HUNTINGTON’S DISEASE SOCIETY OF AMERICA CENTERS OF EXCELLENCE
2024 Program Description

DATES AND DEADLINES

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<th>Activity</th>
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<tr>
<td>Online submission form</td>
<td>Open by October 10, 2023</td>
</tr>
<tr>
<td>Completed application for funding</td>
<td>due by November 27, 2023</td>
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<tr>
<td>Letters of Designation</td>
<td>by Early February 2024*</td>
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*All grants are retroactive to January 1, 2024

MISSION

The goal of the HDSA Center of Excellence (COE) program is to increase access to the best possible multi-disciplinary clinical care and services for individuals affected by Huntington’s disease (HD) and their families through a geographically diverse network of local and/or regional clinical centers. In addition to clinical and social services, the Centers will provide professional and lay education in the geographic areas they serve, are involved in HD clinical research and work with HDSA locally and nationally in its efforts to continually improve the lives of those affected by HD and their families.

OBJECTIVES

- To design a US standard for best practice multidisciplinary care in the management of HD and to provide access to services for families with HD.
- To select and support clinics and/or institutions that excel with regard to: knowledge and experience in caring for patients and families with HD, education of HD in their local community, use of a multidisciplinary care team approach for HD, and offer opportunities for participation in HD clinical research.
- To directly support the HDSA mission by developing and maintaining relationships with the HDSA local, regional and national community, including among the HDSA Centers of Excellence network.

CLINICAL AND SOCIAL SERVICES

HDSA Centers of Excellence provide comprehensive multidisciplinary clinical service for patients and families affected by HD. Services are centered around an organized HD clinic in which an individual’s clinical care needs are defined, plans are made to fulfill those needs, and follow-up is provided to continually optimize clinical management. While attending to the individual, needs will be considered in the context of the family unit impacted by HD.

Based on the size and scope of clinics within the HDSA Center of Excellence program, as determined by the levels of criteria, some services may be readily available on campus or provided at off-site facilities at the discretion of the Center. Responsibility for the treatment plan should be retained by the Center so that HD families will benefit from the Center’s expertise. Individuals should be seen annually or semi-annually at the HDSA Center of Excellence for HD treatment management; the personnel at an HDSA Center of Excellence does not replace the primary care provider (PCP) and is expected to work in concert with the PCP.

Core HDSA Center of Excellence personnel must have established and demonstrated expertise in caring for a person with HD. Depending on the level of services offered, HDSA Centers of Excellence will be categorized as Level 1, 2 or 3. Requirements are briefly summarized in the following table and expanded below. Click on the left column to jump to details.
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<td>Required onsite or on campus: psychiatrist, psychologist, physical therapist, occupational therapist, speech-language pathologist, nutritionist</td>
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<td>Partner Sites: On Site: Clinic director, neurologist, Social Worker, triage/help line Access to: mental health services, genetic counselor, research opportunities, ancillary services.</td>
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Collaboration with HD Community

Participate and/or collaborate in HDSA community educational efforts, disseminate HDSA information and resources, and connect families to HDSA support groups, chapters and affiliates.

Expectations for Community Participation and Training

Center Director: 2 HDSA sponsored events annually. Social worker: Professional Training Day at HDSA Annual Convention. Other Center staff: Encouraged to attend at least 1 HDSA sponsored event annually.

Unique Programs

Description of any new or unique programs instituted by your HDSA Center of Excellence over past 12 months. For new applicants, describe any new programs you might institute with your designation.

Indigent Care

Procedures must be in place for providing care to those without insurance or the ability to pay.

Budget and Funding Plan

Provide a budget in tabular form; include funds to send SW to Professional Training. For regional sites: include budget for each partner site on main budget sheet. Note: When budgeting, keep in mind that HDSA traditionally provides awards of up to 90% of requested budget.

Financial Reconciliation

An annual reconciliation of how award funds were spent, signed by an authorized official of the institution/university, is due no later than January 31. New awards cannot be processed or paid without an accepted reconciliation.

Other Support and Institutional Commitment

Include any other forms of financial or in-kind support your HDSA Center of Excellence will receive this year including space, equipment, grants, gifts.

Terms and Conditions

This set of good community citizenship principles are to be signed by an official authorized to sign on behalf of your institution.

DESIGNATION AND PROGRESS REPORTS

As of January 1, 2024, designation as an HDSA Center of Excellence is valid for three years, regardless of designation level. To maintain designation and funding, current HDSA Centers of Excellence must complete an annual progress report that is due HDSA by November 27, 2023 and is subject to review by the Center Programs Education and Advisory Committee (CPEAC). In addition, existing HDSA Centers of Excellence must submit a financial reconciliation for 2023 funds no later than January 31, 2024.

In any year in which an unsatisfactory Progress Report is submitted or upon failure to deliver the services or adhere to the terms and conditions delineated in the letter of award, HDSA reserves the right to suspend the HDSA Center of Excellence designation and grant funding until such time as identified deficiencies have been satisfactorily addressed. Said deficiencies must be resolved within 90 days of suspension or the HDSA Center of Excellence designation will be revoked and the grant terminated.

GRANT PROCESS

For parties seeking designation at a new level, please contact Arik Johnson, PsyD (AJohnson@hdsa.org), to discuss your eligibility. Existing HDSA Centers of Excellence will be informed as to whether they are required to complete an application or a progress report. A site visit by representatives of HDSA may be a part of the designation/renewal process.
REVIEW AND SCORING OF APPLICATIONS
Applications will be reviewed by the HDSA Center Programs & Education Advisory Committee (CPEAC). All applications will be scored, using the following criteria:

- The quality of the overall application/services
- Geographic diversity
- Unique offerings or particular characteristics that add to the HD clinic
- Use of funds and proper distribution of budget
- Miscellaneous (e.g., HD community citizenship, research)

More than 50 percent of the emphasis will be placed on the first criterion which is the overall quality and completeness of the application and HD services provided at the prospective HDSA Center of Excellence. The scoring of applications is part of an internal review process used by CPEAC to determine outcomes. Therefore, scores will not be shared with any site submitting an application for designation as an HDSA Center of Excellence, regardless of whether or not the site is given designation.

DECISION NOTIFICATION
Applicants will be notified by e-mail after a designation decision has been made by CPEAC and no later than early February 2024. All awards are retroactive to January 1, 2024. If a clinic is designated as an HDSA Center of Excellence, an award letter will be sent to the Center’s medical director. If a clinic does not receive the HDSA Center of Excellence designation, the clinic director will receive feedback detailing areas for improvement in future applications.

*If you have any questions about the HDSA Center of Excellence program please direct them to Arik Johnson, PsyD, Chief Mission Officer at AJohnson@hdsa.org.

FULL ELIGIBILITY REQUIREMENTS AND EXPECTATIONS FOR HDSA CENTERS OF EXCELLENCE

Patient base at time of application
Reported patient numbers should reflect individual patients, not individual visits. Numbers may include tele-neurology patients. Centers of all levels must have a proven record of new patients seeking care annually. At the time of application for HDSA Center of Excellence status:

- Level 1 applicants should serve a minimum HD patient base of 150. Each Level 1 Partner Site must serve a minimum patient base of 10.
- Level 2 applicants should serve a minimum HD patient base of 75.
- Level 3 applicants should serve a minimum HD patient base of 25.

Minimum HD-specific clinic time (Equivalent to)
HDSA Centers of Excellence hold regular organized multidisciplinary HD clinics.

- Level 1: equivalent to at least one full day per month. Each Level 1 Partner Site is required to offer clinic the equivalent of one half day 4 times annually.
- Level 2: equivalent to at least one full day per month.
- Level 3: equivalent to at least one half day per month.

Prior support
Level 1 and 2 HDSA Center of Excellence applicants should have a substantial track record of institutional support for HD or movement disorder clinic prior to the award. This is not necessary for Level 3 applicants.
Relationship with partner clinic that expands geographic access to care (Level 1 only)

A Level 1 HDSA Center of Excellence must have established a formal partnership with other HD clinic(s) within a specific region as delineated in their application and award. Each HDSA Center of Excellence Partner Site that is associated with a Level 1 Center of Excellence MUST:

- Expand geographic access to HD care
- Be outside of the applicant’s university or hospital system
- Provide a detailed letter of support to the Level 1 application
- Have a minimum of 10 HD patients at time of application
- Be an established movement disorder clinic or HD clinic staffed by professionals with knowledge of HD including a neurologist and social worker
- Provide access to or offer HD genetic testing
- Offer access to ancillary therapies
- Offer lay, professional and community HD education
- Provide access to or information about HD research and clinical trial opportunities

Level 2 and 3 Centers of Excellence are not expected to have partnerships with additional sites.

Administration

Clinic directorship

All HDSA Centers of Excellence are usually led by a medical director or co-director who is either a neurologist or psychiatrist well-qualified in the movement disorder field with expertise in HD. While it is strongly preferable that the HDSA Center of Excellence Director be a licensed physician, consideration will be given to a qualified professional who has demonstrated and documented expertise in Huntington’s disease. In those instances, where the Director is not a physician, then the co-Director must be a licensed physician with expertise in HD.

Operations Committee

An Operations Committee (3-4 persons) comprised of a Center Director and other senior Center professionals is required at all HDSA Centers of Excellence. This Committee:

- Convenes multidisciplinary team and oversees clinical practice
- Manages relationships with collaborating professionals
- Notifies HDSA of personnel changes in HD team within 30 days of change
- Oversees Center operations
- Is responsible for timely and proper reporting
- Investigates complaints made by patients and families utilizing the HDSA Center of Excellence in cooperation with the assigned representative from the Center Programs Education and Advisory Committee (CPEAC)
- Operations Committee meets a minimum of once a year and records minutes of meeting. Minutes should be made available to HDSA upon request.

Complaints lodged against an HDSA Center of Excellence:

From time to time, HDSA receives a complaint from an HD family regarding a specific HDSA Center of Excellence. HDSA takes these grievances seriously and as such, two representatives from the Center Programs Education and Advisory Committee (CPEAC) are assigned by the Chair of the Committee to investigate the issue(s) raised by the family. These representatives connect with both the Operations Committee of the HDSA Center of Excellence in question as well as the family to jointly determine whether or not the grievance is valid and, if so, what action should be taken to ensure it does not recur. Grievances are rare and are usually settled amicably.
Center Advisory Board:

A Center Advisory Board is required at all HDSA Centers of Excellence and should include representatives from local HDSA chapters or affiliates and/or the local HD community, HD family members, local business leaders, and the Center director as a non-voting member. This board:

- Provides feedback on whether the needs of the local HD community are being met
- Meets at least once per year (virtually or in-person) to assess programs and services delivered by the HDSA Center of Excellence prior to submission of an annual Progress Report or application for re-designation. Minutes of meetings should be available to HDSA upon request.
- Provides a letter of support at annual review.

Clinical services

Level 1 and 2 HDSA Centers of Excellence are expected to have a full multidisciplinary team with comprehensive care available on clinic days, including access to ancillary providers, without requiring a separate appointment day. Level 3 HDSA Centers of Excellence are expected to have core personnel in clinic on clinic day, but may refer patients to community based providers for ancillary services.

**Level 1:**

The following providers **must** be present onsite at the primary site on clinic days. See note below for required staff for partner sites on clinic days.

- Clinic director
- Neurologist
- Genetic counselor compliant with the 2015 HDSA protocol
- Social worker (minimum MSW, licensed and meets all institution/clinic requirements (i.e. HIPAA training and certification)
- Research personnel to facilitate participation in onsite clinical studies
- Service triage or “help line” personnel such as a clinic coordinator, social worker, nurse, or other identified staff person to coordinate scheduling and ensure timely access to needed services

Additional providers must be available on clinic days and can be either in the clinic or on campus (within walking distance or a short drive):

- HD-experienced psychiatrist or neuropsychiatrist
- Psychologist or neuropsychologist
- Physical therapist
- Occupational therapist
- Speech-language pathologist
- Nutritionist

On HD clinic days, patients in a Level 1 HDSA Center of Excellence should have access to these services on the same day for an initial evaluation.

If your clinic offers telemedicine, provide a description of the program and its use.

**Partner sites**

The following providers must be present on site on clinic days

- Clinic director
- Neurologist
- Social worker (minimum MSW, licensed, meets all institution/clinic requirements (i.e. HIPAA training and certification)
- Service triage or “help line personnel to coordinate scheduling and ensure timely access to needed services
Additional providers must be available by community referral with the expectation that the service is provided within one week of the clinic appointment. HDSA does encourage partner sites to offer these services in clinic or via telemedicine through the main HDSA Center of Excellence when possible.

- Psychologist/psychiatrist
- Nurse
- Genetic counselor
- Referrals to research studies (may be made by the social worker or any personnel familiar with opportunities for research participation)
- Ancillary services (physical therapy, occupational therapy, speech-language pathology, nutrition)

*Partner sites may also refer patients and families to their main HDSA Center of Excellence for these services when feasible (easier for family, closer than a community based alternative, or faster appointments). Services may be offered in-person or via telehealth depending upon individual needs.*

Please refer to Section 11 to describe services offered by your partner site(s).

**Level 2:**

The following providers **must** be present onsite on clinic days.

- Clinic director
- Neurologist
- Social worker (minimum MSW, licensed and meets all institution/clinic requirements (i.e. HIPAA training and certification)
- Nurse
- Research personnel to facilitate participation in onsite clinical studies
- Service triage or “help line” personnel such as a clinic coordinator, social worker, nurse, or other identified staff person to coordinate scheduling and ensure timely access to needed services

Additional providers must be available on clinic days and can be either in the clinic or on campus (within walking distance or a short drive):

- Genetic counselor compliant with the 2015 HDSA [protocol](#)
- HD-experienced psychiatrist or neuropsychiatrist
- Psychologist or neuropsychologist
- Physical therapist
- Occupational therapist
- Speech-language pathologist
- Nutritionist

On HD clinic days, patients in a Level 2 HDSA Center of Excellence should have access to these services on the same day for an initial evaluation.

If your clinic offers telemedicine, provide a description of the program and its use.

**Level 3:**

The following providers **must** be present onsite on clinic days.

- Clinic director
- Neurologist
- Social worker (minimum MSW, licensed and meets all institution/clinic requirements (i.e. HIPAA training and certification)
- Service triage or “help line” personnel such as a clinic coordinator, social worker, nurse, or other identified staff person to coordinate scheduling and ensure timely access to needed services
Additional providers must be available by community referral. HDSA encourages Level 3 HDSA Centers of Excellence to provide all services on clinic day either in clinic or on campus if possible.

- Genetic counselor compliant with the 2015 HDSA protocol
- HD-experienced psychiatrist or neuropsychiatrist
- Psychologist or neuropsychologist
- Physical therapist
- Occupational therapist
- Speech-language pathologist
- Nutritionist

On HD clinic days, a Level 3 HDSA Center of Excellence is encouraged but not required to provide patients access to these services on the same day for an initial evaluation.
If your clinic offers telemedicine, provide a description of the program and its use.

**Genetic counseling requirements**

Genetic counseling and testing for persons at-risk for Huntington’s disease is a vital part of the mission of the HDSA Center of Excellence program. All HDSA Centers of Excellence, regardless of funding level, are required to provide access to this service either during clinic, on a separate day or by patient needs (see above for requirements by Level). HDSA Centers of Excellence must follow the [2015 HDSA protocol for genetic testing](#). Since the majority of at-risk individuals elect to self-pay for predictive testing, all HDSA Centers of Excellence must offer a sliding scale for those who cannot afford the out of pocket expense.

**Mental health requirements**

HDSA Centers of Excellence and partner sites must be able at all times to refer a patient for follow-up mental health needs.

- If the primary mental health provider (psychiatrist) is absent from clinic, another team member (psychologist, nurse, (RN/psychiatric nurse practitioner) or social worker) must be capable of performing required consultations, evaluations, recommendations and referrals.
- If a known psychological or psychiatric need exists, there must be a timely plan for a psychologist/psychiatrist to meet with the person(s) and/or family to address issues.

**Research**

Although the primary mission of an HDSA Center of Excellence is to provide clinical service, Centers are also expected to participate, as much as possible, in research benefiting the entire HD community.

- All Level 1 and 2 HDSA Centers of Excellence must be credentialed research sites of the Huntington Study Group (HSG) by the application deadline of November 18, 2022.
- All Level 1 and 2 HDSA Centers of Excellence are encouraged to be active ENROLL-HD sites. Active is defined as having a signed/executed contract with CHDI Management, Inc. by the application deadline of November 18, 2022.
- A Level 3 HDSA Center of Excellence is not required to provide or participate in HD research opportunities, but is strongly encouraged to do so. All Level 3 sites are expected to provide their patients with updated information about clinical studies and trials in their area.
- Level 1 Partner site(s) are not required to provide or participate in HD research opportunities, but it is strongly encouraged that they do so. Partner site(s) must provide their patients with updated information about clinical studies and trials in their area.
Education

The Educational Mission of the HDSA Centers of Excellence involves the following:

- Consultation, training, presentation, and supervision of education in HD for community providers and science professionals.
- Education of the general public about Huntington’s disease,
- Educational events and activities in support of HDSA chapter/regional activities.
- Disseminate HDSA educational resources and information to community at large and to HDSA Center of Excellence patient base.

Outreach:

- HDSA Centers of Excellence must provide in-service training (via telephone, zoom or in-person) to all appropriate staff at local long-term care (LTC) facilities and assist in identifying placement in LTC facilities for HD patients and families.
- HD advocacy for general public, public officials and agencies, potential donors, etc. Support of HDSA advocacy initiatives as needed.
- Collaboration with university/institution to promote the HDSA Center of Excellence both within the university/institution system but also to the community at large. For new applicants, describe how your university/institution would promote your designation as an HDSA Center of Excellence.
- Connect HD families to HDSA resources and information as well as to support groups, chapters and affiliates.
- The Social Worker is expected to provide education, referrals and assistance to HD families both inside and outside clinic hours.

Collaboration with local HDSA community

There are many ways in which HDSA Centers of Excellence and HDSA chapters, affiliates and regions can support each other. Consistent with the HDSA mission, close relations between Centers and HDSA chapters/affiliates are highly desired. Some ways that HDSA Centers of Excellence and chapters/affiliates may assist each other include:

- Educational programs for people with HD and their families;
- In-services for local Long Term Care facilities;
- Public dissemination of information about HD and HDSA;
- Participation in local HDSA activities, and
- Involvement/connection to HDSA support groups.
- Be an ambassador of HDSA in the community

Expectations for community participation and training

Educational requirements for onsite personnel include the following:

**Center Director**

- HDSA Center of Excellence Directors (including those at partner sites) must attend and actively participate in at least two HDSA sponsored events annually (with at least one being educational).

**Social Worker**

- All HDSA Center of Excellence social workers must attend HDSA Professional Training Day held annually the Thursday prior to the HDSA Annual Convention May 30, 2024 in Spokane, WA). Sufficient funds should be set aside from any grant provided by HDSA to allow for travel and hotel accommodations.
- At the discretion of the HDSA Center of Excellence director and based on availability of the social worker, it is strongly urged that the social worker also attend the two-day HDSA Annual Convention (May 31 – June 1, 2024 in Spokane, WA).

**All Center Staff**

- All other HDSA Center of Excellence staff are encouraged to participate in a minimum of one event (educational) annually.
Unique programs

Describe any new or unique programs or activities that your HDSA Center of Excellence has initiated in the last calendar year. Include the number in attendance, goals/objectives of program/activity and whether it will be incorporated into your clinic permanently. For new applicants, describe any new programs you intend to introduce this year, the intended audience and the goals of the activity.

Indigent care

Procedures must be in place for providing care to those without insurance or the ability to pay. All sites are required to provide clinical care to persons with HD who may lack health insurance or the ability to pay by either creating a sliding scale that will allow a person to pay some portion of the fee or by setting aside a percentage of their annual grant from HDSA that does not exceed 5%. If funds are utilized for indigent care, then a detailed report of the number of persons served and their care costs will be required at the time of renewal/re-application.

Budget and funding plan

Provide a budget followed by specific justifications of each budget item. Major categories that can be funded include personnel, services, supplies, and travel (HDSA events only). Personnel should include percentage of effort and a breakdown of base pay and fringe benefits. Level 1 applicants should include detailed information about funding for their partner site(s) in the area provided.

Please note:
- HDSA allows no more than 5% of any grant to be used for administrative expenses.
- HDSA funds may not be used for travel to non HDSA activities or meetings.
- Funds should be allocated for each social worker to attend HDSA’s annual Professional Training.
- Historically, HDSA awards 50% - 90% of the grant requested at time of application. Your budget should be developed with this caveat in mind.

Financial reconciliation

Upon completion of the grant funding cycle on December 31 of each year, the Grants and Contracts office of your institution will be required to provide a financial audit report detailing how the HDSA Center of Excellence award was spent against the submitted and approved budget. This report must be signed by an authorized financial officer at your institution and must be submitted no later than January 31 of the following year. Any unused funds must be returned to HDSA.

Other support and institutional commitment

If you receive additional funding or in kind support for your HDSA Center of Excellence in the form of grants or individual donations that cover salaries, administrative support and/or space, please provide details in Part 10 of your application.

Terms and conditions

1. Confidentiality
   In connection with an application to be designated as an HDSA Center of Excellence, prospective Centers and HDSA may each provide the other party with financial and other information regarding the disclosing party, including regarding the application and evaluation process. All such information (whether written or oral) provided by either party or any of its affiliated entities or representatives shall be considered “Confidential Information,” unless such information is publicly available prior to such disclosure. In consideration of the application process, each of the prospective Centers and HDSA hereby agrees to keep the Confidential Information confidential and use it solely for the purpose of evaluating the application to become a Center of Excellence and acceptance of such designation (including any related grant), and each party will not disclose any Confidential
Information of the other party without the prior written consent of such other party, unless otherwise required by applicable law.

2. Non-Disparagement
   Each of the prospective Centers and HDSA (including their respective directors, employees and other representatives) agree not to make any negative comments or otherwise disparage the other party or any of its directors, employees, or other representatives, except with respect to any truthful statements made in response to legal proceedings.

3. Agreement to Terms and Process
   Each prospective Center shall be deemed to have agreed to the confidentiality and non-disparagement terms and provisions set forth above automatically in connection with its submission of an application to be designated as an HDSA Center of Excellence. Each prospective Center agrees that HDSA and its directors, advisors and representatives (i) reserve the right, in their sole discretion, to approve or reject any applications; and (ii) shall be free to conduct the application and evaluation process as they in their sole discretion shall determine. Except with respect to a violation of the mutual confidentiality and non-disparagement provisions set forth above, each prospective Center agrees that it shall have no claims whatsoever against HDSA or any of its directors, advisors or representatives arising out of or relating to the application and evaluation process.

4. Right to Revoke Status
   In addition to all other remedies available at law or equity, HDSA hereby expressly reserves the right to revoke the status of an HDSA Center of Excellence and/or require repayment of any awards, in each case as determined by HDSA in its sole discretion, in connection with any violation of the confidentiality and non-disparagement provisions set forth above, or in connection with any misuse of award funds or fraud.

The Terms and Conditions document must be signed by an official authorized to sign on behalf of the institution. The prospective HDSA Center of Excellence director or co-director are not acceptable signers. Please submit the Terms and Conditions document to your institution upon receipt of the Application Package so there is adequate time to process and return it to HDSA prior to the deadline for submission of your application.