



Help for Today. Hope for Tomorrow.

Annual Report FY 2010-2011



Dear Friends of HDSA,

As we look back at the last year of the Huntington's Disease Society of America's impact and efforts to improve the lives of people with Huntington's disease and their families, we see much success. During the 2010-11 fiscal year we ushered in new community service programs, new chapters and affiliates, and laid the groundwork for a new strategic plan that will be the blueprint for the Society's programs of work for the next five years.

We are very proud of the year's achievements, which include the publication of an updated *Physician's Guide for the Management of HD*, a greatly expanded national website section of medical and non-medical resources, the addition of six new chapters and affiliates serving new communities of HD families, the growth of the Team Hope Walk for HD campaign to more than 70 walks and a special scholarship program that made it possible for 150 people to attend the HDSA Annual Convention for the first time.

Additionally, our voice has been sought on the global level. HDSA was recruited to provide leadership on the International Huntington Association and we are integrally involved in the new international observational study Enroll-HD.

Today we turn our attention towards implementation of the new HDSA Strategic Plan, which sets a course for growth so that we can help more families and accelerate the development of treatments and potentially a cure for this devastating disease. The Plan includes the launch of a new HDSA Research Program in addition to the expansion of many of the resources and services that you have come to depend on through HDSA.

We look forward to an exciting year and one that with your help, will expand our ability to deliver *Help for Today, Hope for Tomorrow* to everyone affected by Huntington's disease. Thank you for your partnership and shared vision.

Sincerely,

Donald L. Barr

Chair, National Board of Trustees

Louise A. Vetter

Chief Executive Officer



HDSA: A YEAR IN REVIEW

During the past year HDSA focused its efforts to provide more information about and access to, a greater array of services and other resources for HD families. A prime example of this effort was the publication of the new *Physician's Guide to the Management of Huntington's Disease*.

Publication of the revised Guide made the most current clinical guidelines available to medical professionals inside the HD community, and provided a comprehensive roadmap for physicians with little to no HD training but who perhaps treat just a few people with HD.

Distributing the Guide was also an important tool for identifying physicians who see patients with HD, and after obtaining permission from the doctors, HDSA was able to add hundreds of new listings of medical professionals to the HDSA.org website. This is an incredible resource since we regularly receive calls from people new to HD or people with HD who have moved to a new community and are seeking a doctor who has expertise in this area.

HDSA's Caregivers' Corner Webinar Series continued to be one of the most valuable and popular programs with HDSA constituents. Whether participating in the live webinar or utilizing the archived programs, families were able to learn how to improve their caregiving skills, apply for Social Security and Medicare, advocate for the HD Parity Act and a host of other skillsets that helped them improve the quality of life of a person with HD.

Also excitingly in 2011, HDSA welcomed a National Social Worker to the staff team. In addition to fielding inquiries and working with families directly, he is coordinating and setting new standards and best practices for the 36 HDSA social workers throughout the U.S.

HDSA Support Groups, which grew in numbers to 160 in 2011, were the recipients of new resources as well. We Are HDSA, a monthly newsletter for support group members, was introduced, and the HDSA Clinical Trial Diplomat program provided speakers to almost every

support group during May, which is annually HD Awareness Month. The Diplomats are HD family members who have participated in clinical trials and have gone through training to talk about their experiences to groups of their peers. Being involved in clinical trials and studies is one of the most important opportunities for HD families to participate in improving the understanding of the disease and accelerate the identification of treatments and, hopefully one day soon, a cure.

In February the HD Parity Act was reintroduced in the House for consideration by the new Congress, and in March, a companion bill was introduced in the Senate thanks to the ongoing efforts of the thousands of HDSA advocates who called,



emailed and visited their elected officials. The 14,900 HDSA advocates have helped invigorate activity across the entire HDSA community by giving a loud and united voice to our cause.

Perhaps no activity was more indicative of the energy and expansion of HDSA programs than the Annual Convention in Bloomington, Minnesota. More than 1,000 people attended the Convention making it the largest one ever! More than 125 of these were first-time attendees who were recipients of one of three scholarship programs. In addition to the annual Leadership Training (chapter and affiliate leaders), Professional Training (social workers and other medical professionals) and National Youth Alliance (NYA) pre-convention meetings, HDSA hosted a workshop for young adults representing HD organizations from 15 countries.

Another indication of the growth that HDSA experienced this past year was the expansion of the Team Hope Walk for HD program to 72 events, raising more than \$1,000,000 to support HDSA programs and services. In several cases these walks led to the establishment of new groups that evolved into HDSA Affiliates, expanding the Society's reach into areas it has not previously been able to serve.

Three new affiliates and three new chapters were established in 2011. The chapters evolved from affiliates that increased their calendar of events, and developed a core of volunteer leaders committed to bringing the full range of HDSA support to their community. By year end, there were 45 HDSA chapters and affiliates spread across the country to bring care, support, advocacy and hope to families.

HDSA chapters and affiliates held 21 local educational events during 2011. These "miniconventions" featured local experts—clinicians, researchers and other medical and non-medical professionals—presenting information on topics of relevance to HD families. Themes and topics varied from meeting to meeting, but each contained a clinical trials session, as part of the Society's focus on clinical trials education and recruitment.

Developing new HDSA programs and services is only meaningful when HD families know about them, and HDSA made great strides in

spreading the word in 2011 to the HD community and to the general population. In addition to the expansion of the national HDSA.org website, every chapter and affiliate has a fully functioning website maintained by trained local volunteers to keep it updated and current. Local market media coverage of HDSA events and HDrelated topics also grew significantly, to the point where a new section "HD and HDSA In the News" was created on the national

website to feature articles, television and radio coverage.

All HDSA publications are available for free download on the HDSA website, and for the first time, all of our fundraising campaigns now include a digital component, allowing the Society to reach many more supporters cost-effectively. Given the challenging economy, we are always looking for ways to reach more people by stretching our dollars as far as possible.

HDSA continued its practice of participation and leadership with other organizations to maximize impact for the international HD community. In addition to the management of HDTrials.org, an educational website highlighting U.S.-based HD-specific clinical research, senior staff, trustees and volunteers participated in the World Congress in Melbourne, Australia, the Clinical Research Symposium with the Huntington Study Group, and have worked in close partnership with the CHDI, European HD Network, Huntington's Society of Canada and the International Huntington's Association to name a few.

Many HDSA publications were utilized by other national patient-focused organizations and links to the HDSA website Research Section were found on many websites around the world. HDSA's support of HDBuzz made it possible for this new source of easily-accessible HD research news to be available on the HDSA national website, and those of other HD organizations as well.





Our participation in and support of the NIH/NINDS-led Huntington's iPSC Stem Cell Consortium made possible the creation of over 40 new HD stem cell lines that will be available to both academic and commercial scientists for investigation. iPSC Stem Cells are created from skin "punches" taken from volunteers. While the use of stem cells as a therapeutic is a future goal, the ability to create human neurons from these cells will give researchers a valuable new tool for the investigation of potential therapies.

Clinical trial education and recruitment remained a top priority for the Society. Every Chapter

education event included a session on clinical trials. HDSA participated in ongoing consultations with pharmaceutical and biotech companies to help them develop protocols for future clinical trials that would be more family-friendly and therefore make participation more practical for people with HD and their caregivers.

For all of our work in 2011, we never lose sight of our vision of a world free of Huntington's disease and we have taken specific steps to plan for this. The result is the HDSA Strategic Plan: 2012-2016, which was launched in early 2012 and will guide the work of the Society for the next five years. The creation of the plan included a community survey, months of meetings by the Strategic Planning Committee, consultation from HD leaders, and then an open comment period in which everyone was invited to comment on a draft. Based upon community input, the plan was completed, and its implementation begins in 2012. The Strategic Plan includes details of the new HDSA Research Initiative, which is planned to launch in late 2012.

2011 was a year in which HDSA was able to provide more *Help for Today, Hope for Tomorrow* to everyone affected by Huntington's disease. This was possible due to the active partnership and ongoing support of everyone in the HD community who shares our mission and is willing to do more than just dream of the day when HD is a distant memory.



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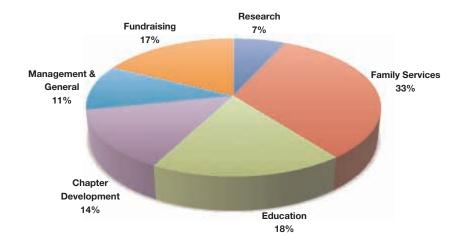
HDSA Fiscal Year Change

In 2010, the HDSA Board of Trustees determined that it would be advantageous for the Society to change its fiscal year from October 1 through September 30 to a calendar year, January 1 through December 31. In order to do so, HDSA had two fiscal years during calendar 2011: October 1, 2010 - September 30, 2011 and a short fiscal year October 1, 2011 - December 31, 2011, making it possible to start a new fiscal year January 1, 2012 that would run through December 31, 2012. Separate financial reports for these two fiscal years follow.



| | 2011 | 2010 |
|--|-----------|--|
| ASSETS | | A STATE OF THE STA |
| Cash and cash equipments | 2,635,987 | 2,683,194 |
| Investments, at fair value | 611,868 | 717,976 |
| Contributions receivable, net | 492,196 | 1,375,458 |
| Pledges receivable, net | 29,616 | 33,691 |
| Prepaid expenses and deposits | 134,265 | 172,751 |
| Cash surrender value of life insurance | 120,756 | 116,018 |
| Property and equipment, net | 68,435 | 27,098 |
| Total Assets | 4,093,123 | 5,126,180 |
| LIABILMES | | |
| Accounts payable and accrued expenses | 396,402 | 363,024 |
| Accrued compensation | 204,922 | 216,709 |
| Research grants psyable | 800,600 | 1,905,000 |
| Deferred rent | 107,933 | 114,890 |
| Obligation under capital lease | 26,911 | 0 |
| Deferred revenue | 104,972 | 224,559 |
| Total Liabilities | 1,641,740 | 2,824,182 |
| Net assets: | | |
| Unrestricted: | | |
| Undesignated | 445,071 | 815,339 |
| Scent-designated | 443,603 | 443,603 |
| | 888,674 | 1,258,942 |
| Temporarily restricted | 1,312,709 | 793,056 |
| Permanently restricted | 250,000 | 250,000 |
| Total Net Assets | 2,451,383 | 2,301,998 |
| Total Liabilities And Net Assets | 4,093,123 | 5,126,180 |

| CONSOLIDATED STATEMENT OF ACTIVITIES FOR THE YEARS ENDED SEPTEMBER 30, 2011 AND 2010 | | |
|---|---|-------------|
| 3,012,1100,100,012,012,012,01 | 2011 | 2010 |
| Support and revenue: | 70 023 | |
| Public donations | 2,353,166 | 2,383,654 |
| Foundation grants and | | 23330255 |
| corporate contributions | 1,176,812 | 2,731,885 |
| Federal campaign | 286,983 | 233,299 |
| Investment income | 11,303 | 16,555 |
| Sale of materials | 17,289 | 23,418 |
| Dongted services | 138,714 | 191,407 |
| Other | 40,486 | 2,532 |
| Total Support and | E- E-0000000000000000000000000000000000 | 597000 |
| Revenue | 4,024,753 | 5,582,750 |
| Expenses: | | |
| Program services: | | |
| Research | 557,768 | 569,877 |
| Family services | 2,056,082 | 2,142,322 |
| Education | 1,495,440 | 1,343,630 |
| Chapter development | 1,192,137 | 1,629,341 |
| ACTEMENT POSTERS OF THE | 5,301,427 | 5,685,170 |
| Supporting services: | | |
| Management and general | 835,282 | 828,483 |
| Fundraising | 1,468,176 | 1,604,126 |
| | 2,303,458 | 2,432,609 |
| Total Expenses | 7,604,885 | 8,117,779 |
| Change in net assets before | | |
| non-operating income | (3,589,132) | (2,535.029) |
| Non-operating income: | | |
| Special events: | | |
| Gross recepts | 4,451,866 | 3,754,438 |
| Less: direct costs | (722,349) | (686,952) |
| Net income from | | |
| special events | 3,729,517 | 3,067,486 |
| Change in Net Assets | 149,385 | 532,457 |
| Net assets - beginning of year | 2,301,998 | 1,769,341 |
| Net Assets - September 30 | 2,451,383 | 2,301,998 |



Note: This chart reflects a 15-month period covering the FY October 1, 2010 - September 30, 2011 and the FY October 1, 2011 - December 31, 2011.

These Consolidated Statements reflect the operations of the Society for te fiscal years as stated and include all affiliates. Please contact the National Office for a full copy of the audited financial statements.

| STATEMENT OF FINANCIAL POSITION AS OF DECEMBER 31, 2011 | | |
|---|-----------|--|
| ASSETS | | |
| Cash and cash equivalents | 2,604,904 | |
| Investments, at fair value | 612,777 | |
| Contributions receivable, net | 501,576 | |
| Pledges receivable, net | 24,616 | |
| Prepaid expenses and deposits | 102,850 | |
| Cash surrender value of life insurance | 120,221 | |
| Property and equipment, net | 62,193 | |
| Total Assets | 4,029,137 | |
| LIABILITIES | | |
| Accounts payable and accrued expenses | 309,398 | |
| Accrued compensation | 152,997 | |
| Research grants payable | 1,550,000 | |
| Deferred rent | 103,763 | |
| Obligation under capital lease | 25,863 | |
| Deferred revenue | 42,722 | |
| Total Liublities | 2,186,743 | |
| Net assets: | | |
| Unrestricted: | | |
| Undesignated | (507.540 | |
| Board-designated | 443,603 | |
| | (63,937 | |
| Temporarily restricted | 1,656,331 | |
| Permanently restricted | 250,000 | |
| Total Net Assets | 1,842,394 | |
| Total Liabilities And Net Assets | 4,029,137 | |

| CONSOLIDATED STATEMENT OF ACTIVITIES FOR THE YEAR ENDED DECEMBER 31, 2011 | |
|--|------------|
| Support and revenue: | |
| Public donations | 763,887 |
| Foundation grants and | 11/2001001 |
| corporate contributions | 318,329 |
| Federal campaign | 76,328 |
| Investment income | 3,553 |
| Donated services | 89,109 |
| Other | (1,472 |
| Total Support and | - |
| Revenue | 1,249,728 |
| MANAGEMENT | 1110100 |
| Expenses: | |
| Program services: | |
| Research | 132,960 |
| Family services | 1,277,259 |
| Education | 349,097 |
| Chapter development | 238,543 |
| | 1,997,859 |
| Supporting services: | |
| Management and general | 249,058 |
| Fundraising | 317,477 |
| | 566,535 |
| Total Expenses | 2,564,394 |
| Change in net assets before | |
| non-operating income | (1,314,666 |
| Non-operating income: | |
| Special events: | |
| Gross receipts | 831,315 |
| Less: direct costs | (125,638 |
| Net income from | - |
| special events | 705,677 |
| Change in Net Assets | (608,889 |
| Net assets - beginning of year | 2,451,383 |
| Net Assets - December 31 | 1,842,394 |

Please note that the expenses on this page for FY October 1, 2011 - December 31, 2011 are included in the pie chart on the previous page.

These Consolidated Statements reflect the operations of the Society for te fiscal years as stated and include all affiliates. Please contact the National Office for a full copy of the audited financial statements.

We would like to thank the following individuals for their generous donations of \$1,000 or more to the Huntington's Disease Society of America during the 2010-2011 Fiscal Year.

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Advanced Financial Co.
Aggregate Recycling Corp.
Albany Molecular Research, Inc.
Alberici Constructors
Allergan Foundation
Algar Construction Corp.
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Our Mission:

To improve the lives of people with Huntington's disease and their families.

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