

# We Are HDSA!



 Huntington's Disease Society of America

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## HDSA Information

### The Voices of HD

This month, HDSA is excited to bring you a special *We Are HDSA!* Titled "The Voices of HD," this newsletter will bring you personal stories of different perspectives of the HD community. From outreach to advocacy to research, HDSA is using September to highlight people who are making a difference. To find out how you can make a difference locally, visit [www.hdsa.org](http://www.hdsa.org). From supporting your chapter and support group to taking an active part in clinical trials and advocacy, there are many ways YOU can be a make a difference in the HD community.

### Please note:

The opinions expressed are solely those of the authors and do not represent the views or policies of HDSA. Individuals should not rely on the information in this newsletter as a substitute for consultations with qualified health care professionals who are familiar with individual medical conditions and needs.

## Getting Involved in Advocacy: I had no idea it would be this easy!

By Laura Hillard Quinn

It all started with an email from the HDSA early in 2010, asking my support for the *Huntington's Disease Parity Act*. The details of the bill grabbed my attention, having seen my family go through very difficult times financially when my father began showing symptoms of the disease. The fact that I have tested gene positive means that MY loved ones may also suffer financially due to the current restrictions for receiving Medicare. I decided that I had to join the cause. **It was easy to get involved and did not require a lot of my time thanks to the tools that HDSA provided.**

In March of 2010, I participated in "HD Advocacy Day on the Hill". We met with Congresswoman Carol Shea-Porter (D-NH) first. This was the first politician I had ever met with personally and probably was a great "starter" meeting for me. We then met with Senator Jeanne Shaheen (D-NH). Both women shocked me with their kindness, willingness to listen and the interest they showed in how HD affected our lives and why we felt this bill was important.

That day, I made a huge observation: our calls matter! As I sat waiting to meet with Senator Shaheen, I heard her staff answering phones and taking detailed notes on each call. As I was leaving Senator Shaheen's office I made a comment about how impressed I was that the staffers actually document constituents concerns. Senator Shaheen said, "Of course they do, We work for our constituents, they elect us to speak for them, and we always want to know what the voters want and are concerned about."

This May, my friend Brett and I met with Massachusetts Senator John Kerry's chief of staff, Stephen Meunier. Senator Kerry's staff had met with HDSA Advocates in 2010, and I had been in touch with Stephen for about a year, so I was very excited for the face-to-face meeting. We walked into the Stephen's office, and before I even launched into my request for support, he stated that the Senator had decided to support this bill and had already contacted New York Senator Kirsten Gillibrand to cosponsor S. 648. All of our hard work paid off!

On July 18th, Brett and I were a part of a group of constituents and HDSA Staff who met with Massachusetts Senator Scott Brown. The meeting went very well, and I was struck by how down-to-earth he was. As we left his office he promised to review the material we had given him and thanked us personally for taking the time to share our stories. **I knew that, by telling my story, I made a difference.**

Being involved as an Advocate has helped me in many ways. I have met amazing new people, and I feel like I am doing something good for our community. It is a great feeling, especially on the days when I struggle. HDSA has many services for our community but the advocacy program has become the one closest to my heart. I am amazed at the effort put into the online services that make it SO easy to participate. Not only do I wish I did it sooner but now that I know how important it is to speak up for HD families, I am much more likely to do to in the future- it's so easy. Get Involved! Speak up for HD at [www.hdsa.org/takeaction](http://www.hdsa.org/takeaction) or contact Jane Kogan at [JKogan@hdsa.org](mailto:JKogan@hdsa.org).

### Ask the Social Worker

In August's *Ask the Social Worker*, Stacey Barton, Social Worker at the HDSA Center of Excellence at Washington University, discusses Long Term Care Insurance. You can find *Ask the Social Worker* at [www.hdsa.org/atsw](http://www.hdsa.org/atsw). If you have any comments on *Ask the Social Worker* or would like to ask a question, send an e-mail to Seth J. Meyer at [smeyer@hdsa.org](mailto:smeyer@hdsa.org) with the subject "*Ask the Social Worker*." We look forward to your questions.

### Care Coordination Portal

HDSA is pleased to offer the HDSA Care Coordination Portal, powered by Lotsa Helping Hands. The HDSA Care Coordination Portal is a free, private, web-based tool that caregivers can use to manage the care and administrative needs of their loved ones as well as the outpouring of support from their network of family and friends. Create your caregiver community today at [www.hdsa.org/carecoordination](http://www.hdsa.org/carecoordination).

### Going Green

*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](mailto:smeyer@hdsa.org) with your name, e-mail address, and city and state so you can be added onto our *We Are HDSA!* e-mail list.

## The HDSA Clinical Trials Diplomat Program

By Karen Tarapata

Teresa Srajer's motivation for being an HDSA Clinical Trials Diplomat is simple. "I want to help find a cure for my family." By volunteering as a Diplomat and talking about the importance of participation in clinical trials and observational studies, Teresa is helping researchers in their quest to understand HD and conquer it.

Diplomats are people who volunteer to talk at HD support groups and information days at HD clinics about the clinical trial process. Like Teresa, most of the volunteers are people who have been part of a clinical trial or observational study or have been a friend or caregiver of a person who participated in one. A Diplomat's talk consists of a PowerPoint presentation with plenty of time after for questions and answers. "For me, it is more about sharing my study participation experience," Teresa shared.

For ten years, Teresa's has participated in various observational studies including the Prospective Huntington At Risk Observational Study (PHAROS), which was an observational study for people who are unaware of their gene status, but are at-risk for development of Huntington's Disease. Last year, Teresa decided to use her experience to encourage others to participate. "As someone who grew up at-risk, I have the same voice they do," she said. "I can share my history."

During her presentations, Teresa says she likes to help people get away from the "fear factor" surrounding participation. "I tell them that the tests are familiar to anyone who has had a neurological exam. I also talk about confidentiality and let people know there has never been a confidentiality breach of a research study. In the study, I am just a number."

Her transition from study participant to Diplomat began last year. "I saw something on the Diplomat program in *The Marker*." Training to become an HDSA Diplomat is held annually at the HDSA Annual Convention. Webinar training is also available. "I couldn't attend the convention, so that is how I was trained," Teresa said. "I like being an active person. I live one hour from Iowa City and three hours from Chicago. In my area, there is not active chapter or group. I didn't want that to limit me, so I participate in a national program."

Clinical trials and observational studies now enrolling need many more volunteers for the work to proceed. Diplomats across the country are using their own stories to make the case for stepping up. "We are a small population so we have to encourage each other to participate," Teresa said. "I enjoy being a Diplomat," she concludes. "I feel like I'm doing something toward finding a treatment for my family. By being an active participant, I can make a difference for them or their kids."

If you would like to have an HDSA Clinical Trials Diplomat speak at your support group or event, or you would like to learn more about being an HDSA Clinical Trials Diplomat, please contact Deb Lovecky at HDSA. Call 800-345-HDSA extension 228 or email [Dlovecky@hdsa.org](mailto:Dlovecky@hdsa.org).

### Educational Events:

**September 17:**

Englewood, CO  
Warren, MI

**September 23:**

Dallas, TX

**September 25:**

Sioux Valley, SD

**October 1:**

Houston, TX

**October 8:**

Baton Rouge, LA  
Tampa, FL

**October 22:**

Eastern, PA  
Birmingham, AL

**November 4:**

Tucson, AZ

**November 5:**

Indianapolis, IN  
Providence, RI

**November 12:**

Christiana, DE

### Caregiver's Corner:

**October 19:**

Care for the Caregiver:  
A Social Work Perspective

**November:**

Gait & Balance

**December 6:**

Safety in the Home

For more information on Caregiver's Corner, please contact Jane Kogan at [JKogan@hdsa.org](mailto:JKogan@hdsa.org).

## It all keeps me sane while living with my at-risk status.

*By Shana Martin, Personal Trainer, Fitness Instructor, Winner of Five Lumberjack World Titles, and HD Advocate.*

My mother was diagnosed with Huntington's disease back in 1985. I was 5 years old. Together, my parents broke the news to me. I remember my dad setting out a bunch of materials provided by HDSA. They sat down and explained to me how HD will affect our lives over the next several years.

Then my dad flipped a coin.

"These are your chances of also having HD," he said.

My question was: "Well which one is it, heads or tails?"

"I can't tell you that," he said but he always went right back to how much research was being funded by HDSA and how many people are working so hard to help. From that point on, optimism became a major value in how I have led my life.

Knowing I would have a far-from-normal childhood, my parents laid a YMCA catalog in front of me and had me pick whatever my heart desired. From that moment on, I found my escape: sports.

I always had four hours after school to be myself, not a caregiver but a goofy kid. This love of athletic escape led to a career as one of the nation's top personal trainers and fitness instructors, five Lumberjack World Titles, a collegiate pole vault record, and a national ranking as a fitness competitor. To this day, athletics are still "my time" to focus on me and not the risk of what may happen in the near future.

In sixth grade I gave my first presentation about Huntington's disease. Until that day, children made fun of me and my mom on a daily basis. But after my "What is Huntington's Disease?" presentation to a group of 12 year olds, my entire world turned around. There was no more teasing, only kids and teachers wanting to learn more and asking how they can help.

At this moment I realized the importance of educating the public about this rare disease.

At the age of 16, I began my journey of polishing and improving my public speaking skills in order to tell anybody and everybody about HD. Through my success in lumberjack sports, I had an easy track to speaking to every media outlet who would listen. Upon joining Kiwanis of Downtown Madison three years ago, I quickly learned service clubs all over the world are always anxious for unique and educational speakers. On a near weekly basis, I've been earning a free lunch or breakfast through educating these groups about Huntington's disease and sharing my personal story.

With every speaking engagement or media interview I complete, I have the satisfaction of knowing I am making a difference. That – along with traveling the world, pushing my body to its physical limits, spending quality time with my mother and father, and smiling as much as possible – helps keep me going despite having this terrible disease in my life.

I truly believe all people should live life to the fullest, whether they are at risk for HD or not. Living this kind of life also includes finding a way to make a difference in the world, whether it be speaking about a cause important to you, volunteering in your community, helping a friend in need, or becoming the scientist who finds a cure for Huntington's disease.

## Clinical Trials

For more information on clinical trials, please visit [www.hdsa.org](http://www.hdsa.org). To sign up for a confidential list to learn about new clinical trial opportunities happening in your area, please visit [www.hdtrials.org](http://www.hdtrials.org).

## ENROLL-HD

Enroll-HD builds upon the knowledge gained from the COHORT study in the U.S., Canada and Australia, and the REGISTRY study in Europe. These studies will now combine into the single, unified, global study. As of this date the protocol has been written and is being finalized based on input from the scientific and lay communities. IRB approvals by sites should begin by the end of 2011. For more information, please visit [www.enroll-hd.org](http://www.enroll-hd.org).

## Burden of Care

In partnership with the Euro-HD Network, the Huntington's Disease Society of America launched two on-line surveys in February to examine the burden of Huntington's Disease on both the caregiver and the person with Huntington's Disease. If you have not already completed one of the surveys, please do so.

For caregivers, please visit [www.hdsa.org/boccaregiver](http://www.hdsa.org/boccaregiver) and complete the survey. For the person with HD, please visit [www.hdsa.org/bofhd](http://www.hdsa.org/bofhd) to take this version. If you are unable to complete the survey yourself, please ask your caregiver to lend you assistance. If you prefer to complete a paper survey or if you have any questions, please contact Seth J. Meyer at [SMeyer@hdsa.org](mailto:SMeyer@hdsa.org).

## Thank you

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



By *Kenneth P. Serbin (aka Gene Veritas)*, author of ***At Risk for Huntington's Disease*** ([www.curehd.blogspot.com](http://www.curehd.blogspot.com)) and recipient of the 2011 HDSA Person of the Year award

As a severely disabling and fatal brain disorder, Huntington's disease carries a deep stigma that often leads individuals and even entire families to hide the truth about their situation.

In learning of my mother's diagnosis of HD on the day after Christmas of 1995, I wanted to get tested immediately. However, my mother's geneticist and the president of the local HDSA chapter warned me against rushing into a test. They pointed out that gene-positive individuals sometimes faced discrimination from employers and insurance companies. So I postponed testing, and I kept my at-risk status private.

I thus entered the "HD closet," a terrible and lonely place where I struggled with the wrenching fears of HD as I watched my mother decline.

In June 1999, I tested positive for HD. That life-jolting event caused me to retreat even deeper into the closet.

I lived in the grips of a massive contradiction: activism for HDSA and the need to shield myself from discrimination.

Enthusiastically, but anonymously, I served on the board of the San Diego Chapter of HDSA from April 1998 to October 2010.

In 2005 I started the blog *At Risk for Huntington's Disease* ([www.curehd.blogspot.com](http://www.curehd.blogspot.com)). To protect my identity, I adopted the pseudonym "Gene Veritas," the "truth in my genes." Since then I have written regularly about the many challenges of HD – including the deeply frustrating experience of the HD closet.

But I knew that, if I wanted to truly defeat stigma, I someday would have to exit the closet.

Thanks to a combination of factors, in 2010 I began giving public speeches about my situation, using my real name.

Now in my fifties, I feel I sufficient gravitas to negotiate the inevitable complications, including discrimination. Crucially, two pieces of federal legislation gave me and other gene-positive people support: the Genetic Information Nondiscrimination Act (GINA) of 2008, which bars certain kinds of discrimination, and the 2010 health-care reform law (the Patient Protection and Affordable Care Act), which, in 2014, will prohibit denial of coverage to people with pre-existing conditions.

Most importantly, HD researchers are making great progress, giving me the confidence that an eventual treatment or cure would end the HD closet forever.

From the scientists, I have begun learning that the closet poses a huge obstacle to their work. Without the active participation of our community in clinical trials and other experiments, the researchers cannot test potential treatments for safety and efficacy.

In my new role as a public advocate and as the 2011 HDSA Person of the Year, I urge everybody in our community to get involved, summoning up the courage we know we possess to exit the terrible and lonely HD closet.

You can make a difference in many ways: by attending the local HD support group, volunteering for your local chapter or affiliate, and joining in HDSA's advocacy and fundraising efforts. I also sincerely believe that if you are at risk, you should seriously consider the possibility of genetic testing.

You can also contact your local HDSA chapter or Center of Excellence to learn more about observational and clinical trials.

Above all, as we exit the HD closet hand in hand, it's time to tell a friend or relative about Huntington's disease and how it affects your family's life. Your personal testimony provides the most effective way to fight stigma, inspire others to join the cause, and build awareness about the need to defeat HD.