HDSA Celebrates 35 years of Care and Cure

THE marker

Huntington's Disease Society of America

Fulfilling the Promise

Research, Education and Family Services

progress in research

hd advocacy

education

care

a message *from* the chair of the board

As I write this last message to you as your Chairman of the Board, I am heartened by the many milestones that the Huntington's Disease Society of America has passed during my tenure. I've seen HDSA grow from a small organization with an annual budget of $1 million to a thriving and vital community of researchers, allied healthcare professionals and HD family members, who are all working together toward one goal—a cure for this devastating disease. Today, we can truly say "We are family!"

So much has happened in just four years. On the research front, our commitment to both basic and clinical research has grown to more than $3.5 million annually. I've seen the creation of the Coalition for the Cure and watched as that wonderful collaboration of HD researchers from around the world moved from examining the most basic of tenets about HD to the development of animal models and now therapeutic studies. It has been most gratifying to realize that so much that has happened in HD research came about because of the critical dollars HDSA was able to invest in its research programs including the Coalition. It is money that you, our donors and HD family members, gave freely with the hope that it would bring answers. I am proud to say to you today that your investment HAS paid off. Today it is no longer of question of IF we will find a cure, or IF we will develop an effective therapy, it is WHEN.

But research is not the only area where HDSA has grown. When I became Chairman of the Board in 1999, we had just undertaken a new pilot program that we hoped would bring high quality medical and social services to our HD families across the United States. The Center of Excellence program was born at Emory University and in just four short years has grown from one model to 17 vibrant Centers that provide a nexus for HD care within a specific geographic region. During that same period, our 31 volunteer-based chapters joined with our newly designated Center program to form a network of family services that is unsurpassed by any HD organization in the world. Our chapters provide the vital link with local community services and thus complete the circle of care.

I am also very proud of the awareness efforts that have occurred on both the chapter and national level. Our awareness ads that appear in regional editions of major publications have brought phone calls and volunteers to our cause. We are proud that two celebrities have stepped forward to lend their names in our fight with HD—Meredith Patterson, who starred in the Broadway production of *42nd Street*, serves as our spokesperson for the *Gift of Hope* and *Generation 2000* while Billy Aaron Brown, who currently stars in "Eight Simple Rules for Dating My Teenage Daughter," serves as our national spokesperson for HDSA's Hoop-a-thon program. We are grateful for their support and enthusiasm.

As I serve my final months as Chairman of the Board, I look to a future that is free of Huntington's Disease and remember a time not so long ago when the word "hope" was not in our vocabulary. We have come so far as a family but there is still much left to do. I will hand over the responsibility for this organization to a very talented and qualified successor, Robert Pearson, President, The Americas, GCI Group, at the HDSA annual Convention in Houston in June. I hope that all of you will join us at our eighteenth annual convention and that I may have an opportunity to offer each of you a heartfelt thank you for your support and a warm goodbye.

Sincerely,

Donald A. King

Don King, Ph.D.

a message *from* the national executive director/ceo

I was recently looking at one of the new awareness ads that HDSA has created with volunteers from Media Networks Inc. It features Jean Miller holding a photo of her daughter Kelly who died a few years ago from juvenile onset HD. I was struck by the courage and determination that radiates from that ad and also by the hope and love.

It is that same courage, determination and hope that has kept this Society going during both good times and bad. Since 1997, HDSA enjoyed an unprecedented period of growth. We were able to increase our commitment to research to almost $4 million while also expanding our family services program to almost $4 million as well. At the same time, HDSA was able to bolster its awareness and education initiatives and the results more than paid off for that investment. In January of last year, *Discover* magazine named HD research as one of the "*Top 100 Scientific Advances of 2001.*" Today HD is viewed as a model for other neurodegenerative diseases and federal agencies like the National Institute of Neurological Disorders and Stroke (NINDS) are partnering with voluntary health agencies like HDSA to find the answers that will eventually lead to a cure. We have been fortunate indeed and blessed with donors who believe in our mission and our ability to fulfill it.

I like to think of 2002 as the year in which the world didn't know what was ahead. Certainly it was a challenging year for the Society. We were forced to make some painful choices and tough decisions in how we would keep all of our programs running in the face of economic uncertainty. Each of us was asked to do more with less.

I am proud to report that every one in our extended HDSA family—our scientists, Centers of Excellence, chapters and staff—rose to that challenge. Through the generosity of our donors and some cost cutting, the Huntington's Disease Society of America fulfilled its financial commitments to all of our research programs and to our family services programs. Our progress could continue. Today we are stronger for the challenges that 2002 wrought and I am very thankful that our HDSA family pulled together to make it happen.

The new year has brought its own new set of challenges and we will all once again be called upon to do more with less. But our courage and determination will not falter. Our hope for the development of effective therapies that will positively impact so many of our HD family members, and our love for those who each day face the burden of this terrible disease, will carry us through the more difficult economic times ahead. But we cannot do it alone. I ask each of you for your support now and throughout the coming year.

We will welcome a new Chairman of the Board in June and we look forward to a bright future as a Society and as a family. And like all families, we are in this fight together, until the end. The Jean and Kelly Miller ad reminds me of every one of our HD families that I have met throughout the years. It reminds me of your daily battle with this devastating disease and renews my personal commitment to do whatever it takes to bring an end to your suffering.

Together we CAN *make this the last generation with HD*.

Sincerely,

Barbara Boyle

Barbara T. Boyle

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Palliative Care in Huntington’s Disease

By Richard Dubinsky, M.D., University of Kansas Medical Center, HD Workgroup Chair

The 18-month project on palliative care, administered by the Huntington’s Disease Society of America and sponsored by the Promoting Excellence in End-of-Life Care program, of the Robert Wood Johnson Foundation, is nearing completion. The End-of-Life Care program is a multi-year project, headed by Ira Byock, MD, a leader in the field of palliative care. The main goal of the program is to provide care and support to people dying of chronic illnesses and their families. The report of the HD Workgroup is scheduled for publication and dissemination in early June of this year. The report will cover the need for palliative care in those with Huntington’s Disease and their families, and the resources that exist to meet those needs, as well as a call for the allocation of resources to fulfill the unmet needs.

Palliative care is the act of providing comfort, and was one of the founding principles of medicine.

Today healthcare focuses on the treatment and cure of disease, yet many conditions are not curable and only the symptoms can be treated. Palliative care can take many forms, including providing information, alleviation of pain and discomfort, and offering resources for families and caregivers. Hospice provides a full range of palliative care for those at the end of life. In Huntington’s Disease, the need for palliative care is much earlier, takes many forms, and changes throughout the course of the disease. In the initial meeting of the HD Workgroup, palliative care was divided into the areas of education, care, and research and public policy.

Palliative care is the act of providing comfort, and was one of the founding principles of medicine.

The need for *education*, as an aspect of palliative care, begins when the possibility of Huntington’s Disease is first raised. Some members of the Workgroup actually defined the need for education as beginning at conception. But no matter how early the need for education may be as an aspect of palliative care, the needs change over time. Early on, there is the need for education about the basic facts of Huntington’s Disease, including the genetics, clinical manifestations, and time course. As the disease becomes clinically apparent, the educational needs change to meet the change in occupational, behavioral and functional status. Unmet educational needs exist in training for medical students, physicians, nurses, social workers, therapists, as well as with first responders, mental health professionals, and most importantly the families of those with Huntington’s Disease.

Providing *care* can be defined in many different ways. This Sub-Committee of the HD Workgroup chose to look at several dimensions or “domains” of care including autonomy, dignity, meaningful social interaction, communication, comfort, safety and order, spirituality, enjoyment, nutrition, and functional competence. They provided examples of the best possible care and worst-case scenarios as well as ways to change care to meet the needs of the patients and their families.

Through a gap analysis of the unmet needs in palliative care, the *research* sub-committee of the HD Workgroup were able to identify many areas that had very little information available to determine the needs for HD.

For example, a great deal is now known about the course of Huntington’s Disease, but information is lacking about patients towards the end of life, specifically those in long-term care facilities. Their needs are not well known, and little is known about how people with Huntington’s Disease spend the last few months or years of their lives.

The *public policy* changes that are needed to help those with Huntington’s Disease and their families are many, and may be similar to those for many neurodegenerative diseases. Specific needs include coverage for medications, in-home care designed to keep people in the community and with their families as long as possible, and improvements in coverage for long term care. An extension or redefinition of Hospice benefits to before the last six months of life is also needed.

The scope of this project was ambitious; the call for action, based upon the results of the HD Workgroup, is even more so.

As a community, we need to disseminate the report to those who provide education and care to those with Huntington's Disease. We also need to advocate for improved and expanded healthcare coverage as we strive to maintain the dignity and comfort of those who need it the most, our families, friends, and patients.

The members of the HD Workgroup are involved in the care of people with Huntington's Disease, in other chronic degenerative disorders, and in the arena of public policy. The membership of the Sub-Committees included:

Education Sub-Committee:
Chair – Marilee Monnot, Ph.D. University of Oklahoma; Carol Clerico, OTR, HDSA Center of Excellence at the University of Virginia Health Systems, Brookes Cowan, Ph.D., University of Vermont, Gary Barg, Editor, *Today's Caregiver.*

Care Sub-Committee:
Chair – Tetsuo Ashizawa, M.D., University of Texas Medical Branch, Martha Nance, M.D., HDSA Center of Excellence at Hennepin County Medical Center, Barbara Heiman, LISW, HDSA Center of Excellence at Ohio State University Medical Center, H. Taylor Butler, LICSW, HDSA Center of Excellence at Emory University, Frances Saldana, HD family caregiver.

Research and Public Policy Sub-Committee:
Chairs – Kathleen Shannon, M.D. Rush-Presbyterian-St. Luke's Hospital, Peter Como, Ph.D., HDSA Center of Excellence at the University of Rochester, Charles Diggs, Ph.D. American Society of Speech-Language-Hearing Association, Bruce Jennings, M.A., The Hastings Center, Richard Dubinsky, M.D.,University of Kansas, Chair HD Workgroup.

HDSA *thanks*

The Robert Wood Johnson Promoting Excellence in End-of-Life Care Program

for their commitment to palliative care and end of life issues for HD

HD Workgroup will lead HDSA's Focus on the Family Forum at HDSA Annual Convention!

Join members of the HD Workgroup on Friday, June 6 at 10:30 a.m. in a panel discussion as they explore palliative care and end of life needs for HD. Peter Como, Ph.D. will Chair this informative forum that will identify gaps and barriers to the delivery of services as well as discuss the many recommendations to the field that will be released shortly by the Robert Wood Johnson Promoting Excellence in End-of-Life Care program. Panelists will also include Tetsuo Ashizawa, M.D. Chair of the Care Sub-Committee, Richard Dubinsky, Chair of the HD Workgroup and acting Chair of the Education Sub-Committee, Kathleen Shannon, M.D., Chair of the Research Sub-Committee, Bruce Jennings, M.A. for public policy, and Frances Saldana for caregivers. A question and answer session will close the Forum. This is an exceptional opportunity to hear about the findings of this innovative Workgroup specifically organized for Huntington's Disease and the recommendations they will be making to public policy makers, educators, professional caregivers, healthcare professionals and family members. Be sure to attend this groundbreaking Forum on June 6.

The HDSA Focus on the Family Forum is partially underwritten by a grant awarded to HDSA to explore palliative care/end of life issues for the Robert Wood Johnson Promoting Excellence in End-of-Life Care program. Ira Byock, M.D., Director of the Promoting Excellence in End-of-Life Care program, will give a keynote address, via videotape, as part of the HDSA Annual Convention's Opening Ceremony.

A Primer on the Americans with Disabilities Act

By Charles C. Diggs, Ph.D.

Dr. Diggs will be conducting a workshop on the ADA/HIPAA and what they mean to those with HD at the HDSA Annual Convention in Houston, TX (June 6–8, 2003).

The Americans with Disabilities Act (ADA) prohibits discrimination of people with disabilities in employment; state and local government programs, services, and activities; public accommodations; and telecommunications. The protections under this law allow the person with Huntington's Disease to remain in the workforce and to enjoy community, social and recreational activities as long as physiologically possible.

Space limitations allow a listing of only a few of these protections:

- Job interviews and applications may not include questions about the nature or severity of a disability.
- Medical examinations may be required only if they are required of all employees in a similar position.
- Employers must make reasonable accommodations for known limitations. Greater flexibility in required work hours, use of assistive technology, and re-distribution of job responsibilities are a few examples of accommodations that can be made. The ADA does not specify accommodations that must be made for all employees with a disability, and employers may offer alternatives to the employee's preferred accommodation as long as the alternative meets the employee's needs.
- Public accommodations (hotels, restaurants, theaters, stadiums, amusement parks, art galleries, shopping centers, grocery stores, public transportation facilities, and many other public establishments that fall into one of the 12 categories specified by the ADA) must provide people with disabilities access to goods and services equal to that provided for patrons without disability. Auxiliary aids and services are to be provided when necessary. Detailed federal regulations describe requirements for accessible parking spaces, slope of ramps, handrails, elevators, audible and visual alarms, accessible seating, counter height, roll-in showers for hotels, and much more.
- A Speech to Speech Relay (STS) service is available for people whose speech cannot be readily understood over the telephone. Go to http://www.stsnews.com/Pages/WhatisSpeechtoSpeech.html for detailed information about this service.

The ADA does have some exceptions and exclusions: employers with less than 15 employees, employees who present a direct threat to the health or safety of others, employer accommodations that change the essential function of a job (e.g., not requiring a receptionist to greet visitors and answer the telephone), and undue hardship (e.g., excessive cost) for an employer or public accommodation. Buildings that existed before the effective date of the ADA and certain historic buildings are also excluded.

Employers and public accommodations may be unaware of their obligations under the law. Therefore, if you do not ask for accommodations, you will not get them. Some companies and establishments may resist compliance, but others willingly cooperate when simply informed of their responsibilities and what can be done.

Passage of the ADA in 1990 has created as much controversy as previous federal legislation that banned discrimination on the basis of race, color, religion, national origin, age, or gender. Proponents have applauded the ADA's enpowerment of people with disabilities to live their dreams, whatever they may be. Opponents have criticized the non-specificity of its provisions, its susceptibility to abuse by people who are not disabled, and the granting of "special treatment" to a small percentage of the population. What is incontrovertible is that the ADA has changed people's lives.

One of the most celebrated examples is Casey Martin, a golfer who teamed with Tiger Woods to win the 1994 National Collegiate Athletic Association (NCAA) golf championship for Stanford. Martin wanted to turn professional and join the Professional Golf Association (PGA) tour, but he had a rare circulatory disorder (Klippel-Trenaunay-Webber syndrome) that so weakened his right leg that he could not walk an entire 18-hole golf course. The NCAA allowed him to use a golf cart, but PGA rules forbid such use and the PGA was not going to make an exception, arguing that walking the course was an essential part of the game. Martin challenged the ruling all the way to the U.S. Supreme Court and won in 2001. The court ruled that the ADA applies to an organization like the PGA Tour which invites public participation in its activities even if eligibility criteria limit participation to an elite few. Walking the course was not viewed as an essential part of golf, and because of Martin's disability, his use of a cart would not give him unfair advantage over his competition because he would be just as fatigued, if not more so, using a cart as his colleagues would be walking. Martin has said, "Without the ADA, I never would have been able to pursue my dream of playing golf professionally." The ADA can also help people with Huntington's Disease pursue their dreams for as long as possible.

More information on the ADA can be found at:

http://www.eeoc.gov/ada/adahandbook.html
http://janweb.icdi.wvu.edu
http://www.usdoj.gov/crt/ada/adahom1.htm

Dr. Diggs is Director of State and Consumer Advocacy at the American Speech-Language-Hearing Association (ASHA) in Bethesda, MD. He is also a member of the HD Workgroup that has investigated the gaps and barriers to service for those affected by HD. The HD Workgroup's Report to the Field is due out shortly and will include recommendations for better care.

HDSA *thanks*

Athena Diagnostics
for their unrestricted
educational grant
to reprint the
Genetic Testing Guidelines for HD

May is HD Awareness Month

Each May, the Huntington's Disease Society of America re-affirms its commitment to the care and cure of HD. Since 1967, when Marjorie Guthrie gathered a small group of HD families in New York, HDSA has remained committed to funding research to find a cure, providing services and support for our HD families and educating both the public and healthcare professionals about this devastating disease. Today we are closer than ever to finding effective therapies that will help those affected by this deadly disease. Please join us in remembering those who have lost their battle with HD and help to bring awareness about this disease to your community. HDSA will have awareness kits ready in early April for you to take to your local newspapers, schools, clubs, organizations, local television and radio stations. If you would like to help raise awareness and increase funding for HD research, please call the National Office or email hdsainfo@hdsa.org.

coalition for the cure-

cutting edge research for hd

by James Gusella, Ph.D. Chair, HDSA Medical and Scientific Advisory Committee

In 1997, as part of its expanding commitment to research, the Huntington's Disease Society of America undertook an innovative approach to solving the problem of Huntington's Disease by establishing the HDSA Coalition for the Cure.

This groundbreaking Coalition brought together senior scientists from the United States, Canada and Europe who had committed their careers to investigating HD, with the mission of forging a team that would work cooperatively to understand the cause of the disorder and to help to develop treatments. As the HDSA Coalition for the Cure grew, additional scientists, with special expertise in areas that emerged from the initial research, joined the team to accelerate the effort. Together, the investigators of the HDSA Coalition for the Cure have been responsible for most of the major advances in HD research that have occurred during the past half decade, as a result of their dedication, collaboration and productivity, and the unwavering support that they have received from HDSA.

Understanding Huntington's Disease begins with genetics, and genetic analysis by Coalition investigators of persons affected by HD, has provided a clear understanding of the criteria that research models must meet to accurately represent the disease mechanism. Coalition investigators were the first to demonstrate that the mutant huntingtin protein has an abnormal property that *promotes the formation of insoluble aggregates* and that this property fulfills the genetic criteria for being involved in the disease mechanism. They were also the *first to demonstrate such insoluble protein clumps in the brains of a mouse HD model* and, in a stunning re-evaluation of long-studied HD post-mortem pathology, the *first to reveal the presence of insoluble clumps of huntingtin protein in a human HD brain*.

Coalition investigators were also the first to use this abnormal protein property to perform *high-throughput drug screening* for new chemical entities that might be of value in treating HD. They were also the *first to apply a fruit fly model* to drug testing for HD. This type of drug screening work has now reached the stage of testing potential compounds in cell and mouse models, with the hope of identifying drugs to test in patients. There are a number of different types of mouse HD model being used in the HD field to investigate different aspects of the disorder. However, *all of the major types of mouse model being used in the HD field were created by Coalition investigators*.

Coalition scientists have made many other notable advances, including the generation of informative *cell models* that allow the investigation of nerve-like cells in a culture dish, the implication of a *defect in cellular energy production as an early event* in the HD disease process, the delineation of *cell-death proteins, known as caspases*, in the eventual demise of HD brain cells, the discovery of a *disruption in the mechanisms that control the expression of many other genes in HD*, the detection of *cellular "stress" proteins as a response to the presence of the HD mutation*, the revelation that *normal huntingtin protein may have protective functions*, and many, many other findings.

Indeed, the output of research results and new ideas that have emerged from the HDSA Coalition for the Cure have both dramatically accelerated HD research within the group and seeded efforts in the larger HD field. It has provided a dramatically better understanding of HD and many clues to be followed for possible treatments. But while the HDSA Coalition for the Cure has been a major success, the culmination of its task still lies ahead.

Today, the flagship research program of the Huntington's Disease Society of America remains at the forefront of HD research with the mission of digging even deeper into the basic events that occur in HD to achieve a more complete understanding of the mechanism of the disorder, all the while using this critical information to search for and evaluate drugs that might be effective in HD patients. With the support of HDSA and the HD community, the HDSA Coalition for the Cure will continue to lead the way in HD research.

Huntington Study Group Research Study Update

If you or a member of your family meets the eligibility criteria for either of the studies listed below, please consider joining an observational trial. There will not be any advancement in HD research without your help.

At-Risk Research Studies

There are currently two at-risk observational studies that are accepting research participants. These studies will determine how accurate the measures are that researchers use in detecting the onset of HD. This will allow researchers to develop clinical trials aimed at postponing or preventing the onset of illness.

PREDICT-HD (Neurobiological PREDICTors of Huntington's Disease) will define the earliest neurobehavioral and radiographic markers of HD. PREDICT-HD is currently recruiting 500 at-risk persons in the US and Canada, age 26 or older, who have undergone predictive testing and have no definite signs of HD. Participants will be examined yearly for a minimum of four years and will undergo brain imaging (MRI).

Additional information is available from recruitment coordinator Elizabeth Penziner at (319) 353-4292, or through the HSG at (800) 487-7671. PREDICT-HD research sites are located at more than 18 sites in the US.

PHAROS (Prospective Huntington At Risk Observational Study)

To date, more than 830 people have volunteered. However, 1,000 are needed for this study and enrollment will continue until July 1, 2003. The study is seeking men and women, between 26 and 55 years of age who are at risk for HD, have not undergone predictive testing, and have no definite signs of HD. Research participants will be examined every 9 months for a minimum of 5 years. Testing for the HD gene will be performed at the beginning of the study, but individual results will never be revealed to either the research participants or the investigators. *For more information, please call the HSG at 800-487-7671.*

Completed Therapeutic Trials

MINO (MINOcycline Dosing and Safety in Huntington's Disease), *A report on the results of this clinical trial will be reported later this year.*

RID-HD (Riluzole Dosing and Safety in Huntington's Disease), Final results of the RID-HD trial will be published in 2003.

Therapeutic Trials in Planning

A series of trials using Coenzyme Q10 will begin in the Spring of 2003 and will examine the potential for high dosages of coenzyme Q10 to slow the progression of HD and the possibility of postponing the onset of HD in healthy gene carriers. For more information, contact the HSG at 800-487-7671.

The Huntington Study Group (HSG) is a non-profit group of physicians and other healthcare providers from medical centers in the U.S., Canada, Europe and Australia, experienced in the care of Huntington's Disease patients and dedicated to clinical research for Huntington's Disease. Both PHAROS and PREDICT-HD are currently recruiting volunteers.

HDSA GRANT AND FELLOWSHIP RECIPIENTS 2002–2003

The HDSA Grant and Fellowship program provides essential funds to those research projects that are in the early stages of development. This "seed money" allows HDSA Grant recipients to advance their research from the preliminary data stage to a mature project status that will then be eligible for grant consideration from larger national agencies like the National Institutes of Health (NIH) and the National Institute of Neurological Disorders and Stroke (NINDS). The HDSA Grant program provides grants of up to $100,000, payable over two years, if renewed.

HDSA Fellowships were created to expand the pool of young investigators who are interested in studying Huntington's Disease. HDSA Fellowships can total up to $80,000 per award, payable over two years, if renewed.

In 2002/03, HDSA will fund almost $500,000 in Grant and Fellowship projects.

The HDSA Grant and Fellowship program is made possible by Founding Leadership Gifts from the Smith Family Research Fund in Memory of Gretchen Ferris Smith, the Dobis Family Fund, the Milek/Fecca/Baker Family Research Fund, the Pilskaln Family and Friends Research Funds and individual Family Fund sponsors.

New Grants 2002–2003

Yury O. Chernof, Ph.D.

Georgia Institute of Technology,
Atlanta, GA

The Role of Protein-Protein Interactions in Cell Toxicity of PolyQ Huntingtin in the Yeast Model

This project uses the yeast model to understand how interactions between the expansion of the polyglutamine region associated with HD and other proteins cause harm to cells. This particular yeast model also allows the investigator to identify chemicals, environmental conditions and mutants that promote huntingtin PolyQ expansion (see glossary for definition of PolyQ).

James A. Huntington, Ph.D.

University of Cambridge,
Cambridge, UK

Structure and Function of Huntingtin

HD produces an abnormal huntingtin protein structurally. The role of the structure of the protein in the progression of Huntington's Disease is unknown. This project will attempt to determine the function of the huntingtin protein by solving its three-dimensional structure (see glossary for definition of three-dimensional structure).

Alyson L. Peel, Ph.D.

Buck Institute for Age Research,
Novato, CA

Activation of Cell Stress Kinase, PKR, as a Cell Death Mechanism in Huntington's Disease

Previous studies from this laboratory have identified a molecule, PKR, that is found in higher amounts in HD brains and is associated with cell stress. This research project proposes that the presence of mutant huntingtin mRNA activates PKR and triggers the cell death process.

Peggy F. Shelbourne, Ph.D.

University of Glasgow,
Scotland, UK

Mutation Length and Neuronal Function in Early Huntington's Disease Pathogenesis

HD is associated with an increase in CAG repeats in the huntingtin gene that encodes the huntingtin protein. The huntingtin protein is found in every cell of the body, yet only brain cells are susceptible to the disease process. Previous studies have also revealed a variation in the number of CAG repeats from tissue to tissue. The purpose of this project is to further investigate the role CAG repeats play specifically in the brain, and the correlation between the size of the CAG repeats and the disease progression.

New Grants 2002–2003

Vanessa Wheeler, Ph.D.

Massachusetts General
Hospital East,
Charlestown, MA

An Investigation into the Role of MSH2 in Huntington's Disease Pathogenesis

In previous studies, it has been found that when HD mice lack a protein known as MSH2, which is used to repair damaged DNA, early events that lead to cell death in Huntington's Disease are delayed. This study will use a mouse model that has had an expanded CAG repeat inserted into the mouse's HD gene, in order to determine the significance of the MSH2 protein and other DNA repair processes found in the progression of HD.

New Grants 2003–2004

Ray Truant, Ph.D.

McMaster University,
Ontario, Canada

Analysis of Huntingtin Associated Proteins in Nuclear Transport

Earlier studies have shown that the huntingtin protein can pass in and out of the cell nucleus. This research project will further investigate the role played by huntingtin protein in the nucleus by asking the following: why is it there, what is it doing there, and is it normally there as part of the protein's yet unknown biological function?

New Fellowships 2003–2004

Luc Djousse, M.D., D.Sc.

Boston University,
Boston, MA

A Genome Scan for Genetic Modifiers of Huntington's Disease

The purpose of this study is to identify other genes that influence the onset of HD by using an expanded version of the study known as HD MAPS, which will include other important features of HD such as the rate of disease progression, weight loss and depression. By identifying the genes that influence the progession of the disease as well as other factors in HD, new treatments may be found that may slow the progression of the disease.

Christopher Meade, Ph.D.

University of Memphis,
Memphis, TN

Does the Cortex Affect the Striatum in HD?

The major site of cell death in HD is the striatum. This research project will investigate whether cell death is due to the effect of the mutant huntingtin acting within the striatal cells or whether it is due to the effect of the mutant huntingtin acting on cortical cells that interact with striatal cells. *In oculo* cultures provide a meaningful way to determine whether HD is cortically driven and serve as a useful model for testing the efficacy of drugs in HD treatment.

New Fellowships 2002–2003

Michael Cyr, Ph.D.
Duke University,
Durham, NC

Dopamine System and Its Contributing Role in the Development of Pathological Conditions in Huntington's Disease

Dopamine is a chemical found in the brain and used to control functions such as cognition, emotion, reward and locomotion. Dysregulation of the dopamine system is thought to play a role in the neurodegeneration of the striatum in Huntington's Disease. This research project will determine whether excess levels of dopamine in the brain contribute to the development of cell stress in the striatum by using an HD mouse model with increased dopamine levels in the brain and in the mutant huntingtin gene.

HDSA IS PLEASED TO ANNOUNCE THE ADDITION OF 8 GRANTS AND FELLOWSHIPS FOR 2003-2004 AS WELL AS THE RENEWAL OF 6 CURRENT STUDIES. THESE EXCITING NEW RESEARCH PROJECTS WILL BE INCLUDED IN THE NEXT ISSUE OF Toward a Cure.

New Researchers for 2003-2004

Pamela Bjorkman, Ph.D.
California Institute of Technology

Janet Dubinsky, Ph.D.
University of Minnesota

Martin Duennwald, Ph.D.
Whitehead Institute

David S. Gary, Ph.D.
Johns Hopkins University

Pietro Mazzoni, M.D., Ph.D.
Columbia University

Kirsten Messmer, Ph.D.
University of Maryland

James L. Pearson, Ph.D.
Duke University

David Sulzer, Ph.D./
Ana Maria Cuervo, Ph.D.
Columbia University/
Albert Einstein University

Renewing Grants and Fellowships

Saumitri Bhattacharyya, Ph.D.
University of Nebraska

Lisa M. Ellerby, Ph.D.
Buck Institute for Age Research

Robert J. Ferrante, Ph.D.
Bedford VA Medical Center

Matthew T. Lorincz, M.D., Ph.D.
University of Michigan

Dinesh S. Rao, M.D.
University of Michigan

Alan M. Tartakoff, Ph.D.
Case Western Reserve

GLOSSARY

aggregates/aggregation: clumping of proteins in cells that interfere with cell functioning.

basal ganglia: a region located at the base of the brain composed of four clusters of neurons, or nerve cells. This area is responsible for body movement and coordination. The neuron groups most prominently and consistently affected by HD—the pallidum and striatum—are located here.

caspases: enzymes that trigger cell death (apoptosis).

cortex: part of the brain responsible for thought, perception, and memory. HD affects the basal ganglia and cortex. See basal ganglia.

cortical cells: nerve cells in the cortex.

HD-MAPS: Huntington's Disease Modifiers of Age at onset in Pairs of Siblings. HD-MAPS is an international consortium of HD clinical research sites participating in the identification of genes that influence onset age of HD.

huntingtin: the protein encoded by the gene that carries the HD defect. The repeated CAG sequence in the gene causes an abnormal form of huntingtin to be formed. The function of the normal form of huntingtin is not yet known.

polyglutamine expansion: extended region in protein caused from the extra copies of CAG codon in certain segments of DNA. Q is an abbreviation for glutamine, therefore, polyglutamine is also abbreviated as polyQ.

positron emission tomography (PET): tool used to diagnose brain functions and disorders. PET produces three-dimensional, colored images of chemicals or substances functioning within the body. These images are called PET scans. PET shows brain function, in contrast to CT or MRI, which show brain structure.

striatal cells: nerve cells found in the striatum, which is damaged in HD brains.

striatum: part of the basal ganglia of the brain. The striatum is composed of the caudate nucleus, putamen, and ventral striatum. See basal ganglia.

three-dimensional structure: the arrangement of side groups of a protein which can freely rotate into different positions, thus allowing the protein to perfectly bind or dissociate with other molecules resulting in a function.

NEW PROJECTS FUNDED UNDER HDSA'S THERAPEUTICS INITIATIVE!

The HDSA Therapeutics Initiatives was created by the Medical and Scientific Advisory Committee (MSAC) with the approval of the HDSA national Board of Trustees in 2001 as a vehicle that would move advanced HD research toward the clinical arena. HDSA awarded the first three Therapeutics Initiative grants in 2002 and a report of those projects appeared in the Fall 2002 issue of Toward a Cure.

In October 2002, the HDSA Board of Trustees approved three new grants and renewed one grant for more than $300,000. These grants will use models of HD (cell or animal) to develop assays (tests) for potential drug screens that may yield an effective therapy.

HDSA would like to thank Bruce and Janet Bergman for their lead gift and their continued support of this innovative program.

Steven M. Finkbeiner, M.D., Ph.D.

Gladstone Institute of Neurological Disease/The J. David Gladstone Institutes, San Francisco, CA

PolyQ Conformation-Based Drug Screen

It has been proposed that the interaction of the PolyQ stretch (polyglutamine expansion) and another protein causes neurodegeneration in HD. This new project will investigate the structure of the PolyQ stretch so that small molecules can be made to interact with the PolyQ stretch and disrupt the process of degeneration.

Susan Lindquist, Ph.D.

Whitehead Institute for Biomedical Research, Boston, MA

Yeast as a Model System for Huntingtin-Mediated Toxicity

A yeast model system has been developed that mimics the toxicity, clumping of huntingtin, and interaction of huntingtin with other glutamine-rich proteins of the polyglutamine (polyQ) expansion disorders. This simple model system will be used to screen more rapidly the small molecules that may alleviate huntingtin-mediated toxicity.

Nancy Muma, Ph.D.

Loyola University, Chicago, IL

Therapeutic Targeting of Transglutaminase for Huntington's Disease

Previous studies have linked transglutaminase proteins with huntingtin protein aggregation that is characteristic of HD. This research project will establish the specific transglutaminase protein involved with HD, as well as determine if inhibition of this protein, using different compounds, will decrease HD clumping.

James Gusella, Ph.D. and Marcy MacDonald, Ph.D.

Massachusetts General Hospital, Boston, MA

The PROMPT Assay

This project will develop an assay to screen for drugs that reduce or prevent the expression of mutant huntingtin in striatal neurons without eliminating the expression of normal huntingtin. The drugs would then be candidates to test in model systems to see if they could intervene at a stage before the damage caused by mutant huntingtin has overwhelmed the susceptible neurons. Any successful drug screen in an HD model could potentially be tested in humans.

HDSA CENTERS OF EXCELLENCE

HDSA has seventeen Centers of Excellence spread across the US to bring comprehensive medical and social services to our HD families. The HDSA Centers of Excellence are located in major medical facilities that have expertise in Huntington's Disease or movement disorders. They have received the Center of Excellence designation from HDSA because of their outstanding understanding and treatment of HD.

The Huntington's Disease Society of America awards an annual grant to each Center of Excellence. In 2002–2003, HDSA's commitment will be $1 million. The HDSA Center of Excellence program is partially underwritten by a generous gift from an anonymous donor.

While each Center of Excellence has unique programs and services, all Centers offer a core set of services that include neurologists, speech, physical and occupational therapists, genetic counselors and genetic testing services, social services, regional referrals and nutritional guidance. HDSA Centers of Excellence also serve as regional information sources for area neurologists and physicians, as well as allied healthcare professionals. The Centers also act as representatives of HDSA, building understanding and support for the HD community it serves through outreach programs, community based educational programs and regional fund raising activities.

The continued growth of this vital and vibrant healthcare program is due to the generous support of donors, large and small, who recognize the importance of having access to a multidisciplinary medical team for HD patients and families. The Center of Excellence program is a cornerstone of HDSA's long-term commitment to the care and understanding of HD.

NEW ENGLAND

The New England HDSA Center of Excellence at Massachusetts General/Tewksbury Hospitals
Boston, MA
Director: Steven Hersch, M.D., Ph.D.
T: 617-726-5892 (MGH)
T: 978-851-7321 (Tewksbury)
Email: cskeuse@partners.org

MIDDLE ATLANTIC

NEW YORK

Upper New York State HDSA Center of Excellence at the University of Rochester HD Family Center
Rochester, NY
Directors: Ira Shoulson, M.D.
Peter Como, Ph.D.
Karl Kieburtz, M.D.
T: 716-273-4147
Email: lbriner@mct.rochester.edu

New York, NY
HDSA Center of Excellence at Columbia Health Sciences/ NYS Psychiatric Institute
New York City, NY
Director: Karen Marder, M.D.
T: 212-305-9172
Email: thorned@sergievsky.cpmc.columbia.edu

Long Island, NY
George G. Powell HDSA Center of Excellence at North Shore University Hospital
Manhasset, NY
Directors: Andrew Feigin, M.D.
Martin Bialer, M.D., Ph.D.
T: 516-869-9527
Email: dzgaljar@nsns.edu

MARYLAND

HDSA Center of Excellence at Johns Hopkins University/Johns Hopkins Hospital
Baltimore, MD
Directors: Christopher Ross, M.D., Ph.D.
Adam Rosenblatt, M.D.
T: 410-955-2398
Email: dpollard@jhmi.edu

VIRGINIA

HDSA Center of Excellence at the University of Virginia HD Program
Charlottesville, VA
Director: Madaline Harrison, M.D.
T: 804-924-2665
Email: psa9m@hscmail.mcc.virginia.edu

SOUTH

GEORGIA

HDSA Center of Excellence at Emory University School of Medicine
Atlanta, GA
Directors: Randi Jones, Ph.D.
J. Timothy Greenamyre M.D., Ph.D.
T: 404-728-4936
Email: yashika_bethel@emory.edu

ALABAMA

HDSA Center of Excellence at the University of Alabama
Birmingham, AL
Director: Leon Dure, M.D.
T: 205-939-6946
Email: smantooth@peds.uab.edu

MIDWEST

OHIO

HDSA Center of Excellence at the Ohio State University College of Medicine and Public Health
Columbus, OH
Director: Sandra Kostyk, M.D., Ph.D.
T: 614-688-4193
Email: gheiman@juno.com

MISSOURI

HDSA Center of Excellence at Washington University School of Medicine
St. Louis, MO
Director: Joel Perlmutter, M.D.
T: 314-362-6909
Email: medsec@npg.wustl.edu

MINNESOTA

HDSA Center of Excellence at Hennepin County Medical Center
Minneapolis, MN
Director: Martha Nance, M.D.
T: 612-347-6024
Email: hcmc.hd.clinic@co.hennepin.mn.us

IOWA

HDSA Center of Excellence at the University of Iowa Hospitals and Clinics, HD Center
Iowa City, IA
Directors: Jane Paulsen, Ph.D.
Henry Paulson, M.D., Ph.D.
Robert Rodnitzky, M.D.
T: 319-353-4307
Email: Elizabeth_penziner@uiowa.edu

SOUTHWEST

TEXAS

HDSA Center of Excellence at Baylor College of Medicine
Houston, TX
Director: Joseph Jankovic, M.D.
T: 713-798-5970
Email: ltipton@bcm.tmc.edu

COLORADO

HDSA Center of Excellence at the Colorado Neurological Institute
Englewood, CO
Director: Lauren Seeberger, M.D.
T: 303-788-4600
Email: Montello@megapathdsl.net

PACIFIC

WASHINGTON

HDSA Center of Excellence at the University of Washington Medical Center
Seattle, WA
Director: Thomas Bird, M.D.
T: 206-221-5390
Email: robinb@u.washington.edu

CALIFORNIA

HDSA Center of Excellence at the University of California Davis Medical Center
Sacramento, CA
Directors: Vicki Wheelock, M.D.
Teresa Tempkin, RCN, MSN, ANP
T: 916-734-6278
Email: Terry@hdteam.org

HDSA Center of Excellence at the University of California at San Diego, CA
Directors: Jody Corey-Bloom, M.D., Ph.D.
Joanne Hamilton. Ph.D.
T: 858-622-5800
Email: jhamilton@ucsd.edu

Contact information may change after publication. Please contact the National Office at 800-345-HDSA or visit the web at www.hdsa.org for updated information.

United Way and Combined Federal Campaign

If you give through the United Way or Combined Federal Campaign, please be sure to identify the Huntington's Disease Society of America (HDSA) by using the number **0526** on your pledge card.

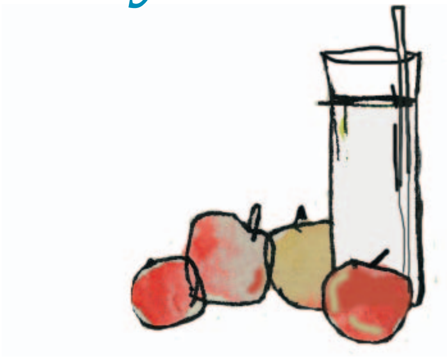
Corporate Matching Gift Fund

You may double or even quadruple your gift to HDSA by enlisting in your company's matching gift program. To double your gift, simply include your employer's matching gift form with your individual contribution. To quadruple your gift, be sure to specify that both your gift and your employer's matching gift are to be included in the

Generation 2000 Research Matching Gift Challenge Fund

Dehydration and HD

by Teresa Tempkin, RNC, MSN, ANP



Though we are still technically in winter, the summer will soon be upon us. This is a good time to remind ourselves that our HD friends and family members need to be aware of the dangers of becoming dehydrated during those summer months.

People with HD are at risk for dehydration, especially in warmer climates. During these times, we throw off excess body heat by sweating. Some people with HD sweat profusely already. As body temperature rises, blood vessels dilate and fluid is lost through the skin as sweat. Ambient air and breezes evaporate this moisture, cooling our core body temperature to keep it in an acceptable range. The hotter it is, the more we sweat, and more fluid is lost. Failure to replace these fluids can result in dehydration.

Why people with HD are more prone to dehydration:

- Cognitive impairment can alter the perception of thirst. People with HD who have difficulty with thinking and organizing their thoughts and actions may be unaware they are thirsty, or not know to drink extra fluids on hot days.
- Motor abnormalities and chorea may prevent some people from getting access to sources of fluids. They cannot drink it if they are unable to get to it! Chorea can interfere with a person's ability to get a drinking vessel to their mouth. This can lead to frustration, and create an additional disincentive to a drinking routine and extra fluids.
- Dysphagia (difficulty swallowing) can be a risk factor for dehydration. Dysphagia is common in mid to late stage HD. Thin liquids, such as water, are the most difficult fluids to manage orally. Many people with dysphagia need to have all their liquids thickened. Complex fluid preparation and oral fatigue can make it difficult to maintain an adequate fluid intake—especially if additional fluids are required.

How can you tell if someone is dehydrated?

- Increased heart rate
- Dry mouth
- Concentrated urine, and voiding fewer times during the day
- Poor tear production

Remember that a person with HD may not ask for fluids, or tell you that they are thirsty. This means that caregivers, family members and friends need to anticipate this need and plan accordingly.

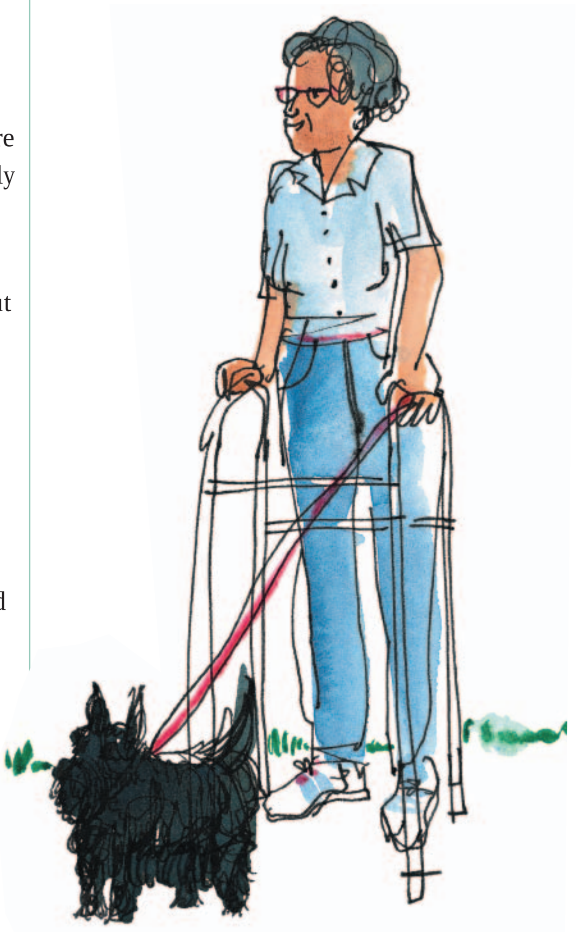
1. Always have fluids available when out and about
2. Drinking water is best. Eight ounces every few hours during the waking hours should be adequate
3. If you are unsure if the person with HD is getting enough fluid, keep track. Actually create a fluid log and write down every time they drink and how much they consume.

When to seek medical attention for dehydration:

- A change in mental status—the person with HD becomes delirious or confused
- Unable to drink or take things by mouth
- Change in vital signs—increased heart rate, decreased blood pressure, increased temperature.

Remember that your loved one with HD is relying on you for good caregiving. When in doubt, seek the advice of your physician or social worker.

Terry Tempkin, RNC, MSN, ANP is co-director of the HDSA Center of Excellence at the University of California at Davis Medical Center.



Caregiver Self Advocacy

Messages to Live By

What does it mean to be a happy person when you are a family caregiver? How can you gain a feeling of confidence in your abilities and have a sense of pride in your achievements? How do you stand up for yourself, take care of yourself and find a balance between your own needs and those of your loved ones? These are heady questions, and ones that have often been discussed.

The National Family Caregiver Association has developed four *Principles of Caregiver Empowerment*. They are the fundamental principles by which caregivers should try to live. Use them as guideposts in your search for a sense of direction and inner peace.

1. Choose to take charge of your life. Don't let your loved one's illness or disability always take center stage.

   We fall into caregiving often because of an unexpected event, but somewhere along the line, you need to step back and consciously say, "I choose to take on this caregiving role." It goes a long way toward eliminating the feeling of being a victim or out of control.

2. Honor, value and love yourself. You're doing a very hard job and you deserve some quality time, just for yourself. Self-care isn't a luxury. It's a necessity.

   Self-care isn't a luxury. It is your right as a human being. Step back and recognize just how extraordinary you are, and remember that your own good health is the very best present you can give your loved one.

3. Seek, accept and at times demand help. Don't be ashamed to ask for help. When people offer assistance, accept it and suggest specific things that they can do.

   Caregiving, especially at its most intense levels, is definitely more than a one-person job. Asking for help is a sign of your strength and an acknowledgment of your abilities and your limitations.

4. Stand up and be counted. Stand up for your rights as a caregiver and a citizen.

   Recognize that caregiving comes on top of being a person, a child, a spouse. Honor your caregiving role and speak up for your well-deserved recognition and rights.

   Become your own advocate, both within your own immediate caregiving sphere and beyond.

Reprinted from NFCA website with permission National Family Caregivers Association, Kensington, MD, the nation's only organization for all family caregivers. Call 800-896-3650 or visit the web at www.nfcacares.org.

NEW ADS MAKE IMPACT ON HD AWARENESS

HDSA will soon be adding three new awareness ads to the current two that appear in rotation in regional editions of major publications through the generosity of Media Networks Inc. With the support of Wayne Powers, President of MNI, both Rachel Eardley and Greg Peters of MNI with Chuck Jennes, a volunteer photographer, have lent their talent and expertise to creating a new series of ads entitled "The Face of HD." Many of you may have already seen one of the new ads featuring Jean and Kelly Miller (see inside back cover). A second ad featuring Shana Martin and her mother Debbie will soon join the rotation with a third to follow. Over the past three years, MNI has provided more than $3 million in free advertising to HDSA, which has increased awareness nationwide about this devastating disease.

Brain Banks

A brain bank is a depository for brain tissue that has been donated by an individual for research purposes. The brain may be disease free or it may be from an individual who has died in the early, middle or late stage of a particular disease. Researchers from around the country contact brain banks regularly to find brain tissue that fits a specific criteria for their research. The need for disease free brains is as great as that of diseased since many researchers use disease-free brains for comparison in their research.

The brain tissue is accepted and stored by various brain banks around the US free of charge to the family of the donor or the donor's estate. There is however, a charge to remove the brain and to send it to the closest or designated brain bank. Fees vary and anyone interested in donating their brain should contact the brain bank that they want to use to find out the average cost and what the family must do to contact the brain bank at the time of death. This information should be included in their estate planning, advance directives or will.

For Huntington's Disease families, there are eight brain banks that currently accept all stages of HD-diseased brains as well as disease-free brains. We urge you to help HD researchers find the answers to this disease. Your help may lead to the cure for HD. Contact your closest brain bank today.

University of California at San Diego
Alzheimer's Disease Research Center
(also performs HD research)
Phone: 858-622-5800
Email: jlgoldstein@ucsd.edu

Harvard Brain Tissue
Resource Center
McLean Hospital, Belmont, MA
Phone: 1-800-BRAINBANK
Email: btrc@mclean.harvard.edu
Website: www.brainbank.mclean.org

Veterans Affairs Hospital in
Upstate New York
Albany, NY
Phone: 518-462-3311 extension 3014
Email: arnulf.koeppen@med.va.gov

The New York Brain Bank
*at Columbia University**
New York, NY
Phone: 212-305-5779
Beeper: 917-889-5275
(emergency donations)

University of Rochester
Department of Neurology,
Movement Disorders Center
Rochester, NY
Phone: 585-341-7500
(if clinic closed ask for movement
disorders physician on call)

University of Washington
Laboratory of Neuropathology
Seattle, WA
Phone: 206-731-6315
Email: tomnroz@u.washington.edu

> *For Huntington's Disease families, there are eight brain banks that currently accept all stages of HD-diseased brains as well as disease-free brains*

Massachusetts General Hospital
Department of Neurology
Charlestown (Boston) MA
Phone: 617-726-1254
Email: hersch@helix.mgh.harvard.edu

Buckeye Brain Bank
Ohio State University
Department of Neurology
Columbus, OH
Phone: 614-293-8531

Note: Due to storage limitations, the Buckeye Brain Bank is restricted to OSU patients only

*supported in part with grant from HDSA

Living At-Risk

Young, Vibrant and At-Risk

Kathy is a young woman of 25, living a good life in New York City while she works as a home visiting teacher with Head Start. In the near future, she plans to pursue her Masters Degree in Social Work, which will complete her certification as a teacher and allow her to pursue a dream of counseling children. Kathy is also at-risk for HD.

HD has been a presence in Kathy's life since she was about nine, when she realized her father was sick. "Because of my dad, I learned about HD as a child," Kathy recalls. "My mother knew that our grandmother had been sick, but my father never told her what she had. She had passed away before my parents met." With her mother, she scoured the local library for information on HD, reading everything she could find.

Her youthful experiences helped her decide on a career. "The reason I work with children is because I grew up with this trauma. My mom was great, but I didn't know how to say, 'I'm having trouble with this.' Sometimes, I couldn't deal with it at all," Kathy remembers. "I work with children to help them identify and deal with things. They have limits with words and cognitive understanding and I want to help them."

After graduating from college, Kathy moved to New York City from Upstate New York. "I love living in the city and all it has to offer, but it has been hard. My older sister, who is 28, was diagnosed when she was 26. I suspected HD for 6 years before that, because of certain changes I saw." Kathy has struggled with her decision to stay in New York in the face of her sister's diagnosis. "I want to be there for her, but I also want to live my own life."

"When I first came to the city," Kathy remembers, "I visited a genetic counselor at the HDSA Center of Excellence at Colombia Health Sciences/NYS Psychiatric Institute. We talked about testing, but I wasn't ready, so the counselor recommended a therapist. I see the therapist two times a week and it has been so helpful. You get more insight than you can with just family and friends. Sometimes your family and friends just want to make you feel good."

A support group of other people at-risk has also become part of Kathy's life in the big city. She found her group through the HDSA website. "I started going about four months after I moved to the city," she says. "We meet once a month. It is very important to me." Currently, Kathy is the youngest member of her support group. "Even though I'm younger than the others, I've lived with HD longer, because of my dad."

People at-risk for HD face many critical life decisions. As a teen, Kathy decided against genetic testing, because she "wanted to live her life the same either way." Now, she says she is beginning to

> *"Because of my dad, I learned about HD as a child," Kathy recalls. "My mother knew that our grandmother had been sick, but my father never told her what she had. She had passed away before my parents met."*

continued on page 19

Being an **HD** *Advocate*

By Kelly Dougherty Munger

AS TOLD TO LAURA SKINNER, PH.D.

Kelly Dougherty Munger with her Dad, Donald Lee

Kelly Munger has lived with the shadow of HD since 1986. Both her father, Donald Lee Dougherty, and grandfather were diagnosed with the disease. When the gene that causes HD was discovered in 1993 and a genetic test was developed for the disease, Kelly decided to learn her HD status for certain. "Since I was thinking about it all the time anyway, I figured I might as well just know," she remembers. "I had a very supportive psychologist in Sioux City, Jim Snowdon, helping me get through it, which is crucial and part of the process." While she was shocked and depressed when a positive result was returned, Kelly began her journey as an HD advocate.

First she became an advocate for herself, adopting a "Do it Now" attitude. She began traveling, visiting Cozumel, Paris, Lucerne and Venice. She made it a point to spend time with her stepchildren and to do things with and for them. "I did many things I always wanted to rather than putting them off," she says. Kelly is fortunate to have the support of her husband, family and friends, but even with this support and her positive attitude, Kelly is sometimes sad and depleted. She has developed several strategies to help her bounce back.

"I have always been a music lover, and often listen to music to lift me up and get me going again," she shares. Her doctors work with her to make certain that the antidepressants, anti-anxiety drugs and sleeps aids that she takes do not interact negatively. Kelly also visits a caring psychologist once a week to talk about her thoughts, feelings, fears, and struggles.

Massage therapy is part of Kelly's emotional and physical therapy, as is Tai Chi, Water Aerobics, and Yoga. Kelly, and the medical professionals who support her, understand that living with HD requires an ever-evolving and broad-based approach.

Kelly is more than an advocate for just herself. She is also an advocate for all people with HD—working to educate and inform people about the disease, while participating in fundraisers and research for HD. She is planning to visit Washington, D.C. soon to lobby Senators and Representatives to improve benefits for people suffering with HD. "Evidently, you can't get on Medicare for two years after you start receiving SSA benefits," Kelly states.

Kelly recognizes that HD research is moving closer and closer to understanding the underlying processes of the disease.

"More money is necessary and more volunteers are needed to participate," Kelly

Become an HDSA Advocate!

Your voice can make a difference in Congress! You can join HDSA's growing list of advocates and give your voice to important issues that affect HD families and other neuro-degenerative diseases. This year promises to be a more active one in healthcare and now is the time to be added to HDSA's list serve.

And, please indicate whether you wish to continue to receive HDSA publications like *The Marker* magazine and *Toward a Cure*. Complete the form to the right and return it in the envelope provided with this magazine.

☐ I want to continue receiving *The Marker* and *Toward a Cure*
☐ Remove my name from the HDSA mailing list

Your Name

Mailing Address

City State Zip

Phone Email

Be sure to include your e-mail so that we can alert you to important bills in Congress. HDSA, 158 W. 29th Street, 7th Floor, New York, New York 10001

Kelly Dougherty Munger with her husband and stepchildren today

affirms. She has willed her brain for research, as her father did, and she actively encourages others to do the same.

"I contacted the Harvard Brain Tissue Resource Center (1-800-272-4622) to have my brain studied upon my death," she explains. "This is very easy to do and a very important and logical decision to help others in the future. Just make your family aware of your brain donation desires and where the paperwork is." (For more information about Brain Banks, please see the article on page 16).

> *Kelly is more than an advocate for just herself. She is also an advocate for all people with HD—working to educate and inform people about the disease*

Kelly encourages people to visit their relative with HD in nursing homes. "I try to imagine what my father was thinking when I went to visit him before he died in January 2002. I imagine that he was thankful for the visit. I am sure he could understand what we said to him, even if he couldn't respond. And I know that he is still asking us to please do something to help stop this disease so that nobody else has to live like this again."

Every one can become an advocate for HD and help to make a difference.

HDSA has a number of ways that you can give your voice to HD. If you are interested in becoming an HDSA advocate, please complete the form on the previous page and return it to HDSA. Be sure to include your email so we can place you on the HDSA Advocacy list serv that alerts our advocates to important bills in Congress.

Living At-Risk
continued from page 17

feel differently. "Recently, I was in a serious relationship. I had to think about marriage and children. There are also financial planning issues that make me ask, 'how much can I really live my life the same either way?' Being at-risk puts a spin on things."

Kathy has just begun to consider participating in a clinical or observational trial. "Being at-risk makes me conscious of everything I do. Everyone drops things, but I think, 'Oh, no. What if the symptoms are starting?' I tend to second-guess myself." Kathy recognizes the value of these studies, though. "There is remarkable work being done in long term studies," she says. "My sister's neurologist has recommended that she join a clinical study in the near future."

Kathy sees HD as a lens through which she views life. "I look at my sister. She is totally at peace with her diagnosis. I guess this is because our father spent so many years in denial. My sister is more at peace than I can ever imagine being. But being at-risk has helped me grow as a person. It has given me empathy and compassion. It makes me patient with people, because I realize that you never know what is going on in their lives. I hope that people can have patience and understand me, because everybody wants to be understood."

Sixth Annual Guthrie Awards Dinner Honors Paul Simon, Christopher Ross, M.D., Wayne Powers and Media Networks Inc.

October 9, 2002 was a star-studded night for the Huntington's Disease Society of America. More than 350 individuals representing the fields of industry, entertainment, research and the HD community gathered at the Marriott Marquis Hotel in New York City to commemorate HDSA's 35 years as a leader in the care and cure of Huntington's Disease while recognizing what would have been Woody Guthrie's 90th Birthday.

Guthrie Awards honoree Paul Simon with Nora Guthrie

Nora Guthrie served as hostess for the evening and fondly recalled her mother, Marjorie, and her father, Woody, and the contributions each made in their time. It was a bittersweet evening of memories that brought tears and laughter to the audience.

Legendary folk singer, Judy Collins, reprised her role as Mistress of Ceremonies and held those in attendance spell bound with her memories of Woody and the impact he had on her music. Though she was recognized as a child prodigy in piano, it was the music of such artists as Woody Guthrie and Pete Seeger that sparked Judy Collins' love of lyrics. She made the evening a very special memory by offering a few verses from Woody Guthrie songs to illustrate her remarks. "Pastures of Plenty" reminded all that Woody was a storyteller who wandered the highways and rails of America seeking the truth and using his songs to battle fascism.

Don King, Ph.D., Chairman of the Board of HDSA, reminded the audience that 35 years ago Woody Guthrie left this earth at the age of 55, but his death brought hope to the thousands that lived in shame and secrecy as a result of Huntington's Disease. Barbara Boyle, HDSA's National Executive Director/CEO, remembered the enormous task that Marjorie assumed when Woody died in 1967 and the origins of what is today the Huntington's Disease Society of America.

Don King, Ph.D. (center), HDSA Chairman of the Board with (l) Vice Chair-Elect, Brendan Condon, of AOL Time Warner and Chair-Elect, Robert Pearson of GCI Group

Legendary folksinger Judy Collins reprised her role as Mistress of Ceremonies

This year, HDSA was proud to present a check in the amount of $120,000 to the HDSA Coalition for the Cure which represented the proceeds from the Woody and Marjorie Guthrie Research Fund. Several of the founding Coalition for the Cure investigators were on hand to accept the check that was presented by Nora Guthrie to James Gusella, Ph.D. who is the new Chair of HDSA's Medical and Scientific Advisory Committee.

Accepting awards in the areas of humanitarianism, commerce and industry, and medical advances were three exceptional individuals and corporation:

Paul Simon, the noted singer and performer, was the recipient of the

Guthrie Award honorees Christopher Ross, M.D.,Ph.D. and Wayne Powers, President of MNI with Barbara Boyle, HDSA National Executive Director/CEO, Nora Guthrie, Don King, Ph.D., HDSA Chair of the Board, and Judy Collins Mistress of Ceremonies

Woody Guthrie Award. Nora Guthrie presented this award which is given each year to an individual in the entertainment industry who exemplifies Woody Guthrie's social activism and personal commitment to the visions and hopes of people.

Christopher Ross, M.D., Ph.D. HDSA's first Chair of the Medical and Scientific Advisory Committee and a noted Coalition for the Cure researcher received the *Guthrie Family Humanitarian Award*, which is presented each year to an outstanding researcher and medical leader who has demonstrated, through his compassion and dedication, a concern for the care and support of those affected by HD and their families. *Michael Hayden, M.D., Ph.D.*, who was the 1999 recipient of that award and very good friend of Marjorie Guthrie, presented the award to Dr. Ross.

Woody Guthrie American Song performs at the 2002 Guthrie Awards Dinner.

Wayne Powers is President of *Media Networks, Inc*. (MNI), a division of Time Warner Inc. Mr. Collins and MNI were honored with the *Marjorie Guthrie Leadership Award* for their ceaseless work in helping to raise awareness about HD through the placement of HDSA ads in regional editions of the major publications they represent. In just the past three years, Mr. Collins and MNI have provided more than $3 million in free advertising to HDSA. Words cannot express how important this contribution has been to educating the public about this deadly disease. We are most grateful for their continued efforts on our behalf. Robert Flaherty, President of Athena Diagnostics and the 2001 recipient of the award presented the *Marjorie Guthrie Award*.

Entertainment was provided by *Woody Guthrie American Song*, who performed several well-known selections of Woody Guthrie. A silent auction raised more than $10,000 for HD research.

As Mistress of Ceremonies, Judy Collins, closed the evening, she reminded each of us that as the Huntington's Disease Society of America celebrates its 35 years of care and cure, it is the wish of all connected with the organization that the answers to the HD puzzle be found soon so that countless Americans will not have to suffer from this devastating disease. "We look to our future and to the future of the children of our HD families as we work to *make this the last generation with HD*."

In 2003, the Huntington's Disease Society of America will celebrate the tenth anniversary of the discovery of the HD gene and commemorate the twentieth anniversary of locating the marker for the defective gene. We hope that you will consider joining us at the 2003 Guthrie Awards Dinner which will be held on October 2, 2003 at the Waldorf-Astoria Hotel in New York City.

In memory of

Martin Bailey
Of St. Louis, MO

HDSA Chairman of the Board
1996–1999

HDSA National Treasurer and
Vice President of
Administration
1989–1995

HDSA will meet in Houston Texas
for Eighteenth Annual Convention

The eighteenth annual HDSA Convention will be held June 6–8, 2003 at the Inter-Continental Hotel in Houston. With a 2003 theme of *Empowering the Family*, this year's convention not only commemorates HDSA's 35 years of caring and curing but also emphasizes the importance of knowing what is new in HD research and care, and what you can do to help end the battle with HD.

The convention will kick off on Friday morning, June 6, with an opening ceremony featuring a special good bye from Donald King, Ph.D., departing HDSA Chairman of the Board. Barbara Boyle, HDSA National Executive Director/CEO, will deliver a "State of the Society" address which will be followed by a videotaped keynote address by Ira Byock, M.D. noted author and Director of the Robert Wood Johnson Promoting Excellence in End-of-Life Care Program.

The *HDSA Focus on the Family Forum* will be devoted to a preliminary report from the HD Workgroup, which studied the gaps and barriers to service for HD patients and families as well as best practices for care and public policy, through a grant from the Robert Wood Johnson Promoting Excellence in End-of-Life Care program. Recommendations in the areas of Education, Care, and Research will be discussed in a panel consisting of members of the HD Workgroup.

Immediately after lunch, a variety of workshops and sharing sessions will be available for attendees. For HDSA chapter leaders, there will be several workshops on budgeting, special events, developing chapter boards and planned giving, which are an absolute must for any growing chapter. An evening reception will offer all a chance to renew old acquaintances.

Saturday morning will feature the *HDSA Research Forum sponsored by Amarin Pharmaceuticals*. The Forum will focus on therapeutics for HD and promises to be informative and engrossing. The afternoon will be filled with more workshops and sharing opportunities. Saturday evening is the HDSA Awards Dinner and gala.

Sunday concludes the HDSA Convention, but not before a morning of round tables. This year, HDSA will host a formal closing ceremony and the formal introduction of HDSA's new Chairman of the Board, Robert Pearson, GCI Group.


Site of 2003 HDSA Annual Convention - Inter-Continental Hotel, Houston, TX

For more information about the 2003 Annual Convention, please contact the National Office at 800-345-HDSA, extension 35 or visit the web at www.hdsa.org. A convention registration form is conveniently provided for your use in this magazine. Please note the special Early Bird registration discount.

And also please note that registration to the Convention does not guarantee you a room reservation at the Inter-Continental. You must call the hotel to make your reservation for rooming. Call the Inter-Continental at 866-342-0831 and be sure to tell the operator that you are attending the HDSA Annual Convention to ensure that you receive the convention hotel room rate.

Airline reservations are the responsibility of the convention attendee. HDSA does not recommend any particular travel agent.

Cancellation policy: cancellations of convention registrations that are received before May 5, 2003 will be refunded in full. Those received on or after May 5 but before May 23, 2003 will receive a 50% refund. Cancellations received on or after May 23, 2003 are non-refundable. All cancellations must be received in writing by mail or fax.

HDSA 2003 Annual Convention Registration pricing (per person):

Early Bird Special (postmarked by March 28, 2003)		
$140 (individual)	$110 per adult (family)	$75 per child under 18 years
Full registration (postmarked March 29 to May 16, 2003)		
$160 (individual)	$130 per adult (family)	$75 per child under 18 years
Late or on-site registration (after May 16, 2003)		
$200 (individual)	$150 per adult (family)	$75 per child under 18 years
One day only (Friday or Saturday)		$80 per person
Saturday night dinner only		$65 per person
Inter-Continental Hotel Pricing (single, double, triple or quad)		$112 per night plus tax

HDSA Launches New Industry Council

HDSA gathered prominent leaders from the fields of research, technology and pharmaceuticals on October 10, 2002 to discuss how the Society might best identify, develop and initiate new commercial ventures to treat individuals at-risk for HD, in partnership with academia, government agencies and corporate enterprises. The HDSA Industry Council opted to focus their energies upon the following key points:

- Identification of the mechanism by which research and HD population data can be shared to help early stage entities and/or institutions accelerate their evaluation of a potential compound, and the role the Industry Council may play in facilitating this sharing of knowledge.
- Development of a coalition with industry that would offer them access to top HD researchers in order to expedite the development of drugs, treatments or therapies to a particular point in the testing process. This would eliminate costly duplication of effort and wasted research hours.
- Process to accelerate the sharing of new research both within and outside the scope of HDSA-led initiatives.
- Formation of a partnership with the National Institutes of Health in order to facilitate access to NIH resources in order to support ventures such as translational research development, large scale screening projects, Cooperative Research and Development Agreements (CRADAs), inter-institutional programs and funding of early stage work.

- Formulation of a plan to obtain patient perspectives and attitudes to treatment.
- Identification of "best practices" in HD research—best mouse model, best assay to test compounds, etc. and how the Council may share these "best practices" to accelerate the efficient development of promising targets for treatment.

The HDSA Industry Council consists of members of HDSA's national Board of Trustees, HDSA-funded researchers and corporate leaders.

Larry Powe, M.D. of Amgen, Inc. serves as Chairman of the Industry Council and is joined by HDSA national Board of Trustees members: *Donald King, Ph.D.* (Chairman of the Board), *Robert Pearson* (GCI Group and HDSA Chair elect), *Charles Dimmler III* (Lundbeck, Inc.), *David McNinch* (AstraZeneca), and *David Lennox, Ph.D.* (QBS, Inc.).

Corporate representatives include: *Michael Wess, M.D.* (Amarin Pharmaceuticals, Inc.), *Gretchen Fieschko* (Amarin Pharmaceuticals, Inc.), *James McDermott, Ph.D.* (AstraZeneca), *Victoria Richon* (Aton Pharma), *William Seltzer, M.D.* (Athena Diagnostics, Inc.), *Peter Reinhart, Ph.D.* (Cogent Neuroscience), and *Christopher O'Brien, M.D.* (Elan Pharmaceuticals).

HDSA Researchers serving on the Industry Council include: *Christopher Ross, M.D., Ph.D.* (Johns Hopkins University), *James Gusella, Ph.D.* (Massachusetts General Hospital and Chair of HDSA's MSAC), *Kenneth Fischbeck, M.D..* (NINDS, National Institutes of Health), *Richard Morimoto, Ph.D.* (Northwestern University), and *Michael Hayden, M.D., Ph.D.* (University of British Columbia).

The HDSA Industry Council is a unique way to bring together the researchers and corporations that will soon be engaged in the development of potential therapies for HD with those affected by or at-risk for the disease. Much like the HDSA Coalition for the Cure, the Industry Council will work in collaboration with HDSA to take that next step in ultimately bringing new therapies for HD to the market. It is an exciting time in HD research and the Society looks forward to reporting more on the progress made by the HDSA Industry Council in our next issue.

Team Hope *Hoop-A-Thon 2003*

Billy Aaron Brown plays Kyle Hennessey on Eight Simple Rules for Dating My Teenage Daughter *and is HDSA's national spokesperson for Hoop-a-thon. Win a trip to meet Billy and his cast members.*

Hi, I'm Billy Aaron Brown of the ABC television show *Eight Simple Rules for Dating My Teenage Daughter* and national spokesperson for the 2003 HDSA Hoop-a-thons. Get ready to leap, run and shoot for Huntington's Disease!

Hoop-a-thon season is here and this year promises to be the very best. For those of you who may not know, a Hoop-a-thon is a fun-filled event that brings together adults and kids of all ages to raise money for HD research by shooting baskets. It's easy to do and loads of fun.

Anyone can organize a Hoop-a-thon and anyone can be a shooter. All you need is a place to shoot hoops; friends, neighbors and family members who will shoot some baskets or pledge money for your shooters; and an event date. HDSA provides the prizes, the how to do it manual, and the materials you need so you can run a successful Hoop-a-thon in your hometown. Middle and High School kids have run Hoop-a-thons. Fraternal and social organizations have sponsored Hoop-a-thons. HDSA Chapters and Centers of Excellence have also organized Hoop-a-thons in their towns.

HD is a devastating disease that affects every member of the family. The only way we will find the answers is through research and so I have made the fight against HD one of my biggest personal goals. I am proud and honored to take part in this fight and I urge each of you to do whatever you can to make a difference.

To celebrate my first year as the national spokesperson for the HDSA Hoop-a-thon, I am offering a Grand Prize to the adult or youth who raises the most money at a single Hoop-a-thon: round trip airfare and two night accommodations for two in LA, plus passes to the set of my television show *Eight Simple Rules for Dating my Teenage Daughter* so you can meet the cast and crew and attend the taping of an episode. I can't wait to meet you and thank you personally for your contribution to our fight against HD.*

Other prizes include:

In the Adult Individual Category (18 years of age and older)

First Prize:
Toshiba TV/DVD

Second Prize:
Jeep Renegade Adult Sports Bike

Third Prize:
Nikon Digital Camera

In the Youth Individual Category (under 18 years of age)

First Prize:
Imperial Techno Foosball Table

Second Prize:
Jeep Renegade Youth Sports Bike

Third Prize:
Konica Mini Camera Kit

First, second and third prizes are awarded using the same criteria in descending monetary order.

**Hoop-a-thons must take place between January 5 and May 15, 2003 and you must register your Hoop-a-thon event in order to be eligible for National prizes. Pledge forms and money from participants must be received on or before May 30, 2003 from the Hoop-a-thon organizers in order for the HDSA National Office to determine the top winner.*

Hoop-a-thons are scheduled in 38 locations throughout the US.
Please call HDSA to find out how you can participate in any of the events listed or call to find out how you can organize your own Hoop-a-thon.

Date Of Hoop	HDSA Chapter	Date Of Hoop	HDSA Chapter
March 2003	New Jersey	April 26, 2003	New England Reg. Office
March 2003	San Diego	April 27, 2003	Upper Midwest Region/ Minnesota
March 2003	Kentucky	April 27, 2003	Indiana
March 5, 2003	New England Reg. Office	May 2003	Washington Metro
March 15, 2003	Iowa (Upper Midwest Reg. Office)	May 2003	Connecticut
March 23, 2003	Northern California	May 8, 2003	North Mid-Atlantic Region
April 2003	North Mid-Atlantic Region	May 8, 2003	Arizona
April 2003	Mid-Atlantic Region	May 13, 2003	Upstate NY
April 2003	Washington Metro	May 17, 2003	Wisconsin
April 2003	Rocky Mountain	May 24/31, 2003	North Mid-Atlantic Region
April 2003	Michigan	June 2003	Northern California
April 3, 2003	Northwest	June 2003	New Jersey
April 5, 2003	Ohio Valley	June 6, 2003	North Mid-Atlantic Region
April 5, 2003	St. Louis	August 2003	Mid-Atlantic Region
April 12, 2003	New England Reg. Office	August 24, 2003	NE Ohio
April 12, 2003	Central Ohio Chapter	September 2003	Northern California
April 12, 2003	Western PA	September 2003	New Jersey
April 19, 2003	North Carolina	September 13, 2003	North Mid-Atlantic Region

Team Hope: Walking for a Cure

September was Walk for a Cure month!

At HDSA's annual Convention last June, attendees were invited to join TEAM HOPE, a set of special events designed for individuals, teams or whole communities. TEAM HOPE offers HD family members and friends the chance to raise money for HDSA by organizing and participating in WALK-a-thons, HOOP-a-thons and BOWL-a-thons throughout the US. Each event is easy to do, comes with a complete manual including pledge forms and instructions for volunteers, and is guaranteed to be fun for all ages.

This September was HDSA's first Walk-a-thon month. More than 750 men, women and children walked for Huntington's Disease in Massachusetts, New York, Delaware, Pennsylvania, Arkansas, New Jersey and Texas. The largest walk was organized by the HDSA New Jersey chapter and took place in Pt. Pleasant, New Jersey. More than 200 people strolled, walked and trotted for a cure for HD.

HDSA's first Walk-a-thon month netted more than $64,000 for HDSA funded research. HDSA thanks everyone who participated and also those who organized these inaugural walks. If you would like more information about how you can organize a Walk-a-thon in your area, please call the HDSA National Office at 800-345-HDSA.

For information about HDSA's HOOP-a-thon, please see page 24.

The Marker is an official publication of the Huntington's Disease Society of America, Inc. 158 West 29th Street, 7th Floor, New York, NY 10001-5300. (212) 242-1968

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The Marker, a periodical of the Huntington's Disease Society of America, Inc., is published twice annually. Its purpose is to provide information and opinion and to relay items of interest to individuals with Huntington's Disease and their families, healthcare professionals, and interested friends and supporters.

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

The Society is a member of the National Health Council, the National Foundation for Brain Research, the International Huntington Association, the National Organization for Rare Disorders, the National Voluntary Health Agencies, the Alliance of Genetic Support Groups and the Independent Sector.

The Huntington's Disease Society of America meets all nine standards of the National Charities Information Bureau.

About the front cover: The four photos represent HDSA's mission statement of funding HD research, providing family services, educating the public and healthcare professionals about the disease and hope for a future free of HD.

CELEBRATION

HDSA Supports Care and Cure Through Celebration of Hope Events

It began with a pilot program at Emory University in 1998. From that first Center of Excellence for the treatment of Huntington's Disease, a movement and demand grew for a network of multidisciplinary facilities across the US that could provide care for those affected by HD. Today, there are 17 Centers of Excellence stretched across the US that work in tandem with HDSA chapters to provide a network of support and services that is unparalleled by any other HD organization in the world.

HDSA funded research began with four grants in 1997. In the span of just 6 years, HDSA's commitment to research has expanded to more than $3.5 million and research is conducted through the HDSA Coalition for the Cure, the HDSA Grant and Fellowship program and Therapeutics Initiative. Many of today's major advances in HD have come about through the support HDSA has been able to provide to these research efforts.

Celebration of Hope events are held annually in major cities throughout the country to support HDSA-funded research and to benefit an HDSA Center of Excellence in that region. They recognize outstanding community leaders in the fields of business, medicine and philanthropy. The galas bring together the community they serve while demonstrating the positive effects an innovative program can have on a region.

In this issue of *The Marker*, we are pleased to share with you the following events:

September 25, 2002

The Second Annual Celebration of Hope dinner was held at the Hyatt Regency Hotel in Columbus, Ohio in support of the HDSA Center of Excellence at Ohio State University. Honorees included *Geoffrey Nelson*, Artistic Director of the Contemporary American Theatre Company (CATCO), *Don Higgins, M.D., Ph.D.*, former Director of the HDSA Center of Excellence at OSU and current Associate Professor at Albany Medical College, and *Cheryl Krueger*, founder and Chief Executive Officer of Cheryl & Co. who received the Distinguished Leadership Award.

Gary Nash and his family were honored with the HD Humanity Award.

(l-r) Lana Chandler, Lauren Becker, Michele Revelle, Event Committee members are joined by Thomas Tierney, former State Senator Marian Bergeson and Leslie Thompson, Ph.D., the 2002 honorees, with Marilyn C. Brewer, Assemblywoman and Event Co-Chair, and Peggy Goldwater Clay, Event Committee member.

October 2, 2002

This glittering event was held at the Hyatt Newporter, in Newport Beach, CA, to benefit HDSA funded research at the University of California at Irvine. Honorary Chairs of the event were *former President Gerald Ford and his wife Betty Ford*. Committee Co-Chairs were *former State Senator Marian Bergeson and Assemblywoman Marilyn C. Brewer.*

HDSA was proud to honor *Thomas T. Tierney*, CEO of Body Wise International; *Marian Bergeson*, former State Senator and California Secretary of Education; and *Leslie Thompson, Ph.D.*, HDSA-funded researcher.

Linda Oades gave a moving and eloquent tribute to her late husband Skip. Major contributors for the evening's festivities included *John Hagestad* of the Sares Regis Group; the *Allergan Foundation, the C. Brewer Company* and *Joan Winchell*.

October 8, 2002

William Fox Dinner (l-r) Joseph Gerber of Cozen O'Connor, Chip Roach, Dinner Chair, Mark Blaskey of Pepper Hamilton LLP, Sandy and Bill Fox

The G. William Fox Corporate Humanitarian Dinner was held at the Four Seasons Hotel in Philadelphia to support research.

Honorees included *Cozen O'Connor* and *Pepper Hamilton LLP* for their outstanding commitments to the health, safety and well-being of men, women and children through their corporate citizenship in many greater Philadelphia charities.

A special Leadership Award was presented to *Robert Madden*, past president of the HDSA Delaware Valley Chapter.

Chip Roach, President of Prudential Fox and Roach Realtors, and Chair of this prestigious event, served as Master of Ceremonies. Vice Chairs included *Steven Earhart, Joseph A. Gerber, Harmon Spolan, Mark Blaskey* and *Bill and Sandy Fox*.

OF HOPE

Denver Dinner (l-r) Honorees Artemis Khadiwala-Donian, Darby and Lorraine Smith with Dinner Chair Florence Ruston and honorees Scottie Taylor Iverson and Jeff Snowdon

October 23, 2002
The Denver Center for the Performing Arts played host to this elegant evening of jazz and philanthropy to benefit the HDSA Center of Excellence at the Colorado Neurological Institute. *Florence Ruston*, noted Denver philanthropist, served as Honorary Chair of the gala. Corporate Chairs included *Tim Stillwell* and *Randy Jensen*. *Nanette Ward* served as Auction Chair.

Honorees for this 2002 Celebration of Hope event were *Scottie Taylor Iverson* of Swan Taylor Denver; *Artemis Khadiwala-Donian*, community leader and well known volunteer; *Lorraine and Darby Smith*, philanthropists; and *Jeff Snowdon*, former HDSA Chapter President and longtime volunteer.

Theresa Marchetta, local TV newswoman served as Mistress of Ceremonies. Major contributors for the gala included *Dusty and LaFawn Biddle*, *Denver Center for the Performing Arts*, *Athena*, *Drs. Mark Harrison and Eileen Fish*, *Florence Ruston*, *Level 3 Communications*, *Scotti and Kevin Iverson*, *S&S Plumbing Services*, and *Darby and Lorraine Smith*.

Norm Early, former District Attorney of Denver and current children's book author, served as the auctioneer at the live auction.

Honoree Dr. Martha Nance with her father, Dr. Walter Nance

October 30, 2002
The Hilton Minneapolis was the site of the 2002 Celebration of Hope Dinner to benefit the HDSA Center of Excellence at Hennepin County Medical Center. *Congressman Jim Ramstad* served as Event Chair for the gala, with *Chris Conangla* of TV UPN 29 and *Randy Olson*, Educational Director of Minnesota Project Innovation, serving as MC's for the evening.

The Minnesota Celebration of Hope honored *Barbara Andrews*, longtime HDSA volunteer and owner of Andrews Group; *Thomas Heffelfinger*, US States Attorney for Minnesota; and *Martha Nance, M.D.*, Director of the HDSA Center of Excellence at Hennepin County Medical Center.

The Sally Hogan Award was presented to the *Berges-Shriver Family*. The award is given each year to a family that demonstrates courage and conviction in their battle with HD. Gayle Saunders, former HDSA Minnesota Chapter Board member, presented the award. A special tribute was paid to *Bruce and Janet Bergman* for their continued financial support of the HDSA Center of Excellence at HCMC.

Major contributors included *Peregrin Management*, *Bruce and Janet Bergman*, *Yoplait-Columbo* and *Jack* and *Gretchen Norqual*.

Honorees Bill and Ramona Johnston (left) with San Diego Chargers Coach Marty Schottenheimer and his wife Pat

Honorees Cheryl and Ron Kendrick will serve as Chairs of the 2003 Celebration of Hope event in San Diego

November 1, 2002
HDSA honored *Kurt Benirschke, M.D.*, Professor Emeritus at the University of California at San Diego; *Jerry Coleman*, announcer of the Padres and *his wife Maggie Coleman; Ron Kendrick*, Executive Vice President of branch banking operations for Union Bank of CA and *his wife Cheryl Kendrick*, Campaign Director for the United Way of San Diego County at an elegant Celebration of Hope event that was held at the Manchester Grand Hyatt in San Diego.

Honorary Chairs of the evening's events were *Dean* and *Susie Spanos* of the San Diego Chargers. *Laura Buxton* and *Stan Miller*, TV newscasters, served as Mistress and Master of Ceremonies.

continued on page 28

Special guests included San Diego Chargers players *Tim Dwight* and *Drew Brees* and *Marty Shottenheimer*, coach for the Chargers.

Bill and Ramona Johnston were honored with the HD Family of the Year Award.

Major contributors of the event, which benefited both the HDSA Center of Excellence at the University of California at San Diego and HDSA research, included *Dean and Susie Spanos*, *Union Bank*, *HDSA San Diego Chapter*, *Charlene and Patti Berger*, *Madeline Kuhn*, *San Diego National Bank*, and *Michael and Delia Riley*.

A live auction featured San Diego Chargers player *Marcellus Wiley* as the guest auctioneer.

Vicki Wheelock, M.D., Director of the HDSA Center of Excellence at UC Davis accepts award from Conrad Pappas, M.D., Ph.D.

January 23, 2003

A stellar evening at the Hyatt Hotel in Sacramento provided support for the programs at the HDSA Center of Excellence at the University of California at Davis Medical Center. Honorees for this Celebration of Hope event included *Vicki Wheelock, M.D.*, Director of the HDSA Center of Excellence at UC Davis, *The Roberson Family* and *Bob Earl*, President of Sundt Construction of Sacramento. *Laura Penna*, the local health reporter, served as Mistress of Ceremonies. The event was attended by more than 260 individuals and included a silent auction.

All Family Funds, cash gifts, pledges, tributes, memorials or bequests established or renewed in 2003 will be matched through the

Generation 2000: Fulfilling the Promise

Research Matching Gifts Challenge Fund

Upcoming Events:

HDSA is pleased to announce the following Celebration of Hope events for the care and cure of HD. If you would like more information about a specific event, please contact the HDSA National Office at 800-345-HDSA.

May 16, 2003 Baltimore, MD: in support of the HDSA Center of Excellence and research conducted at Johns Hopkins Hospital/Johns Hopkins University.

May 17, 2003 Boston, MA: in support of the HDSA New England Center of Excellence at Massachusetts General Hospital/Tewksbury Hospital and research conducted in Massachusetts.

June 2003 San Francisco, CA: wine tasting and auction to benefit research conducted in San Francisco.

June 2003 Iowa City, IA: Celebration of Hope reception to benefit the HDSA Center of Excellence at the University of Iowa.

Spring 2003 Atlanta, GA: Celebration of Hope event to benefit HDSA-funded research and the HDSA Center of Excellence at Emory University.

July 2003 Novato, CA: cocktail reception to benefit HDSA-funded research at the Buck Institute for Age Research.

August 2003 Long Island, NY: golf tournament to benefit George G. Powell HDSA Center of Excellence at North Shore University Hospital.

September 19, 2003 Denver, CO: Celebration of Hope dinner to benefit HDSA Center of Excellence at the Colorado Neurological Institute.

September 2003 Minneapolis, MN: casino night and dinner to benefit HDSA-funded research in Minnesota.

September 2003 Northern CA: golf tournament to benefit HDSA-funded research in region.

September 2003 Sacramento, CA: Celebration of Hope dinner to benefit programs at the HDSA Center of Excellence at the University of California at Davis Medical Center.

September 2003 Columbus, OH: Celebration of Hope dinner to benefit the HDSA Center of Excellence at Ohio State University.

September 30, 2003 Seattle, WA: in support of the HDSA Center of Excellence at Washington University School of Medicine and research conducted in Washington.

October 2003 San Diego, CA: Celebration of Hope event to benefit HDSA-funded research and HDSA Center of Excellence at the University of California at San Diego.

November 4, 2003 Philadelphia, PA: Third Annual G. William Fox Corporate Humanitarian Dinner to benefit research.

Imagine Yourself Driving Down the Road in the Open Air!

It's once again time for the HDSA Driving Toward a Cure BMW Sweepstakes. This year, we are pleased to offer a 2003 BMW Z4 2.5i convertible or $25,000 cash as our first prize. Just imagine yourself cruising down that open road, top down, gently blowing breezes swirling around you in your newly redesigned roadster! Or imagine yourself $25,000 richer. Tickets are limited so be sure that you call for yours today.

And remember, for every two tickets that you buy or sell for HDSA, you receive a third one free. Tickets are $100 each (three for $200) and limited to just 2,500. Winners will be drawn at the 2003 HDSA Annual Convention in Houston Texas on June 7 during the annual gala and awards dinner. Winners need not be present to accept their prize.

All proceeds benefit HDSA research initiatives including the HDSA Coalition for the Cure, the Grant and Fellowship program and HDSA's Therapeutics Initiative. The donation you make may be the one that completes the HD puzzle so please be generous.

Additional prizes include: Second prize of $5,000 cash, Third prize of $2,500 cash, Fourth prize of $500 cash and Fifth prize of $500 cash.

For more information or for additional tickets, please contact the HDSA National Office at 800-345-HDSA or email hdsainfo@hdsa.org. You can also visit the HDSA national web site at www.hdsa.org to request your 2003 Driving Toward a Cure Sweepstakes tickets today!

HDSA would like to extend its sincerest thanks to BMW North America for helping to make this annual sweepstakes possible.

Winner of Super Bowl Drawing Goes to Sunny California

In December, HDSA invited our friends and family members to enter our inaugural Super Bowl Sweepstakes while raising vital funds for HD research. To make it really interesting, HDSA offered as a Grand Prize a weekend package to Super Bowl XXXVII, which was held in sunny San Diego on January 26, 2003.

Our winner was Susan Farque of Little Rock, Arkansas. A second prize of $2,000 went to Peter King of Farmington, Connecticut and a third prize of $1,000 went to Randy Dougherty of Wheatland, Missouri.

HDSA would like to express its thanks to the National Football League, the San Diego Chargers and to Bill Johnston, Public Relations Director for the San Diego Chargers for their support.

Final Edition of HDSA's Journal of Hope

At the 2003 HDSA Annual Convention Awards Dinner and Gala, HDSA will officially kick off the tenth anniversary commemorating the discovery of the gene in 1993 and the twentieth anniversary of finding the marker for the gene.

To celebrate this momentous event and to conclude the 35th anniversary celebration of the founding of HDSA, the Society will be publishing a final edition of the much-treasured *Journal of Hope*. We invite readers to send tributes or memorials to remember a loved one who has so courageously battled HD so it can be included in this final edition. We also invite you to enclose a photo of your loved one so it can be included in a moving slide presentation during the Convention gala.

Please be sure to identify your loved one on the back of the photo and include your name as well. Photos cannot be returned.

HDSA also asks that you make your contribution to *Generation 2000: Fulfilling the Promise* so that advances in HD research can continue. Please use the envelope that can be found in this magazine to write your message of hope for the final edition of the *Journal of Hope* and to make your contribution to *Generation 2000*.

GIVING OPPOR

YOU CAN MAKE A DIFFERENCE

Huntington's Disease is a family disease. It affects every member of the family socially, economically and emotionally. HDSA was formed 35 years ago to do something about this devastating disease that reaches from one generation to the next. HDSA funds research that will soon develop effective treatments and that will eventually lead to a cure, while providing support and services to those affected by the disease and their families. It also educates both the public and healthcare professionals about HD. HDSA accepts no government funding and relies upon the generosity of donors, like you, to continue our mission.

You are a vital part of our ability to continue our financial commitment to research. Since the creation of the HDSA Coalition for the Cure, HD research has accelerated tremendously. Our scientists now say "when we find" not "if." Your gift of hope has made this possible. Your commitment to HDSA-funded research has brought us to the brink of an effective therapy for our HD family members.

So too have your generous contributions to HDSA provided vital services to our HD families. Our Centers of Excellence have seen a tremendous growth in the number of HD patients they see in their regions and they have eagerly reached out to the community at large to provide educational opportunities to the public, HD family members and allied healthcare professionals alike. Today, HDSA spans the country with a network of resources and referrals that is unmatched by any other HD organization in the world. Without your continued support, HDSA could not offer this wonderful set of services to our HD families.

There are many ways that you can continue to show your support to HDSA's mission of research, care and education. Every dollar contributed is used to advance the care and cure of HD.

Contributions to any of HDSA's giving programs may be made through the HDSA national web site at www.hdsa.org or through the National Office. To make a gift on-line, simply click on "Ways to Give" and then select the program to which you wish to contribute. Below are just a few of the ways that you can make a difference in the lives of every man, woman and child affected by Huntington's Disease.

Generation 2000: Fulfilling the Promise

In January 2001, HDSA launched phase two of Generation 2000: Fulfilling the Promise in an effort to raise $25 million for HD research over the next five years. Our scientists tell us that we are close to developing effective therapies and ultimately a cure for this deadly disease. But to accomplish our goal, we need your help.

Through the generosity of a few HD families, HDSA has created a matching gift fund for phase two of Generation 2000. Every gift made, whether through a Family Fund, individual donation, tribute or memorial will be matched dollar for dollar by the Research Matching Gifts Challenge Fund. Please consider making your donation today. Together we CAN make this the last generation with HD.

HDSA Family Funds

The HDSA Family Fund program was created to provide family members and friends with the opportunity to contribute more than one might be able to individually. A Family Fund may be created in honor of your family or in memory of a loved one. With an annual gift, a Family Fund may sponsor or co-sponsor an HDSA Coalition for the Cure investigator or a grant or fellowship recipient or it may partially fund a research project. Family Funds may also be designated to support any of HDSA's family service or educational programs such as The Marker magazine or the Family Guide Series which provide free information to members of the HD family and healthcare professionals. To create your Family Fund, please contact the National Office.

Cash and Pledges

Charitable cash contributions and pledges provide significant tax benefits while supporting HDSA's three pronged mission statement—to fund HD research, provide services and support for our HD families and educate the public and healthcare professionals about HD.

Pledges may be made over a period of three years or longer and may be payable quarterly, semi-annually or annually.

Tribute & Memorial Gifts

Gifts made as a tribute to or in memory of a loved one help HDSA to provide the support and commitment needed to advance the care and cure of HD. A personal acknowledgement is sent to the individual or family in whose honor the gift has been made and a separate receipt is sent to the donor for tax purposes.

Stock, Securities or Real Estate

Gifts of stock, securities or real estate provide tax benefits while avoiding all capital gain taxes. Gifts allow the donor to claim the current market value (not the purchase price).

Heritage Club

- Individual planned giving—you can remember HDSA in your estate plans by joining the Heritage Club. Use your will, trust or estate assets to make a contribution to HDSA while receiving valuable tax benefits. Below are types of planned giving that you may consider:
  - Bequests—remember HDSA in your will
  - Gifts of Personal Residence or Farms with a Retained Life Estate
  - Life Income Gifts - Charitable Gift Annuity, Pooled Income Fund or Charitable Remainder Trust
  - Gifts of Insurance

For more information about HDSA's Heritage Club please contact the National Office.

One Man's Way to Remember

Dan Heitt was a very unique yet modest man. He became involved in HDSA's Northern California chapter in late 1999. In addition to being in the early stages of Huntington's Disease, Don had leukemia. At that time though Don had no significant health problems as a result of either condition.

Don felt compelled to help HDSA in ways that were meaningful to him. He was always interested in the problems that affected others and frequently offered ideas of how HDSA might improve its services to HD families in California. He routinely attended three support groups in the San Francisco Bay area and eventually became involved in the local HDSA chapter's Family Services Committee that helped guide new and innovative programs for HD families in that area.

Unfortunately, Don Heitt's leukemia flared up following minor surgery in late October 2002 and he was hospitalized until his death in December. He had no immediate family but was surrounded by numerous friends during his hospitalization. In spite of his very grave condition, Don maintained his wonderful sense of humor.

He will forever touch those who were fortunate to know Don Heitt. And true to form, Don has touched the lives of thousands of patients who suffer from HD and their families in Northern California. You see, Don Heitt included HDSA in his will and provided a bequest that is to be used for family services in the Northern California region. The Don Heitt HDSA Social Work Chair for Family Services will specifically fund the regional social worker position that provides much needed services to families. It will be administered through the HDSA Center of Excellence at the University of California at the Davis Medical Center, which currently provides limited social services as part of their annual grant.

HDSA is pleased to remember Don Heitt with this fitting tribute. His legacy and generosity will not be forgotten. HDSA wishes to remind you that you too can remember HDSA in your will. Please call the National Office at 800-345-HDSA to talk about planned giving.

All Family Funds, cash gifts, pledges, tributes, memorials or bequests established or renewed in 2003 will be matched through the

Generation 2000: Fulfilling the Promise

Research Matching Gifts Challenge Fund

HDSA Chapters

HDSA has volunteer-based chapters and affiliates across the US to serve our HD families. HDSA chapters and affiliates help to raise funds to support HDSA-funded research, provide support and family service to those affected by HD and their families and educate both the public and healthcare professionals about HD.

ALABAMA

Alabama Support Group
Pinson, AL
T: 205.325.3877

ARIZONA

Arizona Affiliate
Phoenix, AZ
T: 602.222.9321
T: 888.267.3411

ARKANSAS

Arkansas Affiliate
T: 800.558.3370

CALIFORNIA

Greater California Chapter
Beverly Hills, CA
T: 888.443.7252

Northern California
Sacramento, CA
T: 510.232.4868

San Diego Chapter
San Diego, CA
T: 760.752.1844

COLORADO

Rocky Mountain Chapter
Wheat Ridge, CO
(Also serves MT area)
T: 888.740.4372 (CO only)
T: 303.321.5503 (help)

CONNETICUT

Connecticut Chapter
Southington, CT
T: 800.840.9907

DELAWARE

Delaware Valley Chapter
Norristown, PA
(Also serves southern NJ area)
T: 610.277.1006

FLORIDA

South Florida Chapter
North Miami, FL
T: 305.271.7411

GEORGIA

Georgia Chapter
Atlanta, GA
T: 770.279.9207

ILLINOIS

Illinois Chapter
Rolling Meadows, IL
T: 630.443.9876

INDIANA

Indiana Chapter
Indianapolis, IN
T: 317.271.0624

IOWA

Iowa Chapter
Bedford, IA
T: 712.523.2291

KENTUCKY

Kentucky Chapter
Louisville, KY
T: 502.637.4372
T: 800.784.3721 (help KY)

MARYLAND

Maryland Chapter
Baltimore, MD
T: 410.467.5388

MASSACHUSETTS

Massachusetts Chapter
Framingham, MA
(Also serves MA, ME, NH, RI, & VT areas)
T: 888.872.8102
T: 508.872.8102

MICHIGAN

Michigan Chapter
Dimondale, MI
T: 517.646.0920
T: 800.909.0073 (help)

MINNESOTA

Minnesota Chapter
Minneapolis, MN
T: 612.371.0904

MISSOURI

St. Louis, MO
T: 314.961.4372

NEW JERSEY

New Jersey Chapter
Cranbury, NJ
T: 609.448.3500

NEW YORK

Upstate NY Chapter
Rochester, NY
T: 585.341.7400

NORTH CAROLINA

North Carolina Chapter
Cary, NC
T: 919.387.7812

OHIO

Central Ohio Chapter
Columbus, OH
T: 614.460.8800

Northeast Ohio
Chesterland, OH
T: 440.423.0506

Ohio Valley
Cincinnati, OH
(Also serves WV area)
T: 513.741.4372

OKLAHOMA

Oklahoma Chapter
Oklahoma City, OK
T: 405.810.0695

PENNSYLVANIA

Western Pennsylvania
Pittsburgh, PA
(Also serves WV area)
T: 412.833.8180

SOUTH DAKOTA

Sioux Valley Chapter
Sioux Valley, SD
(Also serves ND, MT)
T: 605.334.9917

TENNESSEE

Mid-South Affiliate
Cordova, TN
T: 901.755.0205

TEXAS

Texas Affiliate
Flower Mound, TX
T: 972.724.1367
T: 800.910.6111

VIRGINIA

Washington Metro
Fairfax, VA
T: 703.204.4634
T: 703.323.1403 (help)

WASHINGTON

Northwest Chapter
Seattle, WA
(Also serves OR area)
T: 206.464.9598
T: 703.323.1403 (help)

WISCONSIN

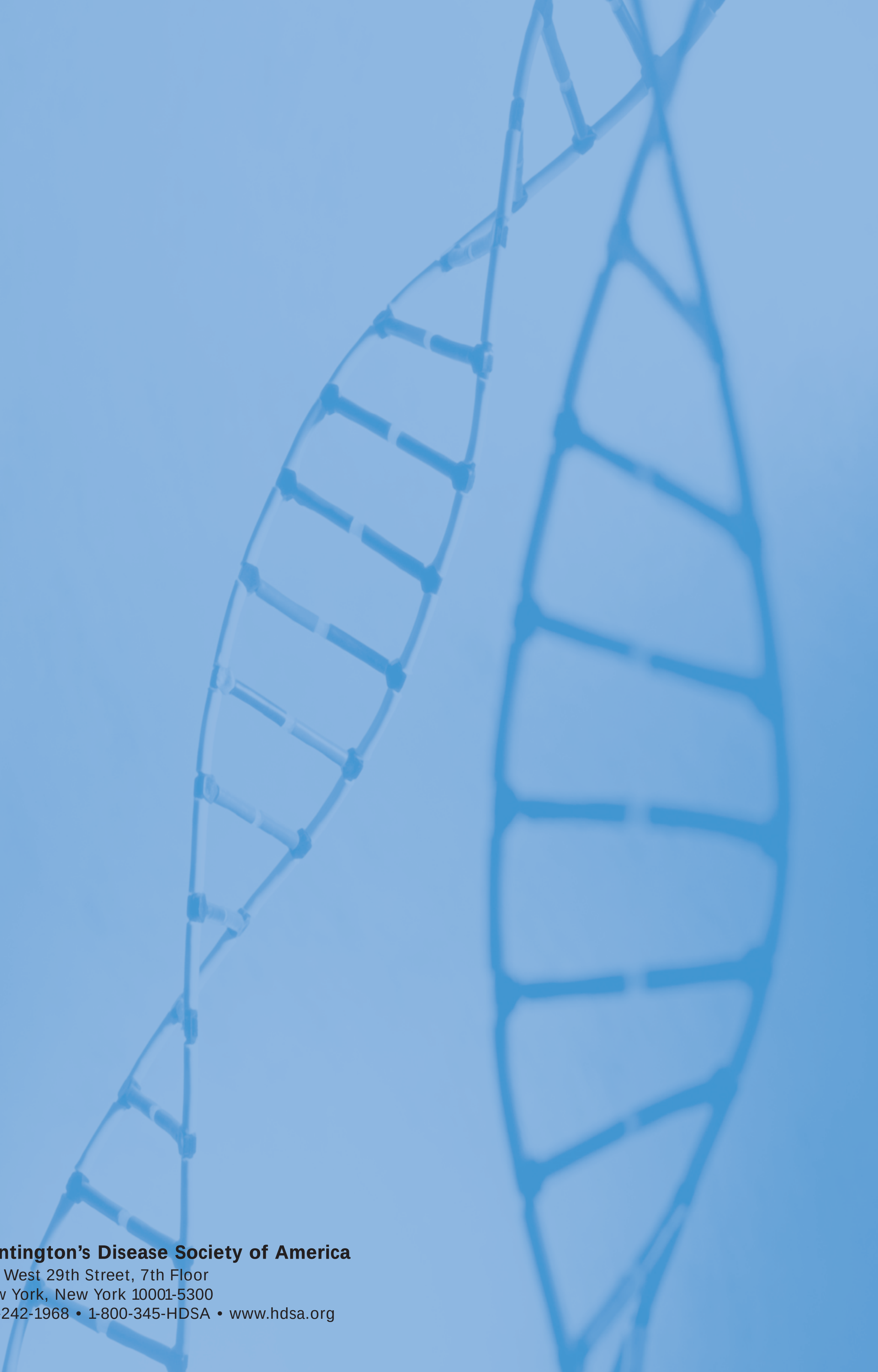
Wisconsin Chapter
Wauwatosa, WI
T: 414.257.0248
T: 879.330.2699 (help)

Contact information may change after publication. Please contact the National Office at 800-345-HDSA or visit the web at www.hdsa.org for updated information.

THE FACE OF HUNTINGTON'S

"My only child, Kelly, died of complications related to Huntington's Disease. Kelly's favorite color was pink. Is there any mystery then that, whenever I walk the beach at sunrise, the skies are painted in shades of pink? To some, probably not. To me, these are a gift from Kelly letting me know that love is endless."

Jean Miller



HDSA

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