

Help for Today. Hope for Tomorrow.



**Huntington's Disease
Society of America**

Update On HDSA Community Programs

www.HDSA.org

Dear Friends,

At the beginning of the year, HDSA published our goals and plan of work for 2011. It is our pleasure to share some of the accomplishments thus far, as well as to inform you about what's on the horizon.

This year, we have expanded our *Caregiver's Corner* webinar series and our *Clinical Trials Diplomat* program, introduced the *Huntington's Disease Parity Act* in the House and Senate, created websites for each of HDSA's 41 Chapters and Affiliates, had Team Hope Walks in over 70 cities around the country, updated *A Physician's Guide to the Management of Huntington's Disease*, and much more!

The best way to find out what is going on at the HDSA is to visit the HDSA national website, **www.hdsa.org**, and see what new research updates, programs, services, and publications are available. There is new information on the website daily, so visit often.

Once you've looked through this booklet, please reach out to us to explore the different ways that you can utilize HDSA's programs, services, and publications.

Thank you for your continued support of the Huntington's Disease Society of America and for everything you do for the Huntington's Disease community.

Sincerely,

The Huntington's Disease Society of America

www.hdsa.org

Community Services, Education, Advocacy

Community Services

We Are HDSA!

In November 2010, thanks to a generous grant from Lundbeck, HDSA was able to introduce a support group newsletter. *We Are HDSA!* has proved to be widely popular, providing information on a variety of topics including caregiver issues, family planning, clinical trials, and advocacy. *We Are HDSA!* features an 'Ask the Expert Column' where physicians, social workers, genetic counselors, and other professionals provide answers to questions they frequently receive.

As we enter the second year of publication, *We Are HDSA!* is going green. Starting in October, 2011, issues will be published in electronic form and, along with being available on our website, will be sent out via e-mail. Don't wait until we stop printing *We Are HDSA!*. Sign up for the electronic version today! Send an e-mail to Seth J. Meyer at smeyer@hdsa.org with your name and e-mail address so you can be added onto our *We Are HDSA!* e-mail list. You will receive *We Are HDSA!* during the first week of every month.

Ask the Social Worker

On June 1st, HDSA launched a new column entitled Ask the Social Worker. Found at www.hdsa.org/atsw, Ask the Social Worker provides a new way for people to reach out to HDSA Social Workers and find new information about programs and services provided through HDSA around the country. Updated bimonthly, Ask the Social Worker is an exciting column that helps readers become familiar with our network of social workers throughout the country. To ask a question, please e-mail Seth J. Meyer at smeyer@hdsa.org with the subject line "Ask the Social Worker."

HDSA Care Coordination Portal

HDSA is pleased to launch, in association with Lotsa Helping Hands, the Care Coordination Portal. The Care Coordination Portal provides caregivers the ability to reach out to their friends and families as needed for concrete and emotional support at no charge. The portal can help you inform your care team when you need help to get your loved one to an appointment or when you just need some respite. The portal also provides a place for you to post pictures and receive messages of support. Sign up today at www.hdsa.org/carecoordination.

HDSA Helpline

HDSA is here to help you. Do you have a question about HD? Do you need information about the local services that HDSA provides? Call Seth J. Meyer, LMSW at 800-345-4372 ext. 240 during HDSA business hours, or e-mail at smeyer@hdsa.org. Seth can connect you with your local support groups, social workers, and resources that are appropriate for you and your loved one.

Starting a Support Group in your Area

Do you have an interest in starting an HD support group in your area? Please fill out the New Support Group Application at www.hdsa.org/sgapp. If you have any questions or want to know more about starting a support group, please reach out to Seth J. Meyer at smeyer@hdsa.org or via phone at 212-242-1968 ext. 240.

HDSA Equipment Board

Do you have gently used durable medical equipment that you don't need anymore? Are you looking for used equipment, such as wheelchairs, Broda chairs, walkers, and commodes? Visit the HDSA Equipment Board, a place for people to advertise gently used medical equipment that is no longer needed. You can find a link to the Equipment Board in the Living with HD section of the HDSA website.

Note: HDSA does not participate in any equipment transaction, nor can it take possession of posted equipment. Donation receipts cannot be issued for posted equipment

HDTrials.org

HDTrials.org is a clinical trial notification site created by members of the HD Community and managed by HDSA. Registration is simple: provide an email address (which may be anonymous or a pseudonym through Gmail, Yahoo, Hotmail, or any other service), and your zip code or postal code (in Canada). When new clinical trials or studies are approved you will be notified by email about the study and the sites near the zip/postal code you provided. You can register with multiple zip/postal codes if you would like to notify other family members about trials in their area as well. Please register so you will learn about new opportunities to participate in clinical trials and studies as soon as they are available.

HDSA Social Workers

HDSA currently has 37 Social Workers around the country working to provide help and hope to the HD community. HDSA social workers provide information, referrals, and help start and maintain support groups. They provide in-service trainings to agencies that have an interest in working with people with Huntington's Disease and can connect you with local resources. To find your local HDSA Social Worker, go to the Living with HD Section of the HDSA Website.

Brain Bank

Making the gift of a brain from a person with HD to research is a wonderful way to contribute to advancing treatments. Scientists from the nation's top research and medical centers request tissue for their investigations. Though one brain can provide many samples, to validate research it is often necessary to supply a variety of brain specimens. At the current time, there is only one brain bank that accepts HD brains from across the country. If you or your family is interested in learning more about brain donations, please contact the Harvard Brain Tissue Resource Center at 800-BRAIN BANK (800-272-4622) or visit them at www.brainbank.mclean.org. It is advised that families start this process early, so brain donations can be accepted.

Coming Soon: **Law Enforcement Education Toolkit**

Caregivers and social workers have expressed a need to educate local law enforcement about HD. To help meet this need, HDSA has convened a workgroup to develop a tool kit that can be used by social workers and caregivers alike to help their local law enforcement personnel, first responders and in the event it becomes necessary, their courts have an understanding of what HD is, why a person may behave seemingly inappropriately or aggressively and thereby foster a better understanding in the community and help avert disease related confrontations. The Workgroup is currently developing a manual for law enforcement and a tool for caregivers that will be piloted this Fall. For more information, please contact Jane Kogan at jkogan@hdsa.org.

Visit HDSA at www.hdsa.org

Education

A Physician's Guide for the Management of Huntington's Disease: Third Edition

One of the most important resources for the HD community, A Physician's Guide has been updated. Thanks to a generous educational grant from Lundbeck, HDSA is able to provide a complimentary copy of A Physician's Guide to *every HD family* when they provide information about the primary care physician and neurologist of their loved one with HD. HDSA will also send copies to each of these neurologists and primary care physicians, and will contact each provider to get their permission to be listed on the HDSA website. This initiative will help HDSA expand the knowledge-base of HD-savvy practitioners – as well as disseminate the most up-to-date information on HD to date in a targeted manner. Please call Anita Mark-Paul at 800-345-4372 extension 219 or email Anita at amarkpaul@hdsa.org for your copy of the Guide.

Please Note: HDSA does not share any information nor is there a record of who "recommended" a doctor to receive a complimentary copy.

Clinical Trials Diplomat Program

HDSA Clinical Trials Diplomats are trained volunteers who believe that clinical trials are important to advancing research, treatments, and a cure for HD. Diplomats are usually people who have participated in a clinical or observational study, who are trained by HDSA to provide information, and who answer questions about clinical trials in small group settings such as support group meetings. To learn more about the Clinical Trials Diplomats program, schedule a Diplomat to speak in your community or to become a Diplomat, please contact Deb Lovecky at Dlovecky@hdsa.org.

Updated & New Family Guide Series Publications

HDSA's Family Guide Series publications provide a broad-based overview of the many facets of Huntington's disease. This year, several publications in the Series were updated. Also, there is now a new title in the Series about effective communication with healthcare providers.

- **Caregivers' Guide to Communicating with Healthcare Providers:** This new pamphlet provides an overview of how caregivers can present what they see and experience during caregiving to their loved one's doctors in an effective way.
- **Physical & Occupational Therapy for Huntington's Disease:** This pamphlet provides helpful information and resources for people in all stages of HD and was updated to include new trends in HD care.
- **Nutrition & Huntington's Disease:** This pamphlet discusses the nutritional needs in early, middle and late stage HD and provides hints for increasing calorie intake and recipes.

All of HDSA's Family Guide Series publications are available for download. To download a publication, please go to www.hdsa.org and click on "Living with HD" and then, under Resources, click on Publications. You must have a PDF reader on your computer in order to access and download these publications. Contact Anita Mark-Paul at amarkpaul@hdsa.org to order printed copies of these publications.

Field-Based Educational Grant Program

HDSA is pleased to renew the grant program inaugurated in 2009 to support educational events offered by HDSA Chapters, Affiliates, Support Groups and HDSA Centers of Excellence through December 2011. Events can range from a guest speaker at a support group to a half or full day educational day with multiple speakers. To qualify for an educational grant, event organizers must complete and submit an application, proposed budget and program at least 30 days in advance of the event. For more information, please contact Deb Lovecky at Dlovecky@hdsa.org.

Clinical Trials & Advocacy Educational Workshops

HDSA has developed a 45 minute workshop that provides an overview of the clinical trials process, as well as a 30 minute presentation about the Huntington's Disease Parity Act. When offered as part of an educational event funded through the educational grants program described above, HDSA will provide a speaker and take home materials. When you are planning an educational event, include the clinical trials and advocacy workshops in your program. For more information, please contact Deb Lovecky at dlovecky@hdsa.org.

Caregiver's Corner Webinars

HDSA's Caregiver's Corner webinars are now a monthly offering! These web-based workshops and seminars are geared to topics of interest for caregivers. Each Caregiver's Corner webinar is 60 minutes with a presentation and question/answer session. The entire series of Caregiver's Corner webinars is archived in the "Living with HD" section of the HDSA national web site, and will be available as podcasts starting in July. For more information, please contact Jane Kogan at jkogan@hdsa.org.

A Caregiver's Guide to Huntington's Disease

In partnership with We Move, HDSA has printed a limited number of copies of this new guide for caregivers. Pick up a free copy at the HDSA Marketplace or go to www.wemove.org to download the file.

Marker Magazine

Published annually by HDSA, the Marker magazine can be downloaded from the HDSA website. To download, please go to www.hdsa.org and click on "Living with HD" and then, under Resources, click on Publications. Browse past issues for information about Living Positively with HD, Living at Risk, information and resources for Caregivers, HD Research, Care, Advocacy and more.

Coming Soon: **Spanish Language Translations of HDSA Publications**

Coming this summer, many of HDSA's Family Guide Series publications, as well as the Fast Facts About HD, will be available in Spanish. Thanks to a grant from Lundbeck, a limited number of copies will be available in print. These publications will also be available for download from the HDSA website. To download a publication, please go to www.hdsa.org and click on "Living with HD" and then, under Resources, click on Publications.

Coming Soon: **Disability Application Toolkit**

Coming this summer, HDSA will build on its Disability Strategies Webinar series and create a section of the website devoted to the Disability application process. The new section will contain an overview of the criteria, the process, frequently asked questions, and more. For more information, please contact Jane Kogan, Manager of Programs, Services, and Advocacy, at jkogan@hdsa.org.

Visit HDSA at www.hdsa.org

Advocacy

Huntington's Disease Parity Act of 2011 (S. 648/H.R. 718)

HDSA is working to secure Congressional support in the House and Senate for the *Huntington's Disease Parity Act*, which would make it easier for people with HD to receive Disability and Medicare benefits. The *Huntington's Disease Parity Act* will compel the Social Security Administration (SSA) to revise the outdated and medically inaccurate guidelines that it uses to determine disability for HD. It would also waive the two year Medicare waiting period for individuals who are disabled by HD. Taken together, these two provisions will make it much easier for people who are disabled by HD to receive Social Security Disability Insurance (SSDI) and Medicare benefits. You can go to www.hdsa.org/advocacy to learn more about the bill, download resources, and get involved. For more information please contact Jane Kogan at jkogan@hdsa.org.

HDSA E-Advocacy Center & Advocacy Toolkit

HDSA gives you the tools you need to become a successful advocate for the Huntington's Disease Parity Act! Go to HDSA's E-Action Center, www.hdsa.org/takeaction to personalize a letter to Congress, send a letter to the editor, and more! Huntington's Disease Parity Act resources, including copies of the Bills, background information, and costs, are available for download on the HDSA advocacy website, www.hdsa.org/advocacy.

Thank You

Thank you so much to everyone who participated in HDSA's *Let's Talk About HD* Campaign to promote the *Huntington's Disease Parity Act* during HD Awareness Month and to everyone who called Congress on HDSA National Call-in Day!

We need **YOUR** involvement to continue our momentum in the House and Senate.
Become an HDSA E-Advocate for HD at www.hdsa.org/join.

Online & Social Media Engagement

HDSA Advocacy is active on Face book and in the blogosphere! The HDSA Advocacy Face book group now has almost 3000 advocates and our main HDSA Face book page has more than 5600 friends. HDSA's YouTube videos about HD Awareness Month and National Call-in Day were viewed by over 1500 people and HDSA Advocates have been featured on the blog, "At Risk For Huntington's Disease," the Help-4-HD Blog Talk Radio Show, the "Faceless Faces of Huntington's Disease: I am No Longer a Faceless Face" Project, and actively promote their advocacy efforts on HDSA Chapter and Affiliate Face book pages. Be sure to add us to your social media network and friend us on Face book – just go to Face book and search HDSA to find us.

Burden of Care Survey

HDSA has partnered up with the Euro-HD network on an international survey to understand the social, economic, and medical challenges caregivers and people with HD face daily. Both surveys are completely confidential. HDSA will share the collected information with the

Euro-HD Network and we will use the data to help in our advocacy efforts so we can help to improve the lives of people living with HD. If you haven't done so already, please complete the survey as a person with HD at www.hdsa.org/bofhd or as a caregiver at www.hdsa.org/boccaregiver. If you prefer to complete a paper survey or have any questions, please contact Seth J. Meyer at SMeyer@hdsa.org.

Coming Soon: Genetic Information Nondiscrimination Act Resources

In July, HDSA will launch a new section of the website devoted to the Genetic Information Nondiscrimination Act (GINA) that will feature frequently asked questions about what GINA does, GINA and the workplace, GINA and health insurance, case examples, and more! There will also be a GINA webinar on July 13 that will be available for download from the new section. For more information, please contact Jane Kogan at jkogan@hdsa.org.

Visit HDSA at www.hdsa.org

Communications & Marketing

HDSA Website: www.hdsa.org

The HDSA national website continues to evolve to serve the needs of everyone affected by HD. In addition to expanded lists of resources (searchable by state) and enlarged research, clinical trials, advocacy and community resource sections, the HDSA Forum, constituency extranets, the equipment exchange board, new sections such as “HD and HDSA In The News” have been added.

Chapter/Affiliate Websites

This year HDSA created new websites for all 41 Chapters and Affiliates. These sites will focus on the work being done in the Chapter/Affiliate’s area, and provide lists of local resources (medical and non-medical) and other information of importance to the HD Community. To find your local chapter/affiliate website, go to the website and click on “find HDSA in Your Community.” Then click on your state. The chapter listing will now include the link to the chapter website.

National Youth Alliance (NYA)

The NYA continues to be the place for youth with HD in their families to come together for support. It has greatly expanded its activities this year to include year-round fundraising, participation in advocacy events, recruiting of more members (Friendster days), and working with a new international youth alliance. This year at Convention, the NYA is hosting an international youth conference that will include 18 individuals from outside of the US, who will meet with 5 NYA members to discuss issues of relevance and create materials to be used for educational and recruitment purposes in their home countries. The international representatives will also attend NYA Day before the HDSA Annual Convention, and attend the Convention as well. If you know someone between the ages of 9 and 29 from an HD family please suggest they visit www.hdsa.org/nya and join the NYA.

HDBuzz

Several HD researchers have banded together to provide their insight into HD research in lay terms for the benefit of the HD Community. HDBuzz is made possible by an international collaboration including HDSA. HDBuzz is a new website dedicated to covering HD science news. Articles are also available on the HDSA national website as an additional resource in our research sections. Topics include HD basics and explanations of new discoveries and potential therapeutic approaches being investigated around the world. For more information, go to www.HDBuzz.org.

HDSA Forum

To supplement the 130+ support groups HDSA hosts throughout the U.S., we've added an online Forum to the national website. The Forum is a place for people to share their thoughts, concerns, best practices and offer support to other members of the HD community. Participants can start new topic threads and comment on existing ones. It's a great venue for those who want to share their experiences online, and others who are seeking guidance, or reassurance from someone who has experienced HD. The HDSA Forum is open to anyone through a simple registration process on the site. There is also an NYA Forum that is restricted to NYA members.

Visit HDSA at www.hdsa.org

HDSA in Your Community

Forming an HDSA Affiliate

HDSA is proud to announce that we currently have 41 Chapters and Affiliates across the country and we are adding more each year. Affiliates and chapters are critical to HDSA's ability to reach more families and expand our impact on the lives of everyone affected by HD. To become an Affiliate, identify a group of eight or more volunteers who have expressed interest in supporting HDSA's three part mission and elect an Affiliate Chairperson to be the volunteer leader, providing leadership to ensure that all Affiliate activities are conducted in accordance with HDSA By-laws, Policies and Operating Procedures for HDSA Affiliates. Then reach out to Nancy Rhodes, who will organize a call with the Chair of the National Field Committee (NFC) and the HDSA Regional Staff person to walk you through the process of creating an Affiliate letter of intent and plan of work to share with HDSA. These items will then be sent to the NFC and ultimately to the HDSA Board of Trustees for a vote. Successful Affiliates can graduate to become a chapter. For more information, please contact Nancy Rhodes, Director of Field Development and Operations, at (212) 242-1968 x234 or via e-mail at nrhodes@hdsa.org.

Team Hope Walk

The Team Hope Walk is our largest national grassroots fundraising event. Thousands of families, friends, co-workers, neighbors and communities walk together each year to support HDSA's fight to improve the lives of people affected by HD and their families. Team Hope takes place in more than 70 cities nationwide. Since its inception in 2007, Team Hope has raised close to \$2 million, thanks to the support and tireless commitment from walkers like you. From becoming a national or local sponsor, to forming a team, to volunteering, you too can help make a difference in so many lives. Join Team Hope Walk for HD, and help us provide help for today, hope for tomorrow. For more information, please contact: Stacey Landis, Manager of Field Events and Operations (212) 242-1968 x233 or via e-mail: slandis@hdsa.org. To visit the Team Hope website, please visit this link: www.hdsa.org/teamhope.

Visit HDSA at www.hdsa.org

Notes:



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