



Help for Today. Hope for Tomorrow.

Annual Report
FY 2009-2010

Dear Friends of HDSA

The 2009-10 Fiscal Year was an important one for HDSA, as the Society focused on strengthening all of its programs by improved integration of all efforts through the standardization of all messaging and branding; improvement of communication and work flow between the National Office, Regions and Chapter and Affiliates; and the adoption of new technologies to deliver information to previously unreachable parties. This was driven through several initiatives and a concerted effort to expand the family services and access to resources for every person affected by Huntington's disease.

While the Society experienced many successes in these areas, we are determined to do more in the coming year -- in both the number of people we reach and the resources we can provide to them.

While we concentrate on short-term goals in our annual "Plan of Work" we understand that in order for HDSA to grow we need to address long-term goals as well.

Therefore, based on conversations between the Board of Trustees, Senior Staff members and volunteers, it was determined that a new strategic plan would be developed to provide a framework for the future of the Society. This plan will be developed in FY 2010-11 and implemented in FY 2011-12 with the objective of creating a blueprint to provide even more *Help for Today and Hope for Tomorrow* to everyone affected by Huntington's disease

We look forward to growing the organization and impact of our work with you. Thank you for your continued dedication and support.

Sincerely,



Louise A. Vetter
Chief Executive Officer



Donald L. Barr
Chair, National Board of Trustees

HDSA: A YEAR IN REVIEW

If there was a single phrase with which you could characterize the work of HDSA during Fiscal Year 2009-2010 it was “focus on the families.”

To put this into practice each HDSA department created a plan of work to expand the Society’s presence into more locations than ever before. This was one of the main topics at HDSA’s first Field Staff Retreat, in which regional directors met to discuss best practices and participate in workshops on subjects ranging from data base management to standardized branding. Training continued through the year via webinars and regular distribution of new materials through the Field Extranet.

One way in which this objective was achieved was through the creation of new chapters and affiliates. The New York Metro Affiliate graduated to chapter status and new affiliates in Northern Florida and Long Island were chartered.

In areas that did not yet have a chapter or affiliate, HDSA helped individuals start support groups. These groups would be led by HDSA social workers from neighboring areas, or by an individual trained by HDSA.

The Team Hope Walk program was another way in which HDSA expanded its reach, while at the same time raising funds to support programs of research, care and education. For the first time a national corporate sponsor Lundbeck was recruited and the program included over 50 walks. In many places, the Team Hope Walks were the first notice to people that there was a resource which could provide help, and a way to meet others with a common goal—to fight Huntington’s disease. In some places this resulted in a support group being formed; in other cases a committee was established to begin the formation of an affiliate and establish a permanent presence for HDSA in that locale.

One of the most valuable and popular programs ever created by the Society had its introduction this year: *HDSA Caregivers Corner Webinars*. The Webinars covered a wide variety of topics, from coping strategies for caregivers to nutrition, how to apply for disability support and a host of

other topics. Community members were able to participate in the webinars by asking questions, and when completed, a copy of the webinar is made available on the HDSA website, so it can be accessed at any time of the day or night by anyone who was unable to attend the live session.

In an effort to expand the number of physicians with a working knowledge of Huntington’s disease, HDSA held its first CME program, “HD101.” Forty-five physicians attended the program, and a curriculum monograph was published. Based on feedback from the participants, plans are underway to translate the course to a broad audience online.

Another significant meeting brought together the Directors of the HDSA Centers of Excellence. This



was an opportunity for the HD clinical thought-leaders to share best practices and develop plans for the evolution of this program, which pioneered the Team Approach to HD care and is a key resource for the HD community.

The *Genetic Testing* and *Long Term Care* editions of the Family Guide series were updated, and *The Marker* and *Toward A Cure* were published this year to share important HD news. All were made available in both print and online versions.

More than 800 people attended the 25th Annual National Convention in Raleigh, North Carolina in June, making this the biggest convention in

HDSA history. As in previous years, HDSA Social Workers, Chapters Leaders and members of the NYA (National Youth Alliance) met the day before the start of Convention for intensive workshops to learn about new initiatives and new HDSA resources. For the first time, the Opening Ceremony and Keynote Address, the Focus on the Family Care Forum and the Research Forum were videotaped and made available on the HDSA website, so that those who could not attend were able to view the three major symposia. As in previous years, powerpoint presentations from the individual workshops were also available to download.

HDSA continued to emphasize Clinical Trials Education over the past 12 months. A new syllabus was developed for local Education Events, and a new program, “HD Diplomats” was created for this purpose.

The “Diplomats” are community members who have participated in a clinical trial and are interested in sharing their experience with others to answer questions and hopefully motivate involvement.

A Clinical Trials section of the national website (www.hdsa.org) was created, and a “Local Clinical

Trial Site Finder” was added to make it easy for interested parties to identify sites in their area. HDTrials.org registration continued to grow and HDSA worked closely with other organizations and the sponsors of all ongoing clinical trials to encourage community participation in this critical activity.

The national website expanded its Research section and added a new Clinical Trials section to ensure that the most current news in these areas was available to everyone interested in the progress being made towards new therapies for HD.

The HDSA Advocacy Program reached new heights in 2009-2010, with more than 5000 e-advocates participating in the push to move the Huntington’s Disease Parity Act through Congress. In March, 100 HDSA Advocates visited Capital Hill to meet with their Representatives on HDSA National Awareness Day. Thousands of phone calls were made and emails sent on behalf of the Act that day by those who could not attend in person. By the end of the year, 153 Representatives had signed on as co-sponsors of the bill and there were very few members of Congress who had not been contacted by at least one constituent asking for their support.

HDSA continued to expand its collaboration with other HD organizations on an international basis this year. Staff and Trustees, as well as many members of the *HDSA Coalition for the Cure* attended and participated in international conferences, such as the EHDN (European HD Network) Conference in Prague. HDSA staff were active members of an international youth working group and directed a survey of medical prescription practices by physicians who regularly see people with HD. HDSA was also very active as a member of the International Huntington Association and continued to make its publications available for use by other organizations who do not have the resources to develop them on their own.

HDSA is a community, supporting the HD families nationally and around the globe. Whether online, on facebook or twitter, or through the personal channels of support groups and chapters, our goal is to provide Help for *Today and Hope for Tomorrow* to everyone touched by HD.



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**STATEMENT OF FINANCIAL POSITION
AS OF SEPTEMBER 30, 2010 AND 2009**

	2011	2010
ASSETS		
Cash and cash equivalents	2,683,194	3,002,276
Investments, at fair value	717,976	806,979
Contributions receivable, net	1,375,452	1,072,882
Pledges receivable, net	33,691	166,320
Prepaid expenses and deposits	172,751	148,199
Cash surrender value of life insurance	116,018	110,838
Property and equipment, net	27,098	18,077
Total Assets	5,126,180	5,325,571
LIABILITIES		
Accounts payable and accrued expenses	363,024	544,949
Accrued compensation	216,709	274,789
Research grants payable	1,905,000	2,507,500
Deferred rent	114,890	113,314
Deferred revenue	224,559	115,478
Total Liabilities	2,824,182	3,556,030
Net assets:		
Unrestricted:		
Undesignated	832,273	41,002
Board-designated	443,603	443,603
	1,275,876	484,605
Temporarily restricted	776,122	1,034,936
Permanently restricted	250,000	250,000
Total Net Assets	2,301,998	1,769,541
Total Liabilities And Net Assets	5,126,180	5,325,571

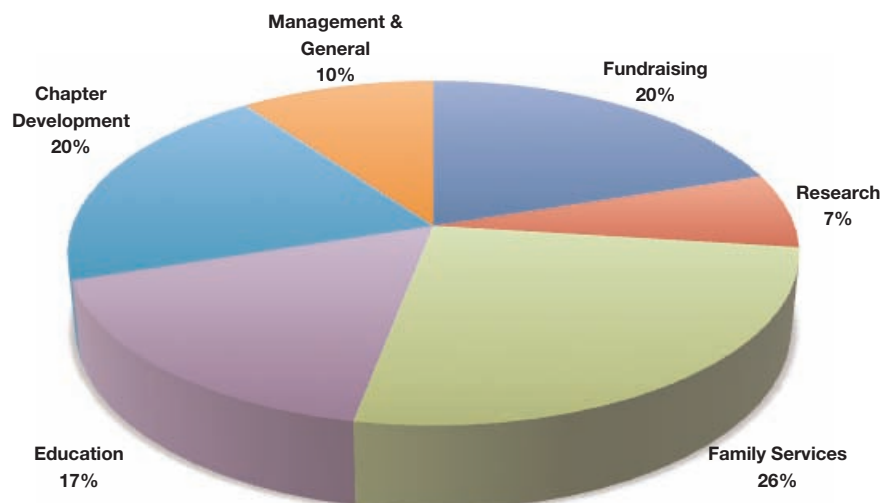


**Huntington's Disease
Society of America**

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

**CONSOLIDATED STATEMENT OF ACTIVITIES
FOR THE YEARS ENDED SEPTEMBER 30, 2010 AND 2009**

	2011	2010
Support and revenue:		
Public donations	2,383,654	2,730,231
Foundation grants and corporate contributions	2,731,885	3,284,380
Federal campaign	233,299	299,787
Investment income	16,555	87,786
Sale of materials	23,418	49,772
Donated services	191,407	90,069
Other	2,532	1,044
Total Support and Revenue	5,582,750	6,543,069
Expenses:		
Program services:		
Research	569,877	2,017,682
Family services	2,142,322	2,124,771
Education	1,343,630	835,254
Chapter development	1,629,341	1,650,770
	5,685,170	6,628,477
Supporting services:		
Management and general	828,483	948,373
Fundraising	1,604,126	1,141,438
	2,432,609	2,089,811
Total Expenses	8,117,779	8,718,288
Change in net assets before non-operating income	(2,535,029)	(2,175,219)
Non-operating income:		
Special events:		
Gross receipts	3,754,438	4,061,129
Less: direct costs	(686,952)	(1,642,800)
Net income from special events	3,067,486	2,418,329
Change in Net Assets	532,457	243,110
Net assets - beginning of year	1,769,541	1,526,431
Net Assets - September 30	2,301,998	1,769,541



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