



Huntington's Disease
Society of America



Help for today. Hope for tomorrow.

**Annual Report
FY 2008-2009**

HDSA: A Year in Review

HDSA: A Year in Review

The 2008-2009 Fiscal Year was an exciting one: new leadership and a renewed dedication to all three parts of HDSA's Mission, and a special focus on the needs of our community through expanded access to resources and the delivery of family services.

Even more, three therapeutic Phase 3 clinical trials got underway and two more prepared to begin recruiting; and two observational trials that had already yielded valuable information about the progression of HD continued to recruit and add to our understanding of the mechanisms involved in Huntington's Disease.

It was also a year in which the message of the devastation of Huntington's Disease and the needs of people affected by HD were heard throughout the halls of Congress, as HR 678, The Huntington's Disease Parity Act, was introduced in the House of Representatives, and garnered many co-sponsors committed to changing Social Security regulations and waive the two-year waiting period for Medicare for qualified individuals with HD. This was a community-wide achievement as more than 12,000 HDSA E-Advocates networked with other community members to contact their Representatives, to make them aware of the devastation of Huntington's Disease and the needs of their constituents affected by HD.

The 24th Annual HDSA National Convention was a huge success, bringing more than 700 attendees to Phoenix, Arizona, the greatest number in 10 years,

to participate in six tracks of workshops, symposiums and training sessions. For the second year, the National Youth Alliance (NYA) held a special pre-Convention Education Day for more than 95 members, at the same time that professional training sessions were being held for the Chapter and Affiliate leaders, and HDSA Social Workers.

HDSA's flagship research consortium, the HDSA Coalition for the Cure held two conferences to review the state of HD research and plot the future objectives of their innovative team approach to basic research. Their work continues to not only set the course for the translational work that results in potential therapies, but also act as a resource for the translational and clinical scientists, who count on the Coalition for assistance with questions that arise in the course of their own work.

Members of the Coalition and several members of HDSA Senior Staff and Board of Trustees participated in the World Congress on Huntington's Disease in Vancouver in September. At the Congress, which was hosted by HDSA Coalition for the Cure member Michael Hayden, HDSA representatives led seminars and met with counterparts from all over the world to share ideas, materials, and discuss how to better coordinate efforts on an international scale. As a result of discussions at the International Huntington Association (IHA) Meetings, held concurrently with the World Congress, HDSA is actively involved in reviews of genetic testing guidelines, clinical trial designs and other issues of importance to the world-wide community of HD families.

While the expanded roster of clinical trials of potential therapies was exciting, the Society recognized that it had to increase its efforts to recruit people to take part in the trials. Therefore, in addition to HDTrials.org, the Society made building awareness of and education about clinical research a priority. A new clinical trials section was added to the research section on the national website, and new initiatives for clinical trial education at all local and national education events began to take shape.

The Society's educational initiatives were also restructured and renewed. In addition to the National Convention and the many chapter and affiliate educational events, thanks to generous corporate support, HDSA created the *HD Education Packet for Healthcare Professionals*, which included brochures dedicated to Movement, Cognition and Behavioral symptomatic manifestations of the disease. The Society also produced the *Juvenile HD Resource Directory* and updated three important editions of the *Family Guide Series: Long Term Care, Genetic Testing and Juvenile HD*. These guides are distributed free of charge, as are many Society publications, and available for download on the HDSA website. The national website listings of local resources were also greatly expanded, and a new NYA section was added to foster greater communication among NYA members, and to make more people aware of the NYA and the projects it undertakes.

The Society's 38 chapters and affiliates vigorously ramped up their efforts to ensure that HDSA mission programs of research, care and education continued

to expand. The Team Hope Walk for HD Campaign grew from 44 to 55 events, raising both funds to support our programs, and awareness of HD and HDSA in communities throughout the United States. We plan to expand Team Hope activities as our signature community engagement program. Since its inception in 2004, Team Hope has raised more than \$1 million to support HDSA programs.

As important as the programs that were implemented, HDSA leadership also spent extensive time in consultation with volunteers and family members to plan for the expansion of current and the creation of new programs. This crucial groundwork will pay dividends as programs roll out in the 2010 fiscal year, and in future years to come.

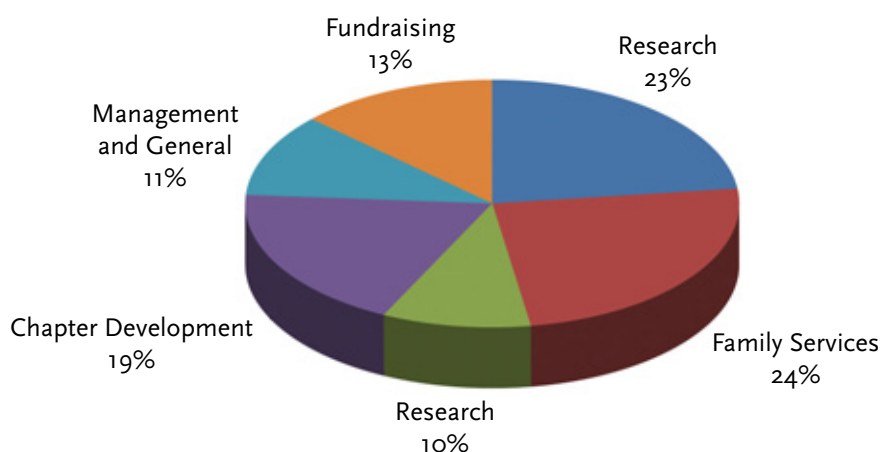
The National Board of Trustees, many HDSA volunteers and dedicated HDSA staff who together bring the Society to life ended the year with renewed confidence that the *Help for Today, Hope for Tomorrow* that we are so dedicated to providing will continue to expand to all members of our HD family. ♦



Huntington's Disease Society of America, Inc., and Affiliates
Consolidated Statement of Activities

Year Ended September 30, 2009

	UNRESTRICTED				
	Current	Board Designated	Temporarily Restricted	Permanently Restricted	Total
Public Support and Revenue:					
Public Donations	\$ 2,433,231	\$ -	\$ 297,000	\$ -	\$ 2,730,231
Foundation Grants and Corporate Contributions	2,333,317	-	951,063	-	3,284,380
Federal Campaign	299,787	-	-	-	299,787
Investment Income	47,727	-	12,923	27,136	87,786
Sale of Materials	49,772	-	-	-	49,772
Donated Services	90,069	-	-	-	90,069
Other	1,044	-	-	-	1,044
Net Assets Released From Restrictions	1,226,281	-	(1,186,383)	(39,898)	-
TOTAL PUBLIC SUPPORT AND REVENUES	6,481,228	-	74,603	(12,762)	6,543,069
Expenses: Program Services					
Research	2,017,682	-	-	-	2,017,682
Family Services	2,124,771	-	-	-	2,124,771
Education	835,254	-	-	-	835,254
Chapter Development	1,650,770	-	-	-	1,650,770
TOTAL PROGRAM SERVICES	6,628,477	-	-	-	6,628,477
Supporting Services:					
Management and General	948,373	-	-	-	948,373
Fundraising	1,141,438	-	-	-	1,141,438
TOTAL SUPPORTING SERVICES	2,089,811	-	-	-	2,089,811
TOTAL EXPENSES	8,718,288	-	-	-	8,718,288
NET LOSS FROM OPERATIONS BEFORE NONOPERATING REVENUES	(2,237,060)	-	74,603	(12,762)	(2,175,219)
Nonoperating Revenue: Special Events					
Gross Receipts	3,953,255	-	107,874	-	4,061,129
Less: Direct Costs	(1,642,800)	-	-	-	(1,642,800)
NET REVENUE FROM SPECIAL EVENTS	2,310,455	-	107,874	-	2,418,329
CHANGE IN NET ASSETS	73,395	-	182,477	(12,762)	243,110
NET ASSETS, BEGINNING OF YEAR	(32,393)	443,603	550,259	564,962	1,526,431
NET ASSETS, END OF YEAR	41,002	443,603	732,736	552,200	1,769,541



We would like to thank

Our Corporate and Foundation Contributors

We would like to thank

the following corporations and foundations for their generous support of the Huntington's Disease Society of America during the 2008-2009 Fiscal Year. For a more complete listing of all major donors, please visit the HDSA website, www.hdsa.org. ♦

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