



Huntington's Disease
Society of America



The Faces of HD
HDSA Annual Report FY 2012



Dear Friends of HDSA,

The year 2012 was one of great significance for the Huntington's Disease Society of America. It was a year in which we not only charted a course of achievement for a twelve month period— but one in which we formally introduced and implemented the HDSA Strategic Plan 2012-2017, a comprehensive guide to building an HDSA that offers the full range of services in all areas of the country that our families require.

While we look ahead, it's important to recognize the accomplishments of the past year. Seven new affiliates have been chartered and one affiliate has evolved to chapter status. The Team Hope Walk for HD Program grew to 95 events and the May Awareness Faces of HD Campaign went viral through social media, bringing a new awareness of the disease and its effect on our families. For the first time people could watch presentations from the Annual Convention from their home as the plenary sessions and several workshops were videostreamed live. The Social Security Administration added Juvenile-Onset HD to their Compassionate Allowance Listings and the HD Parity Act was introduced into the U.S. Senate for the first time. Redesigned national chapter and affiliate websites made access to HD information and resources much easier to acquire, and HDSA took on the responsibility of training medical professionals to treat people with HD through a 10-part HD101 Continuing Medical Education series, available on the national website.

We continue to collaborate with and provide materials for other HD Family organizations throughout the world, and promote and educate our families about new research developments as well as clinical studies and clinical trials, as our understanding of HD increases and new potential therapies move their way through the developmental pipeline.

All of our efforts focus on one goal: To improve the quality of life for everyone affected by Huntington's disease. In 2013 we are building on the work completed in 2012 and expanding our reach through the guidelines of the Strategic Plan, which includes the introduction of the new recently launched Human Biology Research Program.

As you read about the Society's achievements in 2012 please remember that our ability to implement these exciting plans is dependent on your support.

Together we can provide Help for Today, Hope for Tomorrow to everyone affected by HD.

Sincerely,

A handwritten signature in black ink, appearing to read "Louise Vetter", written over a light gray rectangular background.

Louise A. Vetter
Chief Executive Officer

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HDSA meets all Standards of Excellence of the Better Business Bureau Wise Giving Alliance, National Health Council and the American Institute of Philanthropy



Federal employee? Support HDSA through the Combined Federal Campaign Designate #0526

2012: A Year In Review

HDSA's community services and public visibility expanded greatly during 2012. A major component of this growth was the introduction and implementation of the HD community-reviewed *HDSA Strategic Plan 2012 -2016*, a blueprint to expand HDSA's reach and ability to improve the lives of everyone affected by Huntington's disease.

The plan identifies specific milestones, the areas of importance for the families that HDSA serves, defines goals and target objectives for the Society over the next five years, and presents guidance for the plans of work to be developed and implemented by the HDSA staff and volunteers to reach the identified goals. Major objectives include:

- Building an HD Community-service organization.
- Supporting HD research & communicating its impact.
- Removing barriers to quality care.
- Becoming the premier communicator of HD information.
- Growing volunteer involvement.
- Operating in a fiscally responsible manner.
- Increasing revenue to grow organizational capacity.

The growth of HDSA's community services, combined with vigorous outreach and nurturing by HDSA's Regional Directors resulted in seven new HDSA Affiliates receiving charters in 2012 (South-eastern Virginia, Arkansas, Las Vegas, Southern Idaho, Utah, Omaha and Tennessee) and the Arkansas Affiliate qualifying to upgrade to chapter status.

This proliferation of new affiliates was reflective of an increase in the number of support groups to more than 170 throughout the country and the growth of the Team Hope Walk for HD Program to 95 Walk-a-thons, which raised \$1.7 million in revenue. In many instances the creation of a support group or Team Hope Walk Event is the first step in organizing members of a local HD community, and the genesis of an HDSA Affiliate.

In addition to the support groups and walks, HDSA Chapters and Affiliates hosted 21 Educa-

tional events featuring presentations by leading scientists, clinicians and community leaders. These events, which are free to attend, allow HD family members to learn about caregiving, clinical trials, and other important topics, as well as meet one-on-one with other members of the HD community and the experts in attendance. The HDSA Clinical Trials Curriculum and presentations by HDSA Clinical Trials Diplomats were part of every educational event in 2012.

The preeminent HDSA educational event, the Annual National Convention, united more than 900 members of the HD community for three days of presentations, workshops and socializing in Las Vegas. The Convention's reach was greatly expanded in 2012, as for the first time, the Friday morning Welcoming and Family Presentations, and Saturday morning Research Colloquium and Clinical Trials Roundup were videostreamed live, with more than 800 viewers during the actual convention and thousands more who visited the HDSA website following the convention. Four workshops were also videostreamed live, making it possible for members of the community who were not able to travel to the convention, to participate from their homes. The overwhelming positive response has led to plans to videostream more convention workshops in 2013.

For the first time the Annual Convention continued through Sunday afternoon, as a new feature, *Clinical Research Initiative Day* allowed investigators from seven different clinical studies to meet with potential participants who were attending the Convention. This program is a natural extension of HDSA's clinical research education initiatives, and provided investigators access to a large group of interested people.

The HDSA Advocacy program grew even stronger in 2012. The 7,600+ HDSA Advocates were able to recruit 146 co-sponsors of the *HD Parity Act* in the House of Representatives, and 12 co-sponsors in the Senate, where the Act was introduced for the first time.

HDSA Advocacy claimed a huge victory in late 2012, as Juvenile-onset HD (JHD) was added to

the Social Security Administrations Compassionate Allowance List, thereby fastracking any application for SSA benefits for a person with JHD. As the year ended, it was learned that adult-onset HD would be added to the list in 2013.

An Advocacy Video Contest, in which HDSA Advocates were invited to produce their own 60 second spot on why they advocated for HDSA yielded many great videos. The winning entry and two runners up were presented at the Annual Convention.

HDSA's webinar offerings grew in 2012, with the *Lunch and Learn* series, which broadened the range of topics presented in the Caregivers Forum.

A *Law Enforcement Toolkit*, comprised of a booklet and a power-point presentation featuring footage of people with HD (distributed on a USB drive) was introduced in 2012. This project was created in response to many requests for materials to

educate police officials who often mistake a person with HD as being intoxicated, or uncooperative. The Toolkit is being distributed by volunteers who use it to explain the complications of Huntington's to local law enforcement officials, who can then utilize the kit to train their officers.

The Long Term Care Workgroup completed its work and furnished a report on recommendations and best practices for people with HD in long term care facilities. This report is being distributed to facilities throughout the US, and is available to family members who can present it to facilities caring for their loved one.

A new *Family Guide Series* brochure, *Talking With*

Kids, was published in 2012. This is a topic of great concern to any HD family. The strategies and information contained in the brochure help parents initiate these difficult conversations and provide appropriate answers to questions that may arise.

In 2012 HDSA directly addressed the problematic shortage of physicians with knowledge of how to treat a person with HD. Through the distribution of the *Physicians Guide to the Treatment of Huntington's Disease*, listings of medical professionals on the national website was increased significantly. However, with the understanding that identifying experienced HD clinicians was not sufficient, HDSA produced a 10-part Continuing Medical Education (CME) series, *HD101*, with all 10 modules available for free on the HDSA national website.

This proactive approach is helping train doctors to understand the challenges facing a person with HD, and provide them with best practices for treating all phases of the disease.

To address the importance of com-

municating the availability and providing the benefits of these new community programs, HDSA redesigned its national website and all chapter and affiliate websites in 2012. After evaluating community feedback, the sites were developed to offer easy-to-use intuitive navigation, with the most-used features prominent and readily available to the first time or regular site visitor. The new sites allow more impactful visual promotion of recent and upcoming events, developments and news items, and new email blast features for chapters and affiliates. The websites are the first step in a complete redevelopment of HDSA digital portals, with a new peer-to-peer fundraising system and CRM system fully integrated with HDSA's accounting system to be launched in 2013.





At the beginning of this annual review we mentioned the increase in media coverage of HD and HDSA. Much of this coverage was due to a program launched to promote and celebrate May is HD Awareness Month, the *Faces of HD*.

The Faces are people from all constituencies of the HD Community: People with HD; caregivers; researchers; clinicians; advocates; politicians; a diverse group of people who have been active in the HD world in some manner. This program helped

convey the devastation of HD and made it relevant to the outside world—making it possible for people who had never even heard of Huntington’s, to understand its impact on entire families and communities. A different *Face* was featured every day in May, and continued with one *Face* per month through the rest of the year. The campaign will be revisited for May Awareness Month in 2013, and has fostered local chapter and affiliate *Faces*, as well as encouraging members of HD families to tell their stories to promote awareness of HD.

By the end of 2012, it was apparent that the focus derived from the planning and research that went into the HDSA Strategic Plan 2012-2017, was already paying off in HDSA’s increased ability to provide *Help for Today, Hope for Tomorrow* to everyone affected by Huntington’s disease.

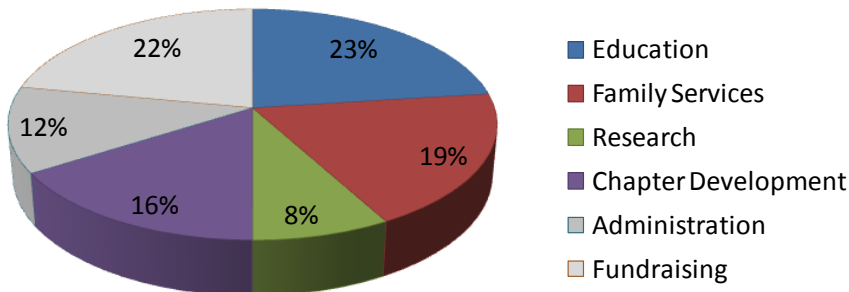
The Society will build on the successes of 2012, and introduce new initiatives that will maintain and expand HDSA’s offerings in 2013. The proliferation of new chapters and affiliates, new volunteers, new events, new community services, new communication vehicles and new voices of support point to the delivery of more and better tools to improve the quality of life for anyone affected by HD.



HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.

**Consolidated Statement of Activities
Year Ended December 31, 2012**

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>
Support and revenue:				
Public donations	\$ 1,214,485	\$ 753,391		\$ 1,967,876
Foundation grants and corporate contributions	586,082	777,380		1,363,462
Federal campaign	298,203			298,203
Investment income	2,238	3,073		5,311
Donated services and materials	340,735			340,735
Other	21,983			21,983
Total support and revenue before restrictions	2,463,726	1,533,844		3,997,570
 Net assets released from restrictions	 <u>729,775</u>	 <u>(729,775)</u>		 <u>0</u>
Total support and revenue	<u>3,193,501</u>	<u>804,069</u>		<u>3,997,570</u>
Expenses:				
Program services:				
Research	570,986			570,986
Family services	1,262,045			1,262,045
Education	1,544,895			1,544,895
Chapter development	1,071,126			1,071,126
	<u>4,449,052</u>			<u>4,449,052</u>
Supporting services:				
Management and general	832,279			832,279
Fund-raising	1,524,435			1,524,435
	<u>2,356,714</u>			<u>2,356,714</u>
Total expenses	<u>6,805,766</u>			<u>6,805,766</u>
 Change in net assets before non-operating income	 <u>(3,612,265)</u>	 <u>804,069</u>		 <u>(2,808,196)</u>
Non-operating income:				
Special events:				
Gross receipts	4,044,123			4,044,123
Less: direct costs	(618,928)			(618,928)
Net income from special events	<u>3,425,195</u>			<u>3,425,195</u>
 Change in net assets	 (187,070)	 804,069		 616,999
Net assets - beginning of year	<u>(63,937)</u>	<u>1,656,331</u>	<u>\$ 250,000</u>	<u>1,842,394</u>
Net assets - end of year	<u>\$ (251,007)</u>	<u>\$ 2,460,400</u>	<u>\$ 250,000</u>	<u>\$ 2,459,393</u>



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.

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Our Vision:

A world free of Huntington's disease.

Our Mission:

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

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