# We Are HDSA!

Huntington's Disease
Society of America

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## HDSA Hosts **Inaugural Congressional Briefing**

*By Jane Kogan, Manager, Advocacy and Program Services, HDSA*

On Thursday, October 27, HDSA invited congressional health staffers from the United States Congress to our inaugural Capitol Hill Briefing, entitled "Our Genetic Future: The Congressional Role." The briefing focused on the scientific, personal, and policy aspects of genomics, the study of the human genome. Louise Vetter, HDSA Chief Executive Officer, hosted the briefing and provided an overview of the milestones in the field of genomics.

Our champions in the House, Congressmen Bob Filner and Brian Bilbray, lent their support by providing staff assistance, spreading the word about the briefing and opening the session. Our champion in the Senate, Kirsten Gillibrand, also helped to promote the event. Rep. Brian Bilbray welcomed all with an impassioned speech about the importance of investing in science and the need for the public and private sectors to work together. Elena Keydel, Chief Health Aide to Congressman Bob Filner, welcomed the group on behalf of the Congressmen and promoted the ***Huntington's Disease Parity Act (H.R. 718).***

The speakers were very well-received by the audience. Eric Gascho from the National Health Council, an agency of which HDSA is a member and with whom we partner on issues concerning chronic diseases, spoke about the challenges and economic benefits in developing personalized medicine using biomarkers as an example; Dr. Christopher Ross, a clinician and researcher, as well as the co-director of the HDSA Center of Excellence at Johns Hopkins University then offered insight into the opportunities that advances in the world of genomics offer using HD as a model for other neurodegenerative diseases; Hope Axelrod, the social worker for the HDSA Metro DC Chapter, also used HD as an example of a genetic disease and spoke about the factors that influence the decision making process of whether or not to take a genetic test for at-risk individuals; and Peggy Tighe, from Strategic Healthcare, reminded the staffers about the Congressional role in genomics, including oversight, funding, and legislation.

The briefing was very successful and was attended by 86 Congressional Health staffers who work closely with members of Congress on the many health-related issues that touch the lives of their constituents every day. Already, several of the briefing attendees have cosponsored the Huntington's Disease Parity Act and we expect to see more cosponsors from this group in the future. Offices represented spanned the nation and represented Republicans and Democrats alike. There were also three Committees represented: the Senate HELP (Health Education, Labor and Pensions) and Finance Committees, and the House Ways & Means Committees, which have jurisdiction over the ***Huntington's Disease Parity Act (S. 648./H.R. 718).*** About two thirds of the staff that attended the briefing were from offices that are not currently supporting the Huntington's Disease Parity Act. HDSA will be following up with these offices in the upcoming months to educate them about the Huntington's Disease Parity Act.

### Briefing by the numbers

86 Attendees
52 Congressional Offices represented
28 Republican offices
23 Democratic offices
1 Independent's office

3 Committees of Jurisdiction:
- Senate Finance
- Senate H.E.L.P
- Ways & Means

39 offices of Members not on S. 648/H.R. 718

*A special thank you to HDSA E-Advocates, who sent almost 1000 invitations to their Members of Congress to invite them to the Inaugural HDSA Briefing!*

To learn more about how you can get involved, please contact Jane Kogan at **jkogan@hdsa.org.**

## Physical and Occupational Therapy:

*Physical and Occupational Therapy,* from our family guide series, provides families with an opportunity to learn more about Occupational Therapy and how it can help people with HD. *Physical and Occupational Therapy* is available for free online or contact Anita Mark-Paul at **amarkpaul@hdsa.org** for a copy. Please note that the first copy is free and every additional copy is $2.00.

## HDSA Disability Portal:

To find out more about applying for Social Security Disability, please visit the disability section of the HDSA National Website at **www.hdsa.org/disability**. Have feedback? Contact Jane Kogan at **jkogan@hdsa.org**

## GINA Webinar & Toolkit

Did you miss HDSA's Lunch and Learn on GINA, the Genetic Information Nondiscrimination Act? HDSA will be offering the webinar again on WEDNESDAY, January 25 at 12:00 p.m. Eastern. Watch your inbox for more information, or sign up by going to the Caregiver's Corner shortcut on the HDSA website. The HDSA website also has a GINA toolkit! Go to **www.hdsa.org/gina** to learn all about how GINA protects YOU!

## HDSA Educational Grants Program:

HDSA is pleased to announce the renewal of the grant program designed to help support HDSA field-based educational events, including guest speakers for support groups in 2012. To apply for an educational grant, please contact Deb Lovecky at **Dlovecky@hdsa.org** or Jane Kogan at **Jkogan@hdsa.org.**

# Occupational Therapy and **Huntington's Disease**

*By Kate H. Lafont, OTR/L, Occupational Therapist, HDSA Center of Excellence at Emory University*

Occupational therapists help a wide range of people from children to adults with a variety of difficulties to maximize their independence with everyday life activities. Therapy can be provided in many settings such as hospitals, outpatient clinics, schools, work, the community, or even at home. Occupational therapists can help individuals with Huntington's disease by maximizing independence and safety with daily activities, which leads to greater well-being and improves quality of life. In addition to working with individuals with Huntington's disease, occupational therapists work with family members and caregivers to provide education and training about specific techniques in several areas, including safety, fine motor, balance, endurance, and overall functioning. A home exercise program can be designed based on current ability to help individuals continue to do as much independently for as long as possible. An occupational therapist can help a person with HD in a variety of other ways.

Safety in your home is important to reduce the risk of falls or injury. This includes recommendations for durable medical equipment as well as simple modifications such as storing commonly used items in easy to reach locations, removing clutter and throw rugs, and identifying safe "hand holds" to steady yourself during high-risk activities. Recommendations for fall prevention and education and training regarding adaptive equipment and/or adaptive techniques can be provided, which is vital to prolonging independence.

Fine motor and balance problems may be affecting an individual's ability to get dressed, take a shower, or perform other daily tasks. Making simple modifications may help the individual continue to participate in several of these activities. For example, one can wrap a washcloth around handles on items such as a toothbrush, pen, or silverware to make them bigger and easier to hold. Similarly, if zippers and buttons are troubling, a change can be made to pullover shirts or elastic pants that are easier to put on or modifications can be made to original clothing by sewing on Velcro. Balance training and exercises can be provided as well to improve functioning safely in everyday activities.

Low endurance or fatigue might be something impacting participation in normal activities. Three tips to maximize ability to complete daily tasks are: follow a routine, incorporate plenty of rest breaks, and simplify activities. For example, eating may be difficult due to getting tired easily. An occupational therapist can make recommendations to lessen these frustrations including using different equipment to adapt the utensils or learning special techniques.

In the later stages of the disease, family and caregiver education is essential. Important topics include positioning and stretching. For example, proper wheelchair seating and education to change positions frequently are needed to increase comfort and decrease risk of injury. Developing an appropriate stretching exercise program can increase participation in daily activities. Participating in stretching exercises regularly can also allow individuals to continue feeding themselves for as long as possible.

In addition to improving physical functioning, there are several recommendations to help minimize cognitive impairment and other psychological aspects of Huntington's disease. Memory strategies include making lists, labeling items, and following a daily routine. Coping strategies can be helpful too, such as continuing with enjoyable daily activities.

In addition, occupational therapists offer support by providing education about support groups and other therapy services. For example, family members may benefit from respite care, which allows caregivers or family members a physical, mental, and emotional break, and ultimately permits caregivers to provide better care by decreasing their overall level of stress.

Occupational therapists can provide necessary recommendations, education, and exercises to help people with Huntington's disease and their families live more productive, meaningful lives. If you or your loved one experience a change in the ability to complete basic daily tasks or have an increase in number of falls, contact your physician to request a referral to an occupational therapist.

## Myths about HD

HDSA is researching myths and misinformation about HD. If you have recently heard any myths or misinformation about HD, please fill out the survey at **www.hdsa.org/myths.** The information gathered will be used for future initiatives.

## Ask the Social Worker

In December's Ask the Social Worker, Joanne Luz answers the question ***"What will my husband's HD look like?"*** You can read this and past *Ask the Social Worker* articles at **www.hdsa.org/atsw.** If you have a question that you would like answered, please e-mail Seth J. Meyer at **smeyer@hdsa.org** with the subject line *Ask the Social Worker* and check back to see if your question is answered!

## Caregiver's Corner:

## February 22

Spirituality & HD

You can access older webinars by going to **www.hdsa.org**, in the Living with HD Section.

## HDSA Article Connect:

This article, along with many others, is now available on the HDSA national website at **www.hdsa.org.** There, you can find archived articles from *We Are HDSA!, The Marker, Toward a Cure,* and *Ask the Social Worker,* along with past Caregiver Corner webinars.
If you have any questions or thoughts, please contact Seth J. Meyer at **smeyer@hdsa.org.**

# Tai Chi for Individuals with **Huntington's Disease**

*By Nicola Briggs, Certified Tai Chi Instructor who works with HD patients and others at the Terence Cardinal Cooke Health Care Center in New York. She can be reached at www.taichischool.com/taichiforeveryone.html*
*Reprinted from The Marker, May 2007*

Tai Chi is an ancient Chinese health system that focuses on harmonizing the body's vital life forces, or "Chi", to provide the benefits of relaxation, increased mental and physical awareness, and gentle conditioning for every part of the body. It is characterized by slow, graceful movement, performed either standing or seated.

Research has shown that consistent Tai Chi practice can significantly improve balance and coordination, which has increased its acceptance within the health care community. It also increases blood, lymphatic, and cerebral-spinal fluid circulation, which has a nourishing effect on the cells and all bodily systems. Principally used to improve the flow of energy throughout the body, Tai Chi is an effective form of self-healing that gives students a concrete feeling of greater independence and confidence. This ancient practice allows students to assume greater responsibility for their own mental and physical health, which is the very essence of internal power. Tai Chi can be a very beneficial activity for people with HD.

Tai Chi exercises can increase range of motion and muscle tone with their gentle stretching movements. Instructors focus on correct postural alignment during each class activity, which helps promote positive body awareness, both external and internal.

Tai Chi practice is a positive way to manage and dissipate depression, angry feelings and behavior. It also provides an avenue for success and a sense of achievement. With its focus of acceptance of one's abilities, as well as limitations, this healing art can help to greatly improve self-esteem.

Tai Chi exercises can be performed standing or seated. Performing Tai Chi exercises can be challenging and the sense of achievement that follows a class is significant. Taking on new challenges stimulates a feeling of satisfaction and accomplishment that greatly improves the quality of life. Tai Chi is a safe and productive way for each individual living with Huntington's disease to explore their personal power.

Performing Tai Chi exercises helps create a state of mental and physical relaxation. This relaxation can temporarily reducing chorea and can be beneficial in delaying the onset of muscular rigidity. It is a progressive exercise, with each classroom experience building upon the previous one, using repeated movements to stimulate memory. It can reduce stress and improve overall focus and concentration. Tai Chi exercise helps to bring about an acceptance of changes, while inspiring hope for the future.

# Hospitals: **Admission and Discharge**

*By Lift Caregiving, **www.liftcaregiving.com***

### Preparing for a Hospital Stay

As you prepare for your loved one's hospital stay, there may be a million things going through your head. But knowing what to expect and how to best prepare can help.

Below are three areas you can begin collecting now, so that when your loved one is admitted, you can focus on being there for him or her emotionally.

### Admissions Paperwork

- With a planned hospitalization, you may be given the opportunity to complete the admissions paperwork in advance, making the process much smoother and admittance much quicker.

*(Continued on page 4)*

# HDSA Information

## HDSA Annual Convention: 27th Annual HDSA Convention

## June 8-10, 2012

red rock
CASINO · RESORT · SPA
Las Vegas

More information will be available in January 2012. Please visit our website at **www.hdsa.org/convention** for updates.

## HDSA Strategic Plan – Community Input

HDSA's National Board of Trustees has just completed work to deliver a 5-year Strategic Plan that will help focus the Society's goals and guide the development of programs that will truly help improve the lives of everyone affected by Huntington's disease.

The final, extremely important step in this process is to ask members of the HD community to review and comment on the plan; and for the Trustees to incorporate these comments and ideas into the final version of the HDSA Strategic Plan.

By mid-January, a draft of the Plan will be available on the national website, along with a feedback form. Notifications will be sent out once this is on-line, and there will be a 30-day period where everyone is invited to provide input, ideas, questions or comments about the document. After reviewing and incorporating community input, the HDSA National Board of Trustees will approve and distribute the final Strategic Plan in the 2nd quarter of 2012.

## Thank you

HDSA thanks Lundbeck for the educational grant that made this newsletter possible.

Moving Together
Lundbeck

# Hospitals: Admission and Discharge (continued)

- Some hospitals will call you to collect this information over the phone. This allows the hospital to verify things such as insurance benefits and coverage.
- You will also be expected to bring copies of documents, including insurance cards and other proof of information you've provided. Bringing your loved one's up-to-date care binder should give the hospital everything they need.

### Care Binder Should Include

- Contact information for all family, professional and informal care partners.
- List of relevant community resources.
- Legal, financial and insurance information.
- Emergency contacts.
- Notes regarding medical visits, tests or surgeries.
- Medical conditions, medications, recent injuries, etc.
- Medical history, dietary habits, allergies and food preferences.
- Medical or personal equipment.
- Loved one's normal daily schedule.
- Travel information.

#### Insurance information

- Policy and phone numbers.
- Services covered.
- Service limitations and exclusions.
- Pre-authorizations, if any, before hospital admission, surgery or other expensive services. If you aren't sure, ask the hospital to get that information for you.
- Information on how second opinions are arranged and who pays for them.
- Customer service information.
- Extra copies of any documents sent to an insurance company; hospitals handle large volumes of paperwork and it is often misplaced.

### Leaving the Hospital

Your loved one may continue to need extra care once he or she leaves the hospital.

Starting well before discharge, observe what the staff is doing and ask to practice things that will be expected of you when your loved one is discharged. Make sure you understand what will be required for providing for your loved one's care needs and safety. If you're not comfortable or confident about your ability to provide this care, it may be better for your loved one's safety if they stay in the hospital longer or to be admitted into a temporary rehabilitation nursing home.

### Questions to ask to help you determine their care needs include:

- What skills are required to care for my loved one?
- Is my loved one prepared for the move?
- Is there someone at home who can, with minimal training, provide the required care? What training will they need?
- Will outside services be needed? Are the services readily available and within my loved one's ability to pay?
- Is there adequate time to arrange services before the intended discharge date? If not, state your needs and request additional days to make the proper arrangements.
- Would the home need modifications? Are they minor, such as installing bathtub bars, or more substantial, such as widening doorways for wheelchair accessibility?