

Spring 2012

THE marker

Huntington's Disease Society of America

Inside:

Advances in HD Pipeline

The DNA of Giving Back

How to Start an HDSA Support Group



Louise Vetter

HDSA Chief Executive Officer

Dear Friends,

In 1997, HDSA released its last formal Strategic Plan that guided the direction of the Society for more than a decade. During that time, the organization grew in every part its mission – research, care and education – but growth and expansion without direction is not true growth. Every organization requires a roadmap that is periodically updated or redrawn to tap into the resources that are a product of its progress. It was time for HDSA to reassess itself as an organization and as a voice of the HD community.

In 2010, your National Board of Trustees undertook the task of creating a new strategic plan that would guide the expansion of the Society over the next five years while simultaneously laying the foundation for the future. Over the next 18 months, a Strategic Planning Task Force, composed of Board Chairman, Donald Barr, Board members Dr. Jang-Ho Cha, Jamie Graham, Steve Ireland and Steve Seekins, and HDSA CEO Louise Vetter, surveyed the HD community, held discussions with individuals from every constituency of the HD community, and collaborated with our researchers to formulate a plan that would address the three parts of HDSA's mission.

In December 2011, a draft of the Strategic Plan was approved by the HDSA National Board of Trustees.

In January of this year, we released the draft Strategic Plan for comment. We invited our chapter and affiliate leaders, our Centers of Excellence staff, our social workers, support group leaders and researchers, as well as the HD community at large, to review the plan in its entirety and comment upon it. We wanted to know what you liked, what you felt was lacking and where we did not go far enough in our design. Your input was vital to helping to

shape the organization well into the future and strengthen HDSA's ability to improve the lives of everyone affected by Huntington's Disease.

Immediately following the close of our comment period in late February, the Strategic Planning Task Force reviewed EVERY comment that we received and fine tuned the plan that would lead us through 2016 and beyond.

In June, during the Opening Ceremony at our 27th Annual Convention, I will unveil the Strategic Plan and how it will be rolled out to all of you. Our goal is to be as transparent as possible in all matters relating to the community. We know that our volunteers are essential to our success in delivering services to those affected by HD and to increasing access to care and research opportunities. In brief the HDSA Strategic Plan for 2012 – 2016:

- Identifies 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.

I hope you will be able to join us in Las Vegas, NV from June 8-10 at the 27th Annual Convention when we introduce our new Strategic Plan, but if you are unable to join us or if you have any questions, please feel free to contact me at Lvetter@hdsa.org. Thank you for all that you do in the fight against HD. ●

The Marker is an official publication of the Huntington's Disease Society of America, Inc.

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Don Barr

HDSA Chairman of the Board

Welcome to this issue of *The Marker*.

This year marks what would have been the 100th birthday of Woody Guthrie. As many of you know, Woody's struggle with HD was the inspiration behind his widow, Marjorie, founding the organization that is today HDSA, shortly after Woody died in 1968. To mark this historic milestone, HDSA, in association with the Woody Guthrie Foundation/Archives, is offering a mobile display of the life and times of Woody Guthrie. One of these displays will be in the HDSA Exhibit Hall at the 27th Annual Convention and I urge everyone to take a few minutes to honor the man behind our organization.

The mobile displays are also available for educational events, Celebration of Hope dinners and Team Hope Walks. To reserve a display for your event, contact Sarah Pattison (SPattison@hdsa.org).

We are also pleased to announce a Woody Guthrie Songfest that will be offered each noon on Friday and Saturday during the Convention. Join us in the Meditation Room for a half hour of song and good times!

I am constantly amazed at how the Convention has grown since I became involved with HDSA many years ago. In 2011, we welcomed more than 1,000 folks to Minneapolis and I am sure that we will eclipse that number this year in Las Vegas! And what a great program we have planned. The Research Forum has been completely transformed and we are pleased to announce that Sarah Tabrizi, MD, FRCP, PhD from University College London, will be our keynote speaker. Following Dr. Tabrizi will be a panel on clinical trials and observational studies. Principal investigators from each study actively recruiting will present a brief overview of their study and then we will open the session up for questions from the audience. To complement this presentation, our researchers

will be on hand in the HDSA Exhibit Hall throughout the Convention to further discuss their projects and studies.

In the afternoon, our always popular Potential New Therapies workshop will offer a snapshot of the cutting edge HD research going on in laboratories worldwide. To finish our research track, Jeff Carroll and Ed Wild from HD Buzz will explain how to translate a research article or news release about HD – what does it all mean? We hope that you will find the new research track informative, interactive and even better than past years.

On the care side, workshops will be grouped by the triad of HD symptoms – cognitive, behavioral and movement – and will offer information along the continuum of HD rather than by stage of disease as in prior years. In addition, we have workshops for youth and young adults, for parents with children affected by JHD, and a track for all attendees that includes our Advocacy Meet and Greet, How to Start a Support Group, Long Term Care, and, back by popular demand, Meet the Board. Also new this year is a face to face Clinical Trials Diplomat training on Saturday at 1:30 PM.

This is a year best described as "more is better!" We have expanded the lunch hour from 60 minutes to 90 minutes and ended our workshops by 4:00 or 4:30 thus allowing our families more time to network, catch up with old friends or just enjoy the stunning views of the Red Rock Canyon just beyond our hotel.

I hope you can join us in Las Vegas, NV from June 8-10 for the HDSA 27th Annual Convention. For more information about the convention, please go to page 14.

I look forward to seeing you there! ●

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Photo of Marjorie Guthrie re-printed with permission of the Woody Guthrie Foundation/Archives.

Photo of Woody Guthrie by Robin Carson, Courtesy of the Woody Guthrie Archives.

Researchers Meet in Palm Springs to Discuss Advances in the HD Pipeline

The theme of the recent CHDI Annual Conference could have been “The Big Picture.” There were many big ideas discussed; demonstrations of promising movement of several targeted approaches progressing through the drug discovery pipeline, discussions of the utilization of multiple approaches for a successful HD onset-slowing/preventing regimen, and the introduction of Systems Biology – looking at the total big picture – to the HD world.

More than 250 scientists from around the world, representing academic institutions, hospitals, big pharma and biotech companies, gathered in Palm Springs for four days of symposia, workshops and networking aimed at producing collaborations that would accelerate the advance of HD science and the progress of potential therapies for those affected by HD.

Successful collaboration was the topic for the opening session of the Conference, as attendees participated in a compelling “team building” exercise, led by Maestro Roger Nierenberg. An experienced symphony conductor, Nierenberg led a group of musicians through a series of exercises focused around a piece of music – and through their interactions demonstrated how they could reinforce key strategic messages, develop leadership methods, as individuals and as a group, improve their ability to work together through their shared vision and shared experiences, and identify methods to achieve defined objectives. These are all great metaphors for the nature of the collaborative efforts that the Conference participants aim to achieve. The session clearly resonated with the scientists in attendance, and was reinforced by many speakers at different sessions, who added orchestral metaphors to their presentations.

Session One: Systems Biology

We know that you will find the huntingtin protein in almost every cell of the human body. Therefore, a relatively new approach to medicine, Systems Biology, attempts to understand disease complexity by examining and collecting data from all of the dynamic biological networks and molecular interactions in the body. This can involve



assembling huge data sets of biological information, such as DNA, RNA, proteins, and integrating this data into models of health and disease. Lee Hood, MD, PhD, is the inventor of Systems Biology, and explained how this approach would work in HD drug discovery, including the stratification of disease into various subtypes, and the creation of new blood markers that will allow the evaluation of the effect of potential drug therapies on the different organs in the body. Hood demonstrated how newly emerging technologies, such as next generation DNA sequencing, targeted mass spectrometry, microfluidic protein chips and other new developments, will transform biology and medicine – and how the current breadth of work on Huntington’s makes it a great candidate for this approach. Hood also explained how utilizing data from different systems allows scientists to subtract out the “noise” that may be misconstrued as facts, or in some cases as biomarkers – leading to more progress via the elimination of false positives and not spending time on dead-end approaches to a disease.

The next speaker, Keith Elliston, PhD, spoke about his introduction to the HD field, and how he will lead CHDI’s efforts to utilize Systems Biology in finding treatments for HD. Elliston has brought his knowledge of this field to other

organizations, and is particularly interested in assessing and analyzing the great amount of information already available, combining it with animal model data and using other new tools such as IPS cells, and new computational methods to model disease progression and improve therapeutic development. Elliston also demonstrated how a simple disturbance of a system could lead to key information about its processes, and therefore a greater understanding of disease causation and progression.

This process will allow scientists to proceed with molecular profiling at central and peripheral tissues, create new models, find the first steps in the disease process, and create digital modeling possibilities – adding *in silico* to *in vitro* and *in vivo* tools for HD researchers.

Jim Gusella's, PhD, presentation focused on work he and his colleagues are pursuing with another large body of data; genetic data gathered from thousands of participants in PREDICT and REGISTRY studies. While it's common knowledge that Huntington's is caused by a mutant huntingtin protein, the age of motor onset and the severity of symptoms are obviously modified by other factors. That's why two people with the same CAG repeat may become symptomatic at ages ten or twenty years apart. Gusella is attempting to identify these genetic modifiers and then determine how they affect the pathogenic processes, such as gene expression, microRNA

expressions, chromatin modification, protein expression, or other processes – with the hope that the findings yield both therapeutic targets and markers to measure their effectiveness.

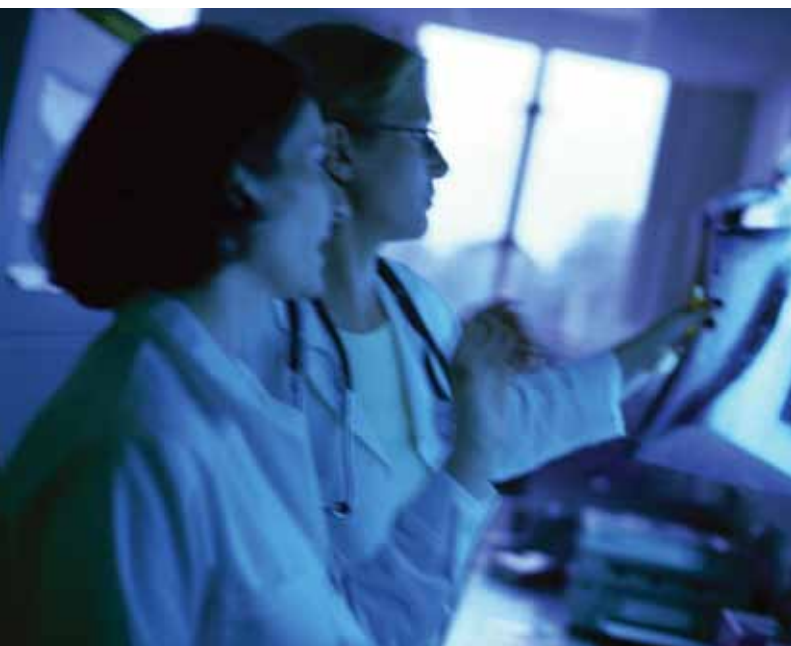
The final speaker of the morning session, Henchman Peng, PhD explained the process by which his group, at the Howard Hughes Medical Institute, is creating 3-dimensional digital models of animal brains that will aid our understanding of synaptic and other processes, starting with a *c.elegans* worm, which has 302 neurons, moving up to *drosophila* (fruit fly) with 100,000 neurons and then to a mouse, with 10,000,000 neurons.

The process starts with a confocal microscope that shows spatial relationships that can be built into 3-D models photographing the brain cells, then computer mapping each and assigning names. The model is then built to include the morphology and location of neurite structures. These models are particularly valuable when applied to brain structure-function studies.

Post-translational modification has been a therapeutic target category for several years. **Session Two** of the Conference focused on progress in the areas of translational and post-translational regulation of huntingtin – how the huntingtin protein may change its function or structure by combining with other biochemical function groups, such as acetate, phosphate, lipids or carbohydrates.

Melissa Moore, PhD from the University of Massachusetts Medical School, discussed how the specific removal of mutant HD RNA would eliminate both RNA and the protein toxicities. Recently a specific knock down of mutant HD RNA by allele-specific RNA interference (RNAi) has entered large animal trials. While this will not work in all cases, Moore described how harnessing one of the RNA quality control pathways that detect and eliminate stalled translation complexes may hold promise, as up-regulation could specifically down regulate mRNAs containing expanded CAG repeats, and thereby slow their creation of new mutant huntingtin proteins.

Naoko Tanese, PhD reported on the discovery that endogenous huntingtin was found to co-localize and co-traffic with mRNA in dendrites (the branched extensions of



neural cells that conduct electrochemical stimulation from other neural cells). Therefore, the huntingtin proteins are clearly involved in protein translation, affecting mRNA – the question is whether it is specific mRNA, or its own mRNA. The presence of RNA binding proteins likely plays a role in ALS and Alzheimer's as well.

The objective of most of the work on post-translational modification of huntingtin revolves around identifying the modification that would affect the toxicity of the protein to negate its effects. Lisa Ellerby, PhD spoke about the approach she is taking at the Buck Institute for Age Research utilizing mass spectrometry. Novel sites of phosphorylation, acetylation and oxidation have been identified, and these sites are being investigated for potential approaches that would utilize these post-translational modifications as targets to provoke therapeutic intervention.

Dimitri Krainc, MD, PhD, reported on his lab's work utilizing acetylation to promote cellular clearance of mutant huntingtin in the autophagy process. He explained how acetylation can also affect phosphorylation, and likely has impact on metabolism, protein stability and aging, mRNA function, splicing and other processes. Krainc's lab believes that isoform-specific HDAC (histone deacetylase) inhibitors would be able to increase acetylation and therefore aid the clearance of mutant huntingtin in cells, avoiding early cell death. They are currently doing a quantitative analysis of the acetylation-ubiquitin switch, searching for an acetyl receptor in the degradation machinery of cells and attempting to validate their therapeutic approach in fruit fly and mice primary neurons.

Marcy MacDonald, PhD, asked the question, "Which of the many post-translational modification sites from the huntingtin primary sequence is the key to pathogenesis?" Acetylation? Methylation? Phosphorylation? Sulfation? Glycosylation? Another? MacDonald's lab is using global phenotyping methods of HD genetic criteria (true dominance, progressivity with CAG size, striatal specificity on knock-in mice) and have noticed distinguished isoforms of full length huntingtin which appear to be altered in location within striatal neurons early in the disease. Mass spectrometry analysis has shown that increasing polyglutamine tract length yields alternate patterns of

phosphorylation in more than a dozen sites across the entire protein. Therefore there may be a post-translational mechanism approach to modulate huntingtin function, subcellular location or other properties that may trigger pathogenesis.

Session Three

featured what may be the most provocative and promising approach to HD therapeutics – silencing or lowering/eliminating the production of the mutant huntingtin protein that causes the disease. The HD community has been hearing about this work for several years now, and significant progress has been made moving this therapeutic targeting down the pipeline toward human trials.

Dinah Sah, PhD, kicked off the session with an overview of one of the major issues of the gene silencing approach – whether to take an allele-specific or non-allele specific approach. As everyone carries two huntingtin genes – one from each parent – the person who has inherited the mutant huntingtin gene, also has one with a normal CAG length. There is considerable evidence that normal huntingtin has a role in neuronal development in the early stages of life, and is involved in normal processes throughout the entire human life span. Therefore, while it is clearly beneficial to lower the amount of mutant huntingtin which causes the symptoms of HD, there has not yet been a determination of how much you can lower the production of normal huntingtin without causing other problems. Some gene silencing approaches are "allele-specific," meaning they only lower the mutant huntingtin. Others target both the mutant and normal huntingtin.

Beverly Davidson, PhD, presented the work her team at the University of Iowa has done using siRNA (small interfering RNA) and mRNA (messenger RNA) to achieve



significant huntingtin-lowering results. It appeared that a 60% reduction in mutant huntingtin created positive results in mice. Davidson also described work done to develop refined miRNA (micro RNA) that would eliminate potential off-targeting (binding with the wrong proteins). Davidson has tested these developments in mice and non-human primate models with positive results, reducing the overall huntingtin levels by 50%. Testing in non-human primates who received the treatment showed improvements in gross and fine-motor testing, as well as chemical and biological measures, demonstrating that the mRNA approach should be safe and has promise. These findings suggest that human clinical trials are in the foreseeable future.

Isis Pharmaceuticals has been working on a gene silencing approach that utilizes anti-sense oligonucleotides (ASOs—single strands of DNA that are designed to bind to a specific protein) as the delivery mechanism. This is placed in the cerebro-spinal fluid (CSF) through an intrathecal pump (implanted in the abdomen, with a line up into the brain). This is a technique that appears to work well as the ASOs distribute nicely to areas of the brain affected by HD, targeting both the wild-type (normal) and mutant huntingtin. The process uses RNaseH, an enzyme that degrades the targeted mRNA molecules which has successfully lowered huntingtin in brain tissues of non-human primates (macaque monkeys).

Isis is also investigating a second approach, targeting single nucleotide polymorphisms (SNPs – a small DNA sequence variation) that also uses RNaseH, and a third approach that targets the CAG repeat sequence itself. Isis is currently evaluating all three approaches to determine which is the most efficient, and therefore, most worthwhile to move forward to clinical trials.

Phillip Gregory, DPhil of Sangamo Biosciences, spoke about a new approach to gene silencing utilizing zinc finger proteins. These are proteins that bind with DNA that use zinc ions to regulate folding. Sangamo is attempting to design engineered zinc finger protein transcription factors, which will up or down regulate gene expression. As they work at the DNA level the factors can theoretically be used to target the gene's transcription process. As the genetic signature of HD is well known, this approach may be the first small molecule drug intervention that could

successfully control huntingtin gene expression. To date, there has been success with this approach in both mouse and human cells. Therefore, work is continuing to fine-tune ZFP TPs for very precise gene targeting.

Bill Kaemmerer, PhD gave an update on the other major gene silencing initiative, the collaboration between his company, Alnylam, and Medtronic. They are using siRNA (small interfering RNA) to suppress both mutant and wild-type huntingtin. The siRNA will be introduced to the central nervous system through direct infusion into the putamen with a Medtronic pump device. The pump is currently being used by 100,000 people in the US for other diseases, so there is confidence in the safety of this mechanism. Alnylam and Medtronic expect to bring this targeted approach to human clinical trials in the next few years.

Kaemmerer spent a large portion of his presentation making the case that this is an essential time to establish a panel of biomarkers – including imaging, biochemical, and behavioral assessments, so that potential therapies can be evaluated in pre-symptomatic, as well as symptomatic patients.

As established in the introduction to the session, there is concern about safety issues involving huntingtin-lowering, especially when wild-type (normal) huntingtin expression is being lowered, in addition to the lowering of mutant huntingtin expression. Neil Aronin, MD, spoke about these issues, asking the audience to consider how clinicians view risk for patients, and the potential clinical implications

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Redefining Independence

Exerpt from “I Met My Father the Night He Died”

By Elizabeth Baxter



I can remember the day my mom and I had the “talk” with my dad about giving up driving. My father’s chorea had gotten worse and he was losing his ability to show good judgment and recognize spatial boundaries while driving alone. After several “close calls,” my mother and I made the difficult decision to take away the keys.

I remember we were all sitting at the round table in the kitchen. My dad was very quiet as my mom pleaded her case. I can still see the look of utter disappointment and betrayal on my dad’s face as she told him he would no longer be making his favorite donut runs to town. When my dad looked across the table at me, I felt as though I had betrayed him, too. I felt so guilty limiting his freedom, but deep in my heart I knew it was the right thing to do. Making that hard decision for my dad was the moment when my role changed from daughter to caregiver, even though I was only 20 years old.

Taking the keys away from my dad was extremely difficult and emotional, because driving is a universal symbol of independence. I know it “killed” my mother to say the words she had been rehearsing in her head for years, but there were too many risks involved in continuing to let dad drive. Looking back, we probably should have made the decision earlier, but my mother told me she thought it “would break his heart.” I know it nearly broke mine.

Once the storm cloud cleared, however, my mom got creative and thought of a new way for my dad to feel

independent. She got my father on our farm’s four-wheeler so he could help her deliver hay to the horses in all the different pastures. To keep him on track, she taught my dad to focus on her back and keep the handle bars pointed in her direction while she walked ahead. When HD finally caused my father to retire, my mother asked him to help her with more chores around the farm, morning and night. It was really cute watching the two of them putting on their barn clothes and heading out together to do the chores, mom in front and dad behind on the four-wheeler.

Chores were not the only thing they did together. My dad would also follow my mom to the riding arena where she would ride her horse while he watched from the four-wheeler. My dad spent many hours each day enjoying time with his loving and patient wife. Anyone could see how happy he was to be with her, doing chores or just sitting on the porch together. Looking back, I think it may have been the happiest time of my dad’s life, simply being with my mom all day.

Feeling useful and remaining mobile added so much to my father’s life those last years. I think it was inspired how my mother redefined independence by getting my dad off the road and on the four-wheeler, able to help her with the chores.

Our story is just one example of how caregivers can look for activities that will keep their loved ones engaged, even as their needs and abilities change. My mom was lucky that my dad responded so well to the idea of the four wheeler and was able to drive it safely. You may have to try several different activities, because something may work one week and not the next. Try not to get too attached to one idea, because HD symptoms are always changing and evolving into new symptoms. My advice is to take a deep breath and stay flexible. New activities may not always work, but then again, they might! ●

Advocacy

In 2009, HDSA launched an advocacy initiative to compel the Social Security Administration (SSA) to update the guidelines they use to determine disability for people with HD and waive the two year waiting period for Medicare benefits once the person with HD was eligible for SSDI or SSI.

Legislation was introduced and, in 2012, the Huntington's Disease Parity Act (HR717/S648) has support from 112 Congressional Representatives and 12 Senators. But much remains to be done if we are to be successful in our efforts to effect a positive change for our family members. Everyone can be an advocate for HD. Below is one advocate's story of how she and her family became engaged in HDSA's advocacy efforts:

Our Way to Make HD in Our Life a Positive Experience

By Kathleen Smulski

After his mother died in 1999, my husband tested positive for HD. One major way that I cope with HD in my life is through advocacy, and working to generate support for the Huntington's Disease Parity Act of 2011 (S. 648 in the United States Senate; HR. 718 in the House of Representatives). The legislation resonates with me personally because my husband will have to stop working and, when he does, I would like him to have access to the healthcare he needs, and to the benefits that he has been paying into. If you want to learn more about the Huntington's Disease Parity Act, you can go to www.hdsa.org/advocacy.

Since my father and I both live in Michigan, we decided to work together to gain support from our Senators. Senator Debbie Stabenow, of Michigan, recently cosponsored S. 648. We are very proud to share how our combined efforts contributed to Senator Stabenow's cosponsorship. The best part about what we did is that anybody can do it! I once heard someone say, "You don't have to be a victim." This was great advice. By taking action, by reaching out to your Senate and Congressional leaders, you will feel empowered and strong rather than helpless.

Our first step was to contact our Senators using the HDSA E-Advocacy Center. All the work is done for you – go to www.hdsa.org/takeaction and enter your zip code, and the letter to your members of Congress in the House and Senate will be provided. You can add your own comment (if desired), sign, send, and boom! You're done. You will hear back, and when you do, you can forward the response to Jane Kogan at jkogan@hdsa.org, and HDSA will follow up on your behalf. If you do this and this only, you are an advocate!

Then, we reached out to our network of family and friends and asked them to send a letter through the E-Advocacy Center. We emphasized the fact that The Huntington's Disease Parity Act is a non-partisan issue. Regardless of their political affiliation, your loved ones can help. The people who care about us were glad to help. In our experience, if you give people something specific to do, like sending a letter, they will do it.

When we got a response, we decided to take it to the next level and request a local meeting. It's a good idea to request a meeting with your Senator(s) and Rep(s). We decided that we'd have more impact making individual appointments rather than a joint appointment. So we contacted Stabenow's local office to request an appointment. It is likely that you will be granted an appointment with a staff person, rather than with the Member. This can be a good thing, because you can then develop a relationship, and the staff person can become a champion and an advocate for the HD community. My husband and I met in person with the Senator's staff person locally, while my father opted for a phone meeting. Once the time and date were set, we did our homework to prepare for the call.

Always rehearse your agenda before meeting and decide who will say what. Be friendly, smile and expect a yes. Write down the name, title, phone number, and email address of person(s) you meet. Explain that you will refer to your agenda to make the best use of everyone's time. Explain that you will be taking notes so you will remember them later. If they say something you don't understand, ask for clarity. Thank them for meeting. Follow up with a letter summarizing your meeting. Follow up on commitments made by contacting them via phone or email.

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Advocacy (Continued from page 7)

This has been a great experience for both my dad and me. If you've never written to Congress, we hope that this inspires you to take action. You can count on HDSA to support you through the process, and to give you the tools to be an effective advocate. Best of luck from both of us. ●

Based on Our Experience We recommend the following:

If you've never done this before, call HDSA. HDSA makes the process easy! They will help you request the meeting, train you, and give you materials. Prepare an agenda in writing. Your agenda should include a bulleted list of things you will discuss. This can be distributed with your other "leave behind" materials.

Consider following a script. This is what we used:

1. Thank you for your time, _____.
2. I'm here to talk to you about the Huntington's Disease Parity Act (S. 648). I am asking for Senator _____'s support as a cosponsor of the bill, S. 648.
3. Are you familiar with Huntington's disease? If yes: Then you are aware that...see below... If no:
 - Huntington's disease (HD) is a rare, neurological, and fatal disease for which there is no treatment or cure.
 - Huntington's disease affects an individual cognitively, psychologically, and physically.
 - HD symptoms typically present during an individual's prime working years—mid 30's – 40's.
 - Currently, 30,000 individuals in our country have HD.
 - HD eventually robs each affected individual of his or her ability to live independently.
 - HD impacts the entire family unit.
4. The problem is: SS Disability guidelines were written 30 years ago when HD was considered only physical.
5. We now know that the early symptoms of HD can also be psychological and cognitive. The physical symptoms generally present later – at times, not at all. Second problem – Medicare's 24 month waiting period once a person with HD is granted eligibility. During the 2 year waiting period, HD has a devastating and destructive impact on the individual's capacity to work or live independently – while they are denied essential healthcare.
5. The Huntington's Disease Parity Act is important to me because: Personal story...plan this out ahead of time, as you want this to be personal, but not too emotional or lengthy.
6. Reference state impact: In my state X individuals are affected by HD.
[HDSA can provide you with fact sheets!]
7. The solution is relatively inexpensive. [HDSA has a cost estimate for the Huntington's Disease Parity Act]
8. Restate impact: S. 648 would revise outdated guidelines for determining disability for SS Disability and remove the 24 month waiting period for Medicare upon eligibility.
9. Ask for questions.
10. Make the ask for support: Can I/we count on Senator _____ to be a champion for Huntington's Disease and cosponsor the Huntington's Disease Parity Act (S. 648)?



Why I Give My Voice to HD

By Marie Clay



I never thought Huntington's disease would be the focus of my life until my husband, Phillip, and then my oldest daughter, Laurie, were diagnosed with HD 13 years ago. Phillip passed away in 2006, and Laurie is now 40. At first, I was absolutely devastated. I cried daily and screamed at God. As a mother, I

knew my daughter's hopes and dreams. I knew how excited she was about being a new mother. In a shocking moment, all those dreams were taken from Laurie and possibly from her son. I was unprepared and I was scared, but I knew I had to do something.

As we all do, I rushed to educate myself about HD. Twelve to fifteen years ago there was far less information available. My sincerest gratitude to the HDSA Center of Excellence at the University of Virginia, and to their amazing staff, for getting us to where we are now, with resources and hope, and to each of the 21 HDSA Centers of Excellence that provide information and care to our loved ones, and supports us in our HD journey.

I have learned over the years that I cannot take HD away from my daughter, but I can fight back and keep my sanity by volunteering, educating, and advocating. Once I learned more about HD, and found ways to get involved, I was able to cope. Gradually, I looked at HD head on. In 2006, I started by selling Amaryllis plants at Christmas. Each year, I educated a new group of people about HD. Today, I have people who order them annually because they want to help. In 2008, I started a support group in Virginia Beach with an ad in the classifieds as a support system for myself and for others in my area. At first, there were only two of us; at our last meeting, we had twelve people. Our support group held our first fundraising event (a pool tournament),

three years ago, and 50 people attended. The second year, we had 100, and we hope to have even more this year. We also hosted our first Team Hope Walk last year.

I am also a huge believer in building education and awareness about HD throughout the community. I have spoken with police training groups throughout the area and have been able to work with our local media on several newspaper articles written about HD and about my daughter, Laurie. I have also spoken about HD on radio and on television. My employer, Geico, has been very generous to me and to my cause. In 2010, I was named Volunteer of the Year. Geico gave \$1000 to HDSA, and I was given a three day trip to the Geico headquarters in Washington, DC and \$500. Best of all, Geico publicized the award nationwide, and educated many people about Huntington's disease and HDSA.

My volunteering has connected me to other amazing members of the HD community, including one of my closest friends, Ruth Hargrave. Ruth understands the challenges I face as an HD family member. We have collaborated in our education, fundraising, and legislative advocacy efforts. I am often struck by how vibrant our HD community is. The more I volunteer, the more connected and empowered I feel, and the more I see what we can do together to help those who can no longer help themselves. I am truly thankful for Ruth, and for the entire HD community. They are my anchors, my support system, and my inspiration. HDSA has given me many opportunities to advocate for our loved ones, opportunities that I would have not been able to acquire on my own. Thank you HDSA for standing by me. ●

Marie Clay lives in Virginia Beach, and is the facilitator of the Virginia Beach HDSA support group. Marie has 3 children and 7 grandchildren. She is passionate about raising awareness for Huntington's disease, and doing everything she can to help people with HD, caregivers, and family member.

Why I Volunteer for HDSA

By Don Higgins, M.D.



When I look back upon my career, it almost seems the path was preordained. Serendipity has smiled on me, providing wonderful opportunities and experiences over the past 25 years. Prior to entering medical school I had the good fortune to gain employment in the lab of Stanley Fahn, MD, an architect of the specialty of Movement Disorders. At Columbia University, I assisted in research characterizing new treatments for Parkinson's disease (PD). Departing this position to start medical school, I returned the next summer to study mechanisms of brain injury in PD, supported by a Parkinson's Disease Foundation Fellowship.

Upon completion of medical school, I attempted a direction change, entering a residency in Internal Medicine at the University of Michigan. During the intern year I realized my error, withdrew from the residency, and accepted a post-doctoral position in the lab of Anne

Young, MD, PhD and John Penney, MD at Michigan. This is where my connection to the Huntington's disease (HD) community was forged. As if it were yesterday, I remember the palpable bond between Anne and Jack and the folks they cared for in the clinic. The resilience of the families confronting the difficulties and obstacles that are HD, and the recognition that they were not alone, was mesmerizing.

While my involvement and dedication to HD deepened during residency/fellowship, it was during my first position after training that HD became a clinical focus. At the Ohio State University, the site of the centennial celebration of George Huntington's description of HD, wonderful colleagues afforded me the time needed to establish an active clinical and research practice dedicated to HD. The support of the Central Ohio Chapter of HDSA was also crucial. This hard work culminated in designation as an HDSA Center of Excellence in 2000. During this time I also became involved in the Venezuela Huntington's Disease Project. Speaking no Spanish, I joined the annual pilgrimage to Maracaibo on three occasions. A life altering experience, it is my sincere hope to return soon.

Since relocating to upstate New York eleven years ago, the HD practice and research has grown substantially at the Albany Medical College. We have organized/co-organized multiple educational events for the HD community and fostered the re-establishment of a Support/Discussion Group in the Capital Region. The group has recently transitioned into an Affiliate of HDSA with aspirations to become a Chapter.

It was the drive, dedication and devotion of the HD community that prompted my entry into this field nearly 20 years ago and encourages my continued commitment today. Once you witness the foundation the families provide to loved ones, the extended hand of a support group member during a time of need, the prolonged hours and effort of the healthcare team, you can't help but be involved. ●

Don Higgins, MD is medical director of the clinic at Albany Medical College in Albany NY. He is an active member of many HDSA committees.

Giving Back

By Shana Martin

At the age of five, immediately upon my mother's diagnosis, my parents sat me down and explained what the future of our family entailed. This included scary facts about what would happen to my mom, and my chance of also one day becoming sick. At the end of the dismal conversation my father presented me with a binder from HDSA, and explained how many people were working hard to help find a cure. At that moment, I knew I wanted to help too.

The next seven years were very challenging. At school the kids would tease me for having the "retarded" mom. At home care-giving for her had become a full time job for my dad and me. Life was a bit of a struggle until one day in sixth grade when my world turned around. I was asked to give a speech to my class about Huntington's disease; I was scared to death. After my presentation I braced myself for more teasing, but instead was showered with questions and encouraging comments. It was at this moment I realized how I could do my part.

I continued speaking, using my media encounters from lumberjack sports and collegiate track and field, to reach a larger audience. The more I spoke, and the more I helped out, the better I felt. I was given a purpose in my life and it became addicting! To feed this therapeutic addiction even further, I joined the Wisconsin Chapter Board of HDSA. Planning walks, galas, conferences, charity adventure trips, selling hearts and flowers, and of course speaking to the community became a second job. Being around all of this, my view of Huntington's disease changed from "devastating" to "hopeful". Seeing all of the money we were raising, families we were helping, and people we were educating was the single most satisfying feeling I ever had. I really was making a difference, and for good "selfish" reasons.

At this point my mom lay unresponsive in a nursing home. The only reprieve from the helpless feeling of not being able to do anything for her were the hours I could sit and tell her about everything we were doing for HDSA. Despite her lack of response I knew she understood what I was saying and was filled with just as much excitement about the work that was getting done. Maybe my volunteering wasn't so "selfish" after all.

There had to be something deeper than this good feeling I was getting from helping others, and according to research, there was. A significant amount of research has been done over the past few years in regards to the health benefits of volunteering. Studies have shown that volunteering can play a role in increasing your overall sense of well being, decreasing chronic pain, and even reducing levels of depression.

Where to start? All HDSA Chapters and Affiliates are eager to pull in more volunteer power. Your local chapter information can be found at: <http://www.hdsa.org/about/chapters-and-affiliates/index.html>. For a more broad range of volunteer opportunities, visit some of your local service organizations such as Kiwanis, Optimist, and Rotary. A website called volunteermatch.org is a great start to search for volunteer opportunities near you.

Even if it is not money, we all have something we can give, and I promise, you will feel great doing it.

"We make a living by what we do, but we make a life by what we give." --Winston Churchill ●

Shana Martin is a fitness professional living at-risk for HD in Madison WI. Her love of fitness led her to five Lumberjack World Titles and ten years of regular appearances on ESPN and the Outdoor Life Network.



The DNA of Giving Back

By Kristen Powers

I had always been an ambitious kid. Starting in third grade, I used to scrawl "Save the Wolves" on old coffee tins with hopes to raise money and preserve the endangered species I am still madly in love with. While I had become accustomed to giving back from a young age, it took on an entirely different meaning in 2005.

That year, my dad informed me that my mum had been diagnosed with Huntington's disease. I had never heard of this disease before and, upon further research, I discovered that I had a 50% chance of inheriting the same disease that would kill my mother in January 2011. As I watched my mother's furious decline into dependency, and in 2006, to a nursing home, I threw my energy into something that could not only distract my worried thoughts, but help me pursue my passion.

My first attempts involved knitting hats that I would sell to benefit HDSA. My mum had taught me how to knit. It meant a lot to me that I continue an activity that she could no longer carry on, as there was no hope she'd ever pick up the knitting needles again. I made over seventy hats in two years and made a little over \$100 by the time I graduated from middle school.

By then, the DNA of giving back was beginning to express itself in my activities. I wanted to be the kid who revolutionized the world. In ninth grade, I started an environmental club called Green Tigers. Through this club, I made great strides

in "greening" my school as well as organized a teen-operated garden that has donated over 200 grocery bags of organic produce to the community while educating over 300 teens. This project led me to the White House for the 2010 Parade Magazine All-American High School Service Team Awards, a spread in Family Circle Magazine, White House Champion of Change in 2011, and recognition as a "Global Teen Leader" in the We Are Family Foundation's prestigious ThreeDotDash program.

When I attended ThreeDotDash's Just Peace Summit in March 2011, my dreams of creating a documentary about Huntington's disease materialized. I'd always loved the power of film to educate and influence the minds of its viewers. Although, I never had the resources or know-how to even begin such a project, there were many program mentors in the entertainment world who helped make my dreams a reality.

Now, *Twitch* follows the genetic testing of a teenager while also exploring the social, economic, political, and medical effects of Huntington's disease.

Giving back to my community, my world, and my family has been the best therapy for coping with the illness and death of my mum. Ever since her diagnosis, I have decided to not waste a single day on this planet. I don't care if I have 100 days or 100 years. I do not need to wait for permission to follow my passion and change this world. I already am. And if I had to guess what my mum would say today, I think should she would tell me, "I'm so proud of you. You are going to change the world. Big time." ●

For more information about *Twitch*, go to www.twitchdocumentary.com.

Kristen Powers is a senior at Chapel Hill (NC) High School. She is the creator of Twitch, a documentary that follows her genetic testing for HD.



Why I am an HD Advocate & Volunteer

By Stacey K. Barton, MSW, LCSW

HDSA Center of Excellence at Washington University School of Medicine

Like the many HDSA Chapter and Center of Excellence social workers across the country, I spend my day on a number of HD-related issues, such as calls from people with HD or family members with medical or social needs, providing HD education to community and student groups, conducting HD research, providing counseling, running support groups and so much more. There is always more work to be done and choices to make about how to utilize the finite human resource that is the HD social worker. For many of us, this includes additional work in advocacy and volunteering.

For social workers, advocacy is in our blood. Most of us probably already had a social justice bent even before graduate school, but certainly we receive additional training and emphasis on advocacy once we enter our training programs. Still, when you are in the midst of dealing with issues on the individual and group level all day, it can be hard sometimes to take a step back and take the time necessary to send letters to legislators, meet with political staff, write letters to the editor, and other higher level activities.

Yet advocacy is a must for affecting change from the top down. If my one letter, mixed with the thousands of letters from other HD advocates, helps change laws that make life easier for HD families, why would I not earmark some time for these activities? Meeting with Congressional staff is not that difficult, and it allows me, as a social worker, to be involved in the process of bringing awareness to HD at a whole new level.

Volunteering in general has always been important to me. I have participated in many a walk-a-thon or trivia night over the years, tutored English as a second language, volunteered on a rape crisis hotline, worked as a volunteer money manager for seniors with cognitive impairment and blindness and more. But once I started working in HD, why wouldn't I focus my volunteer efforts on this same amazing community that I work for every day?

HD volunteering for me often blurs the lines with my professional role. When I attend Chapter Board meetings in the evening, am I working or volunteering? When I facilitate a support group after hours, is that working or volunteering? Ditto for attending fundraisers, traveling to meetings, support groups or educational sessions. In the end, it really doesn't matter. While it is important to save time for my family too, it is equally important that I volunteer. And why not volunteer for the HD community?

I am not unique. My colleagues across the country all give of themselves beyond the confines of their professional role. I feel lucky to serve the HD community and to work with HD families, committed professionals and faithful volunteers every day. ●

Stacey Barton, MSW, LCSW is the social worker at the HDSA Center of Excellence at Washington University School of Medicine in St. Louis, MO. She is a tireless advocate for HD, always seeking ways to educate and inspire others to care.



HDSA 27th Annual Convention is Coming!

Join us in Las Vegas NV for our next Convention! From June 8-10, 2012, HDSA will be bringing experts on movement, cognition and behavior to you in a series of workshops, plenary sessions and panels. This year promises to be even more exciting than last year in Minneapolis.

On Friday, June 8, HDSA will welcome our families and healthcare providers with an Opening Ceremony that includes an update on HDSA's new five year strategic plan, a segment on We Are HDSA! wherein three family members tell their story of coping with the challenges of HD, and a video message from Nora Guthrie celebrating the 100th anniversary of Woody Guthrie's birth in Okemah, OK.

On Saturday morning, HDSA brings you a keynote address by Sarah Tabrizi, MD, FRCP, PhD from University College London who will bring the community up to date on advances in the HD research pipeline and what they mean for all of us. Immediately thereafter, HDSA will present a panel discussion on clinical trials featuring four trials and observational studies that are currently seeking participants. An HSDA Clinical Trials Diplomat will talk about their experience in a research study.

Friday and Saturday afternoons offer a host of workshops that discuss the triad of HD symptoms as well as sessions for youth, field and volunteer development, JHD and a general track. Don't miss the ever popular Potential New Therapies session on Saturday at 1:30PM.

During breaks and at lunch each day, HDSA will offer author readings and a sing along in the Reflections of Hope Meditation room.

Here is a sample of a few new activities HDSA will offer at our 27th Annual Convention:

- An Advocacy Meet and Greet on Friday from 3:00 – 4:30PM. Learn how to be an advocate and meet other advocates in your area.
- How to Start a Support Group on Friday at 1:30PM. Learn the basics of how to start a support group and who to contact at HDSA to make it happen.
- Clinical Trials Diplomat Training. If you would like to learn



how to talk to small groups about your experiences as a research study participant, join us on Saturday at 1:30PM.

- Clinical Research Initiative Day: Sunday June 10. If you are interested in participating in a small scale research study and you can extend your stay in Las Vegas, you can register before or at the HDSA Annual Convention. Many clinical trial and research study investigators will be on hand in the HDSA Exhibit Hall on Friday and Saturday to talk with you individually about their study. If you meet their criteria, you can be a participant in their study on Sunday June 10. You can also pre-register by going to the HDSA web site (www.hdsa.org) and clicking on the link to a description of the studies that will be available on Sunday. Select the study that interests you and contact the investigator listed for that study. It's a great way to be part of the solution to HD. A list of research studies will also be included in the Convention Program book.

Friday evening is the official HDSA Convention Reception and Chapter Awards Ceremony beginning at 6:00PM. At 8:00PM the National Youth Alliance will once again entertain us with their talent show.

Saturday evening, we celebrate our National Award winners at the HDSA Gala and Awards Dinner. To accommodate the inaugural Clinical Research Initiative Day, the HDSA 27th Annual Convention will close after the traditional candle lighting. Dancing to a DJ follows immediately afterward with tunes for all ages.

On Sunday, all are invited to a Clinical Research Initiative Day continental breakfast from 8:00 – 9:30AM. Research studies will begin at 10:00AM. Whether you have registered for a study or not, enjoy a light breakfast with friends and family.

Don't miss your opportunity to meet other HD families, learn more about strategies for coping with the challenges of HD and celebrating the special moments of our lives. ●

Register on line at www.hdsa.org/convention
Registration Information (See next page)

It's Time for the BMW Sweepstakes

Win a 2012 BMW 328i Sedan or \$25,000 cash

For a lucky 13th year, the Huntington's Disease Society of America is pleased to be partnering with BMW North America to offer an exciting way to support HDSA's fight to improve the lives of people affected by Huntington's disease and their families.

For just \$100/ticket, you have the chance to win a brand new 2012 BMW 328i Sedan OR \$25,000 in cash. To sweeten the pot, you get three tickets for every \$200 you spend. The sweepstakes is limited to just 2,500 tickets so your chances of winning have never been better.



To buy your tickets, contact HDSA by phone (800-345-4372) or go online at www.hdsa.org/bmwsweeps to purchase your tickets today! You can also buy tickets at the HDSA 27th Annual Convention. The drawing will be June 9th during the HDSA Annual Awards Dinner and Gala.

Don't wait! Tickets are limited. Act today. You need not be present to WIN!

HDSA extends its warmest thanks to BMW North America for supporting this annual sweepstakes.

GRAND PRIZE:
2012 BMW 328i Sedan
OR **\$25,000 CASH**

Second Prize: \$5,000 cash

Third Prize: \$2,500 cash

Fourth Prize: \$750 cash

Fifth Prize: \$500 cash

BMW disclaimer

Official Rules: No purchase obligation or test drive necessary. No portion of sweepstakes donation is tax-deductible. No responsibility is assumed for lost, late or non-delivered mail. Winners will be selected in a random drawing to be conducted on June 9, 2012. All prizes must be redeemed by September 30, 2012. Sweepstakes open only to licensed drivers who are 21 years of age or older and are residents of the United States (except Puerto Rico). Employees of the Huntington's Disease Society of America and employees of BMW of North America Inc., their retailers, advertising, print and promotion agencies and members of their immediate families are not eligible. Winners will be notified by phone and/or mail. Odds of winning are determined by the number of eligible entries received. Taxes are the sole responsibility of winners. Sweepstakes is subject to all federal, state and local laws and regulations and is void wherever prohibited by law. Entry and acceptance of prize offered constitutes permission to use winner's name, photograph, or other likeness for the purpose of promotion on behalf of the Huntington's Disease Society of America, Inc. unless prohibited by law.

Convention Registration Information

For more information about the HDSA 27th Annual Convention, please visit our website at: www.hdsa.org/convention or call 800-345-HDSA (4372)

REGISTRATION FEES:

Early Bird Registration (Postmarked on or before May 23)
Includes the 2012 Convention Gala

- **Adult:** \$160
- **Family** (2 or more adults): \$125 per person
- **National Youth Alliance** (29 years and younger): \$85
- **Non-NYA member** (Children 18 and younger): \$85

One Day Registration: \$90 per sperson (Friday or Saturday)
Does not include the 2012 Convention Gala

Late or On-Site Registration (Postmarked May 24 and later)
Includes the 2012 Convention Gala

- **Adult:** \$230
- **Family** (2 or more adults): \$180 per person
- **National Youth Alliance** (29 years and younger): \$100
- **Non-NYA member** (Children 18 and younger): \$100

2012 Convention Gala only: \$75 per person

Ways to Give

There are many ways for you to make a contribution to help HDSA improve the lives of people with Huntington's Disease and their families

- **Make a one-time or recurring Donation or a Tribute/Memorial Gift to honor a friend or relative or the memory of a loved one:** Please visit our website, www.hdsa.org and click on the "Donate" icon in the upper left hand corner of the page. This will take you to a secure page where you can make a direct donation to HDSA. Or you can use the donation envelope included in this magazine.
- **Donate Appreciated Stock and/or Mutual Funds:** earn a charitable tax deduction for the full fair market value of the gift while you lower your capital gains taxes.
 - For information on how to make a stock or mutual fund donation please call 1-800-345-HDSA (4372), ext 235
- **Establish a Family Fund:** Join with friends and relatives and pool your resources to honor your family or remember a loved one and make your donated dollars work harder than you could individually.
 - For information on how to establish a Family Fund please call 1-800-345-HDSA (4372), extension 235
- **Make a Planned Gift:** Join the HDSA Heritage Club: For information on making a planned gift to HDSA please call 1-800-345-HDSA (4372), extension 235.
 - Remember HDSA in your Will or Estate Plans.
 - Establish a HDSA Charitable Remainder Annuity Trust, Charitable Lead Trust, Charitable Remainder Trust, Charitable Remainder Unitrust.
 - Name HDSA as a beneficiary of your retirement plan
 - Name HDSA as a beneficiary of your life insurance policy
- **Work Place Giving:**
 - **Matching Gifts:** Your employer or organization may be part of the HDSA Program, which can double your donation.
 - A list of participants is available on our website. If your employer is not part of this program, we would be happy to help enroll your company or organization.
 - **United Way/Community Health Charities/ Combined Federal Campaign:** Giving at work through payroll deductions to support HDSA is simple and there are many convenient ways to contribute. Check to see if your employer participates in any of these workplace giving programs.
- **Become a Corporate Partner:** Businesses of all sizes can help bring us closer to the day when there will be the last generation with HD.
 - Give a cash or grant donation
 - Join an event: Participate or become a sponsor of the hundreds of HDSA events around the country, such as our Team Hope Walks or Celebration of Hope Galas.
 - Workplace Giving: Encourage employee giving through payroll deductions and show your employees that you support their philanthropic efforts by contributing a company match of their gift.

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Advances in the HD Pipeline *(Continued from page 5)*

given the difference between the allele-specific and non-allele-specific gene silencing approaches.

Aronin also talked about the use of adeno-associated viral (AAV) delivery of small RNAs, which have been used very successfully in mice and non-human primates. They have also been used in sheep, showing good spread to important parts of the brain, safety, neuronal growth, and suppression of huntingtin expression. More studies are underway to examine the potential of this gene-silencing approach for human clinical trials.

The organizers of a scientific meeting, like the CHDI Conference, determine the key themes and topics, then invite speakers to make presentations in these areas. However, there are many more approaches to therapeutic targets, and important studies are underway that can't be presented from the stage. Therefore, poster presentations are an essential element of the Conference and a fertile area for the sharing of new ideas and the genesis of many new collaborations.

The posters are important as they highlight the work of many of the lesser-known post-doc researchers, as well as the well-known laboratory leaders. They range from introductions of new animal models, to post-translational modification, experimental medicine, and biological mechanisms, to quality of life studies, sleep studies and other areas of potential therapeutic impact.

To allow attendees to review the 90+ posters, and speak with their presenters, **Session Four** of this year's CHDI Conference was dedicated to just that. Attendees had several hours to visit the poster presentations, interact with the presenters, and share thoughts, data, and make plans for new projects in the year ahead.

A committee also judges the posters and selects the top three to make a formal presentation to the entire meeting; while everyone in attendance votes to select the best poster of the meeting. Jeff Carroll, PhD, was announced as the Poster Award Winner in the closing ceremonies.

One of the most interesting elements of the CHDI meeting is the Featured Speaker who closes Day Two of the Conference. It's usually a world-class scientist working in a related area, who is not part of the HD research community.

This year's featured speaker, Ann Graybiel, PhD, from MIT was no exception. Dr. Graybiel is a widely honored and respected scientist who was introduced as a "mentor" and "inspiration" by many of the assembled HD scientists. She spoke about her work with cortico-basal ganglia networks, and how the field of systems neuroscience could be of benefit to the HD field. The basal ganglia – nuclei at the base of the cerebrum – are deeply involved in a large range of functions, including motor systems, as they connect with the frontal executive areas and prefrontal cortex.

Dr. Graybiel's lab focuses on understanding the dynamics of cortico-striatal pathways and the striatal circuits that are at risk in HD. To do this, they track changes in the cortico-striatal neurons as animals learn, as they form habits, and develop repetitive behaviors. They examined the firing rates of particular neurons and saw them reprogrammed during learning. Thus repetitive learning reprograms the sensorimotor loop. Dr. Graybiel studies other basal ganglia loops that affect sensory, motor, associative and high level emotions. All of these are relevant to understanding the pathogenesis of HD.

These discoveries suggest that it may be possible to reverse damage caused by HD through selective stimulation or by preventing the active stimulation of neurons in one or more of these pathways.

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Advances in the HD Pipeline (Continued from page 17)

Session Five of the Conference addressed small molecule drug discovery for Huntington's. Christopher Schmidt, PhD, spoke about Pfizer's approach, utilizing phosphodiesterase (PDE) inhibitors to affect striatal gene transcription. PDEs are enzymes that can break bonds involved in the structure of the DNA "backbone." PDE inhibitors have been shown to prevent or reverse elements of cortico-striatal dysfunctioning in transgenic models of Huntington's.

Pfizer is currently evaluating the different PDE inhibitors to determine which target the most influential PDE in preclinical models through the use of imaging and physiological outcome markers in the hopes of determining which would be the most effective to go forward to clinical trials.

Vahri Beaumont, PhD then spoke about CHDI's work on the impaired cyclic AMP (cAMP) signaling which alters synaptic plasticity and the dysregulation of transcription in HD. This can be affected very positively by PDE inhibitors, therefore making it a potential therapeutic target.

To date, their work has shown *in vivo* support that this target has a positive effect on treating HD symptoms. Having reviewed data from experiments with the BACHD rat, Pfizer and CHDI are moving forward with this approach, as the data suggests that enhancing cGMP signaling can rectify neuronal and synaptic dysfunction.

Ladislav Mrzljak, MD PhD, presented the progress made in Kynurenin 3-monooxygenase (KMO) inhibitors as a therapeutic target for HD. It was recently demonstrated that the inhibition of KMO may have a neuroprotective effect in rodent models of HD. CHDI has developed highly potent KMO inhibitors with limited brain exposure to determine if the hypothesis of increasing kynurenic acid in the brain through KMO inhibition has value. So far, experiments demonstrate that the CHDI compound restores normal function to the medium spiny neurons in the striatum of HD mouse models, which are damaged in HD.

Mrzljak explained that further experiments to determine the potential benefits of KMO inhibition in rodent HD models will use neurophysiological, molecular, behavior and neuroimaging evaluations.

Novartis's Graeme Bilbe, PhD, closed the session with a description of his work utilizing mGluR5 antagonist (a substance that acts against and blocks an action) as a potential therapy for a number of neurological disorders. Mavoglurant's mode of action is to inhibit glutamate-induced activation of the human mGlu5 receptor. *In vivo*, it has shown efficacy in a variety of animal assays for diseases including Parkinson's, Fragile X Mental Retardation Syndrome and gastro-esophageal reflux disorder. It has also been successful in early clinical trials with people suffering from these diseases. Currently Novartis is investigating its effect on Huntington's, as well as on depression, chronic pain and dystonia.

The **Final Session** of the 2012 CHDI Conference was titled "Building the Clinical Highway," and was chaired by Marg Sutherland, PhD, from NIH/NINDS along with Cristina Sampaio, MD, PhD from CHDI. After Sutherland spoke on the NIH/NINDS' very active participation in HD research, Cristina Sampaio gave a provocative talk about clinical trials: their design, their shortcomings, and what considerations should be investigated for the future.

Sampaio explained that trials may fail for a variety of reasons ranging from the ineffectiveness of the tested compound to improper dosage, an inadequate effect size, a poorly targeted trial population, trial execution, the placebo effect and random effects.

She called on the researchers in attendance to consider better defined, relatively small tailored clinical trials of potential therapies, and called on her colleagues to investigate new techniques being explored in non-neurodegenerative genetic diseases for consideration. Sampaio closed with an explanation that future trial design should include clinicians, scientists, patients, families, and even politicians (for regulatory issue discussion), and that the development of new trial paradigms may be as important as the development of new potential compounds if we are to succeed in identifying therapies that will slow the progression and lead to a cure for HD.

Sarah Tabrizi, MD, PhD presented the findings of TRACK-HD and announced the beginning of Track-On HD, a follow up study.

Since 2008, TRACK-HD has attempted to demonstrate the earliest stages of the neurodegenerative process in Huntington's – many years before any symptom onset in people with the mutant huntingtin gene. The purpose of the study is to establish biomarkers that can be used to determine the success of a therapeutic candidate in a person who is pre-manifest or in the very early stage of HD. Very significantly, TRACK was run as a clinical trial, with blinded results and outside evaluators, to ensure no bias in the analysis of the findings.

The TRACK findings included an algorithm to determine the sample size of participants one would need per percentage effect of a drug to validate a trial.

Other interesting findings included the fact that while there is visible striatal shrinkage many years before symptom onset, the brain is able to adjust to this loss early on, much like a stroke victim may learn to use a different part of his/her brain to regain function.

In addition to imaging, TRACK-HD utilized speed tapping, tongue force, and lifting weights with a participant's non-dominant hand as potentially legitimate measures of therapeutic efficacy.

Tabrizi's presentation used data from the first 24 months of the study. Further findings, from newly released 36-month data will be published later this year.

Track-On HD will continue the work from TRACK, and further refine these pre-manifest biomarkers, as well as hopefully identify the re-routing of signaling in the brain to compensate for early striatal loss.

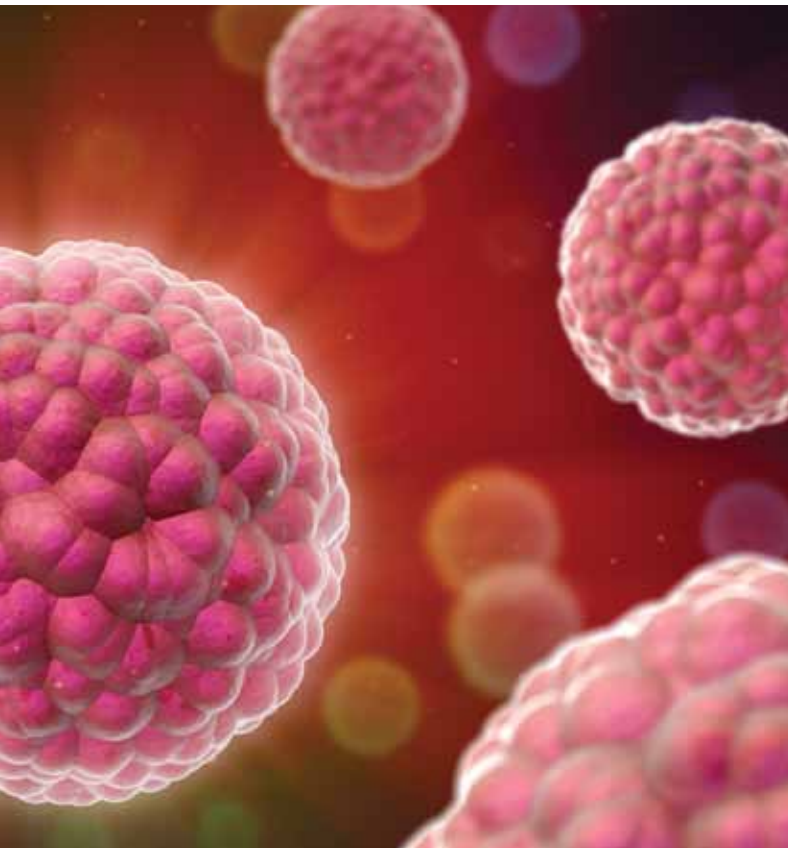
This type of measurable pre-manifest evidence from the TRACK study was part of the reason for the next presentation, by Mark Guttman, MD. His was a call to change the view of HD diagnosis, from a single event to a cascade of events. With the recognition that many people with HD may present cognitive or psychological symptoms years before motor symptom onset, along with the striatal shrinkage visible 20 years before any symptomatic onset, the traditional diagnosis of HD from motor symptoms alone has become a point of debate among researchers, clinicians and HD family members. Guttman offered different scenarios, and asked the audience to become clinicians during his presentation, and consider the challenge the new information presents to the HD diagnostic paradigm that exists today.

This change of paradigm supports the belief of most Conference attendees that successful future therapeutic interventions for people with HD will start well before any symptoms are visible.

Michael Hayden's talk was also a challenge to current thinking on both the average age of onset of HD, and the number of people who may actually be at risk. Hayden, MD, PhD, has led a comprehensive study of HD

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Ways to Give *(Continued from page 16)*

- **Donate your Vehicle:** Call toll free 888-HDSA-151/ 888-437-2151 or e-mail, at your convenience, donations@charitableautoresources.com to speak to an HDSA Vehicle Donation Representative. Our representative will schedule a pickup that's convenient for you, and provide you with confirmation of your donation.
 - Or visit our website, www.hdsa.org, and click on the "How You Can Help" icon to donate your vehicle online. Select the Vehicle donation page, which will take you to a secure page where you can choose to make an online vehicle donation to HDSA.
- **HDSA Marketplace:** Please the HDSA website and browse the HDSA Marketplace. Purchasing a Care2Cure Bracelet or Necklace, amaryllis plant, golf polo shirt and other merchandise makes a difference – and helps us build awareness at the same time. ●

Advances in the HD Pipeline *(Continued from page 19)*

prevalence in British Columbia, and reported that the average age of onset there has moved into the 50s, and will be pushing into the 60s in the next twenty years. He also reported the diagnosis of people with HD in their 80s, 90s, and one as old as 102. His thesis is that with the average lifespan increasing significantly, people who would not have manifested symptoms before they died, will now manifest later in life. This means that the number of people affected by HD may become much higher, and the disease may be re-classified from a rare disease of mid-life to a common disease of old age in the not-too-distant future.

Hayden also presented data of spontaneous mutations in a single generation, usually from a father with a CAG

repeat of 34 or 35 – and a child who then has a CAG repeat of 36, 37, or 38. This finding, taken from a statistically valid large sample in British Columbia, further suggests that the incidence of prevalence and current guidelines may not be accurate.

Robert Pacifici closed the Conference with a reminder that the key to success, as demonstrated by Maestro Roger Nierenberg in the opening session, was listening carefully to your colleagues, and taking the act of collaboration very seriously. Many of the Conference presentations had demonstrated the unique collaborative nature of the HD scientific community, which were amplified, and will be expanded upon from the interactions at CHDI 2012. ●

Brain & Body Donation in HD

By Joel Perlmutter, MD and Stacey Barton, MSW, LCSW

HDSA Center of Excellence at Washington University School of Medicine

Knowledge of Huntington's disease (HD) has come a long way since the discovery of the gene in 1993. Yet despite advances in understanding the genetics of HD or what the brain of someone with HD might look like on an MRI, much is still unknown. It is still essential for researchers to be able to examine brain structures to better understand the pathological changes in HD and this can only be done on actual brain tissue after someone dies.

People interested in donating their brains for HD research can begin by speaking to their neurologist about any local programs for donation. Certain research studies may include brain donation; contact the research coordinator for more information. If no local programs or research studies exist, you can also consider one of the national brain banks such as the Harvard Brain Tissue Research Center. For more information, contact them at: McLean Hospital, 115 Mill Street, Belmont, MA 02178-9106. Phone: (800) 272-4622. Website: <http://www.brainbank.mclean.org/>

Brain donation is generally acceptable to patients of all religions and backgrounds. Patients who have donated their brains are able to proceed with any of their usual funeral wishes, including an open casket. It often helps to think of brain donation as little more than a surgical procedure that happens after death.

Families sometimes ask about the option of donating their brain to HD research and their body to general research or medical school donation programs. There may be some restrictions on the ability to do both, as body donation programs often require that the body be intact. However, some medical school programs may be willing to coordinate with the neurology department, so ask your local doctor or medical school for more information.

When the brain donor dies, typically nothing special needs to be done to prepare the body before it is transported to the place of brain removal. It is important, however, for the brain to be removed and preserved as quickly as possible to prevent degradation of brain tissue. For this reason, it is important for family members and medical providers to be aware of the person's wishes for brain donation so that the process can be done quickly and efficiently. It can be difficult emotionally at the time of death for family members to make such a big decision, so it is important to discuss this well in advance. Donating a brain for research is an amazing gift and it is important to express your wishes in advance.

If you don't have HD, you can still help! Brain banks also need access to brains without neurological disease to have adequate samples for comparison. According to the Harvard Brain Tissue Resource Center (2003), only about 10% of all brains that are banked at their facility are from people without neurological disease.

HD families have been the driving force behind much of the research to date and are often asking for ways to contribute to the knowledge base of HD. There is no greater gift to advance knowledge about HD than brain donation. ●



HDSA Center of Excellence Program

HDSA has 21 facilities that have been awarded the Center of Excellence designation by HDSA. Each provides medical and social services to those affected by HD and their families. Since information changes constantly, please consult the HDSA web site frequently for directory updates as well as for news alerts and exciting programs and services.

NEW ENGLAND

New England

HDSA Center of Excellence Boston, MA

Director: Steven Hersch, MD, PHD
Clinic Phone: 617-726-0894
Social Worker: Judy Sinsheimer, LICSW
see page 24

NEW YORK

HDSA Center of Excellence at University of Rochester Rochester, NY

Director: Kevin Biglan, MD
Clinic Phone: 585-273-4147
Social Worker:
Amy Chesire, LCSW-R, MSG, see page 24

HDSA Center of Excellence at Columbia Health Sciences/NYS Psychiatric Institute New York, NY

Director: Karen Marder, MD, MPH
Clinic Phone: 212-305-9172
Social Worker: Debbie Thorne, LCSW
see page 24

HDSA Center of Excellence at North Shore-LIJ Manhasset, NY

Director: Andrew Feigin, MD
Clinic Phone: 516-570-4477
Social Worker: Pat Lambert, LMSW
see page 24

MID ATLANTIC

HDSA Center of Excellence at Johns Hopkins Baltimore, MD

Director: Christopher Ross, MD, PhD
Clinic Phone: 410-955-2398
Social Worker: Kit McFarlane, LGSW
see page 24

HDSA Center Of Excellence at University of Virginia Charlottesville, VA

Director: Madaline Harrison, MD
Clinic Phone: 866-290-4528/434-924-2665
Social Worker: Ken Cady, MSW, LSW
see page 24

SOUTHEAST

HDSA Center of Excellence at Emory University Atlanta, GA

Director: Randi Jones, PhD,
Stuart Factor, DO
Clinic Phone: 404-778-3444
Social Worker: Lynn Ross, LMSW
see page 25

HDSA Center of Excellence at University of South Florida Tampa, FL

Director: Juan Sanchez-Ramos, MD, PhD
Clinic Phone: 813-974-6022
Social Worker: Nancy Braswell, BA
see page 25

HDSA Center of Excellence at University of Alabama Birmingham, AL

Director: David Standeart, MD
Clinic Phone: 205-996-2807
Social Worker: Amy Holmes, LGSW
see page 25

GREAT LAKES

HDSA Center of Excellence at Rush University Medical Center Chicago, IL

Director: Kathleen Shannon, MD
Clinic Phone: 312-942-5003
Social Worker: Cori Robin, LCSW
see page 25

HDSA Center of Excellence at Indiana University Indianapolis, IN

Director: Kim Quaid, PhD, Joanne
Wojcieszek, MD
Clinic Phone: 866-488-0008
Social Worker: Leo Rafail, BSW
see page 25

HDSA Center of Excellence at Washington University School of Medicine St. Louis, MO

Director: Joel Perlmutter, MD
Clinic Phone: 314-362-3471
Social Worker:
Stacey Barton, MSW, LCSW
see page 25

HDSA Center of Excellence at Ohio State University Columbus, OH

Director: Sandra Kostyk, MD, PhD
Clinic Phone: 614-688-8672
Social Worker: Barbara Heiman, LISW
see page 25

UPPER MIDWEST

HDSA Center of Excellence at University of Iowa Iowa City, IA

Director: Jane Paulsen, PhD
Robert Rodnitzsky, MD
Clinic Phone: 319-353-4307

HDSA Center of Excellence at Hennepin County Medical Center Minneapolis, MN

Director: Martha Nance, MD
Clinic Phone: 612-873-2943
Social Worker: Nina Ross, LICSW
see page 24

Chapters and Affiliates

HDSA currently has 46 volunteer based chapters and affiliates across the United States divided into nine regions. To find out more about the HDSA chapter or affiliate in your area or to talk about ways that you can make a difference in the lives of people living with Hd and their families, contact the Regional Development Director closest to you. And please check the HDSA web site (www.hdsa.org) frequently for news alerts, exciting new programs, and directory changes.

NEW YORK/NEW JERSEY REGION

Greater NY Chapter
New Jersey Chapter
Upstate NY Chapter
 Victoria Hess
 E-mail: vhess@hdsa.org
 Phone: 973-784-4965 x 111
 Fax: 973-784-4966
 Mailing Address:
 P.O. Box 943
 230 Diamond Spring Rd.
 Denville, NJ 07834

MID-ATLANTIC REGION

Delaware Chapter
Metro DC Chapter
Eastern PA Chapter
Western PA Chapter
Central Maryland Affiliate
 Caryn Freas
 E-mail: cfras@hdsa.org
 Phone: 610-260-0421
 Fax: 610-260-0423
 Mailing Address:
 502 W. Germantown Pike, Suite 405
 Plymouth Meeting, PA 19462

NEW ENGLAND REGION

Massachusetts Chapter
Maine Affiliate
Rhode Island Affiliate
New Hampshire Affiliate
Connecticut Affiliate
Western Mass/Albany/VT Affiliate
 Virginia Goolkasian
 E-mail: vgoolkasian@hdsa.org
 Phone: 978-256-0811 ext: 13
 Fax: 978-256-0812
 Mailing Address: 6 Boston Road, Suite
 203 A, Chelmsford MA 01824

NORTHWEST REGION

Northwest Chapter
 Sarah Pattison
 E-mail: spattison@hdsa.org
 Phone: 212-242-1968 x 218
 Fax: 212-239-3430
 Mailing Address:
 505 Eighth Avenue, Suite 902
 New York, NY 10018

UPPER-MIDWEST REGION

Minnesota Chapter
Iowa Chapter
Sioux Valley Chapter
Northern Plains Chapter
Northern Prairie Affiliate
 Michele Asmussen
 E-mail: masmussen@hdsa.org
 Phone: 763-502-1407
 Fax: 763-502-1408
 Mailing Address:
 7362 University Avenue NE, Ste. 303
 Fridley, MN 55432

PACIFIC SOUTHWEST REGION

Northern California Chapter
Orange County Chapter
Los Angeles Chapter
San Diego Chapter
Arizona Affiliate
Las Vegas Affiliate
 Natalie Carpenter
 E-mail: ncarpenter@hdsa.org
 Phone: 949-542-3907
 Fax: 949-542-3976
 Mailing Address:
 27702 Crown Valley Pkwy
 Suite D-4 #336
 Ladera Ranch, CA 92694

SOUTH CENTRAL REGION

Rocky Mountain Chapter
Oklahoma Chapter
Texas Affiliate
Baton Rouge Affiliate
Southwest Oklahoma Affiliate
 Leesa McNeese
 E-mail: lmcneese@hdsa.org
 Phone: 361-774-8247
 Mailing Address: PO Box 81545
 Corpus Christi, TX 78468

SOUTHEAST REGION

North Carolina Chapter
Georgia Chapter
South Florida Chapter
Central Florida Chapter
Northern Florida Affiliate
 Edwina Bullard-Simms
 E-mail: esimms@hdsa.org
 Phone: (407) 507-3831
 Cell: (305) 505-9179
 Mailing Address: 3821 Township Square
 Blvd. #421
 Orlando, FL 32837

GREAT LAKES REGION

Illinois Chapter
Indiana Chapter
Kentucky Chapter
Michigan Chapter
St. Louis Chapter
Northeast Ohio Chapter
Ohio Valley Chapter
Central Ohio Chapter
Wisconsin Chapter
 Deb Boyd
 E-mail: dboyd@hdsa.org
 Phone: 269-629-5452
 Cell: 269-998-8441
 Fax: 269-629-4205
 Mailing Address: PO Box 408
 Richland, MI 49083

HDSA Social Workers

HDSA has 34 social workers placed around the country at its HDSA Centers of Excellence, chapters and affiliates. Social workers are often the first voice a person new to HD will hear when they make the decision to learn more about HD. Social workers aid families during difficult transitions, provide referrals to community based services, help in placing loved ones in long term care facilities and finding new resources for HD families in the areas in which they work.

Information does change periodically so please consult the HDSA web site at www.hdsa.org for the most up to date information on programs and services offered by HDSA.

NEW ENGLAND

HDSA Massachusetts Chapter

Karen Baker, LICSW, MSW
Tel: 508-446-7705
Email: kbaker@hdsa.org

New England HDSA Center of Excellence

Judy Sinsheimer, LICSW
Tel: 617-726-2603
Email: jsinsheimer@partners.org

NEW YORK/NEW JERSEY

HDSA Center of Excellence at University of Rochester

Amy Chesire, LCSW-R, MSG
Tel: 585-341-7519
Email: amy_chesire@urmc.rochester.edu

HDSA Center of Excellence at Columbia Health Sciences/NYS Psychiatric Institute

Deborah Thorne, LCSW
Tel: 212-305-9172
Email: thorned@sergievsky.cpmc.columbia.edu

HDSA Center of Excellence at North Shore/LIJ

Patricia Lambert, LMSW
Tel: 631-234-0136
Email: patalero@aol.com

MID ATLANTIC (DE, DC, PA, MD, VA)

HDSA Center of Excellence at Johns Hopkins University/Hospital

Kit McFarlane, LGSW
Tel: 410-955-2497
Email: cmcfarl1@jhmi.edu

HDSA Metro DC Chapter

Hope Heller, LICSW, LCSW-C
Tel: 571-216-3135
Email: haxelrod@hdsa.org

HDSA Center of Excellence at University of Virginia

Ken Cady, MSW, LSW
Tel: 866-290-4528
Email: KLC2S@virginia.edu

HDSA Western PA Chapter

Peggy Polito, LSW
Tel: 888-779-4372
Email: ppolito@hdsa.org

SOUTH CENTRAL (CO, OK, TX, LA)

HDSA Center of Excellence at Colorado Neurological Institute

Lucy Draayer, LCSW, CMC
Tel: 720-974-4091
Email: ldraayer@thecni.org

HDSA Rocky Mountain Chapter

Sharon Cascone, LCSW
Tel: 303-321-5503
Email: scascone@hdsa.org

HDSA Center of Excellence at Baylor College of Medicine

Erica Thomas, MA
Tel: 713-798-6902
Email: thomasm@bcm.edu

HDSA Texas Chapter

Cheryl Lenheiser, LCSW
Tel: 800-910-6111
Email: clenheiser@hdsa.org

NORTHWEST

HDSA Center of Excellence at University of Washington

Chris Wick, MSW, LICSW
Tel: 888-264-4372
Email: cwick@hdsa.org

HDSA Northwest Chapter

Chris Wick, MSW, LICSW
Same as above

UPPER MIDWEST (MN, IA, ND, SD)

HDSA Center of Excellence at Hennepin County Medical Center

Nina Ross, LICSW
Tel: 612-873-3369
Email: nina.ross@hcmcd.org

HDSA Minnesota Chapter

Jessica Marsolek, LSW
Tel: 612-371-0904
Email: jmarsolek@hdsa.org

HDSA Sioux Valley Chapter

Eileen Krueger, LSW
Tel: 612-910-6651
Email: ekrueger@hdsa.org

HDSA Center of Excellence at University of Iowa

Tel: 319-353-4307
Email: hdcenter@healthcare.uiowa.edu

PACIFIC SOUTHWEST (CA, AZ, NV)

HDSA Center of Excellence at University of California

Davis Medical Center
Lisa Kjer, MSW
Tel: 916-734-6277
Email: lisa.kjer@ucdmc.ucdavis.edu

HDSA Center of Excellence at University of California Los Angeles

Ammie Thakker
Tel: 310-794-1225
Email: Athakker@mednet.ucla.edu

HDSA Orange County Chapter

Jane Putnam, LCSW
Tel: 714-402-5577
Email: jputnam@hdsa.org

HDSA Center of Excellence at University of California San Diego

Lisa Snyder, MSW, LCSW
Tel: 858-822-4800
Email: lsnyder@ucsd.edu

HDSA Arizona Affiliate

Joan Jervis, LPC
Tel: 520-850-8531
Email: jjervis@hdsa.org

SOUTHEAST (NC, GA, FL, AL)

HDSA Center of Excellence at Emory University

Lynn Ross, LMSW
Tel: 404-728-6300
Email: slross@emory.edu

HDSA Center of Excellence at University of South Florida

Nancy Braswell, BA
Tel: 813-974-6022
Email: nbraswel@health.usf.edu

HDSA Center of Excellence at University of Alabama

Amy Holmes, LGSW
Tel: 205-801-8269
Email: afholmes@uabmc.edu

GREAT LAKES (IL, IN, KY, MI, MO, OH, WI)

HDSA Center of Excellence at Ohio State University

Barbara Heiman, LISW
Tel: 614-292-9960
Email: bheiman@hdsa.org

HDSA Central Ohio Chapter

Barbara Heiman, LISW
Same as above

HDSA Ohio Valley Chapter

Mary Beth Bialick, MSW, LISW
Tel: 513-741-4372
Email: mbialick@hdsa.org

HDSA Northeast Ohio Chapter

Tiffany Cousino, LISW
Tel: 440-742-1284
Email: tcousino@hdsa.org

HDSA Michigan Chapter

Danny Berry, LMSW
Tel: 800-909-0073
Email: dberry@hdsa.org

HDSA Center of Excellence at Indiana University

Leo Rafail, BSW
Tel: 866-488-0008
Email: info@iuhdclinic.org

HDSA Indiana Chapter

Leo Rafail, BSW
Same as above

HDSA Center of Excellence at Rush University Medical Center

Corey Robin, LCSW
Tel: 312-942-6087
Email: Cori_B_Robin@rush.edu

HDSA Center of Excellence at Washington University

Stacey Barton, MSW, LCSW
Tel: 314-362-3471
Email: bartons@neuro.wustl.edu

HDSA Kentucky Chapter

Cathy Saliga, LCSW
Tel: 502-637-4372
Email: csaliga@hdsa.org

HDSA Wisconsin Chapter

Jean Morack, ACSW, MSW, MS
Tel: 877-330-2699
Email: jmorack@hdsa.org

Resource Directory (Continued from page 21)

SOUTH CENTRAL

HDSA Center of Excellence at Baylor College of Medicine Houston, TX

Director: Joseph Jankovic, MD
Clinic Phone: 713-798-3951
Social Worker: Erica Thomas, MA
see page 24

HDSA Center of Excellence at Colorado Neurological Institute

Englewood, CO
Director: Rajeev Kumar, MD
Clinic Phone: 303-357-5455
Social Worker: Lucy Draayer, LCSW, CMC
see page 24

NORTHWEST

HDSA Center of Excellence at University of Washington Seattle, WA

Director: Thomas Bird, MD
Clinic Phone: 206-598-4030
Social Worker: Christina Wick, MSW, LICSW
see page 24

PACIFIC SOUTHWEST

HDSA Center of Excellence at University of California Davis Medical Center Sacramento, CA

Director: Vicki Wheelock, MD
Teresa Tempkin, RN, ANC
Clinic Phone: 916-734-6278
Social Worker: Lisa Kjer, MSW see page 24

HDSA Center of Excellence at University of California Los Angeles, CA

Director: Susan Perlman, MD
Social Worker: Ammie Thakker
Clinic Phone: 310-794-1225

HDSA Center of Excellence at University of California San Diego, CA

Director: Jody Corey-Bloom, MD, PhD
Clinic Phone: 858-264-1254
Social Worker: Lisa Snyder, MSW, LCSW
see above

How to Start an HDSA Support Group

Starting, managing, and facilitating a support group can be a rewarding experience. It provides the opportunity for you to help your local HD community, create a meeting place for people to discuss their problems with others who understand, and help people build their support community. Many studies have shown that caregivers who

and Resource Development Manager, Seth J. Meyer, will contact you either by e-mail or phone to discuss the application. This will be helpful for him to determine if the support group application will be accepted. If approved, one of our HDSA social workers will take you through the Support Group Leader training, which discusses both Huntington's disease and support group theory.

The requirements for facilitating a support group are:

1. An e-mail address that is checked regularly (at minimum, weekly).
2. The ability to respond within a week to all HDSA e-mails and contacts.
3. A mailing address.
4. Time to take part in the Support Group Leader training program via phone.
5. The ability to listen and the patience to help a group grow.

Being a support group leader is not easy. It can be hard listening to people talk about problems where there are no easy answers. But helping provide people with a safe place where they can discuss Huntington's disease with a group of people who understand and encouraging them to grow their support system is a humbling experience to which nothing can compare.

If you have any questions about starting a support group or would like to find a support group in your area, please contact Seth J. Meyer at smeyer@hdsa.org or via the national helpline at 800-345-4372. ●

attend support groups have a larger social network, more connections to community resources, and feel better.¹ People who attend support groups also have a more positive outlook on life and a higher self-esteem. For these reasons, support groups are an important part of the HDSA mission.

So how do you start a support group? The first step is to fill out the support group application, found at www.hdsa.org/sgapp. Then, the Community Services

1. Toseland, R.W., Rossiter, C.M., and Labrecque, M.S. (1989) "The Effectiveness of Two Kinds of Support groups for Caregivers" *Social Service Review*, September 415-32.
Hinrichsen, G.A., Rverson, T.A., et al. (1985) "Does Self-Help Help? An Empirical Investigation of Scoliosis Peer Support Groups" *Journal of Social Issues*, 41(1) 65-87

New at HDSA

HDSA is pleased to update our readers on all the new print publications and web based tools for people with HD, their caregivers and families that we introduced in 2011.

New Publications

Spanish language translations of the Family Guide Series. Titles include A Family Guide to Huntington's Disease, Genetic Testing, Nutrition, Physical and Occupational Therapy, Juvenile onset HD, Long Term Care and Communicating with Your Healthcare Provider. All are available in print or on the web for downloading at www.hdsa.org.

A Physician's Guide to the Management of Huntington's Disease (Third Edition). After a decade as one of the most important resources for the HD community, *A Physician's Guide* was updated in 2011. Thanks to a generous educational grant from Lundbeck, HDSA can offer a complimentary copy of *A Physician's Guide* to you and your doctors. To take advantage of this complimentary copy program, send the name, address and phone number of your primary care provider and neurologist, as well as your name, address and phone number to Anita Mark Paul at HDSA. Email Amarkpaul@hdsa.org or fax 212-239-3430 with the information. All physicians are contacted by HDSA to see if they would like to be added to the national web site database of physicians familiar with HD. Note: HDSA does not share information with any agency or funder.

Coming soon: *A Physician's Guide* will soon be available on line for downloading. Just go to www.hdsa.org, click on Living with HD and then publications.

Accessing Publications: almost all of HDSA's most recent publications including past issues of *Toward a Cure*, *The Marker* magazine and *We Are HDSA!* are available for downloading from the national web site. Go to www.hdsa.org/publications.

New Programs

Lunch and Learn: Due to popular demand, HDSA launched a new web based educational series for the HD community in January 2012. Alternating with Caregiver's Corner, Lunch and Learn offers topics of interest to a broader HD audience every other month. All Lunch and Learn webinars are archived on the national web site for additional viewing.

Educational Grants: thanks to an educational grant from Lundbeck, HDSA is once again able to offer support for field based educational programs in 2012. If you are an HDSA Chapter, Affiliate, Support Group or Center of Excellence and would like to plan or have plans to offer an educational program or guest speaker this year, contact Deb Lovecky for an application and additional information (Dlovecky@hdsa.org).

Ask the Social Worker: A new feature on the HDSA national web site, Ask the Social Worker, provides the HD community with a source for problem solving, general information, tips and resources. Look for Ask the Social Worker in the "Living with HD" section.

Services

Support Group Leader Training: this new program/service began in 2011. New support group leaders are trained by HDSA's Community Services and Resource Development Manager prior to the first meeting of the new support group. If you are interested in starting a support group, contact Seth Meyer at Smeyer@hdsa.org or complete the support group application found on the national web site. A workshop on starting an HDSA support group will be offered at the HDSA 27th Annual Convention in Las Vegas in June.

New Social Worker Training: beginning in 2011, HDSA instituted a new training and mentoring program for all new HDSA social workers. Each new social worker is given a standard course on HD and the resources offered by HDSA to the HD community. They are then paired with a veteran

(Continued on page 28)

HDSA Programs (Continued from page 27)

HDSA social worker to assist them in the early weeks with questions, access to resources and as a sounding board for difficult cases. Social worker training is conducted through the Community Services and Resource Development Manager at the HDSA National Office.

Introduced in 2010-11

Publications:

The **Family Guide Series to Huntington's Disease** serves as the building blocks for HDSA educational materials. Each of the seven titles addresses an aspect of HD. Since 2007, HDSA has been revising the series. In 2010, the Family Guide to Nutrition and the Family Guide to Physical and Occupational Therapy were updated while a new title, Family Guide to Communicating with Your Healthcare Provider, was added. The Family Guide series is available in print or on line at www.hdsa.org.

Fast Facts: this popular brochure was updated to reflect changes in our knowledge about HD. It is available in print or on line. This publication can be found in the Living with HD section/Publications on the national web site.

We Are HDSA! This monthly support group newsletter launched in November 2010 with an educational grant from Lundbeck. *We Are HDSA!* is sent the first week of every month to HDSA support group leaders to distribute. An all electronic newsletter was introduced in late 2011. If you would like to be added to the e-list to receive your paperless copy, send an email with your name, city, state, and name of the support group to which you belong to Seth Meyer at smeyer@hdsa.org and you'll never miss an issue. Past issues of *We Are HDSA!* can be found in the Living with HD section of the national web site.

Programs:

Caregiver's Corner: Thanks to an educational grant from Lundbeck, HDSA expanded Caregiver's Corner to a monthly series in 2011. Archived webinars are available in the Living with HD section on www.hdsa.org. To find the date of the next Caregiver's Corner, go to the national web site home page.

HDSA Clinical Trials Diplomats: HDSA launched the Clinical Trials Diplomat program in 2010 which trains HD



family members who have participated in observational research or clinical studies to talk about their experiences in small group settings such as a support group meeting. The next in person training will take place in Las Vegas NV on Saturday June 9 at 1:30PM. during the HDSA Annual Convention. If you are interested in the HDSA Clinical Trials Diplomat program, contact Deb Lovecky.

Advocacy: In 2010, HDSA introduced the Huntington's Disease Parity Act in order to effect change in the guidelines used by the Social Security Administration to determine disability in a person with HD AND to waive the two year waiting period for Medicare benefits once an individual is deemed eligible. In the 112th Congress, the Huntington's Disease Parity Act is known in the House of Representatives as HR718 and in the Senate as S648. Everyone's voice is needed if we are to achieve our goals of easing the disability process and obtaining Medicare benefits immediately after a disability determination for HD. If you are interested in lending your voice, contact Jane Kogan at jkogan@hdsa.org.

Services:

Medical Equipment Exchange Board: launched in July 2010, this tool allows those who have durable medical equipment they no longer need to connect with HD families in need. HDSA serves as the connector – all communication is between the two interested parties. ALL transactions are private and HDSA cannot take possession of any durable equipment nor can we issue a donor receipt for any equipment. The Equipment Exchange Board can be found in the Living with HD – Resources section of the national web site. ●



For the last 27 years, HDSA's Annual Convention has been the largest gathering of Huntington's disease (HD) families in the United States. More than 1,000 people with HD and their family members from across the country are joined by physicians, researchers, social workers and other healthcare professionals to hear about the latest research breakthroughs, new clinical trials, best care practices, advocacy efforts and educational programs while simultaneously renewing friendships and receiving comfort and support from being among others who understand the daily challenges of HD.

Visit us at www.hdsa.org/convention for more information on registration, program updates and Clinical Research Initiatives.





Huntington's Disease Society of America

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New York, New York 10018

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