n with and functions                | lly intograted with                   |  |
| С       |        |  | -                    |   | ng organization opera<br>is). <b>You must comple</b> |             |                              |                                     | my integrated with,                   |  |
| d       |        |  |                      |   | porting organization of                              |             |                              |                                     | rted organization(s)                  |  |
| u       |        |  | -                    |   | nization generally mus                               | -           |                              |                                     |                                       |  |
|         |        |  | •                    | •   | omplete Part IV, Sect                                | •           |                              | ·                                   | a a a                                 |  |
| е       |        | ¬ ·  | ,                    | •   | a written determination                              |             |                              |                                     | II, Type III                          |  |
|         |        |  | _                    |   | ionally integrated sup                               |             |                              |                                     |                                       |  |
| f       | Ent    | ter the nun  | nber of supported    | l organizations                           |  |             |                              |                                     |                                       |  |
| g       | Pro    | vide the fo  | ollowing information | on about the suppo                        | orted organization(s).                               |             |                              |                                     |                                       |  |
|         | (i) Na | ame of suppo   | orted organization   | (ii) EIN                                  | (iii) Type of organization (described on lines 1-10  |             | organization<br>ur governing | (v) Amount of monetary support (see | (vi) Amount of other support (see     |  |
|         |        |  |                      |   | above (see instructions))                            | 1           | ment?                        | instructions)                       | instructions)                         |  |
|         |        |  |                      |   |  | Yes         | No                           |                                     |                                       |  |
| (A)     |        |  |                      |   |  |             |                              |                                     |                                       |  |
|         |        |  |                      |   |  |             |                              |                                     |                                       |  |
| (B)     |        |  |                      |   |  |             |                              |                                     |                                       |  |
|         |        |  |                      |   |  |             |                              |                                     |                                       |  |
| (C)     |        |  |                      |   |  |             |                              |                                     |                                       |  |
| <b></b> |        |  |                      |   |  |             |                              |                                     |                                       |  |
| (D)     |        |  |                      |   |  |             |                              |                                     |                                       |  |
| /E\     |        |  |                      |   |  |             |                              |                                     |                                       |  |
| (E)     |        |  |                      |   |  |             |                              |                                     |                                       |  |
| Tota    | <br>al |  |                      |   |  |             |                              |                                     |                                       |  |
| . 01    | 41     |  |                      |   |  |             |                              |                                     |                                       |  |

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule A (Form 990 or 990-EZ) 2020

Schedule A (Form 990 or 990-EZ) 2020

Page 2 Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi) (Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

| Sec    | tion A. Public Support   |                       |                 |                        |                        |                |                |
|--------|--|-----------------------|-----------------|------------------------|------------------------|----------------|----------------|
| Cale   | ndar year (or fiscal year beginning in)  | (a) 2016              | <b>(b)</b> 2017 | (c) 2018               | (d) 2019               | (e) 2020       | (f) Total      |
| 1      | Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")   | 8,562,031.            | 10,235,578.     | 10,105,837.            | 10,888,668.            | 8,480,494.     | 48,272,608.    |
| 2      | Tax revenues levied for the organization's benefit and either paid to or expended on its behalf  |                       |                 |                        |                        |                | 0.             |
| 3      | The value of services or facilities furnished by a governmental unit to the organization without charge  |                       |                 |                        |                        |                | 0.             |
| 4      | Total. Add lines 1 through 3   | 8,562,031.            | 10,235,578.     | 10,105,837.            | 10,888,668.            | 8,480,494.     | 48,272,608.    |
| 5      | The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount |                       |                 |                        |                        |                |                |
| _      | shown on line 11, column (f)   |                       |                 |                        |                        |                | 4,529,532.     |
| 6      | Public support. Subtract line 5 from line 4  |                       |                 |                        |                        |                | 43,743,076.    |
|        | tion B. Total Support  |                       |                 |                        |                        |                |                |
| Cale   | ndar year (or fiscal year beginning in)  | (a) 2016              | <b>(b)</b> 2017 | (c) 2018               | <b>(d)</b> 2019        | (e) 2020       | (f) Total      |
| 7<br>8 | Amounts from line 4.  Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources                  | 8,562,031.<br>11,983. | 10,235,578.     | 10,105,837.<br>32,605. | 10,888,668.<br>27,014. | 8,480,494.     | 48,272,608.    |
| 9      | Net income from unrelated business activities, whether or not the business is regularly carried on   |                       |                 |                        |                        |                | 0.             |
| 10     | Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) ATCH. 1  | 5,021.                | 23,362.         | 26,892.                | 101,289.               | 81,919.        | 238,483.       |
| 11     | Total support. Add lines 7 through 10  |                       |                 |                        |                        |                | 48,617,549.    |
| 12     | Gross receipts from related activities, etc. (s  | see instructions) .   |                 |                        |                        | 12             |                |
| 13     | First 5 years. If the Form 990 is for organization, check this box and stop here   | <u> </u>              |                 |                        |                        |                |                |
| Sec    | tion C. Computation of Public Sup  | •                     |                 |                        |                        |                | 00.07          |
| 14     | Public support percentage for 2020 (li   |                       | •               |                        |                        | 14             | 89.97 <b>%</b> |
| 15     | Public support percentage from 2019  |                       |                 |                        |                        | 15             | 92.92%         |
| 16a    | 331/3% support test - 2020. If the or  |                       |                 |                        |                        |                |                |
| _      | box and <b>stop here.</b> The organization q   |                       |                 |                        |                        |                |                |
| b      | 331/3% support test - 2019. If the org   |                       |                 |                        |                        |                |                |
| 47.    | this box and <b>stop here.</b> The organization  |                       |                 | _                      |                        |                |                |
| 1/a    | 10%-facts-and-circumstances test - 2   | _                     |                 |                        |                        |                |                |
|        | 10% or more, and if the organization   |                       |                 |                        |                        | -              | •              |
|        | Part VI how the organization meets   |                       |                 | _                      |                        | -              |                |
|        | organization   |                       |                 |                        |                        |                |                |
| a      | 10%-facts-and-circumstances test - 2   | _                     | =               |                        |                        |                |                |
|        | 15 is 10% or more, and if the organization most  |                       |                 |                        |                        |                |                |
|        | in Part VI how the organization meets  |                       |                 |                        |                        |                |                |
| 18     | organization   | on did not chec       | k a box on line | 13, 16a, 16b           | , 17a, or 17b,         | check this box | and see        |
|        | instructions   |                       |                 |                        |                        |                | <u> ▶ □</u>    |

Schedule A (Form 990 or 990-EZ) 2020 Page 3

#### Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

| Sec   | tion A. Public Support  |                 |                 | · 1             | '              | ,               |  |
|-------|---|-----------------|-----------------|-----------------|----------------|-----------------|--|
| Caler | ndar year (or fiscal year beginning in)   | (a) 2016        | <b>(b)</b> 2017 | (c) 2018        | (d) 2019       | (e) 2020        | (f) Total                              |
| 1     | Gifts, grants, contributions, and membership fees   |                 |                 |                 |                |                 |  |
|       | received. (Do not include any "unusual grants.")  |                 |                 |                 |                |                 |  |
| 2     | Gross receipts from admissions, merchandise   |                 |                 |                 |                |                 |  |
|       | sold or services performed, or facilities   |                 |                 |                 |                |                 |  |
|       | furnished in any activity that is related to the  |                 |                 |                 |                |                 |  |
|       | organization's tax-exempt purpose   |                 |                 |                 |                |                 |  |
| 3     | Gross receipts from activities that are not an  |                 |                 |                 |                |                 |  |
|       | unrelated trade or business under section 513   |                 |                 |                 |                |                 |  |
| 4     | Tax revenues levied for the   |                 |                 |                 |                |                 |  |
|       | organization's benefit and either paid to   |                 |                 |                 |                |                 |  |
|       | or expended on its behalf   |                 |                 |                 |                |                 |  |
| 5     | The value of services or facilities   |                 |                 |                 |                |                 |  |
|       | furnished by a governmental unit to the   |                 |                 |                 |                |                 |  |
|       | organization without charge   |                 |                 |                 |                |                 |  |
| 6     | Total. Add lines 1 through 5  |                 |                 |                 |                |                 |  |
|       | Amounts included on lines 1, 2, and 3   |                 |                 |                 |                |                 |  |
| . u   | received from disqualified persons  |                 |                 |                 |                |                 |  |
| b     | Amounts included on lines 2 and 3   |                 |                 |                 |                |                 |  |
|       | received from other than disqualified   |                 |                 |                 |                |                 |  |
|       | persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year                                  |                 |                 |                 |                |                 |  |
| c     | Add lines 7a and 7b   |                 |                 |                 |                |                 |  |
| 8     | Public support. (Subtract line 7c from  |                 |                 |                 |                |                 |  |
|       | line 6.)  |                 |                 |                 |                |                 |  |
| Sec   | tion B. Total Support   |                 |                 |                 |                |                 |  |
|       | ndar year (or fiscal year beginning in)   | (a) 2016        | <b>(b)</b> 2017 | (c) 2018        | (d) 2019       | <b>(e)</b> 2020 | (f) Total                              |
| 9     | Amounts from line 6   |                 |                 |                 |                |                 |  |
| 10 a  | Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar |                 |                 |                 |                |                 |  |
|       | sources   |                 |                 |                 |                |                 |  |
| b     | Unrelated business taxable income (less   |                 |                 |                 |                |                 |  |
|       | section 511 taxes) from businesses  |                 |                 |                 |                |                 |  |
|       | acquired after June 30, 1975  |                 |                 |                 |                |                 |  |
| С     | Add lines 10a and 10b   |                 |                 |                 |                |                 |  |
| 11    | Net income from unrelated business  |                 |                 |                 |                |                 |  |
|       | activities not included in line 10b, whether  |                 |                 |                 |                |                 |  |
|       | or not the business is regularly carried on.  |                 |                 |                 |                |                 |  |
| 12    | Other income. Do not include gain or  |                 |                 |                 |                |                 |  |
|       | loss from the sale of capital assets  |                 |                 |                 |                |                 |  |
|       | (Explain in Part VI.)   |                 |                 |                 |                |                 |  |
| 13    | Total support. (Add lines 9, 10c, 11,   |                 |                 |                 |                |                 |  |
|       | and 12.)  |                 |                 |                 |                |                 |  |
| 14    | First 5 years. If the Form 990 is for   | -               |                 |                 | •              |                 |  |
|       | organization, check this box and stop here.   |                 |                 |                 |                |                 | <u> ▶                             </u> |
|       | tion C. Computation of Public Supp  |                 |                 | (f))            |                | . <b>.</b>      |  |
| 15    | Public support percentage for 2020 (line 8,   |                 |                 |                 |                | 15              | <u>%</u>                               |
| 16    | Public support percentage from 2019 Sche  |                 |                 |                 |                | 16              | <u></u> %                              |
|       | tion D. Computation of Investment   |                 |                 | 40 1 ""         |                |                 |  |
| 17    | Investment income percentage for 2020 (lin  |                 |                 |                 |                | 17              | %                                      |
| 18    | Investment income percentage from 2019 S  |                 |                 |                 |                | 18              | %                                      |
| 19 a  | 331/3% support tests - 2020. If the org   | -               |                 |                 |                |                 |  |
| _     | 17 is not more than 331/3%, check this  |                 |                 |                 |                |                 |  |
| b     | 331/3% support tests - 2019. If the orga  |                 |                 |                 | •              |                 |  |
|       | line 18 is not more than 331/3%, check  |                 | •               | •               | . ,            |                 | <del></del>                            |
| 20    | Private foundation. If the organization d   | iia not check a | a box on line 1 | 4, 19a, or 19b, | check this box | and see instruc | tions                                  |

Schedule A (Form 990 or 990-EZ) 2020 Page 4

### Part IV Supporting Organizations

(Complete only if you checked a box in line 12 on Part I. If you checked box 12a, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, Part I, complete Sections A and D, and complete Part V.)

# Section A. All Supporting Organizations

- 1 Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in **Part VI** how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.

  2 Did the organization have any supported organization that does not have an IRS determination of status.
- 2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in **Part VI** how the organization determined that the supported organization was described in section 509(a)(1) or (2).
- **3a** Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer lines 3b and 3c below.
- **b** Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in **Part VI** when and how the organization made the determination.
- c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in **Part VI** what controls the organization put in place to ensure such use.
- 4a Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.
- **b** Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in **Part VI** how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.
- c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in **Part VI** what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.
- 5a Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in **Part VI**, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).
- **b** Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?
- c Substitutions only. Was the substitution the result of an event beyond the organization's control?
- 6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in **Part VI.**
- 7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).
- 8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).
- 9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in **Part VI.**
- **b** Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in **Part VI.**
- c Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in **Part VI.**
- 10 a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.
  - Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)

|           |      | Yes | No  |
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|----------|--|----------|-------|-------|
| Part     | Supporting Organizations (continued)   |          |       |       |
|          |  |          | Yes   | No    |
| 11       | Has the organization accepted a gift or contribution from any of the following persons?  |          |       |       |
| а        | A person who directly or indirectly controls, either alone or together with persons described in lines 11b and 11c below, the governing body of a supported organization?  | 11a      |       |       |
| b        | A family member of a person described in line 11a above?   | 11b      |       |       |
|          | A 35% controlled entity of a person described in line 11a above? If "Yes" to line 11a, 11b, or 11c, provide  | 110      |       |       |
| ·        | detail in <b>Part VI.</b>  | 11c      |       |       |
| Section  | on B. Type I Supporting Organizations  |          |       |       |
|          | - Are express 5 - 5 - 5 - 5 - 5 - 5 - 5 - 5 - 5 - 5  |          | Yes   | No    |
| 1        | Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or   |          |       |       |
| •        | more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers,  |          |       |       |
|          | directors, or trustees at all times during the tax year? If "No," describe in <b>Part VI</b> how the supported organization(s)   |          |       |       |
|          | effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported   |          |       |       |
|          | organization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the   |          |       |       |
|          | supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.   | 1        |       |       |
| 2        | Did the organization operate for the benefit of any supported organization other than the supported  |          |       |       |
|          | organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part  |          |       |       |
|          | VI how providing such benefit carried out the purposes of the supported organization(s) that operated,   |          |       |       |
| <u> </u> | supervised, or controlled the supporting organization.   | 2        |       |       |
| Section  | on C. Type II Supporting Organizations   |          | Vaa   | Na    |
| _        |  |          | Yes   | NO    |
| 1        | Were a majority of the organization's directors or trustees during the tax year also a majority of the directors   |          |       |       |
|          | or trustees of each of the organization's supported organization(s)? If "No," describe in <b>Part VI</b> how control or management of the supporting organization was vested in the same persons that controlled or managed              |          |       |       |
|          | the supported organization(s).   | 1        |       |       |
| Section  | on D. All Type III Supporting Organizations  | <u> </u> |       |       |
|          | 51. 21. 7.11. Typo III oupporting of garinearions  |          | Yes   | No    |
| 1        | Did the organization provide to each of its supported organizations, by the last day of the fifth month of the   |          |       |       |
|          | organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of |          |       |       |
|          | the organization's governing documents in effect on the date of notification, to the extent not previously   |          |       |       |
|          | provided?  | 1        |       |       |
| 2        | Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported   |          |       |       |
|          | organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how   |          |       |       |
|          | the organization maintained a close and continuous working relationship with the supported organization(s).  | 2        |       |       |
| 3        | By reason of the relationship described in line 2, above, did the organization's supported organizations have  |          |       |       |
|          | a significant voice in the organization's investment policies and in directing the use of the organization's   |          |       |       |
|          | income or assets at all times during the tax year? If "Yes," describe in <b>Part VI</b> the role the organization's  |          |       |       |
|          | supported organizations played in this regard.   | 3        |       |       |
|          | on E. Type III Functionally Integrated Supporting Organizations  |          |       |       |
| 1        | Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see ins   | tructi   | ons). |       |
| a        | The organization satisfied the Activities Test. Complete <b>line 2</b> below.  |          |       |       |
| b        | The organization is the parent of each of its supported organizations. Complete <b>line 3</b> below.   | a laat   |       | ۵۱    |
| С        | The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see   | e instr  | Yes   |       |
| 2        | Activities Test. Answer lines 2a and 2b below.   |          | 169   | NO    |
| а        | Did substantially all of the organization's activities during the tax year directly further the exempt purposes of   |          |       |       |
|          | the supported organization(s) to which the organization was responsive? If "Yes," then in <b>Part VI identify</b>  |          |       |       |
|          | those supported organizations and explain how these activities directly furthered their exempt purposes,   |          |       |       |
|          | how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.   | 2a       |       |       |
| -        |  | _u       |       |       |
| b        | Did the activities described in line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in         |          |       |       |
|          | Part VI the reasons for the organization's position that its supported organization(s) would have engaged in   |          |       |       |
|          | these activities but for the organization's involvement.   | 2b       |       |       |
| 3        | Parent of Supported Organizations. Answer lines 3a and 3b below.   |          |       |       |
| a        | Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or  |          |       |       |
| -        | trustees of each of the supported organizations? If "Yes" or "No," provide details in <b>Part VI.</b>  | 3a       |       |       |
| b        | Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each  |          |       |       |
|          | of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.  | 3b       |       |       |

Page 6 Schedule A (Form 990 or 990-EZ) 2020

| Pa | art V Type III Non-Functionally Integrated 509(a)(3) Supporting Organ  | nizations      | S                           |                                |
|----|--|----------------|-----------------------------|--------------------------------|
| 1  | Check here if the organization satisfied the Integral Part Test as a qualifying  | g trust on     | Nov. 20, 1970 (expla        | in in <b>Part VI</b> ). See    |
|    | instructions. All other Type III non-functionally integrated supporting organi   | zations n      | nust complete Sectio        | ns A through E.                |
| Se | ection A - Adjusted Net Income   | (A) Prior Year | (B) Current Year (optional) |                                |
| 1  | Net short-term capital gain  | 1              |                             |                                |
| 2  | Recoveries of prior-year distributions   | 2              |                             |                                |
| 3  | Other gross income (see instructions)  | 3              |                             |                                |
| 4  | Add lines 1 through 3.   | 4              |                             |                                |
| 5  | Depreciation and depletion   | 5              |                             |                                |
| 6  | Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions) | 6              |                             |                                |
| _7 | Other expenses (see instructions)  | 7              |                             |                                |
| 8  | Adjusted Net Income (subtract lines 5, 6, and 7 from line 4)   | 8              |                             |                                |
| Se | ection B - Minimum Asset Amount  |                | (A) Prior Year              | (B) Current Year<br>(optional) |
| 1  | Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):  |                |                             |                                |
| a  | Average monthly value of securities  | 1a             |                             |                                |
| b  | Average monthly cash balances  | 1b             |                             |                                |
| C  | Fair market value of other non-exempt-use assets   | 1c             |                             |                                |
| d  | I Total (add lines 1a, 1b, and 1c)   | 1d             |                             |                                |
|    |  |                |                             |                                |
|    | Discount claimed for blockage or other factors (explain in detail in Part VI):   | 1e             |                             |                                |
| 2  | Acquisition indebtedness applicable to non-exempt-use assets   | 2              |                             |                                |
| 3  | Subtract line 2 from line 1d.  | 3              |                             |                                |
| 4  | Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).   | 4              |                             |                                |
| 5  | Net value of non-exempt-use assets (subtract line 4 from line 3)   | 5              |                             |                                |
| 6  | Multiply line 5 by 0.035.  | 6              |                             |                                |
| 7  | Recoveries of prior-year distributions   | 7              |                             |                                |
| 8  | Minimum Asset Amount (add line 7 to line 6)  | 8              |                             |                                |
| Se | ection C - Distributable Amount  |                |                             | Current Year                   |
| 1  | Adjusted net income for prior year (from Section A, line 8, column A)  | 1              |                             |                                |
|    | Enter 0.85 of line 1.  | 2              |                             |                                |
| 3  | Minimum asset amount for prior year (from Section B, line 8, column A)   | 3              |                             |                                |
| 4  | Enter greater of line 2 or line 3.   | 4              |                             |                                |
| 5  | Income tax imposed in prior year   | 5              |                             |                                |
| 6  | Distributable Amount. Subtract line 5 from line 4, unless subject to   |                |                             |                                |
|    | emergency temporary reduction (see instructions).  | 6              |                             |                                |
| 7  | Check here if the current year is the organization's first as a non-functional   | ly integra     | ted Type III supporting     | g organization                 |
|    | (see instructions).  |                |                             | · <del>-</del>                 |

Schedule A (Form 990 or 990-EZ) 2020

Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Schedule A (Form 990 or 990-EZ) 2020

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| Secti    | ction D - Distributions Current Year                         |                                    |                                       |    |   |  |  |  |  |
|----------|--|------------------------------------|---------------------------------------|----|---|--|--|--|--|
| 1        | Amounts paid to supported organizations to accomplish ex     | 1                                  |                                       |    |   |  |  |  |  |
| 2        | Amounts paid to perform activity that directly furthers exen |                                    |                                       |    |   |  |  |  |  |
|          | organizations, in excess of income from activity             | 2                                  |                                       |    |   |  |  |  |  |
| 3        | Administrative expenses paid to accomplish exempt purpo      | ses of supported organiz           | zations                               | 3  |   |  |  |  |  |
| 4        | Amounts paid to acquire exempt-use assets                    |                                    |                                       | 4  |   |  |  |  |  |
| 5        | Qualified set-aside amounts (prior IRS approval required - p | rovide details in <b>Part VI</b> ) |                                       | 5  |   |  |  |  |  |
| 6        | Other distributions (describe in Part VI). See instructions. |                                    |                                       | 6  |   |  |  |  |  |
| 7        | Total annual distributions. Add lines 1 through 6.           |                                    |                                       | 7  |   |  |  |  |  |
| 8        | Distributions to attentive supported organizations to which  | the organization is resp           | onsive                                |    |   |  |  |  |  |
|          | (provide details in Part VI). See instructions.              |                                    |                                       | 8  |   |  |  |  |  |
| 9        | Distributable amount for 2020 from Section C, line 6         |                                    |                                       | 9  |   |  |  |  |  |
| 10       | Line 8 amount divided by line 9 amount                       |                                    |                                       | 10 |   |  |  |  |  |
| Secti    | on E - Distribution Allocations (see instructions)           | (i)<br>Excess Distributions        | (ii)<br>Underdistributior<br>Pre-2020 | ns | (iii)<br>Distributable<br>Amount for 2020 |  |  |  |  |
| 1        | Distributable amount for 2020 from Section C, line 6         |                                    |                                       |    |   |  |  |  |  |
| 2        | Underdistributions, if any, for years prior to 2020          |                                    |                                       |    |   |  |  |  |  |
|          | (reasonable cause required - explain in Part VI). See        |                                    |                                       |    |   |  |  |  |  |
|          | instructions.  |                                    |                                       |    |   |  |  |  |  |
| 3        | Excess distributions carryover, if any, to 2020              |                                    |                                       |    |   |  |  |  |  |
| а        | From 2015  |                                    |                                       |    |   |  |  |  |  |
| b        | From 2016  |                                    |                                       |    |   |  |  |  |  |
| С        | From 2017  |                                    |                                       |    |   |  |  |  |  |
| d        |  |                                    |                                       |    |   |  |  |  |  |
| е        | From 2019  |                                    |                                       |    |   |  |  |  |  |
| f        | Total of lines 3a through 3e                                 |                                    |                                       |    |   |  |  |  |  |
| g        | Applied to underdistributions of prior years                 |                                    |                                       |    |   |  |  |  |  |
| h        | Applied to 2020 distributable amount                         |                                    |                                       |    |   |  |  |  |  |
| i        | Carryover from 2015 not applied (see instructions)           |                                    |                                       |    |   |  |  |  |  |
| j        | Remainder. Subtract lines 3g, 3h, and 3i from line 3f.       |                                    |                                       |    |   |  |  |  |  |
| 4        | Distributions for 2020 from                                  |                                    |                                       |    |   |  |  |  |  |
|          | Section D, line 7: \$  |                                    |                                       |    |   |  |  |  |  |
| а        | Applied to underdistributions of prior years                 |                                    |                                       |    |   |  |  |  |  |
| b        | Applied to 2020 distributable amount                         |                                    |                                       |    |   |  |  |  |  |
| с        | Remainder. Subtract lines 4a and 4b from line 4.             |                                    |                                       |    |   |  |  |  |  |
| 5        | Remaining underdistributions for years prior to 2020, if     |                                    |                                       |    |   |  |  |  |  |
|          | any. Subtract lines 3g and 4a from line 2. For result        |                                    |                                       |    |   |  |  |  |  |
|          | greater than zero, explain in Part VI. See instructions.     |                                    |                                       |    |   |  |  |  |  |
| 6        | Remaining underdistributions for 2020. Subtract lines 3h     |                                    |                                       |    |   |  |  |  |  |
|          | and 4b from line 1. For result greater than zero, explain in |                                    |                                       |    |   |  |  |  |  |
|          | Part VI. See instructions.                                   |                                    |                                       |    |   |  |  |  |  |
| 7        | Excess distributions carryover to 2021. Add lines 3j         |                                    |                                       |    |   |  |  |  |  |
|          | and 4c.  |                                    |                                       |    |   |  |  |  |  |
| 8        | Breakdown of line 7:   |                                    |                                       |    |   |  |  |  |  |
| a        | Excess from 2016   |                                    |                                       |    |   |  |  |  |  |
| b        | Excess from 2017   |                                    |                                       |    |   |  |  |  |  |
| <u>c</u> | Excess from 2018   |                                    |                                       |    |   |  |  |  |  |
| d        | Excess from 2019   |                                    |                                       |    |   |  |  |  |  |
| 6        | Fxcess from 2020   |                                    |                                       |    |   |  |  |  |  |

Schedule A (Form 990 or 990-EZ) 2020

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Schedule A (Form 990 or 990-EZ) 2020

Part VI Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.)

|                       |              |         |         |          | ATTACHMENT 1 |          |
|-----------------------|--------------|---------|---------|----------|--------------|----------|
| SCHEDULE A, PART II - | OTHER INCOME | Ξ       |         |          |              |          |
|                       |              |         |         |          |              |          |
| DESCRIPTION           | 2016         | 2017    | 2018    | 2019     | 2020         | TOTAL    |
| MISCELLAENOUS         | 5,021.       | 23,362. | 26,892. | 101,289. | 81,919.      | 238,483. |
| MISCELLAENOUS         | 5,021.       | 23,362. | 20,692. | 101,209. | 01,919.      | 230,403. |
| TOTALS                | 5,021.       | 23,362. | 26,892. | 101,289. | 81,919.      | 238,483. |

# Schedule B

(Form 990, 990-EZ, or 990-PF)

Department of the Treasury Internal Revenue Service

Name of the organization

### Schedule of Contributors

► Attach to Form 990, Form 990-EZ, or Form 990-PF. ► Go to www.irs.gov/Form990 for the latest information. OMB No. 1545-0047

**2020** 

**Employer identification number** 

HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. 13-3349872 Organization type (check one): Filers of: Section: X Form 990 or 990-EZ 501(c)(3 ) (enter number) organization 4947(a)(1) nonexempt charitable trust not treated as a private foundation 527 political organization Form 990-PF 501(c)(3) exempt private foundation 4947(a)(1) nonexempt charitable trust treated as a private foundation 501(c)(3) taxable private foundation Check if your organization is covered by the General Rule or a Special Rule. Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions. **General Rule** For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions. **Special Rules** [X] For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000; or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II. For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 exclusively for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III. For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions exclusively for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc., purpose. Don't complete any of the parts unless the General Rule applies to this organization because it received nonexclusively religious, charitable, etc., contributions Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990. 990-EZ, or 990-PF), but it must answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its

Form 990-PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

For Paperwork Reduction Act Notice, see the instructions for Form 990, 990-EZ, or 990-PF.

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)

Name of organization HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.

Employer identification number 13-3349872

| art I | Contributors (see inst | ructions). Use duplicate | e copies of Part I if add | ditional space is needed. |
|-------|------------------------|--------------------------|---------------------------|---------------------------|
|-------|------------------------|--------------------------|---------------------------|---------------------------|

| (a)<br>No. | (b)<br>Name, address, and ZIP + 4 | (c)<br>Total contributions | (d)<br>Type of contribution   |
|------------|-----------------------------------|----------------------------|---|
| 1_         | N/A                               | \$1,577,568.               | Person Payroll Noncash (Complete Part II for noncash contributions.)    |
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4 | (c)<br>Total contributions | (d)<br>Type of contribution   |
| 2          | N/A                               | \$                         | Person  Payroll  Noncash  (Complete Part II for noncash contributions.) |
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4 | (c)<br>Total contributions | (d)<br>Type of contribution   |
| 3          | N/A                               | \$\$85,000.                | Person Payroll Noncash  (Complete Part II for noncash contributions.)   |
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4 | (c) Total contributions    | (d)<br>Type of contribution   |
| 4          | N/A                               | \$                         | Person Payroll Noncash (Complete Part II for noncash contributions.)    |
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4 | (c)<br>Total contributions | (d)<br>Type of contribution   |
| 5          | N/A                               | \$\$                       | Person Payroll Noncash (Complete Part II for noncash contributions.)    |
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4 | (c)<br>Total contributions | (d)<br>Type of contribution   |
| 6          | N/A                               | \$191,500.                 | Person Payroll Noncash (Complete Part II for noncash contributions.)    |

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)

Name of organization HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.

Employer identification number 13-3349872

| Part I     | Contributors (see instructions). Use duplicate copie | es of Part I if additional space is no | eeded.   |
|------------|--|--|--|
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4                    | (c)<br>Total contributions             | (d)<br>Type of contribution  |
| 7          | N/A  | \$\$\$                                 | Person Payroll Noncash (Complete Part II for noncash contributions.) |
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4                    | (c)<br>Total contributions             | (d)<br>Type of contribution  |
|            |  | \$                                     | Person Payroll Noncash (Complete Part II for noncash contributions.) |
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4                    | (c)<br>Total contributions             | (d)<br>Type of contribution  |
|            |  |  | Person Payroll Noncash (Complete Part II for noncash contributions.) |
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4                    | (c)<br>Total contributions             | (d)<br>Type of contribution  |
|            |  | \$                                     | Person Payroll Noncash (Complete Part II for noncash contributions.) |
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4                    | (c)<br>Total contributions             | (d)<br>Type of contribution  |
|            |  | \$                                     | Person Payroll Noncash (Complete Part II for noncash contributions.) |
| (a)<br>No. | (b)<br>Name, address, and ZIP + 4                    | (c)<br>Total contributions             | (d)<br>Type of contribution  |
|            |  | \$                                     | Person Payroll Noncash (Complete Part II for noncash contributions.) |

Name of organization HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.

**Employer identification number** 13-3349872

Part II Noncash Property (see instructions). Use duplicate copies of Part II if additional space is needed.

| (a) No.<br>from<br>Part I | (b)  Description of noncash property given | (c) FMV (or estimate) (See instructions.) | (d)<br>Date received |
|---------------------------|--|---|----------------------|
|                           |  | \$  |                      |
| (a) No.<br>from<br>Part I | (b) Description of noncash property given  | (c) FMV (or estimate) (See instructions.) | (d)<br>Date received |
|                           |  | \$  |                      |
| (a) No.<br>from<br>Part I | (b) Description of noncash property given  | (c) FMV (or estimate) (See instructions.) | (d)<br>Date received |
|                           |  | \$  |                      |
| (a) No.<br>from<br>Part I | (b) Description of noncash property given  | (c) FMV (or estimate) (See instructions.) | (d)<br>Date received |
|                           |  | \$  |                      |
| (a) No.<br>from<br>Part I | (b) Description of noncash property given  | (c) FMV (or estimate) (See instructions.) | (d)<br>Date received |
|                           |  | \$  |                      |
| (a) No.<br>from<br>Part I | (b) Description of noncash property given  | (c) FMV (or estimate) (See instructions.) | (d)<br>Date received |
|                           |  | \$  |                      |

Name of organization HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. Employer identification number 13-3349872 Part III Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this information once. See instructions.) ▶\$ Use duplicate copies of Part III if additional space is needed. from (b) Purpose of gift (c) Use of gift (d) Description of how gift is held Part I (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee (a) No. from (b) Purpose of gift (c) Use of gift (d) Description of how gift is held (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee (a) No. from (b) Purpose of gift (c) Use of gift (d) Description of how gift is held Part I (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee (a) No. (b) Purpose of gift (c) Use of gift (d) Description of how gift is held from Part I (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee

### **SCHEDULE D** (Form 990)

# Supplemental Financial Statements ► Complete if the organization answered "Yes" on Form 990,

Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.

► Attach to Form 990.

► Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047 **Open to Public** Inspection

Department of the Treasury Internal Revenue Service Name of the organization

Employer identification number

| HUI | NTINGTON'S DISEASE SOCIETY OF AMERICA, INC.   | 13-3349872   |
|-----|---|--|
| Pa  | organizations Maintaining Donor Advised Funds or Other Similar Funds or   | r Accounts.  |
|     | Complete if the organization answered "Yes" on Form 990, Part IV, line 6.   |  |
|     | (a) Donor advised funds   | (b) Funds and other accounts   |
| 1   | Total number at end of year   |  |
| 2   | Aggregate value of contributions to (during year)   |  |
| 3   | Aggregate value of grants from (during year)  |  |
| 4   | Aggregate value at end of year  |  |
| 5   | Did the organization inform all donors and donor advisors in writing that the assets held   | in donor advised   |
|     | funds are the organization's property, subject to the organization's exclusive legal control? .   |  |
| 6   | Did the organization inform all grantees, donors, and donor advisors in writing that grant f  |  |
|     | only for charitable purposes and not for the benefit of the donor or donor advisor, or for a  |  |
|     | conferring impermissible private benefit?   |  |
| Pa  | art II Conservation Easements.  |  |
|     | Complete if the organization answered "Yes" on Form 990, Part IV, line 7.   |  |
| 1   | Purpose(s) of conservation easements held by the organization (check all that apply).   |  |
|     | Preservation of land for public use (for example, recreation or education)  | of a historically important land area  |
|     | Protection of natural habitat Preservation  | of a certified historic structure  |
|     | Preservation of open space  |  |
| 2   | Complete lines 2a through 2d if the organization held a qualified conservation contribution in  | the form of a conservation   |
|     | easement on the last day of the tax year.   | Held at the End of the Tax Year  |
| а   | Total number of conservation easements  | 2a   |
| b   | Total acreage restricted by conservation easements  | 2b   |
| С   | Number of conservation easements on a certified historic structure included in (a)  | 2c   |
| d   | Number of conservation easements included in (c) acquired after 7/25/06, and not on a   |  |
|     | historic structure listed in the National Register  | 2d   |
| 3   | Number of conservation easements modified, transferred, released, extinguished, or term   | inated by the organization during the  |
|     | tax year <b>&gt;</b>  |  |
| 4   | Number of states where property subject to conservation easement is located ▶   |  |
| 5   | Does the organization have a written policy regarding the periodic monitoring, inspect  | tion, handling of  |
|     | violations, and enforcement of the conservation easements it holds?   | Yes No   |
| 6   | Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing  | conservation easements during the year                                       |
|     | <b>&gt;</b>   |  |
| 7   | Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing of   | conservation easements during the year                                       |
|     | <b>▶</b> \$   |  |
| 8   | Does each conservation easement reported on line 2(d) above satisfy the requirements of sect  |  |
|     | and section 170(h)(4)(B)(ii)?   | Yes  No  |
| 9   | In Part XIII, describe how the organization reports conservation easements in its revenue an  |  |
|     | balance sheet, and include, if applicable, the text of the footnote to the organization's finance   | ial statements that describes the  |
|     | organization's accounting for conservation easements.   | v Civallan Assats  |
| Ρá  | Organizations Maintaining Collections of Art, Historical Treasures, or Othe Complete if the organization answered "Yes" on Form 990, Part IV, line 8.   | er Similar Assets.   |
| _   |   |  |
| 1a  | If the organization elected, as permitted under FASB ASC 958, not to report in its revenu of art, historical treasures, or other similar assets held for public exhibition, education,  | le statement and balance sheet works<br>or research in furtherance of public |
| 1.  | service, provide in Part XIII the text of the footnote to its financial statements that describes t   |  |
| b   | If the organization elected, as permitted under FASB ASC 958, to report in its revenue s art, historical treasures, or other similar assets held for public exhibition, education, or resprovide the following amounts relating to these items: | search in furtherance of public service,                                     |
|     | (i) Revenue included on Form 990, Part VIII, line 1   |  |
|     | (ii) Assets included in Form 990, Part X  |  |
| 2   | If the organization received or held works of art, historical treasures, or other similar   | assets for financial gain, provide the                                       |
|     | following amounts required to be reported under FASB ASC 958 relating to these items:   |  |
| а   | Revenue included on Form 990, Part VIII, line 1   | <b>&gt;</b> \$   |
| b   | Assets included in Form 990, Part X   | <b>▶</b> \$  |

Schedule D (Form 990) 2020

|  | Page <b>2</b> |
|--|---------------|
|  | Page Z        |

| Pa        | rt III Organizations Maintaini   | ng Collections of      | Art, Historic       | cal Tre    | asures, o     | r Other  | Similar As      | sets (co | ontinu   | ed)            |        |
|-----------|--|------------------------|---------------------|------------|---------------|----------|-----------------|----------|----------|----------------|--------|
| 3         | Using the organization's acquisition   | n, accession, and c    | ther records        | , check    | any of the    | e follow | ing that ma     | ke signi | ficant   | use c          | of its |
|           | collection items (check all that app   | ly):                   |                     |            |               |          |                 |          |          |                |        |
| а         | Public exhibition  |                        | d                   | Loan o     | r exchange    | prograi  | m               |          |          |                |        |
| b         | Scholarly research   |                        | е 🗍                 | Other      |               |          |                 |          |          |                |        |
| С         |  | rations                |                     | -          |               |          |                 |          |          |                |        |
| 4         |  |                        | and explain         | how t      | hey further   | the or   | ganization's    | exempt   | purpo    | se in          | Part   |
|           |  |                        | •                   |            | ,             | •        | 3               |          |          |                |        |
| 5         | During the year, did the organization  | n solicit or receive d | lonations of a      | art. histo | orical treasu | ures. or | other similar   |          |          |                |        |
|           |  |                        |                     |            |               |          |                 | _        | Yes      |                | No     |
| Pa        |  |                        |                     |            | 3             |          |                 |          |          |                |        |
|           | Complete if the organiza   |                        | s" on Form          | 990, P     | art IV, line  | 9, or r  | eported an      | amoun    | t on F   | orm            |        |
| 1a        | <u> </u>   | tee, custodian or of   | ther intermed       | diarv fo   | r contribut   | ions or  | other assets    | s not    |          |                |        |
|           |  |                        |                     | -          |               |          |                 |          | Yes      |                | No     |
| b         | If "Yes." explain the arrangement i  | n Part XIII and comp   | lete the follo      | wing tab   | le:           |          |                 |          |          |                |        |
|           |  |                        |                     | 9          |               |          | Α               | mount    |          |                |        |
| С         | Beginning balance  |                        |                     |            | 10            |          |                 |          |          |                |        |
| d         |  |                        |                     |            |               |          |                 |          |          |                |        |
| е.        |  |                        |                     |            |               |          |                 |          |          |                |        |
| f         |  |                        |                     |            |               |          |                 |          |          |                |        |
| _         |  |                        |                     |            |               | ıstodial | account liahi   | lity?    | Yes      |                | No     |
|           | =  |                        |                     |            |               |          |                 | -        |          |                |        |
|           |  | TT GIT XIII. OHOOK III | ore in the expi     | anation    | nao boon p    | TOVIACA  | on are zum      |          |          |                |        |
| ıa        |  | ition answered "Ye     | s" on Form          | 990 P      | art IV line   | 10       |                 |          |          |                |        |
|           | Complete ii the organize   |                        |                     |            |               |          | (d) Three year  | re back  | (a) Fou  | r voare        | hack   |
|           |  |                        |                     |            |               |          |                 |          |          |                |        |
| 1 a       |  | 200,001.               | 200,                | 300.       | 207           | , 131.   | 201,            | 077.     |          | 201,           |        |
| b         |  |                        |                     |            |               |          |                 |          |          |                |        |
| С         |  | ٥٤                     |                     | 166        | 1             | 075      | 2               | E E 1    |          | 17             | 004    |
|           |  | -95.                   |                     | 455.       |               | ,075.    | ۷,              | 334.     |          | -              | . 004. |
| d         |  |                        |                     |            |               |          |                 |          |          |                |        |
| е         |  |                        |                     |            |               |          |                 |          |          |                |        |
|           | and programs   |                        |                     |            |               |          |                 |          |          |                |        |
| f         | Administrative expenses  | 060 066                | 0.60                | 0.61       | 0.60          | 506      | 0.65            | 421      |          | 0.6.4          | 0.7.7  |
| g         | End of year balance  | 268,866.               | 268,                | 961.       | 268           | ,506.    | 267,            | 431.     |          | 264,           | 877.   |
|           | Board designated or quasi-endown   | nent >                 | end balance (<br>_% | line 1g,   | column (a))   | held as  | :               |          |          |                |        |
| b         | Permanent endowment ► 92.9   | <u>800</u> %           |                     |            |               |          |                 |          |          |                |        |
| С         | Term endowment ▶ 7.0200  | %                      |                     |            |               |          |                 |          |          |                |        |
|           | The percentages on lines 2a, 2b, a   | ind 2c should equal 1  | 00%.                |            |               |          |                 |          |          |                |        |
| 3a        | Are there endowment funds not in   | the possession of th   | e organization      | on that a  | are held an   | ıd admir | nistered for th | e        |          |                |        |
|           | organization by:   |                        |                     |            |               |          |                 |          |          | Yes            | No     |
|           | (i) Unrelated organizations  |                        |                     |            |               |          |                 |          | 3a(i)    |                | X      |
|           | (ii) Related organizations   |                        |                     |            |               |          |                 |          | 3a(ii)   |                | X      |
| b         | If "Yes" on line 3a(ii), are the relate  | ed organizations liste | d as required       | on Sche    | edule R?      |          |                 |          | 3b       |                |        |
| 4         | Preservation for future generations  Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.  During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? |                        |                     |            |               |          |                 |          |          |                |        |
| Pa        | rt VI Land, Buildings, and Equ<br>Complete if the organize   | ipment.                |                     |            |               | e 11a. S | See Form 9      | 90, Par  | t X, lir | e 10           |        |
|           | Description of property  |                        |                     |            |               | (c) Acc  | cumulated       | (d)      | Book va  | alue           |        |
| 1.0       | Land   | ,                      | ment)               | (01        | iriel)        | аерг     | ecialion        |          |          |                |        |
| _         |  |                        |                     |            |               |          |                 |          |          |                |        |
|           | •  |                        |                     |            | 65 856        |          | 59 951          |          |          | 5 (            | 205    |
| _         | •  |                        |                     |            |               | 2        |                 |          |          |                |        |
| a         | • •  |                        |                     |            |               |          |                 |          |          | ∠ <b>I</b> , ( | , 11.  |
| e<br>Tota |  |                        | 000 Dort V          |            |               |          |                 |          |          | 20 0           | 146    |
| iota      | n. Add iiiles Ta liiiluugii Te. (Colulliii   | (u) musi eyual FOM     | ィョョン, Fall 入,       | COIUIIII   | ווווע ולים) ו | <i></i>  |                 |          |          | د, دے          | , TO.  |

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| Part VII         | Investments - Other Securities.  Complete if the organization answered | "Yes" on Form 990       | Part IV line 11h See Form 990 Pa                          | ort X line 12                                |
|------------------|--|-------------------------|---|--|
|                  | (a) Description of security or category (including name of security)   | (b) Book value          | (c) Method of valuation:<br>Cost or end-of-year market va |  |
| (1) Financi      | al derivatives   |                         |   |  |
| (2) Closely      | held equity interests  |                         |   |  |
| (3) Other _      |  |                         |   |  |
| (A)              |  |                         |   |  |
| (B)              |  |                         |   |  |
| (C)              |  |                         |   |  |
| (D)              |  |                         |   |  |
| (E)              |  |                         |   |  |
| (F)              |  |                         |   |  |
| (G)              |  |                         |   |  |
| (H)              |  |                         |   |  |
|                  | n (b) must equal Form 990, Part X, col. (B) line 12.)                  |                         |   |  |
| Part VIII        | Investments - Program Related.  Complete if the organization answered  | "Yes" on Form 990       | . Part IV. line 11c. See Form 990. Pa                     | rt X. line 13.                               |
|                  | (a) Description of investment  | (b) Book value          | (c) Method of valuation: Cost or end-of-year market va    | •  |
| (1)              |  |                         | Cost or end-or-year market va                             | alue<br>———————————————————————————————————— |
| (2)              |  |                         |   |  |
| (3)              |  |                         |   |  |
| (4)              |  |                         |   |  |
| (5)              |  |                         |   |  |
| (6)              |  |                         |   |  |
| (7)              |  |                         |   |  |
| (8)              |  |                         |   |  |
| (9)              |  |                         |   |  |
|                  | n (b) must equal Form 990, Part X, col. (B) line 13.)                  |                         |   |  |
| Part IX          | Other Assets.  |                         |   |  |
|                  | Complete if the organization answered                                  | "Yes" on Form 990       | , Part IV, line 11d. See Form 990, Pa                     | ırt X, line 15.                              |
|                  |  | scription               |   | (b) Book value                               |
| (1)              |  | ·                       |   |  |
| (2)              |  |                         |   |  |
| (3)              |  |                         |   |  |
| (4)              |  |                         |   |  |
| (5)              |  |                         |   |  |
| (6)              |  |                         |   |  |
| (7)              |  |                         |   |  |
| (8)              |  |                         |   |  |
| (9)              |  |                         |   |  |
|                  | umn (b) must equal Form 990, Part X, col. (B) li                       | ne 15.)                 |   |  |
| Part X           | Other Liabilities.   |                         |   |  |
|                  | Complete if the organization answered line 25.                         | "Yes" on Form 990       | , Part IV, line 11e or 11f. See Form 9                    | 90, Part X,                                  |
| 1.               | (a) Descrip  | tion of liability       |   | (b) Book value                               |
|                  | ral income taxes   |                         |   |  |
| _ ` '            | RRED RENT  |                         |   | 114,721.                                     |
| (3) OBLI         | GATION UNDER CAPITAL LEASE   |                         |   | 3,734  |
| (4)              |  |                         |   |  |
| (5)              |  |                         |   |  |
| (6)              |  |                         |   |  |
| (7)              |  |                         |   |  |
| (8)              |  |                         |   |  |
| (9)              |  |                         |   |  |
| Total. (Colur    | mn (b) must equal Form 990, Part X, col. (B) line 25.)                 |                         |   | 118,455.                                     |
| 2. Liability for | or uncertain tax positions. In Part XIII, provide the                  | text of the footnote to | the organization's financial statements that i            | reports the                                  |

organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII

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|           | C D (1 0111 000) 2020   |         | 1 age 4                  |
|-----------|---|---------|--------------------------|
| Part      | Reconciliation of Revenue per Audited Financial Statements With Revenue per Returnation Complete if the organization answered "Yes" on Form 990, Part IV, line 12a. | n.      |                          |
|           |   | 1       | 8,970,625.               |
| 1<br>2    | Total revenue, gains, and other support per audited financial statements  | •       |                          |
| a         | Net unrealized gains (losses) on investments  |         |                          |
| b         | Donated services and use of facilities  |         |                          |
| C         | Recoveries of prior year grants   |         |                          |
| d         | Other (Describe in Part XIII.)  |         |                          |
| е         | Add lines 2a through 2d   | 2e      | 1,962,840.               |
| 3         | Subtract line 2e from line 1  | 3       | 7,007,785.               |
| 4         | Amounts included on Form 990, Part VIII, line 12, but not on line 1:  |         |                          |
| a         | 1 E77 E60   | -       |                          |
| b<br>C    | Other (Describe in Part XIII.)  | 4c      | 1,579,161.               |
| 5         | Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)   | 5       | 8,586,946.               |
| Part      | XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Retu  | ırn.    |                          |
|           | Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.   |         |                          |
| 1         | Total expenses and losses per audited financial statements  | 1       | 8,781,587.               |
| 2         | Amounts included on line 1 but not on Form 990, Part IX, line 25:  Donated services and use of facilities   2a   31,708.  |         |                          |
| a         | Donated Services and use of Identities 1.1.1.1.1.1.1.1.1.1.1.1.1.1.1.1.1.1.1.   | -       |                          |
| b         | Prior year adjustments  | -       |                          |
| ۲<br>C    | Other losses         2c           Other (Describe in Part XIII.)         2d         2,096,845   | -       |                          |
| d<br>e    | Add lines 2a through 2d   | 2e      | 2,128,553.               |
| 3         | Subtract line 2e from line 1  | 3       | 6,653,034.               |
| 4         | Amounts included on Form 990, Part IX, line 25, but not on line 1:  |         |                          |
| а         | Investment expenses not included on Form 990. Part VIII. line 7b 4a 1,593.  |         |                          |
| b         | Other (Describe in Part XIII.)  |         | 1 550 161                |
| _ c       | Add lines 4a and 4b   | 4c      | 1,579,161.<br>8,232,195. |
| 5<br>Port | Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)  | 5       | 0,232,195.               |
|           | e the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; F   | Part V. | line 4: Part X. line     |
|           | XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional inform  |         |                          |
| SEE       | PAGE 5  |         |                          |
|           |   |         |                          |
|           |   |         |                          |
|           |   |         |                          |
|           |   |         |                          |
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|           |   |         |                          |
|           |   |         |                          |
|           |   |         |                          |
|           |   |         |                          |

### Part XIII Supplemental Information (continued)

SCHEDULE D, PART V, LINE 4:

#### **ENDOWMENT:**

THE SOCIETY'S ENDOWMENT CONSISTS OF ONE DONOR-RESTRICTED FUND, ESTABLISHED BY THE DONOR FOR THE PURPOSE OF FUNDING MEDICAL RESEARCH IN THE FIELD OF HUNTINGTON'S DISEASE.

SCHEDULE D, PART X, LINE 2:

THE SOCIETY FOLLOWS THE PROVISIONS OF THE FINANCIAL ACCOUNTING STANDARDS BOARD'S (THE "FASB") ACCOUNTING STANDARDS CODIFICATION ("ASC") TOPIC 740, INCOME TAXES, AS IT RELATES TO ACCOUNTING AND REPORTING FOR UNCERTAINTY IN INCOME TAXES. BECAUSE OF THE SOCIETY'S GENERAL TAX-EXEMPT STATUS, MANAGEMENT BELIEVES ASC TOPIC 740 HAS NOT HAD, AND IS NOT ANTICIPATED TO HAVE, A MATERIAL IMPACT ON THE SOCIETY'S FINANCIAL STATEMENTS.

SCHEDULE D, PART XI, LINE 2D & 4B:

LINE 2D: TOTAL REVENUE FROM HDSA CHAPTERS OF (\$1,932,226)

LINE 4B: TOTAL PAYMENTS FROM HDSA CHAPTERS OF \$1,577,568

SCHEDULE D, PART XII, LINE 2D:

TOTAL EXPENSES FROM HDSA CHAPTERS (\$2,053,345)

LOSS ON UNCOLLECTIBLE ACCOUNTS (\$43,500)

\_\_\_\_\_\_

(\$2,096,845)

SCHEDULE D, PART XII, LINE 4B:

TOTAL PAYMENTS FROM HDSA CHAPTERS OF \$1,577,568

## **SCHEDULE F** (Form 990)

# **Statement of Activities Outside the United States**

▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16. ► Attach to Form 990.

► Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047 Open to Public Inspection

Employer identification number

Department of the Treasury Internal Revenue Service Name of the organization

HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. 13-3349872 General Information on Activities Outside the United States. Complete if the organization answered "Yes" on Part I Form 990, Part IV, line 14b.

| 1   | <b>For grantmakers.</b> Does the orgother assistance, the grantees' award the grants or assistance? | eligibility for t                         | he grants or  |  | tion criteria used to   | X Yes No  |
|-----|---|---|---|--|---|---|
| 2   | For grantmakers. Describe in I outside the United States.   | Part V the org                            | anization's pro   | ocedures for monitoring t  | he use of its grants and  | d other assistance  |
| 3   | Activities per Region. (The follow  | ving Part I, line                         | 3 table can be  | e duplicated if additional sp  | ace is needed.)   |   |
|     | (a) Region  | (b) Number<br>of offices in<br>the region | (c) Number of<br>employees,<br>agents, and<br>independent<br>contractors<br>in the region | (d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region) | (e) If activity listed in (d) is<br>a program service,<br>describe specific type of<br>service(s) in the region | (f) Total<br>expenditures for<br>and investments<br>in the region |
| (1) | EAST ASIA AND THE PACIFIC   | 0.  | 0.  | GRANTMAKING  |   | 150,000.  |
| (2) | NORTH AMERICA   | 0.  | 0.  | GRANTMAKING  |   | 150,000.  |
| (3) | EUROPE  | 0.  | 0.  | GRANTMAKING  |   | 211,465.  |
| (4) |   |   |   |  |   |   |
| (5) |   |   |   |  |   |   |
| (6) |   |   |   |  |   |   |
| (7) |   |   |   |  |   |   |
| (8) |   |   |   |  |   |   |
| (9) |   |   |   |  |   |   |
| 10) |   |   |   |  |   |   |
| 11) |   |   |   |  |   |   |
| 12) |   |   |   |  |   |   |
| 13) |   |   |   |  |   |   |
| 14) |   |   |   |  |   |   |
| 15) |   |   |   |  |   |   |
| 16) |   |   |   |  |   |   |
| 17) |   |   |   |  |   |   |
|     | Subtotal  |   |   |  |   | 511,465.  |
| b   |   |   |   |  |   |   |
| С   | Totals (add lines 3a and 3b)  |   |   |  |   | 511,465.  |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule F (Form 990) 2020

| 0 - 111- | F (F 000) 0000 |  |
|----------|----------------|--|

| 1     | (a) Name of organization   | (b) IRS code<br>section and EIN<br>(if applicable) | (c) Region  | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of noncash assistance | (h) Description<br>of noncash<br>assistance | (i) Method of<br>valuation<br>(book, FMV,<br>appraisal, other) |
|-------|----------------------------|--|---|----------------------|--------------------------|---------------------------------|----------------------------------|---|--|
| (1)   |                            |  | NORTH AMERICA   | MEDICAL RESE         | 150,000.                 |                                 |                                  |   |  |
| (2)   |                            |  | EUROPE/ICELAND/GREENLAND                              | MEDICAL RESE         | 75,000.                  |                                 |                                  |   |  |
| (3)   |                            |  | EUROPE/ICELAND/GREENLAND                              | MEDICAL RESE         | 73,000.                  |                                 |                                  |   |  |
| (4)   |                            |  | EAST ASIA/PACIFIC                                     | MEDICAL RESE         | 150,000.                 |                                 |                                  |   |  |
| (5)   |                            |  | EUROPE/ICELAND/GREENLAND                              | MEDICAL RESE         | 63,465.                  |                                 |                                  |   |  |
| (6)   |                            |  |   |                      |                          |                                 |                                  |   |  |
| (7)   |                            |  |   |                      |                          |                                 |                                  |   |  |
| (8)   |                            |  |   |                      |                          |                                 |                                  |   |  |
| (9)   |                            |  |   |                      |                          |                                 |                                  |   |  |
| (10)  |                            |  |   |                      |                          |                                 |                                  |   |  |
| (11)  |                            |  |   |                      |                          |                                 |                                  |   |  |
| (12)  |                            |  |   |                      |                          |                                 |                                  |   |  |
| (13)  |                            |  |   |                      |                          |                                 |                                  |   |  |
| (14)  |                            |  |   |                      |                          |                                 |                                  |   |  |
| (15)  |                            |  |   |                      |                          |                                 |                                  |   |  |
| (16)  |                            |  |   |                      |                          |                                 |                                  |   |  |
| 2 Ent | mpt 501(c)(3) organization | by the IRS, or for which                           | bove that are recognized a the grantee or counsel has | provided a sec       | tion 501(c)(3) equiv     | alency letter                   | <b>&gt;</b>                      |   | 5.   |

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Schedule F (Form 990) 2020

# Part III Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 16. Part III can be duplicated if additional space is needed.

| (a) Type of grant or assistance | (b) Region | (c) Number of recipients | (d) Amount of cash grant | (e) Manner of cash disbursement | (f) Amount of<br>noncash<br>assistance | (g) Description of noncash assistance | (h) Method of<br>valuation<br>(book, FMV,<br>appraisal, other) |
|---------------------------------|------------|--------------------------|--------------------------|---------------------------------|--|---------------------------------------|--|
| (1)                             |            |                          |                          |                                 |  |                                       |  |
| (2)                             |            |                          |                          |                                 |  |                                       |  |
| (3)                             |            |                          |                          |                                 |  |                                       |  |
| (4)                             |            |                          |                          |                                 |  |                                       |  |
| (5)                             |            |                          |                          |                                 |  |                                       |  |
| (6)                             |            |                          |                          |                                 |  |                                       |  |
| (7)                             |            |                          |                          |                                 |  |                                       |  |
| (8)                             |            |                          |                          |                                 |  |                                       |  |
| (9)                             |            |                          |                          |                                 |  |                                       |  |
| (10)                            |            |                          |                          |                                 |  |                                       |  |
| (11)                            |            |                          |                          |                                 |  |                                       |  |
| (12)                            |            |                          |                          |                                 |  |                                       |  |
| (13)                            |            |                          |                          |                                 |  |                                       |  |
| (14)                            |            |                          |                          |                                 |  |                                       |  |
| (15)                            |            |                          |                          |                                 |  |                                       |  |
| (16)                            |            |                          |                          |                                 |  |                                       |  |
| (17)                            |            |                          |                          |                                 |  |                                       |  |
| (18)                            |            |                          |                          |                                 |  |                                       |  |

Schedule F (Form 990) 2020 Page 4

| Part | Y Foreign Forms   |     |      |
|------|---|-----|------|
| 1    | Was the organization a U.S. transferor of property to a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)  | Yes | X No |
| 2    | Did the organization have an interest in a foreign trust during the tax year? If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990) | Yes | X No |
| 3    | Did the organization have an ownership interest in a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see Instructions for Form 5471)  | Yes | X No |
| 4    | Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)   | Yes | X No |
| 5    | Did the organization have an ownership interest in a foreign partnership during the tax year? If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865)  | Yes | X No |
| 6    | Did the organization have any operations in or related to any boycotting countries during the tax year? If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990)  | Yes | X No |

Schedule F (Form 990) 2020

Schedule F (Form 990) 2020 Page 5

#### Part V **Supplemental Information**

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information (see instructions).

SCHEDULE F, PART I, LINE 1:

MAINTAINING RECORDS FOREIGN ACTIVITIES:

THE SOCIETY REQUESTS SEMI-ANNUAL FINANCIAL REPORTS FROM GRANTEES'

OFFICES.

SCHEDULE F, PART I, LINE 3, COLUMN (F):

AMOUNTS ARE REPORTED USING THE ACCRUAL METHOD OF ACCOUNTING.

#### **SCHEDULE G** (Form 990 or 990-EZ)

#### **Supplemental Information Regarding Fundraising or Gaming Activities**

Complete if the organization answered "Yes" on Form 990, Part IV, line 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.

Attach to Form 990 or Form 990-EZ.

Department of the Treasury

OMB No. 1545-0047

► Go to www.irs.gov/Form990 for instructions and the latest information. Inspection Internal Revenue Service Name of the organization Employer identification number HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. 13-3349872 Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part. Indicate whether the organization raised funds through any of the following activities. Check all that apply. 1 Mail solicitations Solicitation of non-government grants а Internet and email solicitations f Solicitation of government grants Phone solicitations Special fundraising events C g In-person solicitations d 2a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees, or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? Yes b If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization. (v) Amount paid to (iii) Did fundraiser have (vi) Amount paid to (i) Name and address of individual (iv) Gross receipts (or retained by) custody or control of (or retained by) (ii) Activity or entity (fundraiser) from activity fundraiser listed in organization contributions? col. (i) Yes No 1 2 3 6 8 9 10 Total List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

Schedule G (Form 990 or 990-EZ) 2020

Page 2

|                                  | events with gross receipts   | (a) Event #1 WALKS                    | (b) Event #2<br>GALA  | (c) Other events                | (d) Total events<br>(add col. (a) through        |
|----------------------------------|--|---------------------------------------|---|---------------------------------|--|
| (I)                              |  | (event type)                          | (event type)  | (total number)                  | col. <b>(c)</b> )                                |
| Revenue                          | 1 Gross receipts   | 503,222.                              | 180,368.  | 387,326.                        | 1,070,916  |
| ፠                                | 2 Less: Contributions  |                                       | 166,681.  | 341,849.                        | 978,304  |
|                                  | 3 Gross income (line 1 mine line 2)  |                                       | 13,687.   | 45,477.                         | 92,612   |
|                                  | 4 Cash prizes  |                                       |   |                                 |  |
|                                  | 5 Noncash prizes   | 24,406.                               | 2,240.  | 1,082.                          | 27,728   |
| suses                            | 6 Rent/facility costs  | 1,718.                                | 1,050.  | 21,416.                         | 24,184   |
| <b>Direct Expenses</b>           | 7 Food and beverages   |                                       | 10,310.   | 7,880.                          | 18,190   |
| Direct                           | 8 Entertainment  |                                       |   |                                 |  |
|                                  | 9 Other direct expenses  | 7,323.                                | 87.   | 15,100.                         | 22,510   |
|                                  | 10 Direct expense summary. Add 11 Net income summary. Subtra art III Gaming. Complete if the   | ct line 10 from line 3, colu          | ımn (d)   | <u> </u>                        | 92,612   |
|                                  |  | organization answered                 | Yes" on Form 990, F   | Part IV, line 19, or            | reported more than                               |
|                                  | \$15,000 on Form 990-EZ  | Z, line 6a.                           | (b) Pull tabs/instant   |                                 | (d) Total gaming (add                            |
|                                  | \$15,000 on Form 990-EZ  | Z, line 6a.  (a) Bingo                | ·   | Cart IV, line 19, or            |  |
| Revenue                          | \$15,000 on Form 990-EZ  1 Gross revenue   | (a) Bingo                             | (b) Pull tabs/instant   |                                 | (d) Total gaming (add                            |
| Revenue                          | \$15,000 on Form 990-EZ  1 Gross revenue   | (a) Bingo                             | (b) Pull tabs/instant   |                                 | (d) Total gaming (add                            |
|                                  | \$15,000 on Form 990-EZ  1 Gross revenue   | (a) Bingo                             | (b) Pull tabs/instant   |                                 | (d) Total gaming (add                            |
| Expenses Revenue                 | \$15,000 on Form 990-EZ  1 Gross revenue   | (a) Bingo                             | (b) Pull tabs/instant   |                                 | (d) Total gaming (add                            |
| Revenue                          | \$15,000 on Form 990-EZ  1 Gross revenue  2 Cash prizes  3 Noncash prizes  | (a) Bingo                             | (b) Pull tabs/instant bingo/progressive bingo   | (c) Other gaming                | (d) Total gaming (add                            |
| Expenses Revenue                 | \$15,000 on Form 990-EZ  1 Gross revenue  2 Cash prizes  3 Noncash prizes  4 Rent/facility costs   | (a) Bingo Yes%                        | (b) Pull tabs/instant bingo/progressive bingo   | (c) Other gaming                | (d) Total gaming (add                            |
| Expenses Revenue                 | \$15,000 on Form 990-EZ  1 Gross revenue  2 Cash prizes  3 Noncash prizes  4 Rent/facility costs  5 Other direct expenses  | (a) Bingo   Yes%  No                  | (b) Pull tabs/instant bingo/progressive bingo  Yes% No  | (c) Other gaming  Yes%  No      | (d) Total gaming (add                            |
| Expenses Revenue                 | \$15,000 on Form 990-EZ  1 Gross revenue  2 Cash prizes  3 Noncash prizes  | Yes % No  d lines 2 through 5 in colu | (b) Pull tabs/instant bingo/progressive bingo  Yes%  No  mn (d)   | (c) Other gaming  Yes%  No      | (d) Total gaming (add                            |
| <b>G</b> Direct Expenses Revenue | \$15,000 on Form 990-EZ  1 Gross revenue  2 Cash prizes  3 Noncash prizes  4 Rent/facility costs  5 Other direct expenses  6 Volunteer labor  7 Direct expense summary. Add  8 Net gaming income summary | Yes                                   | (b) Pull tabs/instant bingo/progressive bingo  Yes%  No  mn (d)  1, column (d)  ming activities: in each of these state | (c) Other gaming  Yes%  No  PS? | (d) Total gaming (add col. (a) through col. (c)) |

| Sched | lule G (Form 990 or 990-EZ) 2020 Page <b>3</b>  |
|-------|---|
| 11    | Does the organization conduct gaming activities with nonmembers? Yes  |
| 12    | Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity   |
|       | formed to administer charitable gaming?   |
| 13    | Indicate the percentage of gaming activity conducted in:  |
| а     | The organization's facility   |
| b     | An outside facility   |
| 14    | Enter the name and address of the person who prepares the organization's gaming/special events books and records:   |
|       | Name ▶  |
|       | Address ▶   |
| 15 a  | Does the organization have a contract with a third party from whom the organization receives gaming   |
|       | revenue?  |
| b     | If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ and the  |
|       | amount of gaming revenue retained by the third party ▶ \$   |
| С     | If "Yes," enter name and address of the third party:  |
|       | Name ▶  |
|       | Address ▶   |
| 16    | Gaming manager information:   |
|       | Name ▶  |
|       | Gaming manager compensation ▶\$   |
|       | Description of services provided ▶  |
|       | Director/officer Employee Independent contractor  |
| 17    | Mandatory distributions:  |
| а     | Is the organization required under state law to make charitable distributions from the gaming proceeds to   |
|       | retain the state gaming license?  |
| b     | Enter the amount of distributions required under state law to be distributed to other exempt organizations  |
|       | or spent in the organization's own exempt activities during the tax year 🕨 \$   |
| Par   | Supplemental Information. Provide the explanation required by Part I, line 2b, columns (iii) and (v), and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information (see instructions). |

Schedule G (Form 990 or 990-EZ) 2020

Department of the Treasury

Internal Revenue Service

Name of the organization

### Grants and Other Assistance to Organizations, Governments, and Individuals in the United States

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

► Attach to Form 990.

► Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2020

Open to Public Inspection

Schedule I (Form 990) 2020

Employer identification number

| HUNTINGTON'S DISEASE SOCIETY OF AM   | MERICA, I       | NC.                                |                          |                                       |   | 13-334987                             | 72                                 |
|--|-----------------|------------------------------------|--------------------------|---------------------------------------|---|---------------------------------------|------------------------------------|
| Part I General Information on Grants and   | d Assistanc     | е                                  |                          |                                       |   | '                                     |                                    |
| <ol> <li>Does the organization maintain records to so<br/>the selection criteria used to award the grant</li> <li>Describe in Part IV the organization's proced</li> </ol> | ts or assistand | e?                                 |                          |                                       |   |                                       | X Yes No                           |
| Part II Grants and Other Assistance to D Part IV, line 21, for any recipient the   |                 | _                                  |                          |                                       |   |                                       | es" on Form 990,                   |
| 1 (a) Name and address of organization or government   | (b) EIN         | (c) IRC section<br>(if applicable) | (d) Amount of cash grant | (e) Amount of non-<br>cash assistance | (f) Method of valuation<br>(book, FMV, appraisal,<br>other) | (g) Description of noncash assistance | (h) Purpose of grant or assistance |
| (1) ALBANY MEDICAL COLLEGE   |                 |                                    |                          |                                       |   |                                       |                                    |
| 47 NEW SCOTLAND AVENUE, MAIL CODE 70   | 14-1338310      | 501(C)(3)                          | 34,200.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (2) BETH ISRAEL DEACONESS MEDICAL CENTER   |                 |                                    |                          |                                       |   |                                       |                                    |
| 330 BROOKLINE AVENUE RESEARCH FINANCE OFFIC  | 04-2103881      | 501(C)(3)                          | 150,000.                 |                                       |   |                                       | MEDICAL RESEARCH                   |
| (3) BETH ISRAEL DEACONESS MEDICAL CENTER   |                 |                                    |                          |                                       |   |                                       |                                    |
| 109 BROOKLINE AVENUE, RM 215   | 04-2103881      | 501(C)(3)                          | 35,950.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (4) CLEVELAND CLINIC FOUNDATION  |                 |                                    |                          |                                       |   |                                       |                                    |
| 9500 ECULID AVE, S-31 CLEVELAND, OH 44195  | 34-0714585      | 501(C)(3)                          | 24,000.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (5) COLUMBIA UNIVERSITY MEDICAL CENTER   |                 |                                    |                          |                                       |   |                                       |                                    |
| 54 HAVEN AVE. 2ND FLOOR NEW YORK, NY 10032   | 80-0496512      | OTHER                              | 75,000.                  |                                       |   |                                       | MEDICAL RESEARCH                   |
| (6) DUKE MOVEMENT DISORDERS CENTER   |                 |                                    |                          |                                       |   |                                       |                                    |
| 932 MORREENE ROAD DURHAM, NC 27705   | 56-0532129      | 501(C)(3)                          | 26,290.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (7) EMORY UNIVERSITY   |                 |                                    |                          |                                       |   |                                       |                                    |
| 1599 CLIFTON RD, 4TH FL, MAILSTOP 1599-001B  | 58-0566256      | OTHER                              | 24,750.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (8) ERLANGER HEALTH SYSTEM   |                 |                                    |                          |                                       |   |                                       |                                    |
| 979 E THIRD STREET, SUITE C830   | 62-6000101      | 501(C)(3)                          | 14,500.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (9) FREDERICK BRINTER CENTER FOR PARKINSON'S DI  |                 |                                    |                          |                                       |   |                                       |                                    |
| 1 SOUTH PROSPECT STREET ARNOLD 2   | 03-0219309      | 501(C)(3)                          | 18,843.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (10) GEORGETOWN UNIVERSITY HD CERC   |                 |                                    |                          |                                       |   |                                       |                                    |
| 2115 WISCONSIN AVENUE, NW, SUITE 200   | 53-0196603      | 501(C)(3)                          | 26,500.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (11) HENNEPIN HEALTHCARE RESEARCH INSTITUTE  |                 |                                    |                          |                                       |   |                                       |                                    |
| 825 8TH STREET SOUTH MINNEAPOLIS, MN 55404   | 41-1677920      | 501(C)(3)                          | 34,975.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (12) HENRY FORD HEALTH SYSTEM  |                 |                                    |                          |                                       |   |                                       |                                    |
| 2799 WEST GRAND BLVD., CFP-463   | 38-1357020      | 501(C)(3)                          | 9,000.                   |                                       |   |                                       | COMMUNITY SERVICES                 |
| <ul> <li>Enter total number of section 501(c)(3) and</li> <li>Enter total number of other organizations list</li> </ul>  | •               | •                                  |                          |                                       |   |                                       |                                    |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

## **Grants and Other Assistance to Organizations, Governments, and Individuals in the United States**

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

2020
Open to Public

Inspection

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service ► Attach to Form 990.

► Go to www.irs.gov/Form990 for the latest information.

Name of the organization Employer identification number HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. 13-3349872 **General Information on Grants and Assistance** 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and No 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States. Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed. (f) Method of valuation (book, FMV, appraisal, other) (c) IRC section (d) Amount of cash (e) Amount of non-(g) Description of 1 (a) Name and address of organization (b) EIN (h) Purpose of grant (if applicable) cash assistance noncash assistance or assistance or government (1) JOHNS HOPKINS UNIVERSITY 600 N. WOLFE STREET, CMSC 8-121 52-0595110 | 501(C)(3) 34,550. COMMUNITY SERVICES (2) MARY HITCHCOCK MEMORIAL HOSPITAL ONE MEDICAL CENTER DRIVE 02-0222140 501(C)(3) 9,500. COMMUNITY SERVICES (3) MASSACHUSETT GENERAL HOSPITAL 04-2697983 501(C)(3) 149 13TH STREET, RM 10126 26,500. COMMUNITY SERVICES (4) MASSACHUSETTS GENERAL HOSPITAL BANK OF AMERICA N.A. PO BOX 414876 04-3167352 501(C)(3) 75,000. MEDICAL RESEARCH (5) MOVEMENT DISORDERS FOUNDATION P.O. BOX 886 ENGLEWOOD, CO 80151 27-1618835 501(C)(3) 35,950. COMMUNITY SERVICES (6) NORTHWESTERN UNIVERSITY 710 N. LAKE SHORE DRIVE, #1124 36-2167817 501(C)(3) 34,200. COMMUNITY SERVICES (7) NORTHWESTERN UNIVERSITY FEINBERG SCHOOL OF 633 CLARK ROOM G547 EVANSTON, IL 60208 36-2167817 501(C)(3) 55,672. MEDICAL RESEARCH (8) OCHSNER HEALTH SYSTEM 1515 JEFFERSON HWY. 7TH FL CLINIC TOWER 72-0502505 501(C)(3) 16,820. COMMUNITY SERVICES (9) OHIO STATE UNIVERSITY WEXNER MEDICAL CENTER 395 W. 12TH AVENUE, 7TH FLOOR 31-1145986 501(C)(3) 48,500. COMMUNITY SERVICES (10) OREGON HEALTH AND SCIENCE UNIVERSITY 3181 SW JAM JACKSON PARK RD, OP 32 93-1176109 GOVT 9,268 COMMUNITY SERVICES (11) OSF HEALTHCARE ILLINOIS NEUROLOGICAL INSTIT 38-3852646 501(C)(3) 6.875 OSF GRANTS, P.O. BOX 775655 COMMUNITY SERVICES (12) REGENTS OF THE UNIVERSITY OF CALIFORNIA, DA 4860 Y STREET, SUITE 3700 94-6036494 501(C)(3) 71,100. COMMUNITY SERVICES 2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table . . . . . . . 

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Schedule I (Form 990) 2020

### **Grants and Other Assistance to Organizations, Governments, and Individuals in the United States**

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

2020
Open to Public Inspection

Schedule I (Form 990) 2020

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service ► Attach to Form 990.

► Go to www.irs.gov/Form990 for the latest information.

Name of the organization Employer identification number HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. 13-3349872 **General Information on Grants and Assistance** 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and No 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States. Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed. (f) Method of valuation (book, FMV, appraisal, other) (g) Description of (c) IRC section (d) Amount of cash (e) Amount of non-1 (a) Name and address of organization (b) EIN (h) Purpose of grant (if applicable) grant cash assistance noncash assistance or assistance or government (1) ROWAN UNIVERSITY 201 MULLICA HILL ROAD 22-2764819 OTHER 15,000. COMMUNITY SERVICES (2) RUSH UNIVERSITY MEDICAL CENTER 1201 W. HARRISON STREET, SUITE 300 36-2174823 501(C)(3) 42,275. COMMUNITY SERVICES (3) SANFORD HEALTH 2301 E 60TH STREET N, ROUTE 5031 45-0226909 501(C)(3) 18,861. COMMUNITY SERVICES (4) STANFORD UNIVERSITY 485 BROADWAY, 4TH FLOOR 94-6174066 OTHER 15.538. COMMUNITY SERVICES (5) THE RECTOR & VISITORS OF THE UNIVERSITY OF 101 HOSPIAL DR, DAVIS 5 RM 5293, PO BOX 800 54-6001796 501(C)(3) 42,584. COMMUNITY SERVICES (6) THE REGENT OF THE UNIVERSITY OF CALIFORNIA-POB 748872 LOS ANGELES, CA 90074 94-6036493 501(C)(3) 25,000. COMMUNITY SERVICES (7) THE RESEARCH FOUNDATION FOR THE STATE UNIVE STONY BROOK UNIVERSITY, W5510 MELVILLE LIBR 14-1368361 501(C)(3) 9,000 COMMUNITY SERVICES (8) THE TRUSTEES OF COLUMBIA UNIVERSITY IN THE 622 WEST 168TH STREET PH-19 ROOM 316 13-5598093 501(C)(3) 44.788 COMMUNITY SERVICES (9) TRUSTEES OF INDIANA UNIVERSITY 980 INDIANA AVENUE INDIANAPOLIS, IN 46202 35-6001673 26,579. COMMUNITY SERVICES (10) TRUSTEES OF THE UNIVERSITY OF PENNSYLVANIA 3451 WALNUT STREET PHILADELPHIA, PA 19104 23-1352685 501(C)(3) 36,000. COMMUNITY SERVICES (11) UC REGENTS BOX 957089, 1125 MURPHY HALL 95-6006143 501(C)(3) 45,674. COMMUNITY SERVICES (12) UNIVERSITY NEUROLOGY, INC. 77 GOODELL STREET, SUITE 310 16-1359213 501(C)(3) 12,750. COMMUNITY SERVICES 2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table . . . . . . . 

JSA

E1288 1 000

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### **Grants and Other Assistance to Organizations, Governments, and Individuals in the United States**

► Attach to Form 990.

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

2020

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service

► Go to www.irs.gov/Form990 for the latest information.

Open to Public Inspection

Name of the organization Employer identification number HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. 13-3349872 **General Information on Grants and Assistance** 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and No 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States. Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed. (f) Method of valuation (book, FMV, appraisal, other) (g) Description of (c) IRC section (d) Amount of cash (e) Amount of non-1 (a) Name and address of organization (b) EIN (h) Purpose of grant (if applicable) grant cash assistance noncash assistance or assistance or government (1) UNIVERSITY OF ALABAMA BIRMINGHAM 1720 7TH AVENUE, S. SC 460A1 63-0649108 501(C)(3) 46,007. COMMUNITY SERVICES (2) UNIVERSITY OF CALIFORNIA, MOVEMENT DISORDER 150 MEDICAL SURGE 1 IRVINE, CA 92697 95-2226406 GOVT 16,500. COMMUNITY SERVICES (3) UNIVERSITY OF CALIFORNIA, SAN DIEGO 9500 GILMAN DRIVE (MC0041) 95-6006144 501(C)(3) 48,500. COMMUNITY SERVICES (4) UNIVERSITY OF COLORADO, ANSCHUTZ MEDICAL CA P.O. BOX 910238 DENVER, CO 80291-0238 84-6000555 501(C)(3) 26,500. COMMUNITY SERVICES (5) UNIVERSITY OF FLORIDA 33 TIGERT HALL, P.O. BOX 113001 59-6002052 OTHER 24,000. COMMUNITY SERVICES (6) UNIVERSITY OF IOWA, DEPARTMENT OF NEUROLOGY 200 HAWKINS DR, 8820-12JPP 42-6004813 COVT 34,200. COMMUNITY SERVICES (7) UNIVERSITY OF KANSAS MEDICAL CENTER 3901 RAINBOW BLVD, MS30 48-1108830 501(C)(3) 9,000 COMMUNITY SERVICES (8) UNIVERSITY OF LOUISVILLE 500 SOUTH PRESTON STREET, SUITE 113 61-1014882 501(C)(3) 14.750. COMMUNITY SERVICES (9) UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL 55 LAKE AVENUE, NORTH 04-3167352 OTHER 240,000 MEDICAL RESEARCH (10) UNIVERSITY OF MIAMI OFFICE OF RESEARCH ADMINISTRATION, P.O. BOX 59-0624458 501(C)(3) 11,500. COMMUNITY SERVICES (11) UNIVERSITY OF MISSISSIPPI MEDICAL CENTER 64-6008520 8,425 2500 N. STATE STREET JACKSON, MS 39216-4505 GOVT COMMUNITY SERVICES (12) UNIVERSITY OF NEBRASKA MEDICAL CENTER 988440 NEBRASKA MEDICAL CENTER 47-0049123 501(C)(3) 17,926. COMMUNITY SERVICES 2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table . . . . . . . 

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule I (Form 990) 2020

Department of the Treasury

Internal Revenue Service

# **Grants and Other Assistance to Organizations, Governments, and Individuals in the United States**

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

► Attach to Form 990.

► Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2020

Open to Public Inspection

Schedule I (Form 990) 2020

| Name of the organization  |                                 |                                    |                          |                                       |   | Employer identificat                  | ion number                         |
|---|---------------------------------|------------------------------------|--------------------------|---------------------------------------|---|---------------------------------------|------------------------------------|
| HUNTINGTON'S DISEASE SOCIETY OF A   | MERICA, I                       | NC.                                |                          |                                       |   | 13-33498'                             | 72                                 |
| Part I General Information on Grants an   | d Assistanc                     | е                                  |                          |                                       |   | '                                     |                                    |
| <ol> <li>Does the organization maintain records to set the selection criteria used to award the grant in Part IV the organization's process.</li> </ol> | ts or assistand<br>dures for mo | ce?                                | of grant funds in th     | e United States.                      |   |                                       | X Yes No                           |
| Part II Grants and Other Assistance to Deart IV, line 21, for any recipient to  |                                 | •                                  |                          |                                       |   |                                       | res on Form 990,                   |
| (a) Name and address of organization<br>or government   | (b) EIN                         | (c) IRC section<br>(if applicable) | (d) Amount of cash grant | (e) Amount of non-<br>cash assistance | (f) Method of valuation<br>(book, FMV, appraisal,<br>other) | (g) Description of noncash assistance | (h) Purpose of grant or assistance |
| (1) UNIVERSITY OF PITTSBURGH PHYSICIANS   |                                 |                                    |                          |                                       |   |                                       |                                    |
| 3600 FORBES AVENUE, 9TH FLOOR, CUBICAL 9  | 23-2919472                      | OTHER                              | 34,200.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (2) UNIVERSITY OF ROCHESTER MEDICAL CENTER  |                                 |                                    |                          |                                       |   |                                       |                                    |
| 601 ELMWOOD AVENUE, BOX 673   | 16-0743209                      | OTHER                              | 43,500.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (3) UNIVERSITY OF SOUTH CAROLINA SCHOOL OF MEDI   |                                 |                                    |                          |                                       |   |                                       |                                    |
| 1 MEDICAL PARK RD, SUITE 230  | 57-6001153                      | GOVT                               | 15,500.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (4) UNIVERSITY OF SOUTH FLORIDA   |                                 |                                    |                          |                                       |   |                                       |                                    |
| 13220 USF LAUREL DRIVE, ROOM 4105   | 59-0879015                      | 501(C)(3)                          | 30,000.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (5) UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER   |                                 |                                    |                          |                                       |   |                                       |                                    |
| DEPARTMENT OF NEUROLOGY, P.O. BOX 301418  | 74-1761309                      | OTHER                              | 35,950.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (6) UNIVERSITY OF UTAH  |                                 |                                    |                          |                                       |   |                                       |                                    |
| 650 KOMAS DRIVE, #106A  | 87-6000525                      | 501(C)(3)                          | 26,500.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (7) UNIVERSITY OF WASHINGTON  |                                 |                                    |                          |                                       |   |                                       |                                    |
| 1959 NE PACIFIC STREET SEATTLE, WA 98195  | 91-6001537                      | GOVT                               | 60,342.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (8) UNIVERSITY OF WISCONSIN - MADISON   |                                 |                                    |                          |                                       |   |                                       |                                    |
| 21 N. PARK STREET, STE. 6401  | 39-6006492                      | 501(C)(3)                          | 14,450.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (9) UT MEDICAL CENTER   |                                 |                                    |                          |                                       |   |                                       |                                    |
| 1924 ALCOA HIGHWAY BOX U52  | 31-1626179                      | 501(C)(3)                          | 14,500.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (10) VANDERBILT UNIVERSITY MEDICAL CENTER   |                                 |                                    |                          |                                       |   |                                       |                                    |
| MEDICAL CENTER NORTH A-0118   | 35-2528741                      | 501(C)(3)                          | 42,269.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (11) VIRGINIA COMMONWEALTH UNIVERSITY   |                                 |                                    |                          |                                       |   |                                       |                                    |
| 800 EAST LEIGH ST., SUITE 3100, POB 843039  | 54-6001758                      | GOVT                               | 19,000.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| (12) WASHINGTON UNIVERSITY  |                                 |                                    |                          |                                       |   |                                       |                                    |
| 700 ROSEDALE AVENUE, CMPUS BOX 1034   | 43-0653611                      | 501(C)(3)                          | 37,875.                  |                                       |   |                                       | COMMUNITY SERVICES                 |
| 2 Enter total number of section 501(c)(3) and   | government                      | organizations lis                  | sted in the line 1 ta    | ble                                   |   |                                       | 43.                                |
| 3 Enter total number of other organizations lis   | ted in the line                 | 1 table                            |                          |                                       |   |                                       | 17.                                |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule I (Form 990) (2020)

| Part III | Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22. |  |
|----------|---|--|
|          | Part III can be duplicated if additional space is needed.   |  |

| (a) Type of grant or assistance | (b) Number of recipients | (c) Amount of cash grant | (d) Amount of non-cash assistance | (e) Method of valuation (book, FMV, appraisal, other) | (f) Description of non-cash assistance |
|---------------------------------|--------------------------|--------------------------|-----------------------------------|---|--|
|                                 |                          |                          |                                   |   |  |
|                                 |                          |                          |                                   |   |  |
|                                 |                          |                          |                                   |   |  |
| i                               |                          |                          |                                   |   |  |
|                                 |                          |                          |                                   |   |  |
|                                 |                          |                          |                                   |   |  |
|                                 |                          |                          |                                   |   |  |

**Part IV** Supplemental Information. Provide the information required in Part I, line 2, Part III, column (b); and any other additional information.

SCHEDULE I, PART I, LINE 1:

MAINTAINING RECORDS FOR GRANT ACTIVITIES:

THE ORGANIZATION REQUESTS SEMI-ANNUAL FINANCIAL REPORTS FROM RECIPIENTS.

Compensation Information
For certain Officers, Directors, Trustees, Key Employees, and Highest **Compensated Employees** 

► Complete if the organization answered "Yes" on Form 990, Part IV, line 23. Attach to Form 990.

► Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047 Inspection

Department of the Treasury Internal Revenue Service Name of the organization

HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.

Part I Questions Regarding Compensation

13-3349872

Employer identification number

|    |  |    | Yes | No |
|----|--|----|-----|----|
| 1a | Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.  |    |     |    |
|    | First-class or charter travel Housing allowance or residence for personal use  |    |     |    |
|    | Travel for companions Payments for business use of personal residence  |    |     |    |
|    | Tax indemnification and gross-up payments Health or social club dues or initiation fees  |    |     |    |
|    | Discretionary spending account  Personal services (such as maid, chauffeur, chef)  |    |     |    |
| b  | If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to   | 1b |     |    |
| 2  | explain  | 10 |     |    |
| 2  | directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line   |    |     |    |
|    |  | 2  |     |    |
| _  | 1a?  |    |     |    |
| 3  | Indicate which, if any, of the following the organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III. |    |     |    |
|    | Compensation committee X Written employment contract   |    |     |    |
|    | Independent compensation consultant  X Compensation survey or study  |    |     |    |
|    | X Form 990 of other organizations X Approval by the board or compensation committee  |    |     |    |
| 4  | During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:   |    |     |    |
| а  | Receive a severance payment or change-of-control payment?  | 4a |     | X  |
| b  | Participate in or receive payment from a supplemental nonqualified retirement plan?  | 4b |     | Х  |
| С  | Participate in or receive payment from an equity-based compensation arrangement?   | 4c |     | Х  |
|    | If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.  |    |     |    |
|    | Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.   |    |     |    |
| 5  | For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any   |    |     |    |
|    | compensation contingent on the revenues of:  |    |     |    |
| а  | The organization?  | 5a |     | X  |
| b  | Any related organization?  | 5b |     | X  |
|    | If "Yes" on line 5a or 5b, describe in Part III.   |    |     |    |
| 6  | For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any   |    |     |    |
|    | compensation contingent on the net earnings of:  |    |     |    |
| а  | The organization?  | 6a |     | X  |
| b  | Any related organization?  | 6b |     | X  |
|    | If "Yes" on line 6a or 6b, describe in Part III.   |    |     |    |
| 7  | For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III.   | 7  |     | Х  |
| 8  | Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject   |    |     |    |
|    | to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe   |    |     |    |
|    | in Part III  | 8  |     | Х  |
| 9  | If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in   |    |     |    |
|    | Regulations section 53.4958-6(c)?  | 9  |     |    |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule J (Form 990) 2020

Schedule J (Form 990) 2020 Page 2

#### Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that aren't listed on Form 990, Part VII.

Note: The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

| (A) Name and Title                   |      | (B) Breakdown of W-2 and/or 1099-MISC compensation |                                     |                                     | (C) Retirement and          | (D) Nontaxable | (E) Total of columns | (F) Compensation   |  |
|--------------------------------------|------|--|-------------------------------------|-------------------------------------|-----------------------------|----------------|----------------------|--|--|
|                                      |      | (i) Base<br>compensation                           | (ii) Bonus & incentive compensation | (iii) Other reportable compensation | other deferred compensation | benefits       | (B)(i)-(D)           | in column (B) reported<br>as deferred on prior<br>Form 990 |  |
| LOUISE VETTER                        | (i)  | 274,376.   | 0.                                  | 0.                                  | 14,250.                     | 42,017.        | 330,643.             | 0.   |  |
| 1 <sup>CHIEF</sup> EXECUTIVE OFFICER | (ii) | 0.   | 0.                                  | 0.                                  | 0.                          | 0.             | 0.                   | 0.   |  |
| GEORGE YOHRLING                      | (i)  | 233,994.   | 0.                                  | 0.                                  | 11,750.                     | 1,367.         | 247,111.             | 0.   |  |
| 2SR. DIR. MISSION & SCI AFFAIRS      | (ii) | 0.   | 0.                                  | 0.                                  | 0.                          | 0.             | 0.                   | 0.   |  |
| NANCY RHODES                         | (i)  | 151,999.   | 0.                                  | 0.                                  | 1,879.                      | 2,200.         | 156,078.             | 0.   |  |
| DIRECTOR OF FIELD DEV & OPER.        | (ii) | 0.   | 0.                                  | 0.                                  | 0.                          | 0.             | 0.                   | 0.   |  |
| DEBRA LOVECKY                        | (i)  | 151,476.   | 0.                                  | 0.                                  | 7,800.                      | 15,718.        | 174,994.             | 0.   |  |
| DIR OF PROGRAM SERV & ADVOCACY       | (ii) | 0.   | 0.                                  | 0.                                  | 0.                          | 0.             | 0.                   | 0.   |  |
| CHRISTOPHER COSENTINO                | (i)  | 126,438.   | 0.                                  | 0.                                  | 6,807.                      | 42,065.        | 175,310.             | 0.   |  |
| 5DIRECTOR OF MARKETING & COMM.       | (ii) | 0.   | 0.                                  | 0.                                  | 0.                          | 0.             | 0.                   | 0.   |  |
| ROSEMARY COLUCCIO                    | (i)  | 220,662.   | 0.                                  | 0.                                  | 8,913.                      | 13,307.        | 242,882.             | 0.   |  |
| CHIEF OPERATING OFFICER              | (ii) | 0.   | 0.                                  | 0.                                  | 0.                          | 0.             | 0.                   | 0.   |  |
|                                      | (i)  |  |                                     |                                     |                             |                |                      |  |  |
| _ 7                                  | (ii) |  |                                     |                                     |                             |                |                      |  |  |
|                                      | (i)  |  |                                     |                                     |                             |                |                      |  |  |
| _ 8                                  | (ii) |  |                                     |                                     |                             |                |                      |  |  |
|                                      | (i)  |  |                                     |                                     |                             |                |                      |  |  |
| 9                                    | (ii) |  |                                     |                                     |                             |                |                      |  |  |
|                                      | (i)  |  |                                     |                                     |                             |                |                      |  |  |
| _10                                  | (ii) |  |                                     |                                     |                             |                |                      |  |  |
|                                      | (i)  |  |                                     |                                     |                             |                |                      |  |  |
| _11                                  | (ii) |  |                                     |                                     |                             |                |                      |  |  |
|                                      | (i)  |  |                                     |                                     |                             |                |                      |  |  |
| _12                                  | (ii) |  |                                     |                                     |                             |                |                      |  |  |
|                                      | (i)  |  |                                     |                                     |                             |                |                      |  |  |
| 13                                   | (ii) |  |                                     |                                     |                             |                |                      |  |  |
|                                      | (i)  |  |                                     |                                     |                             |                |                      |  |  |
| 14                                   | (ii) |  |                                     |                                     |                             |                |                      |  |  |
|                                      | (i)  |  |                                     |                                     |                             |                |                      |  |  |
| 15                                   | (ii) |  |                                     |                                     |                             |                |                      |  |  |
|                                      | (i)  |  |                                     |                                     |                             |                |                      |  |  |
| _16                                  | (ii) |  |                                     |                                     |                             |                |                      |  |  |

Schedule J (Form 990) 2020

#### Part | Supplemental Information

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

SCHEDULE J, PART 1:

COMPENSATION DETERMINATION:

COMPENSATION IS DETERMINED BY A COMBINATION OF A REVIEW AND APPROVAL BY

INDEPENDENT PERSONS, COMPARABILITY DATA, AND CONTEMPORANEOUS

SUBSTANTIATION OF THE DELIBERATION AND DECISION BY THE BOARD.

#### **Noncash Contributions**

► Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.

Attach to Form 990.

HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.

OMB No. 1545-0047 Inspection

Department of the Treasury Internal Revenue Service Name of the organization

► Go to www.irs.gov/Form990 for instructions and the latest information.

13-3349872

Employer identification number

| Par | Types of Property                    |                               |  |   |                         |      |     |    |
|-----|--------------------------------------|-------------------------------|--|---|-------------------------|------|-----|----|
|     |                                      | (a)<br>Check if<br>applicable | (b) Number of contributions or items contributed | (c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g | Method of noncash conti |      |     |    |
| 1   | Art - Works of art                   |                               |  |   |                         |      |     |    |
| 2   | Art - Historical treasures           |                               |  |   |                         |      |     |    |
| 3   | Art - Fractional interests           |                               |  |   |                         |      |     |    |
| 4   | Books and publications               | 1                             |  |   |                         |      |     |    |
| 5   | Clothing and household               |                               |  |   |                         |      |     |    |
|     | goods                                |                               |  |   |                         |      |     |    |
| 6   | Cars and other vehicles              |                               |  | 0.  | SEE SUPP                | INFC | )   |    |
| 7   | Boats and planes                     |                               |  |   |                         |      |     |    |
| 8   | Intellectual property                |                               |  |   |                         |      |     |    |
| 9   | Securities - Publicly traded         | l                             | 22.  | 222,699.  | FMV                     |      |     |    |
| 10  | Securities - Closely held stock      |                               |  |   |                         |      |     |    |
| 11  | Securities - Partnership, LLC,       |                               |  |   |                         |      |     |    |
| • • | or trust interests                   |                               |  |   |                         |      |     |    |
| 12  | Securities - Miscellaneous           |                               |  |   |                         |      |     |    |
| 13  | Qualified conservation               |                               |  |   |                         |      |     |    |
| . • | contribution - Historic              |                               |  |   |                         |      |     |    |
|     | structures                           |                               |  |   |                         |      |     |    |
| 14  | Qualified conservation               |                               |  |   |                         |      |     |    |
|     | contribution - Other                 |                               |  |   |                         |      |     |    |
| 15  | Real estate - Residential            |                               |  |   |                         |      |     |    |
| 16  | Real estate - Commercial             |                               |  |   |                         |      |     |    |
| 17  | Real estate - Other                  |                               |  |   |                         |      |     |    |
| 18  | Collectibles                         |                               |  |   |                         |      |     |    |
| 19  | Food inventory                       | 1                             |  |   |                         |      |     |    |
| 20  | Drugs and medical supplies           |                               |  |   |                         |      |     |    |
| 21  | Taxidermy                            |                               |  |   |                         |      |     |    |
| 22  | Historical artifacts                 |                               |  |   |                         |      |     |    |
| 23  | Scientific specimens                 | 1                             |  |   |                         |      |     |    |
| 24  | Archeological artifacts              |                               |  |   |                         |      |     |    |
| 25  | Other ► (DONATED GOODS )             |                               | 309.   | 73,058.   | FMV                     |      |     |    |
| 26  | Other ►()                            |                               |  |   |                         |      |     |    |
| 27  | Other ►()                            |                               |  |   |                         |      |     | -  |
| 28  | Other ►(                             |                               |  |   |                         |      |     |    |
|     | Number of Forms 8283 received        | bv the ora                    | anization during the tax v                       | ear for contributions for   |                         |      |     |    |
|     | which the organization completed I   |                               | =  |   | 29                      |      |     |    |
|     | ,                                    | ,                             | ,  |   |                         |      | Yes | No |
| 30a | During the year, did the organizat   | ion receive                   | by contribution any prope                        | rty reported in Part I, line  | s 1 through             |      |     |    |
|     | 28, that it must hold for at least t |                               |  |   | - 1                     |      |     |    |
|     | to be used for exempt purposes for   | -                             |  |   | -                       | 30a  |     | X  |
| b   | If "Yes," describe the arrangement   |                               |  |   |                         |      |     |    |
| 31  | Does the organization have a         |                               | tance policy that require                        | es the review of any  | nonstandard             |      |     |    |
|     | contributions?                       |                               |  |   |                         | 31   | Х   |    |
| 32a | Does the organization hire or use    |                               |  |   |                         |      |     |    |
|     | contributions?                       | -                             |  | •   |                         | 32a  | Х   | ĺ  |
| b   | If "Yes," describe in Part II.       | <b>-</b>                      | · •  |   |                         |      |     |    |
| 33  | If the organization didn't report an | amount in o                   | column (c) for a type of pro                     | perty for which column (a   | ) is checked.           |      |     |    |
|     | describe in Part II.                 |                               | , , , , , , , , , , , , , , , , , , ,            |   | <i>,</i>                |      |     |    |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule M (Form 990) 2020

Schedule M (Form 990) (2020) Page 2

Part II Supplem

**Supplemental Information.** Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.

SCHEDULE M, LINE 32A:

THE SOCIETY IS THE RECIPIENT OF PROCEEDS FROM THE SALES OF VEHICLES AND

SECURITIES DONATIONS THROUGH UNRELATED INTERMEDIARY ORGANIZATIONS.

Schedule M (Form 990) (2020)

#### SCHEDULE O (Form 990 or 990-EZ)

#### Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on Form 990 or 990-EZ or to provide any additional information.

▶ Attach to Form 990 or 990-EZ.

OMB No. 1545-0047

Ombox 2020

Open to Public Inspection

Employer identification number

Department of the Treasury Internal Revenue Service

Name of the organization

► Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.

13-3349872

PART III - PROGRAM SERVICES 4D:

EDUCATION PROVIDES INFORMATION AND EDUCATION THROUGH PUBLICATION AND DISTRIBUTION OF NEWSLETTERS, BROCHURES AND SCIENCE UPDATES.

FORM 990, PAGE 1, PART I, QUESTION 5, AND PAGE 5, PART V, QUESTION 2A:
PAYROLL:

THE SOCIETY CURRENTLY EMPLOYS 36 INDIVIDUALS. PAYROLL AND BENEFITS ARE PROCESSED THROUGH A PROFESSIONAL EMPLOYER ORGANIZATION (PEO) WHICH FILES THE FORM W-3 ON THE SOCIETY'S BEHALF UNDER THE PEO'S FEDERAL EIN#.

THEREFORE THE SOCIETY DOES NOT FILE A FORM W-3.

FORM 990, PART VI, SECTION B, LINE 11B:

REVIEW OF FORM 990:

MANAGEMENT THOROUGHLY REVIEWS AND SUBSEQUENTLY PROVIDES AN ELECTRONIC DRAFT COPY OF FORM 990 TO THE GOVERNING BODY FOR REVIEW BEFORE FILING WITH THE IRS.

FORM 990, PART VI, SECTION B, LINE 12C:

CONFLICT OF INTEREST POLICY:

OFFICERS AND TRUSTEES ARE REQUESTED TO ANNUALLY SIGN DOCUMENTATION.

FORM 990, PART VI, SECTION B, LINE 15A AND 15B:

OFFICER COMPENSATION:

COMPENSATION IS DETERMINED BY A COMBINATION OF A REVIEW AND APPROVAL BY

Schedule O (Form 990 or 990-EZ) 2020 Page **2** 

Name of the organization
HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.

Employer identification number 13-3349872

INDEPENDENT PERSONS, COMPARABILITY DATA, AND CONTEMPORANEOUS

SUBSTANTIATION OF THE DELIBERATION AND DECISION OF THE BOARD.

FORM 990, PART VI, SECTION C, LINE 19:

GOVERNING DOCUMENTS:

THE SOCIETY MAKES ITS BY-LAWS, ARTICLES OF INCORPORATION, IRS FORM 1023,

ANNUAL REPORTS, AUDITED FINANCIAL STATEMENTS, IRS FORM 990 DOCUMENTS,

CONFLICT OF INTEREST POLICY AND PRIVACY POLICY AVAILABLE TO THE PUBLIC

UPON REQUEST.

EDUCATION

FORM 990, PART XI, LINE 9:

OTHER CHANGES IN NET ASSETS:

INCLUDES LOSS OF UNCOLLECTIBLE ACCOUNTS (\$43,500)

FORM 990, PART III, LINE 4D - OTHER PROGRAM SERVICES

DESCRIPTION GRANTS

TOTALS

ATTACHMENT 1

EXPENSES

REVENUE

757,658.

757,658.

ATTACHMENT 2

FORM 990, PART VI, LINE 17 - STATES

AL, AK, AZ, AR, CA, CO, CT, DE,

 ${\tt FL,GA,HI,ID,IL,IN,IA,KS,KY,LA,ME,MD,MA,MI,}$ 

MN, MS, MO, MT, NE, NV, NH, NJ, NM, NY, NC, ND, OH, OK, OR, PA,

RI, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY

Name of the organization Employer identification number HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC. 13-3349872 ATTACHMENT 3

#### 990, PART VII- COMPENSATION OF THE FIVE HIGHEST PAID IND. CONTRACTORS

| NAME AND ADDRESS  | DESCRIPTION OF SERVICES | COMPENSATION |  |  |
|---|-------------------------|--------------|--|--|
| J&R GRAPHICS<br>56 ELIZABETH AVE<br>ELMWOOD PARK, NJ 07407          | GRAPHIC DESIGN          | 126,721.     |  |  |
| LIBSHAP REALTY CORP<br>125 PARK AVE 11TH FLR<br>NEW YORK, NY 10017  | REALTY                  | 300,283.     |  |  |
| THORN RUN PARTNERS, LLC<br>100 M ST SE<br>WASHINGTON D.C., DC 20003 | ADVOCACY                | 110,000.     |  |  |

Department of the Treasury

### **Related Organizations and Unrelated Partnerships**

 $\blacktriangleright$  Complete if the organization answered "Yes" on Form 990, Part IV, line 33, 34, 35b, 36, or 37.

► Attach to Form 990.

Internal Revenue Service

► Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization

HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.

Employer identification number

13-3349872

| Part I | Identification of Disregarded Entities. Complete if the organization | answered "Yes" or              | Form 990, Part I                              | V, line 33.                |                           |                               |
|--------|--|--------------------------------|---|----------------------------|---------------------------|-------------------------------|
|        | (a) Name, address, and EIN (if applicable) of disregarded entity     | <b>(b)</b><br>Primary activity | (c) Legal domicile (state or foreign country) | <b>(d)</b><br>Total income | (e)<br>End-of-year assets | (f) Direct controlling entity |
| (1)    |  |                                |   |                            |                           |                               |
| (2)    |  |                                |   |                            |                           |                               |
| (3)    |  |                                |   |                            |                           |                               |
| (4)    |  |                                |   |                            |                           |                               |
| (5)    |  |                                |   |                            |                           |                               |
| (6)    |  |                                |   |                            |                           |                               |

Part II Identification of Related Tax-Exempt Organizations. Complete if the organization answered "Yes" on Form 990, Part IV, line 34, because it had one or more related tax-exempt organizations during the tax year.

| (a) Name, address, and EIN of related organization   | <b>(b)</b><br>Primary activity | (c) Legal domicile (state or foreign country) | (d)<br>Exempt Code section | (e) Public charity status (if section 501(c)(3)) | (f) Direct controlling entity | Section 5 contr | 12(b)(13)<br>olled |
|--|--------------------------------|---|----------------------------|--|-------------------------------|-----------------|--------------------|
|  |                                |   |                            |  |                               | Yes             | No                 |
| (1) HUNTINGTON'S DISEASE SOCIETY OF AMERICA 90-0658125 505 EIGHTH AVENUE, SUITE 902 NEW YORK, NY 10018 | PROGRAM SRVC                   | NY  | 501(C)(3)                  | 7  | HDSA NAT'L                    |                 | Х                  |
| (2)  |                                |   |                            |  |                               |                 |                    |
| (3)  |                                |   |                            |  |                               |                 |                    |
| (4)  |                                |   |                            |  |                               |                 |                    |
| (5)  |                                |   |                            |  |                               |                 |                    |
| (6)  |                                |   |                            |  |                               |                 |                    |
| (7)  |                                |   |                            |  |                               |                 |                    |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule R (Form 990) 2020

Schedule R (Form 990) 2020 Page **2** 

| Part III Identification of Relabecause it had one or |                                |   |                               |   |                                 | nswered "Yes"                          | on I    | Form                        | n 990, Part IV,   | line        | 34,                              |                                |
|--|--------------------------------|---|-------------------------------|---|---------------------------------|--|---------|-----------------------------|---|-------------|----------------------------------|--------------------------------|
| (a) Name, address, and EIN of related organization   | <b>(b)</b><br>Primary activity | (c) Legal domicile (state or foreign country) | (d) Direct controlling entity | (e) Predominant income (related, unrelated, excluded from tax under sections 512 - 514) | (f)<br>Share of total<br>income | (g)<br>Share of end-of-<br>year assets | Disprop | h)<br>portionate<br>ations? | (i)<br>Code V - UBI<br>amount in box 20<br>of Schedule K-1<br>(Form 1065) | Gene<br>man | ij)<br>eral or<br>aging<br>tner? | (k)<br>Percentage<br>ownership |
|  |                                | oou,  |                               | ,   |                                 |  | Yes     | No                          |   | Yes         | No                               |                                |
| (1)  | _                              |   |                               |   |                                 |  |         |                             |   |             |                                  |                                |
| (2)  |                                |   |                               |   |                                 |  |         |                             |   |             |                                  |                                |
| (3)  | _                              |   |                               |   |                                 |  |         |                             |   |             |                                  |                                |
| (4)  |                                |   |                               |   |                                 |  |         |                             |   |             |                                  |                                |
| (5)  |                                |   |                               |   |                                 |  |         |                             |   |             |                                  |                                |
| (6)  |                                |   |                               |   |                                 |  |         |                             |   |             |                                  |                                |

Part IV Identification of Related Organizations Taxable as a Corporation or Trust. Complete if the organization answered "Yes" on Form 990, Part IV, line 34, because it had one or more related organizations treated as a corporation or trust during the tax year.

| (a) Name, address, and EIN of related organization | <b>(b)</b><br>Primary activity | (c) Legal domicile (state or foreign country) | (d)<br>Direct controlling | (e) Type of entity (C corp, S corp, or trust) | (f)<br>Share of total | (g)<br>Share of<br>end-of-year assets | (h)<br>Percentage<br>ownership | (i)<br>Section<br>512(b)(13)<br>controlled<br>entity?<br>Yes No |
|--|--------------------------------|---|---------------------------|---|-----------------------|---------------------------------------|--------------------------------|---|
| (1)  |                                |   |                           |   |                       |                                       |                                |   |
| (2)  |                                |   |                           |   |                       |                                       |                                |   |
| (3)  |                                |   |                           |   |                       |                                       |                                |   |
| (4)  |                                |   |                           |   |                       |                                       |                                |   |
| (5)  |                                |   |                           |   |                       |                                       |                                |   |
| (6)  |                                |   |                           |   |                       |                                       |                                |   |
| (7)  |                                |   |                           |   |                       |                                       |                                |   |

(7)

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Transactions With Related Organizations. Complete if the organization answered "Yes" on Form 990, Part IV, line 34, 35b, or 36.

| Not   | e: Complete line 1 if any entity is listed in Parts II, III, or IV of this schedule.                       |                          |                               |             | Y         | res N    | 10 |
|-------|--|--------------------------|-------------------------------|-------------|-----------|----------|----|
| 1     | During the tax year, did the organization engage in any of the following transactions with one or more re- | elated organizations lis | sted in Parts II-IV?          |             |           |          |    |
| а     | Receipt of (i) interest, (ii) annuities, (iii) royalties, or (iv) rent from a controlled entity            |                          |                               |             | 1a        |          | X  |
|       | Gift, grant, or capital contribution to related organization(s)  |                          |                               |             |           | Х        |    |
|       | Gift, grant, or capital contribution from related organization(s)  |                          |                               |             | 1c        | Х        |    |
|       | Loans or loan guarantees to or for related organization(s)   |                          |                               |             | 1d        |          | Х  |
|       | Loans or loan guarantees by related organization(s)  |                          |                               |             | 1e        |          | X  |
|       | ,  |                          |                               |             |           |          |    |
| f     | Dividends from related organization(s)   |                          |                               |             | 1f        |          |    |
| a     | Sale of assets to related organization(s)  |                          |                               |             | 1g        |          | Χ  |
| h     | Purchase of assets from related organization(s)  |                          |                               |             | 1h        |          | Х  |
| i     | Exchange of assets with related organization(s).   |                          |                               |             | 1i        |          | Х  |
| i     | Lease of facilities, equipment, or other assets to related organization(s).                                |                          |                               |             | 1j        |          | X  |
| ,     |  |                          |                               |             |           |          |    |
| k     | Lease of facilities, equipment, or other assets from related organization(s)                               |                          |                               |             | 1k        |          | Х  |
| ı     | Performance of services or membership or fundraising solicitations for related organization(s)             |                          |                               |             | 11        | Х        | _  |
| m.    | Performance of services or membership or fundraising solicitations by related organization(s).             |                          |                               |             | 1m        |          | Х  |
|       | Sharing of facilities, equipment, mailing lists, or other assets with related organization(s)              |                          |                               |             | 1n        | Х        | _  |
|       | Sharing of paid employees with related organization(s)   |                          |                               |             | -         | Х        | _  |
| Ū     | onaring or paid employees with related organization(s)   |                          |                               |             |           |          |    |
| n     | Reimbursement paid to related organization(s) for expenses   |                          |                               |             | 1p        |          | Х  |
|       | Reimbursement paid by related organization(s) for expenses   |                          |                               |             | 1q        |          | Х  |
| ч     | Treilinbursement paid by related organization(s) for expenses 1.1.1.1.1.1.1.1.1.1.1.1.1.1.1.1.1.1.1.       |                          |                               |             |           |          |    |
|       | Other transfer of cash or property to related organization(s)  |                          |                               |             | 1r        |          | Х  |
|       | Other transfer of cash or property from related organization(s)  |                          |                               |             | 1s        |          | X  |
| 2     | If the answer to any of the above is "Yes," see the instructions for information on who must complete the  | his line, including cove | ered relationships and transa | ction thres |           |          | _  |
|       | (a)  | (b)                      | (c)                           |             | (d)       | <u> </u> | _  |
|       | Name of related organization   | Transaction              | Amount involved               | Method of   | of deterr |          |    |
|       |  | type (a-s)               |                               | amou        | nt involv | ved      |    |
|       |  |                          |                               |             |           |          | _  |
| (1)   |  |                          |                               |             |           |          |    |
| ( - / |  |                          |                               |             |           |          | _  |
| (2)   |  |                          |                               |             |           |          |    |
| (-/   |  |                          |                               |             |           |          | _  |
| (3)   |  |                          |                               |             |           |          |    |
| (-,   |  |                          |                               |             |           |          | _  |
| (4)   |  |                          |                               |             |           |          |    |
| ``'   |  |                          |                               |             |           |          | _  |
| (5)   |  |                          |                               |             |           |          |    |
| (-)   |  |                          |                               |             |           |          | _  |
| (6)   |  |                          |                               |             |           |          |    |
| \ - / |  |                          | 1                             |             |           |          |    |

Part V

Schedule R (Form 990) 2020

#### Part VI Unrelated Organizations Taxable as a Partnership. Complete if the organization answered "Yes" on Form 990, Part IV, line 37.

Provide the following information for each entity taxed as a partnership through which the organization conducted more than five percent of its activities (measured by total assets or gross revenue) that was not a related organization. See instructions regarding exclusion for certain investment partnerships.

| (a) Name, address, and EIN of entity | (b) (c) Primary activity Legal domicile (state or foreig country) |  | (d) Predominant income (related, unrelated, excluded from tax under |     | (e) (f) re all partners section 501(c)(3) rganizations? |  | (g)<br>Share of<br>end-of-year<br>assets | (h) Disproportionate allocations? |    | (i)<br>Code V - UBI<br>amount in box 20<br>of Schedule K-1<br>(Form 1065) | (j)<br>General or<br>managing<br>partner? |    | (k)<br>Percentage<br>ownership |  |
|--------------------------------------|---|--|---|-----|---|--|--|-----------------------------------|----|---|---|----|--------------------------------|--|
| (4)                                  |   |  | sections 512 - 514)   | Yes | No  |  |  | Yes                               | No |   | Yes                                       | No |                                |  |
| (1)                                  |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (2)                                  |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (3)                                  |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (4)                                  |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (5)                                  |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (6)                                  |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
|                                      |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (8)                                  |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (9)                                  |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (10)                                 |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (11)                                 |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (12)                                 |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (13)                                 |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (14)                                 |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (15)                                 |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
|                                      |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |
| (16)                                 |   |  |   |     |   |  |  |                                   |    |   |   |    |                                |  |

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#### Part VII Supplemental Information

Provide additional information for responses to questions on Schedule R. See instructions.