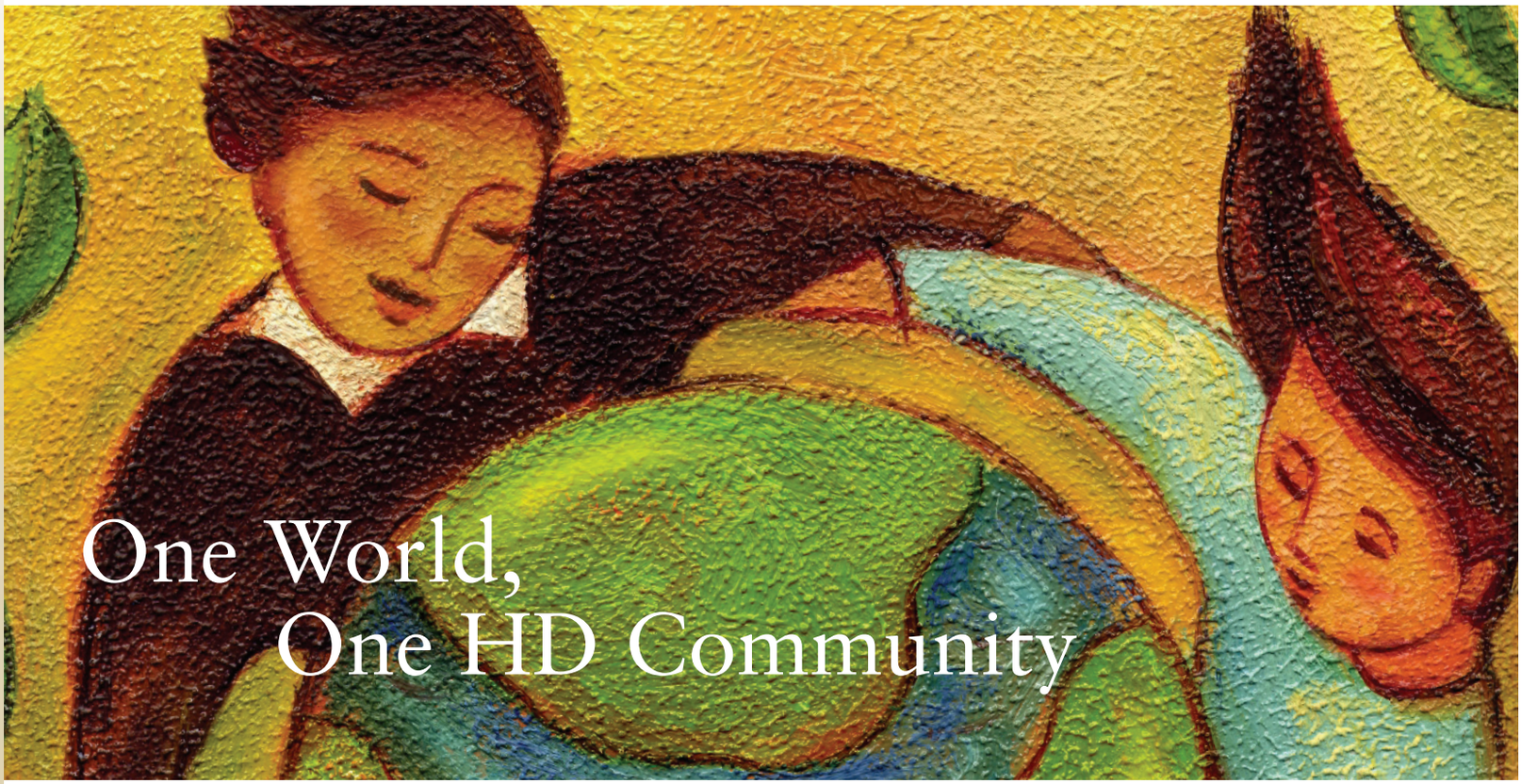
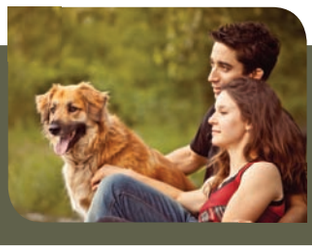
Spring 2011

THE marker

Huntington's Disease Society of America



One World, One HD Community



INSIDE:

From the Desks of

Donald L. Barr, HDSA Chairman of the Board and Louise Vetter, HDSA Chief Executive Officer

Dear Friends:

Welcome to a new issue of *The Marker* magazine! We are very excited about the positive progress HD research is taking both at the basic science level and in the many clinical and observational trial opportunities offered to our families.

In this issue we feature an update on the scientific conference hosted by CHDI in February that brought together investigators from around the world for three days of collaboration, thought-provoking discussion and new research trends to consider.

We are also pleased to bring you up to date on two studies being conducted at the University of Iowa – KIDS-HD and PREDICT-HD. Each article contains information on who to contact if you would like to be considered for either study. Or if you are attending the HDSA annual convention in Bloomington MN this year, both PREDICT and KIDS-HD will be in the Exhibit Hall ready to answer your questions!

For our caregivers, this issue offers information about respite care and how to go about finding it in your community, new caregiver services through the Medicare website and an article about navigating emergency room visits by Dr. Steve Hersch from the New England HDSA Center of Excellence.

For those living at-risk, Dr. Jang-Ho Cha offers advice on how to live positively with HD while Dr. Kim Quaid from the HDSA Center of Excellence at Indiana University writes about decision making in reproductive options.

For people with HD, Katie Moser takes you through how she will be adapting her house for HD. And of course, this issue also contains information about the 26th Annual HDSA Convention. If you have not been to an HDSA Convention, now is the time! We have so many special convention activities planned in addition to an impressive array of workshops and plenary sessions. As a teaser, this year we are offering an "Ask the Expert" opportunity in the Exhibit Hall – rotating health professionals who will be on hand each afternoon to answer your questions about HD. And of course there is the always popular Focus on the Family Care Forum that promotes "Healthy Eating for the HD Family" as well as our Research Forum on Saturday morning. An up to the minute convention program is posted on the HDSA national website. Take a few minutes to see all that we offer and book your hotel room today!

Finally, I'd like to draw your attention to the many new programs and services that HDSA has developed and launched over the past year thanks to donors like you. Your dollars have helped to support many of these initiatives. If you are not familiar with our Caregiver's Corner series, our new Lotsa Helping Hands care coordination portal, our HDSA Clinical Trials Diplomat program or our new publications including our support group newsletter, *We Are HDSA*, take a moment to read about each and then catch up by visiting www.HDSA.org.

We hope that you find this issue informative and helpful. As always, we appreciate your feedback and encourage you to send your thoughts and comments. Email our editor, Deb Lovecky, at dlovecky@hdsa.org.

In closing, our volunteers and donors are our lifeblood. We could not do the work we do without your help. Please consider making a donation to HDSA today so we can continue to serve the HD community through education, outreach and awareness.

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Update on the Pipeline for Drug Discovery

Every year, CHDI invites leading HD researchers, as well as others investigating related diseases, to view presentations on major HD initiatives, share ideas and initiate collaborations that will move the quest for treatments and a cure closer to reality. This February's conference brought together investigators from over twenty countries.

Traditionally the opening keynote address is made by a person directly affected by Huntington's, and this year Ken Serbin, an active member of the San Diego Chapter of HDSA, moved the audience with his story of growing up in an HD family, and what he faces as a person who has tested positive for the mutant gene. Many members of the HD world already knew Ken as Gene Veritas, a pseudonym he has used to maintain anonymity for many years. This was Ken/Gene's coming out address. While he will continue to write as Gene Veritas, he also wants everyone to know Ken Serbin, and it was apparent from his presentation, how many people he has helped educate, and how tireless he is in his quest to motivate and assist everyone working in labs around the world to find the therapies we all desire.

From the opening scientific session of the conference, chaired by Neil Aronin of the University of Massachusetts School of Medicine and Seung Kwak of CHDI, it was clear that CHDI's primary effort continues to be directed at *reducing mutant huntingtin*, the cause of Huntington's Disease. This was confirmed when, in response to a question, Robert Pacfici, CHDI's Chief Scientific Officer, commented that 50% of CHDI's research investments this year would be toward "gene silencing."

Of course, this is no simple task. Clearly, huntingtin has a role to play in early development and normal cell health. This was demonstrated twenty years ago, through experiments in which mice were bred with no huntingtin gene — and they died before birth. Scott Zeitlin of the University of Virginia School of Medicine, who was involved in those early experiments, spoke about new work that is underway to determine how much huntingtin is necessary, or conversely, how far can you lower huntingtin without affecting normal biological functions.

This is of critical importance, as in early attempts at gene silencing, it has proved difficult to lower the mutant huntingtin without lowering the wild type (normal) huntingtin as well.

Clearly, huntingtin has a role to play in early development and normal cell health.

There are two promising approaches to this task. One uses Antisense oligonucleotides (ASOs) and the other uses RNA Interference (RNAi). Both methods will involve a direct infusion into the central nervous system. ASOs are currently in a Phase II Clinical Trial in ALS, so the safety and tolerability of that method has passed the initial Phase I screening, a positive sign for their use in HD as well.

Karen Chen of the Spinal Muscular Atrophy Foundation (SMA) talked about using these approaches in SMA, a disease that is also caused by a single mutated gene. Presentations on other diseases is always a valuable part of the CHDI conference, as it broadens the understanding of HD scientists, and often leads to new collaborations, or the ability to identify findings that can be of

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HDSA Research

benefit to HD therapeutic development (articles on ASOs and RNAi are posted on the HDSA website, www.hdsa.org).

Andreas Weiss of Novartis announced a development that will help determine the effectiveness of gene silencing techniques. Novartis has created a method to measure the amount of huntingtin in tissue, which will allow clinicians to determine if a potential gene silencing therapy is successful, and the extent of its effect.

The presence and participation of Novartis, and a number of other major pharmaceutical and biotech companies, was another very positive development at this conference. Whereas there has always been a presence, this year there were more representatives from the commercial sector than ever before, and more announcements of developments.

Doug Macdonald, Director of Drug Discovery for CHDI closed the session with an overview of the different gene silencing approaches that CHDI is supporting, and their efforts to develop a new brain scanning technique to measure levels of mutant huntingtin in the brains of people with HD.

The second session examined *Neuronal Communication*, or how brain cells interact chemically, a process that is altered in HD. George Yohrling of CHDI and Michael Levin of UCLA chaired the session. Neuronal Communication is another high priority focus for CHDI.

There is evidence that a problem may be caused by too much communication, or "overexcited" synapses in HD. Lynn Raymond of the University of British Columbia presented her work on this condition, and how a currently available drug, memantine, has corrected this problem in mouse models.

Addressing the movement aspect of HD, Michael Orth from the University of Ulm spoke about his work with the "motor cortex," an outer surface of the brain, which needs to be stimulated at high levels to cause physical movements in people with HD.

Vahri Beaumont, who leads the synapse study team at CHDI, described their efforts, and their collaboration with Pfizer Neuroscience, to study phosphodiesterase-10. Blocking this protein in mice seems to reverse many of the synapse communication issues caused by HD.

The last speaker of the day was Nicholas Waters of Neurosearch who presented new data on the effectiveness of ACR-16 (Huntexil). This information provides a platform for further clinical trials of ACR-16, which will determine if it will be approved by the Food and Drug Administration (FDA) or European Medicines Agency (EMA) regulatory agencies.

Day Two began with a focus on *Bioenergetics*, chaired by Larry Park of CHDI and Timothy Greenamyre of the University of Pittsburgh. Bioenergetics is how food nutrients are utilized to produce energy that fuels all body functions. This is an area that has been under scrutiny for many years, as to whether it is mitochondrial dysfunction that produces the symptoms of HD, or whether they are a byproduct of the HD mutation. Normal brain function requires a great deal of energy, and the lack thereof can cause symptoms in people without the HD mutation, to show HD-like symptoms.

Holly Hetherington of Yale University spoke about MRSI, which is an imagining technique that can detect which chemicals are present in different parts of the brain, and may therefore aid in understanding the energy problems caused by the huntingtin mutation.

Mitochondrial behavior in Parkinson's was the topic of Sarah Berman's (University of Pittsburgh) talk. She is studying abnormal proteins present in Parkinson's Disease, and her findings may prove helpful to understanding mitochondrial problems in HD.

CHDI's Leticia Toledo-Sherman described her work in attempting to alter energy metabolism in HD, by blocking a protein called pyruvate dehydrogenase complex kinase (PDHK). This protein

may alter the way mitochondria "digest" nutrients and turns them into energy.

The afternoon was dedicated to *Poster Viewing*. At a conference of this magnitude, there is only time for a few of the most advanced developments to be formally presented. There are many more important discoveries to be shared which are represented by complex posters that describe the work, give scientific details, and results. During this session, each poster creator was available to answer questions, and share ideas with the other conference participants. These conversations allow for the detailed sharing of new data and provocative ideas which may lead to further collaborations, and certainly further advancement in the years ahead.

The featured speaker of Day Two was the pre-eminent neuroscientist Dr. Solomon Snyder from Johns Hopkins University. Dr. Snyder shared his work from the 1960s to present, including breakthroughs in our understanding of how neurons work, the discovery of how nitrous oxide affects neurons and much more. Recently Dr. Snyder's lab discovered a protein called Rhes which affixes to the huntingtin protein, and is found in greatest concentrations in the areas of the brain most affected by the HD gene mutation. Dr. Snyder believes that Rhes may be the reason that these areas are so susceptible to mutant huntingtin and he continues to investigate this action.

*Growth Factor*s was the theme for Day Three. A growth factor is a chemical produced by the brain that aids growth and maintains the health of brain cells. Jonathan Bard of CHDI and Clive Svendsen of Cedars-Sinai Medical Center chaired the session that included an overview of the many growth factors and their effects. Dr. Svendsen also presented his own work on Glial cell derived neurotropic factor (GDNF) with Parkinson's patients, and how the direct infusion of GDNF into the brains of some patients had resulted in beneficial results.

Moses Chan from NYU explained how too much growth factor can cause a decline in memory and mood in mice. His work involves determining how the growth factor functions once it finds its specific receptor, and why adenosine seems to mimic the effect of some growth factors in the brain.

Brain-derived neurotropic factor (BDNF) is produced by cortex neurons, which react with the parts of the brain that are most affected by mutant huntingtin. Jord Alberch of the University of Barcelona is trying to understand why BDNF levels are low in people with HD which could lead to a potential target for therapeutic development.

Alex Kiselyov of CHDI is working on designing just such drugs, and his team is working with specially designed molecules to target receptors that may lead to maintaining neuronal health.

The final session of the conference was dedicated to the reorganization of CHDI's internal teams to focus on specific aspects of HD. Each team works on several approaches to drug development. Robert Pacifici explained that CHDI is pursuing more than 10 potential drug candidates at any time, which is more than most large pharmaceutical entities have in their pipelines for all neurodegenerative diseases. Ignacio (Nacho) Munoz Sanjuan, VP of Biology at CHDI, presented his team's work to inhibit a protein, Kynurenine 3-monooxygenase (KMO), which is increased in mouse models of HD, and how blocking it might alleviate some symptoms. While initial work has shown some improvement in HD mice, lowering KMO has also produced some negative effects, so more work will be needed to determine its value.

Celia Dominguez, CHDI VP of Chemistry, explained how her team approaches drug design, using their work on reducing the activity of HDAC4. HDACs (Histone deacetylases) alter which genes are turned on and which are turned off, and HDAC inhibitors have reduced symptoms in HD mouse models, but caused other side effects. Dominguez explained how they determined which HDAC to target, and how the team is working to modify existing drugs that may be used to create HDAC inhibition without the negative effects.

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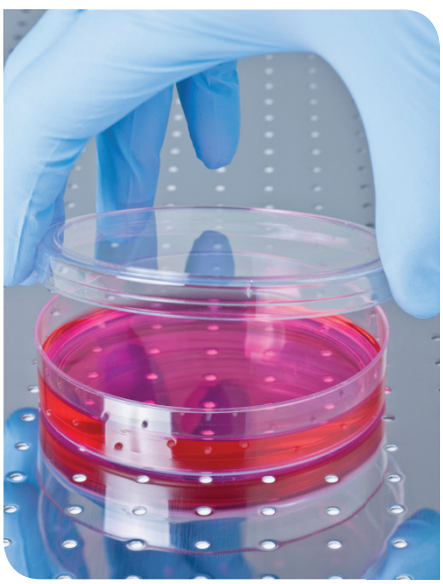
Dr. Snyder believes that Rhes may be the reason that these areas are so susceptible to mutant huntingtin and he continues to investigate this action.

Second Induced Pluripotent Stem Cell (IPSC) Consortia Workshop

In 2009, through the American Recovery and Reinvestment Act (ARRA), NINDS funded three consortia, to develop well characterized, publically available, induced pluripotent stem cell (iPSC) lines for familial forms of Parkinson's disease (PD), Huntington's Disease (HD) and Amyotrophic Lateral Sclerosis (ALS). The first iPSC consortia workshop was held in February of 2010, and during the 10 months that followed, over 87 fibroblast lines (12 – ALS, 18-HD, 29-PD, 1-GBA, 3-FTD, 24-population or unaffected family controls) and 25 iPSC lines have been developed and will be publically available for research through the NINDS repository at Coriell.



On December 15, 2010, consortia members met in Bethesda, MD, to discuss the progress that had been made, and share the development of applicable methodologies, the types of phenotype analyses being utilized, and to create a standard analysis method for iPSC lines. The assembled group also tried to identify any major factors that could prevent the teams from completing their targeted objectives within the two-year project time frame.

Members of major pharmaceutical and biotech companies were invited to attend this meeting, to learn about the iPSC initiative, and to voice their interest in participating in the next phase of the consortia's work. Representatives of HDSA and other disease-specific non-profit organizations were present to discuss their role in the next phase as well.

The Huntington's Disease iPSC consortium is lead by Dr. Leslie Thompson from UC Irvine. Members of the consortium include Drs. Steven Finkbeiner (J.D. Gladstone Institute), Jim Gusella (Massachusetts General Hospital), Clive Svendsen (Cedar-Sinai Medical Center), Chris Ross (Johns Hopkins University), Hongjun Song (Johns Hopkins University), Vanessa Wheeler (Massachusetts General Hospital) and Marcy MacDonald (Massachusetts General Hospital), Nick Allen (University of Cardiff), Elena Cattaneo (University of Milan), Marco Onorati (University of Milan), Paul Kemp (University of Cardiff), and Kwang-Soo Kim (McLean Hospital).

The HD iPSC consortium has created a series of iPSC lines from both control and HD patient fibroblasts. The fibroblast and iPSC lines have CAG repeat lengths ranging from 20 to 180 repeats. The HD mutation does not affect reprogramming efficiency and all iPSC lines express the full range of pluripotency.

The use of a novel protocol, primitive multipotent neural stem cells (EZ spheres) were generated from a subset of iPSC lines (180 CAG repeats, 66 CAG repeats and 33 CAG repeats) to enable easy expansion and distribution of reprogrammed lines to members of the consortium. EZ spheres consistently allowed the generation of forebrain neurons, some of which expressed striatal specific markers.

After presentations by all three consortia, discussion revolved around the challenges they faced. There was consensus that there should be a focus on the development of methods that permit cost-effective, large-scale generation of iPSCs that facilitate easy distribution and standardization to allow for standard analyses by different labs, and quality control of cells used for all future experimentation. The groups also discussed the development of protocols for the storage of differentiated cells, methods to increase the efficiency of specific cell derivations, and ways to shorten the length of time in culture.

In addition, there were discussions about the creation of reference compound libraries for testing specific cellular pathways, and the need to expand the number of available iPSC lines for all three consortia.

Representatives of Pfizer, GSK and Lundbeck attended the sessions and expressed their interest in participating

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Participant Involvement Leads to Breakthroughs in PREDICT-HD Study

Have you ever wondered what happens with all the information collected during a Huntington's Disease (HD) study visit?

Participants in PREDICT-HD visit a nearby study site once a year and complete a series of cognitive (thinking) tests and questionnaires, undergo a motor exam and have blood and urine samples taken. As a research participant, your important job is finished for the year at the end of the visit day, and now it's up to the research scientist to turn these data into a research breakthrough.

Researchers in PREDICT-HD analyze information from people who have been tested for the HD gene expansion (positive or negative) to determine the earliest signs of HD. Their goal is to target future drug treatments to delay or even prevent the devastating symptoms of HD. The data from over 1,000 PREDICT-HD participants has led to 62 articles published in peer-reviewed medical journals detailing various findings about the earliest indicators of HD.

Recent findings, published in the January issue of the medical journal *Neuropsychology*, offer further support for the finding that small changes, such as those in cognitive ability, can be detected very early on in the disease. The journal article reports that by using sensitive measures, neurocognitive (thinking ability) signs of HD can be detected in people as far as a decade from estimated disease diagnosis. Researchers in the article say cognition is an important target for treatment, because even subtle changes can affect work performance, driving and the ability to manage one's finances.

PREDICT-HD has changed the way scientists and doctors think about HD by showing that thinking ability and mood changes often do occur before a neurologist makes a formal diagnosis.

The study itself has also changed. The new "2.0" version of PREDICT-HD, implemented last year, has introduced new tasks and questionnaires, as well as the use of tablet and laptop computers that allow researchers to analyze the data collected at a much more rapid pace. But one thing hasn't changed: **new participants are still needed and encouraged to join the study.**

HDSA Chairman of the Board, Don Barr of Cleveland is a PREDICT-HD participant who completed his second annual study visit last year. He said he felt it was his duty as an HD family member to get involved in research. "This study could unlock the mystery of HD," Barr said. "I urge the HD community to continue to get more involved in research."

North Carolina resident Lauren Holder takes part in PREDICT-HD because she wants to contribute to finding treatments and a cure for HD. "Do it and help the HD community," Holder said, encouraging others to take part in HD research. "We're helping the researchers and we're helping ourselves."

If you have tested positive or negative for the HD gene and haven't been diagnosed with symptoms, you may be eligible to participate. For more information about enrolling, please visit www.predict-hd.net. You can also email the study at predict-hd@uiowa.edu, or call 319-353-4307. You can also find our YouTube channel by searching "PREDICT-HD." ■

Decision-Making
for Reproduction in Individuals At-Risk for HD

By Kimberly A. Quaid, PhD, HDSA Center of Excellence at Indiana University

The Prospective Huntington At-Risk Observational Study (PHAROS) is a multi-site observational study that aims to establish whether experienced clinicians can reliably determine the earliest clinical symptoms of HD in a sample of 1001 individuals at 50% risk for Huntington's Disease (HD) who have chosen not to be tested. As part of the funding for the study, the NIH included money to conduct qualitative interviews with a subset of PHAROS participants. Interviewers were recruited from the research coordinators from the top PHAROS enrollment sites. Unstructured open-ended qualitative interviews were conducted on a subsample of 55 PHAROS participants at six PHAROS sites across the country: Atlanta GA, New York City, NY; Dublin, OH; Wichita, KS; Minneapolis, MN; and Indianapolis, IN.

Most of the literature on reproduction in those at-risk for HD has focused on the impact of genetic testing on reproductive decision-making. In our interviews, we sought to understand the reproductive decisions in those at-risk who had chosen not to be tested. After reading and re-reading our interview transcripts, we identified three groups of participants:

1. Those who had children despite knowledge of their risk,
2. Those who did not know their risk prior to having children; and
3. Those who knew of their risk and chose not to have children.

For those in Group 1 who knew of their risk and decided to have children, we identified four main themes:

1. Hoping for a Cure,
2. Feeling Guilty,
3. Magical Thinking; and
4. Just Another Something.

The theme "Hoping for a Cure" reflects the fact that several individuals in this group stated explicitly that their decision to have children was based on the hope for a cure in the near future. The idea was that by the time their children reached the age of onset of symptoms, there would be a cure available and they would not have to worry about developing HD. The second theme "Feeling Guilty" reflects the feelings of guilt expressed by some participants about the decision to have children despite their genetic risk. The third theme "Magical Thinking" embodies the stated belief, on the part of participants, that they simply would not get HD. The fourth theme "Just Another Something" was a direct quotation from one of our participants and reflects the desire on the part of our participants to live their lives as normally as possible while refusing to let the risk of HD influence their decisions, including the decision whether or not to have children. From this perspective, HD was just one possible negative event in a long list of potential negative life events and should not be given any special attention when making life choices.

For Group 2, those who had children before they knew of their risk, we identified two major themes:

1. Too Little Too Late, and
2. Getting It Wrong.

The theme "Too Little Too Late" reflects the fact that in this group, many lacked information about HD or the inheritance of HD prior to choosing to start a family.

Living With HD

The second theme "Getting It Wrong" characterizes the participants in this group who had information about HD, but whose information was either inaccurate or simply wrong. Thus, in this group, they made the choice to start a family without fully understanding the genetic aspects of HD and only later came to appreciate the fact that they may have already passed on the genetic mutation that causes HD.

For the third group of participants, those who knew of their risk for HD and chose not to have children, we identified three main themes:

1. Vigilant Witness,

2. Stopping HD; and

3. Being Alone.

For the main theme "Vigilant Witness" participants shared poignant stories about witnessing the decline and death of family members due to HD. Many had been actual caregivers of sick relatives, often a parent, and most had witnessed the destructive forces of HD in several generations. In the second theme in this group, "Stopping HD," many had been told in no uncertain terms, and sometimes by their own family members, not to have children, and to stop the line of HD in their family. This advice was taken to heart. In the third theme, "Being Alone," participants described how they lived their lives avoiding intimate relationships, or denied themselves having children in order to avoid harm to others should they become ill. As a consequence of these choices, many voiced worry about the fact that if they were to become ill, there was no one to take care of them.

When predictive testing using linkage first became available in 1986, many health professionals, myself included, believed that one major use of the technology would be to allow individuals at-risk to determine whether or not they carried the HD gene and use further testing and reproductive technologies to prevent passing on the HD gene. We believed this because that was what we were told by individuals at-risk. However, the number of individuals at-risk choosing to be tested remains low; most requests for testing come after the at-risk individual has completed his or her family, and the number choosing prenatal testing is miniscule.

The decision whether or not to have a child is intensely personal under the best of circumstances. When there is a 50% chance to pass on an incurable genetic disorder, the decision becomes even more complicated. There are your hopes and wishes for the future, the experience of HD in your family, your fears of future illness, and the desires of your partner, all which need to be factored into an irrevocable choice. We did this study to shed light on some of the factors that go into making these decisions and hope we did so in a manner that is respectful of all choices that were made and adds to our understanding of the experience of being at-risk for HD. ■

Reference: Quaid KA, Swenson MM, Sims SL, Harrison JM, Moskowitz C, Stepanov N, Suter GW, and Westphal BJ for the Huntington Study Group PHAROS investigators and coordinators (2010) What were you thinkin?: Individuals at risk for Huntington disease talk about having children. Journal of Genetic Counseling 19:606.

…Research— continued from page 3.

In addition to the formal presentations, Gillian Bates and colleagues announced HD PLoS, a peer-reviewed online journal which will allow for quick publication of new work on HD.

Jeff Carroll of MGH/Harvard Medical School and Ed Wild of UCL Institute of Neurology introduced HDBuzz.net which will feature articles on HD science written by scientists in easy to understand terminology.

At the end of each day, and at the final gathering to mark the end of the conference, the unique collaboration between members of the HD research community, both academic and those from biotech and pharma, was striking. The evening's conversations were a continuation of presentations, and while the difficulty of the shared objectives is clear, the progress being made is just as evident, and very promising. ■

The Earliest Signs of HD:
A Review of Kids At-Risk for HD Study

By: Dr. Peg Nopoulos, Department of Psychiatry, University of Iowa Hospitals and Clinics

Is it possible that there are subtle signs of Huntington's Disease (HD) throughout life – even as far back as childhood? This is a question being asked by researchers at the University of Iowa who are conducting a study on children and adolescents who are at-risk for HD.

We know from studies in adults who have had presymptomatic testing for HD, that subtle changes in brain structure, thinking, behavior, and motor skills can be detected up to 15 years before onset of disease. Is it possible that these changes are present lifelong and therefore can be detected in childhood?

One reason why it is thought that signs of HD can be seen lifelong is that the gene responsible for the disease is an important gene in the development of the brain. It may be that when this gene is abnormal, then brain development is also abnormal and it may lead to subtle signs of the disease that can be detected lifelong and all the way back into childhood. These may be changes in thinking or learning, mood, behavior, growth, development, or motor skills. Understanding when these changes begin can help us understand important things about the nature of HD.

More importantly, identification of the earliest signs of the disease may help to track signs and symptoms over time and possibly help to better identify the earliest phases of disease onset. Ultimately, this could help treatment and even prevention strategies for HD.

Funded by the National Institutes of Health (NIH) and the CHDI Foundation, The Study of Kids At-Risk for Huntington's Disease (referred to in short as Kids-HD) is being conducted by Dr. Peg Nopoulos at the University of Iowa in Iowa City. Participants can come to Iowa from anywhere in the country and are reimbursed for airfare, mileage (if driving), hotel and meal costs for their visit to the study site. Participants are also compensated for their time and participation in the study. A typical day for the study includes paper and pencil testing of thinking skills, filling out forms regarding behavior and emotion, a motor examination, collection of blood or saliva (spit) sample, and a brain MRI scan.

We know from studies in adults who have had presymptomatic testing for HD, that subtle changes in brain structure, thinking, behavior, and motor skill can be detected up to 15 years before onset of disease.

Parents or grandparents may accompany the study participant. Siblings can be enrolled together and tested on the same day for convenience of the families.

Eligible participants are children or adolescents from ages 6-18 years of age who have a parent OR a grandparent who has either tested as gene-expanded for HD or has been given the clinical diagnosis of HD. If the potential participant has a grandparent with HD and their own parent has not been tested, that parent does not need to get tested in order for the child/adolescent to be enrolled.

Although the blood or saliva will be assessed for the HD gene expansion, results of this assessment are for research purposes ONLY – the results are blinded and are not released to the participant, the family, or any member of the research team including Dr. Nopoulos.

For more information on this study, email Kids-HD@uiowa.edu or call tollfree: 1-866-514-0858. ■

Living With HD

Adapting My House for HD

By: Katie Moser

In February 2010 I bought a house. I was probably the most difficult able-bodied person that Bob, the realtor, ever had to deal with. Some of my requests I thought were pretty normal, that I wanted a house with two floors that was not attached to any other houses. After this simple request came all my others; I wanted minimal, if any, steps to enter, a bedroom, bathroom, and laundry room on the first floor, doorways and hallways that were easy to navigate, an attached garage, and property that was not on a hill. I did not share with Bob that I was planning for my future, when I would start to develop the symptoms of Huntington's Disease.

I know eventually I will have to do some work on my house, mostly on the kitchen, because as a prolific baker I spend a lot of time in there. The rest will be on the first floor bedroom and bathroom, and a ramp to help with the two stairs in front.

Currently my bedroom and bathroom are on the second floor, along with my closet, which is a room itself. When I start to experience symptoms, and movements that affect my balance and my ability to walk, I will move down to the main floor. Unfortunately, I will have to leave my closet upstairs.

In the bedroom, I might require a bed and mattress that is firmer and easier for me to sit up on and stand from, as well as to turn and position myself in, which could also require grab bars positioned on one or both sides. I will look into different lighting that might be attached to the wall above my bed,

instead of the current lamp I have on a bedside table. Also putting an arm chair in my bedroom will give me a place to sit when I am dressing. Throughout my house, including my bedroom, I will make sure that there is no clutter or extra furniture that requires stepping over or around, because I know that this could cause me to fall.

In the bathroom across the hall, I will need to install a new tub or larger shower stall that would allow me to place grab bars in and around it, and put a shower chair or bench to sit on while I bathe and dry off. Luckily I already installed a hand held shower hose and non-slip mat, which will continue to be useful when I'm symptomatic. I do need to find a mat for outside the tub that has a non-slip bottom, or my caregiver might have to make sure the floor is dry before I step out of the tub.

I will also need to place grab bars or a 3-in-1 commode around the toilet to make it safer to sit on and stand from. Some of these items might be covered by my insurance if I work with my doctor to obtain them.

Some of these items might be covered by my insurance if I work with my doctor to obtain them.

When I was looking for furniture I found a dining room set that had chairs with a wider area between the legs, and two arm chairs, which make them more difficult to tip over or fall out of. I will need to move the throw rug that is beneath the table to prevent tripping and put good lighting throughout my house with switches that do not require effort to turn on and off.

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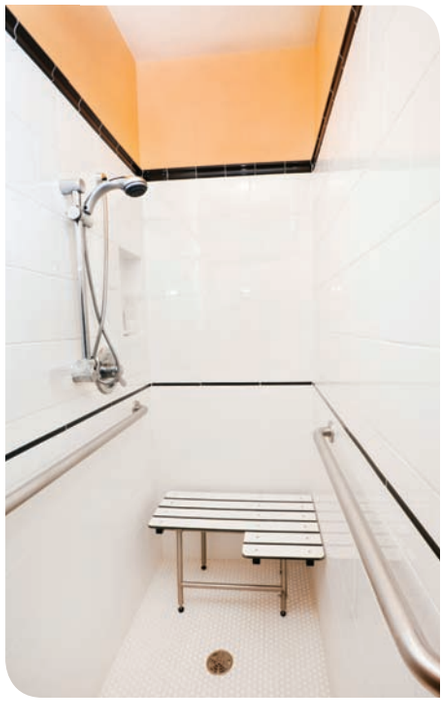
Living with HD



These are some of my plans for making my home handicapped accessible before I become symptomatic. When the time comes, I will need help with many of these tasks, such as building the wheelchair ramp at my front door, so I will look for someone who has the knowledge and experience to do this. My caregiver and I will also speak with my doctor or social worker to be referred to an occupational therapist who can come into my home and suggest additional changes to the environment.

If you find that you are having difficulty in your home, for any reason, I encourage you to speak to your doctor and seek the advice of an OT to make any necessary changes to maintain your safety and independence. ■

Katie Moser is an HD friend, family member, advocate, caregiver, and patient. She graduated from Elizabethtown College in 2003 with a degree in Occupational Therapy and a Peace Studies minor. In 2007, Katie was the subject of a front-page New York Times story, "Facing Life With A Lethal Gene," which subsequently won a Pulitzer Prize. She enjoys traveling to speak about HD, which happens often in her position with Lundbeck, Inc. as Manager of Advocacy and Patient Support. Her current life goals are to find a cure for Huntington's Disease and travel to all 50 states.

…Research— continued from page 4.

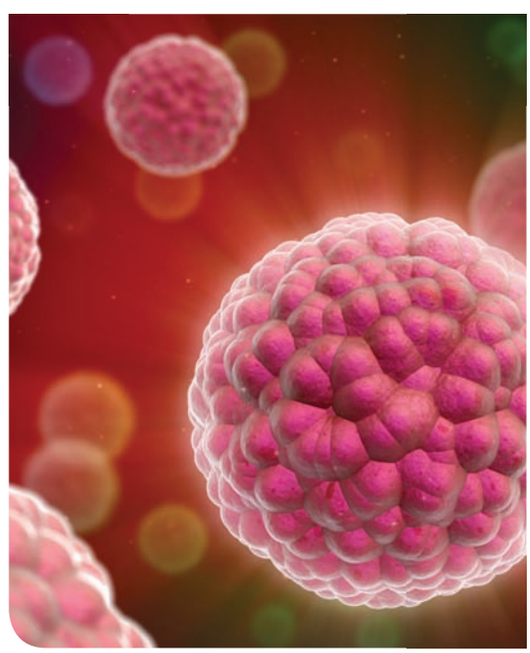
with the consortia in the "pre-competitive" work to be done. They agreed that there was valuable work being done in academia that could help accelerate potential drug development opportunities for them, and that industry very likely had already developed, but currently did not use assays and other resources that could be of benefit to academic laboratories.

Since the creation of this iPSC consortia, CHDI, the Michael J. Fox Foundation and the ALS Association have contributed funding to support the work of these investigators, while others present at the conference, including members of HDSA, Project ALS, and Parkinson's Disease Foundation voiced their support for the continuation of this unique project.

As plans are being made to secure funding that will enable the continuation of the work of the consortium, it was clear that the most immediate benefit of these iPSC lines will be to provide an *in vitro* system for target validation and screening, and to evaluate the potential of proposed therapies.

The creation of an NIH/NINDS website, with information on the protocols, and the formal banking of the lines at the Coriell repository, for access by any non- or for-profit entity, are among the next steps for the consortia.

In early discussions around the creation of this initiative, the collaborative nature of the HD research community was cited as a motivating factor. The development of the initial set of iPSC lines, and the continued efforts to expand the reach of the consortium to deliver important tools to scientists around the world exemplify the value of these collaborative efforts. ■



Augmented Communication Devices

By: Kathleen Samulski, Wayne Assistive Technology

Introduction

Communication ties us to our environment. Whether it's to socialize, express needs or convey information, communication is what connects us to the world. When the ability to communicate deteriorates or is lost, individuals may feel isolated and trapped. Over time, the loss of access to communication with loved ones and caregivers, and they with us, can break down the system of communication and even caretaking. Those at-risk for Huntington's Disease (HD), HD positive, HD symptomatic, and HD caregivers live in fear of a time when communication may be of concern. Fortunately, with all of the recent technological advances, there are many non-traditional ways to access communication.

Augmented Assistive Communication (AAC)

Augmented Assistive Communication (AAC) is the implementation of hardware and software to assist individuals who have cognitive and physical limitations that prevent them from communicating in their environment. AAC can range from simple eye-gaze methods to elaborate systems that can cost many thousands of dollars. The exciting 2010 release of Apple's iPad™ is changing the playing field for those who have obstacles in effectively communicating. This article will focus on iPad™ technology, access methods and various apps, which offer alternate communication access for those with special needs. It is important to note that the earlier these methods and tools are introduced, the more useful they are. Future users can help program language and learn to use devices while they are cognitively and physically well.

Apple iPad™

The Apple iPad™ is a tablet computer that offers access by direct select – meaning that individuals physically interact with the touch screen to make their choices. The iPad 2™ is 9.5" by 7.3." It is .34 inch thick and weighs 1.3 pounds. The iPad 2™, which was recently released, has a camera, digital recorder, built-in microphone, and built-in speakers. The iPad™ has a 10-hour active-use battery life. When the device is off or in sleep mode, no battery life is used.

iPad™ Applications (apps)

The term "app" is short for application. Within iPad™ technology the apps are represented on the screen as icons in the shape of squares – mimicking shortcuts on a computer desktop.Each app is somewhat the equivalent to a software program that resides on a computer for a particular task – word processing, picture editing, Internet surfing, etc. Upon touching the app icon on the iPad™, the application launches just as a double click to the shortcut on a desktop would launch software on a computer. Now the user can access the app for the desired purpose by a touch of the screen. For example, checking the weather from their iPad™, users may use a weather app. One might listen to music with an Internet radio app. We can check Facebook with the Facebook app. It is exciting to witness app developers targeting iPad™ technology to create medical apps to help those with special needs.

Access

When fine motor skills deteriorate, it may be difficult for individuals to use

—continued on page12.

their fingers to touch the iPad™ screen to choose their desired output. But they can select an app that has a switch program that will allow them to scan their choices using a switch and then select the one they want using a second switch. Hands, feet, heads, elbows, and more can be used as access points.

Mounting

The iPad™ can easily be mounted to allow access to individuals with special needs. It can be mounted to tables, wheelchairs, hospital beds and more, thus providing the individual with continuous access to their device.

Applications

AAC

Proloquo2Go: comes with a complete library of core language, allows the user to customize language, uses pictures or text, and offers speech output.

TapSpeak Choices: offers drop and drag for creating and editing communication boards, has large library of symbols, has switch accessibility, users can record their own voice or use voice supplied.

Simple Text to speech: these apps offer simple text to speech features and the option to create a core library.

– Speak It

– NeoKate

– NeoPaul

– Talk Assist

– iCommunicate

Other AAC Devices

– Grace: simple picture system that builds sentences from relevant images.

– ArtikPics

– Look2Learn: uses photographs to express wants and needs.

– Predictable: unique communication aid solution.

Visual Schedules: create schedules ranging from simple to elaborate which prepare individuals for the future.

– First Then Visual Schedule

Conclusion

The exciting iPad™ device technology keeps us on our toes! It's expanding at an incredibly rapid rate. Please contact the author if you have questions.

Although the emphasis in this article was on AAC, there are numerous iPad apps that could benefit people with HD:

- E-books – reducing the weight of lugging books, turning pages
- Word prediction – reducing keystrokes
- Speech Recognition Software – reducing keystrokes
- Gaming apps – easily access games, for example, crosswords, Sudoku and scrabble using the accessible touch screen

You can contact Kathleen by emailing: Kathleen.samulski@lpps.info or visit www.resa.net/atrc. ■

Burden of HD Survey for Caregiver and the Person with HD

The Huntington's Disease Society of America has partnered with the Euro-HD Network to collect information on the burden of care for Huntington's Disease. The two surveys, provided by the Euro-HD Network, seek to measure the economic, social and psychological impact of Huntington's Disease on both the caregiver and the person with HD. HDSA has adapted each survey so it can be answered online. All data collected by HDSA will be shared with the Euro-HD Network so it can be incorporated into their study results.

Both surveys are completely anonymous but HDSA is asking for the city and state in which you reside and an email you wish to share. The geographic information will be used for future legislative efforts. The email would be used only to clarify responses on the survey. If you do not wish to give the email you use daily, you can create one just for this survey by going to hotmail, gmail, yahoo, etc.

We invite caregivers to go to www.hdsa.org/boccaregiver. We invite people with HD to go to www.hdsa.org/bofhd to complete the self-assessment. If you are unable to complete the survey yourself, please ask your caregiver for assistance.

Should you have any questions, please contact Deb Lovecky at dlovecky@hdsa.org. If you cannot complete the survey online and prefer to answer the questions on a printed survey, please contact Seth Meyer at smeyer@hdsa.org or call 800-345-4372 ext. 240.

Living Positively At-Risk for HD

Jang-Ho Cha, MD PhD, Chair, Center Programs & Education Advisory Committee

I am often asked by HD patients and their families about what the best way is to live.

I wish I knew for sure. This is a really tough question to answer, but here's what I know: At this point, there is no treatment or intervention that is known for sure to slow down or delay the progression of HD. As a result, there is nothing that I can tell people for sure that will be helpful.

On the other hand, there are reports about medications or nutritional supplements that might be helpful. Should one try to start taking these medications? Most of the time, **the answer is no**.

For example, a fairly typical occurrence is that there is a report that some scientist somewhere has administered a medication to HD mice with beneficial effects. "Should I start taking it?" For one, I think it is good news any time there is any progress, but one should be very careful about interpreting these kind of reports. For every report of benefit in an HD mouse, even more important questions are raised:

- Will this treatment work in people with HD?
- Will this treatment work in people who are at-risk for HD?
- Is this treatment safe for people with HD?
- Will this treatment be harmful for people with HD?
- What is the right dose?
- Have these results been duplicated by another lab?

These are important questions, and most of the time, the answer is "I don't know." By the way, these questions are so important that we would all like to know. Unfortunately, there are no quick answers for these important questions. It is exactly these kinds of questions that are addressed in clinical trials, and answering these important questions is **why participation in clinical trials is so important**.

So what are we to do in the meantime? For all experimental medications that do not have an adequate safety record, I strongly recommend **not taking these medications**. Even well-researched medications are eventually found to have serious, even deadly side effects, so I am very reluctant to recommend any medication that hasn't been subjected to careful review by the Food and Drug Administration (FDA). I think that there is more experience for the nutritional supplements, creatine and coenzyme Q10, although still not approved by the FDA, and so I discuss these options with my patients. Importantly, the jury is still out on whether these nutritional supplements are really helpful or not.

Finally, I recommend non-medication approaches. I am a firm believer that **maintaining mental and physical activity is helpful for both HD patients and at-risk persons**. Part of my belief comes from working closely with HD patients; I think those patients who do more, do better, with appropriate limits for what they can handle.

In 2001, Anton van Dellen and Tony Hannan, both then at Oxford University in England, made an amazing observation regarding **environmental enrichment**. They did an experiment in which one group of HD mice were housed in standard conditions and the other group was put into an enriched environment. For mice, this means a new toy in the cage every three days, and exercise wheel, and other mice. There were no medications given to the mice. Surprisingly, the 'enriched' mice showed better motor performance,

—continued on page 21.

"Ask Medicare"
A Website in Support of Caregivers

Everyone is aware that Medicare is a health insurance program for people age 65 or older, but it is also available to people under age 65 with certain disabilities, including people with HD of any age who can meet disability and other eligibility requirements.

As in so many other aspects of daily living, the caregiver of a person with HD is often the one to apply for and manage their loved ones benefits. To help with that process, the Centers for Medicare and Medicaid Services has created a portal to the Medicare website specifically for caregivers called **Ask Medicare**, which can be found at www.medicare.gov/caregivers.

This web page brings together many sources of information on services and benefits available to Medicare recipients, as well as some specifically for caregivers. Some of the links are specifically about Medicare and its benefits and others take you to trustworthy sources of information, outside the Medicare program, about issues that affect the disabled and their caregivers.

For those who have not yet applied for benefits, there is a section called **Navigating Medicare**, which can help walk the caregiver through the application process. It also contains information about Medicare Drug Plans and Medigap Insurance from private insurance companies. There is also a webpage that can help you create an online file of your loved ones medical records, called a **Personal Health Record** which, for example, could help get your loved one the fastest and best care in an emergency by providing information about medications, allergies, and other important data.

Caregivers looking for information on benefits can go to a section called **Help with Billling**, which can help you find out what your loved one's coverage includes, how to read the summary statement and how to file an appeal.

Another section is called **Care Options** and covers topics such as finding a doctor who takes Medicare, how to locate local Home Health Care providers and how to prepare to pay for Long Term Care. Medicare does not have programs designed specifically for people with HD, but some of the available services may help some families cope.

Finally, there is a section called **Overwhelmed? Get Help**. This area of the website covers topics such as finding local eldercare resources or getting help with paying for prescription drugs.

Did you know that there are state programs for people with limited income and resources that pay some or all of Medicare's premiums and may pay Medicare deductibles and coinsurance?

Or that Social Security has programs to help people with Medicare with prescription drug costs?

Or that Medicare will pay for preventative care such as annual physicals, flu shots, cancer screenings, and some other tests?

Downloadable handbooks can also be found on the site, including: *Resources and Benefits for Caregivers* and the *Handbook for Long-Distance Caregivers*. Finally, caregivers can sign up for a bi-monthly e-newsletter with information on important dates such as open enrollment, changes in the program, etc.

Caregiving for a loved one who is disabled by HD requires patience and persistence, a thick skin and a generous heart.

Caregiving for a loved one who is disabled by HD requires patience and persistence, a thick skin and a generous heart. In the struggle to balance caregiving, career and other family responsibilities, **Ask Medicare** is a timesaving information resource. ■

Navigating Emergency Room Visits

By Steven Hersch, MD, PhD
HDSA New England Center of Excellence at Massachusetts General Hospital, Department of Neurology

The emergency room (ER) is the last place anyone wants to be, but sometimes it's the only place to deal with serious medical problems. For individuals with Huntington's Disease (HD), emergencies can include physical injuries, infections, aspiration, psychiatric problems, like severe depression or psychosis, and sometimes just reaching a point where it's no longer physically safe to be at home. An ER visit can be especially difficult when the staff there doesn't know you, and is unfamiliar with HD. No matter who you are, emergency room care can take a long time and may not always solve the problem you went there for in the first place.

A trip to the ER may also have nothing to do with HD, but having HD can have an impact on your experience. For example, HD can be intimidating to ER staff that may be challenged by the neurologic symptoms and also by some of the personality and behavioral symptoms. These challenges can affect their interactions with you. ER staff can also sometimes deal poorly with individuals with HD because they don't understand the disease and its effects.

To help avoid some of the difficulties caused by HD from becoming crises that necessitate visiting the ER, obtain regular medical care. If you have a question about whether the ER is your best option for a particular problem, try to reach your regular physician or the doctor on-call for advice before going.

Travel to an ER by ambulance is often unavoidable and will almost certainly mean going to the closest one. If it's safe for you go on your own, or with someone you know, you can choose a hospital that might know you or at least have your records and prior lab and radiology studies.

Here are my suggestions:

- Bring a list of your medications and supplements or the medication bottles themselves.
- If you are participating in a drug study, bring information about the study, such as the consent form and the study drug.
- Bring a list of your medical problems, medical history, allergies, and medications you have used in the past but that might not have worked.
- If you have any X-rays related to the problem causing the ER visit, bring them.
- Bring your insurance information.
- Bring contact information for your regular doctors in case the ER staff needs to reach them and also to facilitate getting records from the ER visit back to them.
- If it seems possible that your ER visit will become an admission to the hospital, bring any personal items you might need like your cell phone and its charger, a change of underclothes, or any other indispensible personal items.

If you are discharged from the ER, be sure you understand what happened, save any written information you are provided about the visit and about recommendations or arrangements for follow-up; go over any instructions you receive about what to do after you get home; ask the ER to send records to your physicians; and have a plan for what to do for follow-up on any tests or treatments. ■

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What You Need to Know
About Respite

To be most effective, you should consider respite services much earlier than you think you will need them.

Respite will be most helpful if you use it before you become exhausted, isolated, and overwhelmed by your responsibilities.

- Family caregivers need to have sufficient and regular amounts of respite time. Respite needs to be meaningful and purposeful for caregivers as well as safe and enjoyable for the care receiver.
- Respite is most effective when combined with other services and assistance, but don't wait to take your break. Respite will give you a chance to step back and recharge.

Sometimes, you may need respite in emergencies to deal with a personal health crisis or other immediate situation that might put the care recipient in harm's way. Emergency or crisis respite may be more difficult to find, so familiarizing yourself with providers who might offer emergency respite or even registering in advance with such providers, is important.

In 1997, the first Lifespan Respite Program was established. In 2009, the US Administration on Aging funded twelve states to implement State Lifespan Respite Programs, which are designed to help families find respite providers and to help them access respite payment resources. Additional states were funded to establish such systems in 2010. Many of the state programs are still in their early implementation phase, but are available to assist families in navigating the maze of respite programs and funding streams by offering a single point of entry for respite. Your first stop for information should be www.archrespite.org where you will find your state's **Lifespan Respite Program** if it has one.

If your state does not have a State Lifespan Respite program, first check the ARCH National Respite Locator at www.respitelocator.org to find emergency or planned respite. You can also check this website for your State Respite Coalition. Private organizations such as Easter Seals, the Alzheimer's Association, University Centers on Disabilities, or United Cerebral Palsy may also be able to refer you to respite services in your community.

Types of Respite

Respite programs may utilize an available bed in a health care facility for families who require extended respite options and whose family member requires skilled care; whereas, other respite programs may only offer time-limited (a few hours) services in the family's home.

Respite services are usually offered on a sliding fee schedule, or there may be a combination of family fees, state, and federal funding, including Medicaid waivers, and/or private insurance. Providers may be paid or unpaid in many of the following models.

In-Home Models

Many families prefer respite that is provided in the home. There are several advantages:

- The care recipient may be most comfortable in the home and does not have to adjust to a different environment.
- The parents/caregivers may be more comfortable if the care recipient does not have to leave the home.

- The home is already equipped for any special needs the child/adult may have.
- The cost is relatively economical (especially if voucher systems are used to pay for services).

Sometimes in-home care is coordinated by a broker, an individual or agency who agrees to recruit, provides basic training, and keeps a database of all respite providers. Families can be matched with a provider by calling the broker and are usually responsible for training, payment, and repeat scheduling. If you have a Lifespan Respite Program in your state, they will be able to assist you in finding providers, payment resources and training options.

Some typical models used in in-home respite are home-based services, sitter-companion services and consumer directed respite.

Out of Home Models

Out of Home respite provides an opportunity for the care recipients to be outside the home. Families are free to enjoy time in their own home without the constraints of constant care, and they can devote more attention to siblings and other family members.

Listed below are some special considerations regarding Out of Home models.

- Transportation may be required and special equipment may need to be moved.
- The individual receiving care may not like the unfamiliar environment or may have difficulty adjusting to the changes.
- The services may be offered in a variety of settings more restrictive than the care recipient's home, such as special medical centers or nursing homes.

Certain service organizations, such as Easter Seals, human service agencies, or community-based private independent respite providers may offer respite in a center-based setting, employing trained staff and/or volunteers.

Other types of Out of Home respite facilities include: residential facilities, hospital-based, camps, and adult day care centers.

How to Choose a Respite Provider

Some states require licensing for respite providers. If your state does not, it is even more important to do a thorough background and qualifications check, especially if you are dealing with individuals who are not associated with companies or agencies. Most company and agency providers will have done background and reference checks for their employees, but do not assume, ask instead.

The idea is to get to know the prospective provider as well as possible before committing to the relationship. Then, you must communicate your expectations in very specific terms. Finally, these expectations should be in writing to help assure that both parties understand them, and will not need to rely on memory if and when difficulties arise later. A variety of consumer guides, workbooks, and checklists also are available to help you sort out the myriad of options you may have in your community, and in some instances, offer guidance on training the provider.

How Do I Pay for Respite?

A range of possible state and federal funding sources may be available to help you pay for respite. If you have a **State Lifespan Respite Program** or **State Respite Coalition**, they should be able to link you to existing funding sources or assist with possible funding sources that may be unique to your state. For state-by-state information on funding sources for adult respite, visit the **Family Caregiver Alliance Family Navigator Program** (www.caregiver.org). Check www.archrespite.org frequently for new information on state by state respite funding sources for all ages.

A Few Funding Possibilities Include:

Medicaid Waivers: Generally, every state offers some respite assistance though Medicaid Waivers. Check with your state's Medicaid office.

Medicare Hospice Benefit: If someone you love is in hospice, their caregivers are eligible for respite funding under Medicare.

National Family Caregiver Support Program: Funding may also be available if you are caring for someone over the age of 60 or are the relative of an adult with certain disabilities, through the National Family Caregiver Support Program which is administered through your local Area Agency on Aging (AAA). Visit the Elder Care locator service at www.eldercare.gov to contact your AAA about respite funding options.

State Family Caregiver Support Programs: If your state has a state-funded family caregiver support program (visit www.caregiver.org), you may have respite funding available. ■

Reprinted in part from ARCH National Respite Network and Resource Center (2010). The ABC's of Respite, A Consumer Guide for Family Caregivers, Chapel Hill: ARCH Issue Brief, 201. http://www.archrespite.org/images/ARCG/ABCs_of_Respite_11_2010.pdf.

Join HDSA at the 26th Annual Convention
Bloomington, MN: June 24-26, 2011

Be sure to mark your calendar for the 26th Annual HDSA Convention. This year promises to be even better than last with more of everything! HDSA has been working closely with the Minnesota chapter to bring you exceptional speakers and activities.

In response to a record audience last year in Raleigh, NC, HDSA has added three new educational tracks plus a new "What You Missed Yesterday" track that will repeat three popular workshops from the day before.

The convention will kick off with an Opening Ceremony on Friday morning that will feature readings of state and federal proclamations, an inspirational keynote speaker, a warm welcome from Don Barr, HDSA's Chairman of the Board, and an update on the State of the Society by Louise Vetter, HDSA CEO.

The Focus on the Family Care Forum follows the Opening Ceremony and this year will address "Healthy Eating for the HD Family." The afternoon offers something for everyone with loads of special convention activities, workshops, and opportunities to make new friends.

The Convention Reception will begin at 6:00 pm this year and will include both the National Youth Alliance (NYA) Silent Auction and a Chapter Awards Ceremony. This is truly a night for our chapter leaders and volunteers to shine.

Saturday brings us the HDSA Research Forum beginning at 9:00 am plus the ever popular Potential New Therapies in the afternoon. These two sessions provide our HD families with a look at what is going on along the pipeline of drug discovery from both the research and development perspective.

Saturday afternoon offers more workshops and additional special convention activities. Be sure to consult your convention program book regularly so you can take advantage of **ALL** the 26th Annual HDSA Convention has to offer!

Saturday evening we celebrate our outstanding leaders and volunteers with National Awards and our dinner gala. And don't forget the BMW Sweeps which will be pulled that night! You can still purchase tickets for that dream car or cash prize. See page 19 for details.

Sunday morning we bid farewell to old friends and new at the convention's traditional Closing Ceremony. Join us early in the morning for a Continental Breakfast and networking opportunity.

The 26th Annual HDSA Convention is sponsored by Lundbeck, NeuroSearch, Medivation, Medtronic, MetLife, Alnylam, Isis, Raptor, Vertex, Evotec, Novartis, AMRI, and Biotechnology Industry Organization. ■

A Sample of Special Convention Activities

- Author signing of *A Physician's Guide to the Management of Huntington's Disease (Third Edition)*. Be among the first to receive an autographed copy of the new updated Physician's Guide. All you need to do is fill out a card with the name and address of your primary care provider and neurologist so we can send them a copy too! Signings at noon each day.
- Join our Walk for a Cure on Saturday morning at 7:00 am.
- Meet the HDSA Board of Trustees on Saturday afternoon at 1:00 pm.
- Ask the Expert table: each day healthcare professionals will be on hand in the Exhibit Hall to answer your questions about meds, treatment options, nutrition, Social Security Disability Insurance, and more.
- Join our Circle of Hope song fest each afternoon from 2:00 pm – 2:30 pm in the Reflections of Hope Meditation Room.
- And don't forget the HDSA Activity Center for People with HD. Open from 10:30 am to 5:30 pm each day, the center offers activities specifically for people with HD. Consult the program book for a schedule of activities.

It's Time for the BMW Sweepstakes
Win a 2011 BMW 328i Sedan or $25,000 Cash

For the 12th year in a row, 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 Research and programs to fight Huntington's Disease.

For just $100/ticket, you have the chance to win a brand new 2011 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 email hdsainfo@hdsa.org. You can also buy tickets at the 26th Annual HDSA Convention. The drawing will be June 25th 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:	**2011 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**

GOOD LUCK!

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 25, 2011. All prizes must be redeemed by September 30, 2011. 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.

Early Bird Registration (on or before June 1): Includes the 2011 Convention Gala

Adult: $155

Family: $120 per person (2 or more adults)

National Youth Alliance: $80 (29 years and younger)

Non-NYA Member: $85 (Children 18 and younger)

Late or On-Site Registration (June 2 and later): Includes the 2011 Convention Gala

Adult: $230

Family: $180 per person (2 or more adults)

National Youth Alliance: $80 (29 years and younger)

Non-NYA Member: $85 (Children 18 and younger)

One Day Registration (Friday or Saturday):

$85 per person per day (Does not include the 2011 Convention Gala.)

2011 Convention Gala Only:

$70 per person

Hotel Information: Sheraton Bloomington Hotel, Minneapolis South
Rate for a single, double, triple or quad room is $109 plus taxes.

Registration for Convention does not ensure a room reservation at the Sheraton Bloomington Hotel, Minneapolis South. You must make your room reservations separately with the hotel by calling 866-837-4278. (Mention that you are attending the Huntington's Disease Society of America's Convention and the convention dates to receive the special discounted rate).

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

In recognition of Huntington's Disease awareness month, HDSA is organizing a Let's Talk About HD Advocacy Campaign designed to get more people engaged in HDSA's grassroots movement to enact the Huntington's Disease Parity Act of 2011 (H.R. 718/S. 648). Each week in May, HDSA will ask advocates to take a specific action to raise awareness, educate Congress, and strengthen the HDSA advocacy base. HDSA will also offer ways for your friends, family members, co-workers, and others to get involved. To participate in our Let's Talk About HD campaign, join the HDSA E-Advocate network at www.hdsa.org/join.

LET'S TALK ABOUT HD ACTIVITIES

Recruit Your Team!

Recruit your Awareness-Raising Team by asking 10 friends, family, and community members to commit to educate Congress in May and to **call Congress to support H.R. 718/ S. 648 on May 31**.

Week of May 15: Educate the Media!

Write a letter to the editor to your local newspaper encouraging your Representative and Senators to cosponsor the Huntington's Disease Parity Act (H.R. 718/ S. 648). Ask your Team to write letters as well. HDSA will provide a letter to personalize and a list of local newspapers.

AND, be sure watch your inbox for an invitation to a special Advocacy webinar on **May 17 at 12 pm EST**.

Week of May 22: Educate Congress!

Email your Representative and your two Senators and ask them to cosponsor the Huntington's Disease Parity Act (H.R. 718/ S. 648). Increase your outreach by asking your Team to participate in this activity.

The Finale of our Let's Talk about HD Campaign will be a National Call-in Day to Congress, on May 31! See page 21 for more information, and sample messages!

May 31 is National Call-in Day: Call Congress to Urge Their Support for H.R. 718/S. 648

May 31 is National Call-in Day for HDSA Advocates! As a grand finale to our Let's Talk About HD Campaign, HDSA is asking everyone who cares about Huntington's Disease to call their Representative and their two Senators and ask them to cosponsor the Huntington's Disease Parity Act (H.R. 718/S. 648). You can find out who represents you at www.hdsa.org/takeaction.

Calling is EASY and can make a real difference in the lives of everyone in the HD community. HDSA will send our E-Advocates an action alert with talking points, background information, even the telephone numbers so calling on Tuesday, May 31 could not be easier! ■

The Huntington's Disease Parity Act of 2011 (H.R. 718/S. 648) is important for all people affected by Huntington's Disease. When enacted into law, this bill would make it easier for people with HD to receive Social Security Disability and Medicare benefits.

When passed, the Huntington's Disease Parity Act (H.R. 718/S. 648) will:

- Direct the Social Security Administration (SSA) to revise its outdated medical and evaluation criteria for determining disability for people with HD.
- Waive the Medicare two year waiting period for individuals disabled by Huntington's Disease.

The bill number for the Huntington's Disease Parity Act in the House of Representatives is H.R. 718. The bill number for the Huntington's Disease Parity Act in the Senate is S. 648. For more information about the Huntington's Disease Parity Act, please contact Jane Kogan at jkogan@hdsa.org.

Advocacy

The more personal you can make it, the more your message will resonate! Talk about your connection to Huntington's Disease and what makes the Huntington's Disease Parity Act important to you.

Become an E-advocate today at www.hdsa.org/join. Please mark your calendar now, and ask your friends, family, and community to participate.

No access to a computer? No problem! **You can call the Capitol Switchboard at 202-224-3121** and ask for your Representative, and your two Senators, by name. When you call your Representative and Senators, ask to speak to the person who is responsible for healthcare. To maximize your impact, be sure to write down the names of the people you speak to so that HDSA can follow up!

Here is a Sample Message for your Representative:

My name is Name and I am a constituent of Name of Rep from City, State who cares about Huntington's Disease. I am asking Name of Rep to show his/her support for HD families by cosponsoring H.R. 718, the Huntington's Disease Parity Act of 2011.

Here is a Sample Message for your Senators:

My name is Name and I am a constituent of Name of Senator from City, State who cares about Huntington's Disease. I am asking Name of Senator to show his/her support for HD families by cosponsoring S. 648, the Huntington's Disease Parity Act of 2011.

The more personal you can make it, the more your message will resonate! Talk about your connection to Huntington's Disease and what makes the Huntington's Disease Parity Act important to you. If you, or someone you know, has struggled with the disability process or had no insurance coverage during the Medicare waiting period, please let your member of Congress know. After you make your calls, be sure to remind your friends and family to call for HD. Together we can make thousands of calls and make the Huntington's Disease Parity Act a reality!

…Living— continued from page 13.

delayed onset of symptoms, and slower progression. In 2010, collaborating with these scientists, we published a paper in the Journal of Neuropathology and Experimental Neurology that showed that the brains of enriched mice had much smaller amounts of the abnormal huntingtin protein deposits. These results told us that enriching the mice's environment seems to make their brain more resistant to the harmful effects of the mutant huntingtin protein. Read that sentence again. Using your brain makes it stronger.

So, maintaining mental and physical activity is not optional. By the way, this advice holds true for all of us, whether we come from HD families or not! ■

There Are Many Ways
For You to Make Your Contribution to HDSA

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 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 with this issue.

- **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 800-345-HDSA (4372), ex. 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.
- **Make a Planned Gift:** Join the HDSA Heritage Club:
  - 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

For information on making a planned gift to HDSA please call 800-345-HDSA (4372), ex. 235.

- **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.
- **Donate Your Vehicle:** call toll free 888-HDSA-151/888-437-2151 or email 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.

Please visit our website regularly and browse the HDSA Marketplace. Purchasing our Care2Cure Bracelets, holiday cards, amaryllis plants, and other merchandise makes a difference – and helps us build awareness at the same time. ■

New at HDSA

2010 was a busy year for HDSA. The Programs and Services Department created several new publications, programs and services for people with HD, their caregivers and their families.

Here is a brief list and description of what is new at HDSA!

NEW PUBLICATIONS

Updated Family Guide Series These pamphlets serve 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. Go to Living with HD section – Publications on the national website to find a complete list of all publications available for downloading.

Coming Soon Spanish translations of The Family Guide Series both in print and on line. Watch the HDSA national website (www.hdsa.org) for updates.

Fast Facts This popular trifold brochure was updated to reflect changes in our knowledge about HD. It is available in print or online. This publication can be found in the Living with HD section – Publications on the national website.

We Are HDSA! This new monthly support group newsletter launched in November 2010 thanks to an educational grant from Lundbeck. *We Are HDSA!* is sent the first week of every month to all HDSA support group leaders to distribute at their regular meeting. If you are a member of an HDSA support group, and your support group leader is not distributing *We Are HDSA!*, please email Deb Lovecky at dlovecky@hdsa.org.

In October, an all electronic format will be introduced and the print version of *We Are HDSA!* will disappear. So now is the time to sign up for the electronic version. Send an email with your name, city, state, name of the support group to which you belong and the email address you want to use to receive *We Are HDSA!* and you'll never miss an issue.

Past issues of *We Are HDSA!* can be found in the Living with HD section of the HDSA national website.

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 has been updated. Thanks to an educational grant from Lundbeck, HDSA can offer a complimentary copy of A Physician's Guide to 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. You can email amarkpaul@hdsa.org or fax 212-239-3430 with the information. We will also send you a copy free of charge upon receipt of the physician information.

Please Note: Physician information is being requested so HDSA can increase local resources on the national web site but only after the physician has been contacted and agrees to be listed. HDSA does not share any information nor is there a record of who "recommended" a doctor to receive a complimentary copy.

—continued on page 24.

Advocacy

NEW PROGRAMS

Caregiver's Corner Thanks to an educational grant from Lundbeck, HDSA has expanded Caregiver's Corner to a monthly series. Join us live at noon each month or view our archived library in the Living with HD section on www.hdsa.org. To find the date of your next Caregiver's Corner, go to the national website home page.

Educational Grants Thanks to an educational grant from Lundbeck, HDSA is once again able to offer support for field based educational programs in 2011. 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).

HDSA Clinical Trials Diplomats In June 2010, HDSA launched the Clinical Trials Diplomat program 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 immediately before the HDSA Convention on Thursday June 23 at 3:30 p.m. in Bloomington, MN at the Sheraton Hotel. If you are interested in the HDSA Clinical Trials Diplomat program, contact Deb Lovecky.

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. Please note that 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 website.

HDSA Care Coordination Portal HDSA has partnered with Lotsa Helping Hands to provide a free caregiving coordination service for our HD families. The Care Coordination Portal allows family, friends, neighbors and colleagues to create a community to assist with daily tasks such as meal delivery and rides. You can access the HDSA Care Coordination Portal at www.hdsa.org/carecoordination. ■

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HDSA, Inc., is a national not-for-profit organization founded in 1986 to help individuals with Huntington's Disease and their families.

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From the Cast of *House*
OLIVIA WILDE "13" &
PETER JACOBSON
"DR. TAUB"

Huntington's Disease
much more than a storyline

It's a devastating genetic neurodegenerative disease that destroys the lives of 30,000 Americans who are symptomatic, the 250,000 at risk and their families.

Huntington's Disease Society of America programs of research and care are finding the answers to Huntington's – and making discoveries that will help us treat and cure Alzheimer's, Parkinson's and many other diseases.

For information or to help please visit
www.hdsa.org or call 1-800-345-HDSA today

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