



HDSA Minnesota Highlights

December 2009



Good News Only. . . .

This is my inaugural newsletter as the incoming president for the Minnesota Chapter of HDSA, and I wish to thank my predecessor, Jill Sinclair, for her leadership and dedication to the families of Minnesota. She will continue to serve on the board for another year but leaves her role as president of an organization that is in great shape with a strong team of volunteers serving on various committees and working on exciting fundraisers. Jill has been the champion of this fantastic newsletter, and I believe you'll all be encouraged by the vast amount of useful information that you'll see inside this edition.

By way of introduction, my family has been involved with HDSA for over ten years as my wife served on the board 12 years ago. She has HD and now lives in one of the wonderful group homes in Burnsville. I have two adult children who are at risk and we channel our "energy" in the fight against this disease by raising money for research and awareness. We'd best be known as the Hoop-a-thon family. You'll read more about the event and my family in the "The Other Side of a Dark Disease" by Dr. Martha Nance in this edition.

At my place of business we occasionally have what we call "good news only" days. During those days we try to focus on things that make us feel good despite the fact that we have many challenges around us. So, my inaugural letter to you is titled the "good news only" edition of the chapter newsletter. Inside you'll read good news from our doctor and social worker and details from the World Congress on HD. (Did you know there was such an event?) We have some exciting fundraisers happening in 2010, and the listed support group sites around the state provide a resource for families in need of help. You'll also see that we've made some new friends with our newest HDSA affiliate in Grand Forks, ND and plan to work closely on services and programs that benefit our families. Our 2009 State Convention was held in October and those who

attended heard about the 8 Reasons for Hope. Lots and lots of good news!

On behalf of the volunteers who serve in the MN Chapter of the Huntington's Disease Society of America, we wish you a safe and happy holiday season. We'll continue to work on your behalf, but what we ask from you in return is to get involved — stay hopeful — reach out for help — attend a fundraiser — become an advocate — keep smiling.

Sincerely, Bryan Viau,
HDSA Minnesota Chapter President



Rick and Mary Barlow in Alaska.

Angels Among Us

2006 was one of the hardest years of our lives. I knew that something was wrong with my husband Rick. I had been told it was Tourette's syndrome, but that diagnosis no longer made sense to me.

My First Angel

We were having some financial problems, and I suggested to Rick that I take on a part-time job in addition to my regular work. Rick was retired and at home 24/7, but he thought it was a good idea. After hearing that, I went to my best friend Kathy's house and cried for hours. How could this man that I loved so much be so uncaring? How could I work two jobs while he was at home doing nothing? It didn't make sense. Well, it didn't make sense to Kathy either. With her help through winding channels, we finally got in touch with Dr. Parshos and then Dr. Nance.

We received a letter in the mail full of difficult medical terminology but I could understand enough to determine that Rick had Huntington's Disease. We'd never heard of it, and there is no history of Huntington's in the family.

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UPCOMING EVENTS

The Blast — February 27, 2010



Rick Allan and his daughter Carleigh

The Other Side of a Dark Disease

Martha A. Nance, MD

Hennepin County Medical Center HDSA Center of Excellence

If you have ever seen, heard, or read about Huntington's Disease (HD) in the media, you have undoubtedly seen a portrayal of anguish, sadness, and suffering. There is another side to HD, though, which needs to be told, a story of beauty, courage, engagement, and inspiration. As a physician specializing in HD in Minnesota, I have been privileged to be a part of the stories I share below. I am sure that there are similar stories from other families around the country facing other types of disease or trauma, but even if these stories are commonplace, they deserve to be told as an antidote to the erosive acid of the stories that fill the Internet, television, and newspapers on daily basis. The names of children and my patients have been changed to protect their privacy, except where the individuals are already known to the public.

I. It is 1998. Ten-year-old BJ has learned that his mother has HD, and he wants to do something to help. But what can a ten year old do? BJ likes to play basketball, so with a little encouragement from his father, he organizes a "hoop-a-thon" in which he and his buddies collect pledges and sink as many free throws as they can in five minutes. They have fun, and so they do it again the next year. And the next year. And the next. Twelve years later, this amazing early spring festival of health and youth and hope has raised over \$500,000 for HD research. Crunch, the Minnesota Timberwolves mascot shows up. The whole Apple Valley community shows up. The local hamburger place donates its weekend proceeds to the event. Six thousand graduates of Eastview High School over the last ten years have heard of HD. BJ's mother, now in the late stages of her disease, instead of being shunned as so many others with HD seem to be, has been a welcomed spectator throughout BJ's basketball career. A college senior in 2009, BJ captained his team to a 30-1 record and a quarterfinal appearance in the national tournament.

II. It is an April evening in 2001 and Joe is sweating. He is in the midst of the first ADE (Auction-Dinner-Entertainment) for HD event, organized in honor of his recently deceased wife. He has packed his guests in at the Pavilion in Belle Plaine, Minnesota, and the room is hot with the crowd of people. Joe is an auctioneer, soon to be inducted into the Minnesota State Auctioneers Hall of Fame, and is well known in the community of about 4,000 people, about forty miles southwest of Minneapolis. There are tables full of food and drink and live and silent auctions scheduled for the event. Every barber shop, restaurant, and gift shop in a twenty-mile radius has donated something for the raffle or the silent auction. A local artist's painting and a large recycled plastic porch rocking chair are among the live auction items. Joe has shaken hands with everyone, finished the raffle, and is just now completing the live auction. He has poured his heart and soul into this event. "Just one more thing," he says. "We thank you for everything you have done for us tonight. But just one more thing before we go. . . . My wife had difficulty brushing her teeth because of her HD. So I bought her an electric toothbrush, and it made that part of her life just a little bit better. If she needed an electric toothbrush, I'm sure there's someone else out there with HD who could use an electric toothbrush, too. I'm going to stand up right now and pledge to buy a \$30 electric toothbrush for someone else with HD." He voice cracks slightly. "Who else will stand up with me and buy a toothbrush for somebody with HD?"

One person stands up, then another, then a whole family, a whole table, and pretty soon at least two thirds of the people in the room are standing. Tears mixed with sweat, people applauded for a long time, and I just about fell off my chair. I had over 100 toothbrushes and a story of love to hand out to my HD patients that year and every year since then, thanks to Joe, his family, and the community of Belle Plaine.

III. It was a frigid night in February 2005 during the Midwinter Blast, a fundraising event to support the HD Center of Excellence that I direct in Minneapolis. This event also had a live auction, and Joe from Belle Plaine was at the microphone again. Maybe what happened next has to do with how Joe ended up in the Hall of Fame. Maybe it's one of those Minnesota things. Maybe I am naïve and it was all a contrived gimmick. It was amazing, nonetheless. There were three or four prizes that sold for modest amounts, but during the auction, a water pitcher was passed around the audience with the instruction to add some cash to it, and it would be auctioned off as the last item. Dollars, quarters, ten-dollar bills, all ended up in the pitcher. Joe got the bids going, and soon the pitcher sold for \$2000 to a lady from Burnsville. "Take it back," she said. "Sell it again." The next time it sold for \$1500. "Do it again," the second winner said. "Sell it again," the third winner said. Four times Joe sold the water pitcher, for \$1500 to \$2000 each time. An anonymous donor (we found out later) matched the auction bids that night. In the end, a plastic jug of dollar bills (that none of the winners kept) raised over \$10,000 for Huntington's disease care and services.

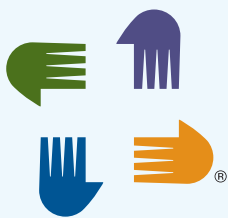
IV. The year 2009 was the fifth year of the "JJ" Golf Tournament and the second year I have attended. JJ was a hockey star in the 1970s from Bloomington Jefferson High School (and I suspect he was also a class prankster). He had a good life, a beautiful wife, and two nice kids before HD tore his life apart. His wife, although still involved, has ended their marriage, and HD interferes with JJ's ability to work, cook for himself, and organize his life. He is skinny, has severe chorea (the involuntary reaching and lurching movements that make non-understanders recoil from people with HD), no longer drives, and struggles to manage his daily affairs. Seeing what has happened to JJ, his high school buddies—mostly from Jefferson, but some from archrival Bloomington Kennedy—got together to create a trust fund for JJ and his kids, help him organize his medical and financial affairs, make sure he eats, and drive him to appointments. A

hundred and forty people showed up for a charity golf tournament to support JJ. At the post-golf dinner, the Jefferson guys were on one side of the room, and the Kennedy guys on the other, chucking memories and barbs and gentle threats at each other throughout the evening, all in good fun, and all for JJ. How many of your high school classmates would show up at your golf tournament, drive you to your doctor's appointment, and help you write your checks?

V. The week before the JJ Golf Tournament, I saw Paul, one of my long-time HD patients. He came to his appointment with his daughter, who told me this story about her daughter, Ellen. Ellen was in fourth grade. At her elementary school in White Bear Lake, fourth-graders are invited to become "Core Values Leaders." To become a leader, the student has to propose a "Core Values Initiative" and explain why it is important and reflects certain core values. The selected projects are carried out by the class. For Ellen, who loves her grandfather and who has attended HD Hoop-a-thons every year of her life, it was a no-brainer to propose a "Fun Run for HD" to take place during recess. Her teachers accepted her proposal right away. The kids put up posters around the school and all the grades contributed pledges, parents made sure each kid had a prize at the end of the run, and Ellen rummaged around in her dresser drawers where she has many HD Hoop-a-thon T-shirts, so that each kid could wear an HD T-shirt on the Fun Run day. At the end of recess that day, Ellen had collected \$680, which she presented to her grandfather to give to HD research.

Closing thoughts

As it passes from generation to generation, HD insinuates itself into the fabric and history of a family and community. I have heard many stories of sadness, scorn, and hopelessness among my patients. But I hope that these tales of humanity and generosity will serve as a reminder that families, friends, and communities have the potential to do great good—and that the goodness, in turn, will rub off on others in ways that we may never know. All of the stories I have told have to do with raising money, but you need to know that the generosity of these families and communities does not stop at the checkbook. Paul and a number of his family members have participated in HD research studies, as have JJ and some of Joe's children. Paul will tell you proudly that tetrabenazine is available in the United States today because of him! The lady from Burnsville not only bought a pitcher of money and then returned it, but along with her daughter, also opened a group home for people with HD, which has been a stunning success and help to the community. BJ's mother, who worked on advocacy with the HD chapter for many years, lives in the group home. And BJ, when he addressed the World Congress on Huntington's Disease in Vancouver last month, had no idea that the Hoop-a-thon that he started half a generation ago has empowered another ten year old to bring her energy and creativity to the fight against HD.



HD CENTER OF EXCELLENCE We're Here for You!

The HD Center of Excellence continues to provide excellent clinical services for patients and families facing the diagnosis of Huntington's Disease. If you are scheduled for an appointment on the third Wednesday of the month you have the possibility to meet with any or all members of a multidisciplinary team, depending on the recommendations of the physician. You will be seen by either Dr. Martha Nance or Dr. Scott Bundlie, who will then determine what additional specialist(s) you may need to see. Those specialists include a social worker, dietitian, speech-language pathologist, occupational therapist, physical therapist, genetic counselor,

research nurse and/or neuropsychologist. Your visit is shaped around your needs and we're here to offer you support, provide ideas/solutions for gait or daily living issues, analyze your swallowing and determine your menu/calorie needs, link you with resources in the community, find out what social or psychological needs you may have, and/or determine if neuropsychological testing is appropriate. Our genetic counselor is available to discuss test results with you or answer any questions you may have. Or you may want to explore opportunities for participation in a research project by meeting with our research nurse. It's a one-stop coordination of services to best fit your needs as you face the challenges associated with HD. ■ **QUESTIONS?** Please call 612-873-2595, Option 4. Or check our web page at www.hcmc.org. Click on Hennepin A-Z, then scroll down to the "H" section and click on **Huntington's Disease Center of Excellence**.

Support Group meetings are for people who are at risk for HD, persons with HD, and families of people with HD.

DULUTH, MN

Bayshore Nursing Home
1601 St. Louis Avenue
Every fourth Tuesday, 6–7:30 p.m.
Facilitator: Angela Sjodin

RICHFIELD, MN

Oak Grove Lutheran Church
7045 Lyndale Avenue S.
Every third Saturday,
10:30 a.m.–12 p.m.
Facilitator: Jessica Hancock

ROCHESTER, MN

Bethany United Methodist
1835 19th Avenue NW
Every third Saturday, 3 p.m.
Facilitator: Jessica Hancock

GRAND FORKS, ND

Altru Hospital
Meeting rooms F and G,
1200 S. Columbia Road
Every second Saturday,
10:30 a.m.–12 p.m.
Facilitator: Jayne Brown, LSW
(701) 352-1620

For more information, contact
Jessica Hancock, LSW, at
(612) 371-0904 or
jhancoc1@good-sam.com.



Research and Care-Giving Are the Focus of World Congress on HD

By Bill Kaemmerer, MN-HDSA board member

Over 700 scientists, physicians, caregivers, patients, and family members from around the world registered for the World Congress on Huntington's Disease held in Vancouver, British Columbia, September 12-15, 2009. Participants' days were busy with an opening session each day (BJ Viau spoke at the first one of these sessions about the Hoop-a-thon and related experiences). Then, during the late morning and early afternoon, participants broke out into parallel "Science Sessions" and "Care Sessions," and each day culminated in a group "Evening News" session designed to recap the highlights of all sessions in terms everyone could understand. Care Sessions covered topics such as Living with HD, Symptomatic Therapy for HD, Improving the Quality of Life for People with HD, and Coping Strategies for HD Families. As a neuroscientist, I attended the combined sessions and the Science Sessions. The following are some highlights of the Science Sessions.

Raif Reilmann of the University of Muenster, Germany, reported on the engineering of gadgets to measure motor performance in HD patients more precisely than a doctor's observations, so that clinical trials of treatments can be more informative and perhaps shorter. So, if you participate in a clinical trial in the future and find yourself asked to push a (clean) lever with your tongue just hard enough to match a force displayed on a computer screen, know that it is for a good cause.

Clive Svendson from Cedar-Sinai Medical Center in Los Angeles reported on a powerful new tool for investigating HD. Recently, others have found a "master gene" that, when put into adult cells (such as skin cells, for example), induces them to become like stem cells, which are capable of making most other kinds of cells in the body, including brain cells. Dr. Svendson reported that he and his colleagues have been able to make these "induced pluripotent stem cells" (iPS cells) using skin cells from a juvenile HD patient. They have also made iPS cells from individuals who are HD-expansion gene-negative. By growing brain cells from each person's iPS cells, they are currently seeking to "replay the disease over and over again in the dish" to better understand the HD-specific differences between the brain cells from the gene-positive and gene-negative individuals. These cells may also provide a faster way to screen potential drugs for HD in a dish, which would make it easier to select the drugs that merit human trials.

Marcy MacDonald of Massachusetts General Hospital in Boston reported research results about the biology of HD cells and whether cells in HD get sick and eventually die because they can't make enough energy for themselves. Using genetically manipulated cells from mice (some having a CAG expansion and others without the HD gene), Dr. MacDonald and her colleagues have evidence indicating that the machinery for making energy is, in fact, intact in HD cells. Instead, the cells don't make enough energy because of an action by the mutant HD protein that is making the cell "think" that it doesn't have to make more energy. These results suggest that one focus for HD therapy development can be on ways to correct this incorrect signal.

Gill Bates spoke in the opening session on the last day of the conference. Bates is known in the HD scientific community as the first person to be successful at putting part of the human expanded HD gene into a mouse, thus making the first "transgenic mouse model"

of the disease. She spoke of using this mouse, among other purposes, for testing whether a class of drugs (known as histone deacetylase inhibitors, or HDACs) can be beneficial in HD. These HDACs affect the way genes are made available for use in cells. There is evidence that the HD gene itself, when expanded, affects how other genes are used (in possibly detrimental ways). Bates found that HDACs can be beneficial in an HD mouse, but the drug used in the research is too toxic for human use. Now, she and her colleagues are narrowing down the type of HDAC (there are more than ten kinds) that is most responsible for the beneficial effect in the HD mice. This will lead to better understanding of what is going wrong in HD and may lead to a specific type of HDAC drug that could be safe enough to be used in patients.

Perhaps even more important, in terms of getting to the day when an effective therapy for HD is available, is a new tool described by Robert Pacifici, Chief Science Officer of the Cure Huntington's Disease Initiative (CHDI) Foundation. The CHDI Foundation has organized a web-based repository for information about any and all drug targets for treatment of Huntington's Disease that are proposed by analyses of the human genome or by scientists, researchers, clinicians, pharmacologists, etc. Each drug target essentially has its own "Facebook page" for collecting information about it. On continuing review, each drug target will be given a score from 0.0 to 5.0 indicating how close the evidence for that target has moved it (and treatments that target it) to the goal of a treatment available in the clinic. (Right now, the Huntington gene itself has a score of 4.0, indicating that attacking the mutant protein itself is a good strategy, but a treatment doing this is not yet ready for clinical use.) This repository should help speed the accumulation and communication of information among scientists, making all of their work, whether funded by CHDI, the Huntington's Disease Society of America, or by other means, more efficient.

In addition to the oral sessions, there were also over 250 poster presentations on both scientific and care-giving topics. Summaries of all of these presentations, including the care-giving topics, can be downloaded for free from Wiley-Blackwell's journal, *Clinical Genetics*, at www3.interscience.wiley.com/journal/122564786/issue. The next World Congress on Huntington's Disease will be held September 11-14, 2011, in Melbourne, Australia.

Outgoing Board Members

A BIG THANK YOU to the three outgoing MN Chapter board members: Don Ellingson, Judy Ellingson, and Rebecca Milless who ended their terms this fall. Don, Judy, and Rebecca each contributed unique and supportive qualities to the board. Don and Judy were stalwart supporters of every event, putting in overtime as volunteers and attending as enthusiastic participants. Their commitment and energy helped to make every event in which they were involved a success. As board members, they shared their dedication to the HDSA mission and helped any way they could to see that the chapter served the needs of the community. Rebecca served as chapter secretary and then as chapter treasurer and worked tirelessly to streamline and organize the finances and budget process. Her significant contribution as a board member allowed the chapter to function efficiently and effectively. She also contributed to the overall progress of the chapter by bringing creative problem solving and heartfelt commitment to every issue. Thank you Don, Judy and Rebecca!

Young People Unite!

I am looking to find people under the age of thirty who are interested in getting more involved in the HD community, whether it be volunteering, starting a support network, or creating your own fundraiser. Young people are the key to making this the last generation affected by HD, and we need everyone to get more involved. If you are at risk, gene positive, gene negative, know someone with HD, or just want to help the cause, please contact me so we can get something started.
**BJ Viau, 952-270-5428,
 hoopathon@yahoo.com.**

EIGHTH ANNUAL
 MINNESOTA STATE
 CONFERENCE ON
 HUNTINGTON'S DISEASE

Eight Ways To Have

HOPE

The Eighth Annual HDSA State Conference on Huntington's Disease was held on Saturday, October 3, 2009. Volunteers from Minnesota and North Dakota worked together to organize this event to support the mission of HDSA by promoting

and supporting research and medical efforts to eradicate Huntington's Disease; assisting people and families affected by Huntington's Disease to cope with the problems presented by the disease; and educating the public and health professionals about Huntington's Disease.

This year's conference focused on "Eight Ways To Have Hope." BJ Viau kicked off the day with a message on "Hope through Action," sharing specific ways we can all help make a difference for people with HD. Matt Bower, a genetic counselor from the University of Minnesota, provided "Hope through Knowledge" by updating attendees on the latest information in HD genetics. Our keynote speaker, Dr. Jang-Ho Cha, a researcher and neurologist from Massachusetts General Hospital in Boston, provided "Hope through Research" with a presentation titled "CSI: HD." Cha spoke about the latest methods of HD research being used by scientists around the world. Dr. Martha Nance spoke about "Hope through Excellent Care," providing details about patient care throughout the stages of HD. She also reminded us about the HD patient research studies and clinical trials that are currently recruiting participants. Dana Steinart inspired us all with "Hope through Humor" and shared how she stays positive in spite of HD. Mary Johnson educated us about the services available at Pathways and emphasized hope as a part of self-care.



HDSA State Conference: HDSA members welcoming the Northern Plains Affiliate (NPA) members and pledging to work together on projects and fundraisers. The NPA held a successful hoop-a-thon and Hope walk/run this year and looks forward to growing to chapter status in the coming years. Left to right: Bobbi Higgins, MN HDSA Chapter board member; Arnette Cariveau, Northern Plains board member; Bryan Viau, president of the Minnesota HDSA Chapter; Char Brekken, Northern Plains board member; Jayne Brown, Northern Plains social worker; Brenda Westacott, and Brent Mureddu.

In Sympathy

The members of the Huntington's Disease community extend deepest sympathy to the families of the following friends at their deaths:

Deborah Adams

Denise Adams

Curtis Steinbach



Angels Among Us

continued from page 1

My Second Angel

Dr. Parshos called me about the information we'd received in the mail and arranged for us to meet Dr. Nance in just two days. She explained HD to us, said that Rick definitely had the disease, and gave the phone number for the social worker. We both felt confident with her on our side.

We attended our first event alone and were both terrified, to say the least. What we read, saw, and heard about the disease scared us to death.

My Third Angel

We attended the support group in Richfield where we met the O'Briens, who took us under their wing. They encouraged us to get involved, to keep attending the support group, and to find our way along with everyone else.

We have only missed two meetings in three years. I believe that there is so much to give and receive in these meetings, I hate to miss them.

My Fourth Angels

These two angels are probably the most incredible people in the world! My cousin Doug and his wife Joanne embraced HD as soon as Rick was diagnosed. Joanne is a breast cancer survivor but decided that everyone knew about breast cancer and nobody knew about HD. They have listened to me when I'm sad, and they spend time with Rick and understand his disease. They don't judge Rick or anyone else. Without them I never could have attended the convention this year in Arizona. They are always a phone call away, they never say no, and they always just want to help. They know everyone in the HD community that we know. They have attended everything that we attend: our support group, the Blast, the Dinner in New Prague, the Hoop-a-thon. They are the best HD cheerleaders we could ever ask for. They tell everyone who will listen about HD — we are all lucky to have them with us.

God gives us a lot to handle sometimes, but He always gives us angels to help us on our way. I am so grateful for all my angels and all the ones that help us without our knowing it.

Sincerely, Mary Barlow

HD Quick Guide

Important services, information and support — for those in Minnesota affected by Huntington's Disease

State and Federal Economic/Medical Assistance

The National Office of the Huntington's Disease Society of America has a webpage form set up to help those needing to start the Social Security disability benefits process. Go to www.hdsa.org site and click on the "Get Help/Info/Learn" tab for more information. Below is a short explanation of the various programs.

Social Security Disability Insurance (SSDI)

Individuals need to have paid into Social Security and worked enough hours to receive the benefit.

Supplemental Security Income (SSI)

Medical Assistance (MA)

Minnesota's Medicaid program. It provides health coverage to low income families, children, pregnant women, people age 65 and over, and people who are disabled. Residence, income, asset, and immigration status guidelines must be met to get MA.

Medicare

Medical insurance for people over 65 and certain disabled persons. Medicare has two parts:

Part A: pays for hospital, skilled nursing facilities, hospice, and some home health services. Most people do not pay a premium for Part A.

Part B: pays for care from a doctor, outpatient hospital facility, and some other care not paid for by Part A. There is a monthly premium for Part B.

Minnesota Care

Health care program for people who do not have health insurance. Income, asset, residence, and insurance guidelines must be met. There is a monthly premium for Minnesota Care coverage. The premium amount is based on family size, income, and the number of persons covered. Phone: (651) 297-3862 or (800) 657-3672

General Assistance Medical Care (GAMC)

GMAC pays for current and future covered medical services. Coverage can only go back to the date you turn in an application or written request for health care. To qualify you must have lived in Minnesota for at least 30 days, intend to stay in the state (this may not apply if you have a medical emergency), be a U.S. citizen or a qualifying non-citizen, not be eligible for MA, and meet income and asset limits.

GAMC — Hospital only (GHO)

Pays for hospital bills and doctor charges needed for a hospital stay. Coverage can only go back to the date you turn in an application or a request to apply. You are responsible for the first \$1,000 of each hospital stay.

Medicare Savings Programs

If you are enrolled or eligible to enroll in Medicare and your assets are below \$10,000 for one person or \$18,000 for two people, you may qualify for one of the following programs:

Qualified Medicare Beneficiary (QMB)

Pays monthly Medicare premiums, deductibles, co-payment and co-insurance.

Service Limited Medicare Beneficiary (SLMB) Pays monthly Medicare Part B premiums.

Qualified Individual Program (QI) Pays monthly Medicare Part B premium.

Prescription Drug Program (PDP)

If you get QMB or SLMB, you may also be able to get PDP. To be eligible for PDP you must have lived in Minnesota for six months, not have Medigap or other insurance that pays for prescription drugs, and not have had prescription drug coverage in the last four months. If you have PDP you must register with Rx Connect by calling (800) 333-2433 and pay the first \$35 of prescription drug costs each month. PDP will pay the rest.

Qualified Working Disabled (QWD)

Pays for Medicare Part A premiums if you cannot get free Medicare Part A.

MN Department of Human Services

651-296-8517 or 1-800-657-3659 or at www.dhs.state.mn.us/healthcare.

Social Security

To apply for social security, call (800) 772-1213 or visit www.ssa.gov.

County Economic/ Medical Assistance

County Medical Assistance (Medicaid)

Visit your local county Economic Assistance Office to apply or call your county to request the applications. To find your county contact information you can call (651) 291-0211 or (612) 340-7400. There are limited spots for the waived programs: Elder Waiver, CADI Waiver (Community Assistance of Disabled Individuals), TFRA Waiver (for children), Utility Assistance, Food Assistance, and Housing Assistance.

Medical Care Resources

Huntington's Disease Society of America's Center of Excellence at the Hennepin County Medical Center

701 Park Avenue, Mail Code P5
Minneapolis, MN 55415
e-mail: hcmc.hd.clinic@hcmcd.org

Martha A. Nance, M.D., HD Clinic Director
Dawn Radtke, Research Nurse
Clinic hours: M-TH, 8:00 a.m. - 4:00 p.m.
(612) 873-2595 or (612) 873-2515

The HD Clinic is located in HCMC in the Neurology Clinic. The HDSA Center of Excellence provides multidisciplinary care to HD patients and families and offers the following services: neurologist (medications, general direction), neuropsychologist/neuropsychometric testing, dietician (high-caloric diets), social services (advanced directives, financial referrals, advanced care referrals), occupational therapy (walker, wheelchair, grab bars, etc.), physical therapy (strength and ambulation training), speech language pathology (swallow evaluations, augmentative and alternative communication evaluations), genetic counselor (testing).

Genetic Testing

Huntington's Disease Society of America's Center of Excellence at the Hennepin County Medical Center

Carol Ludowese, MS, CGC
HD Genetic Counselor, (612) 873-4686
University of Minnesota, Fairview
420 Delaware Street SE (MMC 485)
Minneapolis, MN 55455, (612) 624-8948

Protection of Assets

It is recommended that anyone at risk or newly diagnosed should contact an attorney and/or financial planner to discuss the impact HD will have on the family's financial resources.

At Home Support

The following list of physical services, adult day care, home care, etc., is maintained by the National HDSA Website for informational purposes only. Inclusion on this list does not constitute an endorsement or recommendation by HDSA or the MN Chapter HDSA.

ADULT DAY CARE

The Courage Center

3915 Golden Valley Road
Golden Valley, MN 55422
(612) 520-0307

St. Olaf Senior Day Stay Program

2929 Emerson Avenue North
Minneapolis, MN 55411
(612) 287-3558

Care Break Adult Day Program

5430 Boone Avenue North
New Hope, MN 55428
(612) 531-7700

Sojourn Adult Day Services

4497 Shore Line Drive
Spring Park, MN 55384
(612) 471-6080

HOME HEALTH CARE

Becklund Home Care

8421 Wayzata Boulevard
Golden Valley, MN 55426
(612) 544-0315

Best Care Home Health

3014 University Avenue SE
Minneapolis, MN 55414
(612) 378-1040

MN Visiting Nurse Agency (MVNA)

2021 East Hennepin Avenue
Suite 230
Minneapolis, MN 55413
(612) 617-4600

Home Health Services of Allina

2750 Arthur Street
Roseville, MN 55113
(651) 636-4663

Long-Term/ End-of-Life Care

Many local nursing homes have the capacity to care for patients with HD. The MN Chapter Social Worker can provide training for nursing home staff new to Huntington's Disease. In addition there are also the following institutions that specialize in long-term and end-of-life care for those with HD:

Good Samaritan University Specialty Center

22 27th Street, Minneapolis
(612) 673-6260

Sonshine and Hope

Home for Huntington's

14808 Chicago Avenue South
Burnsville
(952) 435-0909

They have an opening available for a resident at this time. If you would like more information, please call Angie Priebe at (612) 203-2284.

Red Wing Health Care Center

(612) 388-2843

HD Hobby Farm

56605 Nature Avenue, Pine City
(320) 629-6245

Tadd's Lighthouse

651 4th Street NW
Richmond
(320) 597-2661

Hospice of the Twin Cities, Inc.

10405 6th Avenue North, Ste 250
Plymouth
(763) 531-2424, (800) 364-2478

Local Support

Minnesota HDSA Social Worker and Support Groups

Jessica Hancock, LSW
(612) 371-0904

MN Chapter HDSA

Bryan Viau, President
(Contact Bryan through the HDSA Upper Midwest Office listed below)

HDSA Upper Midwest Office

7362 University Avenue, #212
Fridley, MN 55432
(800) 865-4342 or (763) 502-1407
lpeterson@hdsa.org
www.hdsa-mn.org
Helpline: (612) 371-0904



HUNTINGTON'S DISEASE SOCIETY OF AMERICA

HDSA Minnesota Chapter
7362 University Avenue, Suite 212
Fridley, MN 55432

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Night of a Thousand Stars!

2010 HDSA Blast

Saturday, February 27, 2010
at the Metropolitan Ballroom

Save this Date and watch for more information coming soon!



1. Former MN board president and current NFC chair and national board of trustees member Leon Tibben presenting Angie Priebe with the Volunteer of the Year award. 2. Faces from the crowd, including MN Chapter board member Gwen Johnson 3. One of the many great gift packages donated at last year's silent auction.

A new bill (HR 678) has been introduced in the U.S. House of Representatives to amend the Social Security Act for HD. The amendments will revise the criteria for evaluating disability in a person diagnosed with HD (to include all aspects of HD, not just motor symptoms) and waive the 24-month waiting period for Medicare eligibility for individuals found to be disabled by HD. The more representatives that are "co-sponsors" of the bill (implicitly indicating they will vote in favor of it), the sooner the committee may move the bill to the floor for a vote. At this writing, 37 representatives have signed on as co-sponsors, but **none** of the representatives from Minnesota have done so yet. You can help by contacting your representative and asking him or her to co-sponsor HR 678.

(1) Google the words "US House of Representatives."

(2) Under the first item listed, click on the "Write Your Representative" link — it will take you to <https://writerep.house.gov/writerep/welcome.shtml>.

(3) On the "Write Your Representative" screen, select your state (e.g., Minnesota), and enter your five-digit zip code.

(4) This will take you to the web page for your representative, where you will fill in the form with your name and address, then type in your message. You can keep it short.

(5) When you are done, click on "Send E-mail" and your message is sent to your representative.

If you have any trouble with this, another way you can help is to go to the national HDSA website and go to <http://www.hdsa.org/living-with-huntingtons/advocacy/hd-petition.html> and sign the petition. Or, write your representative a letter asking him or her to co-sponsor HR 678, and send it through the U.S. Mail to Representative [Name], U.S. House of Representatives, Washington, D.C., 20515. Help us all make a difference — you can do it!

RESOURCES

HDSA Minnesota Chapter
7362 University Avenue, Suite 212
Fridley, MN 55432
www.hdsa-mn.org
hdsamn@hdsa-mn.org
(612) 371-0904

Leigh Peterson
HDSA Upper Midwest Reg. Director
7362 University Avenue, Suite 212
Fridley, MN 55432
(763) 502-1407/(800) 865-4352
lpeterson@hdsa.org

HD Center of Excellence Clinic
Hennepin County Medical Center
701 Park Avenue
Minneapolis, MN 55415
(612) 873-2515
www.hcmc.org

HDSA National Office
158 West 29th Street, Seventh Floor
New York, NY 10011
(800) 345-HDSA
www.hdsa.org

Hereditary Disease Foundation
www.hdfoundation.org

Help Us Pass House 678 — The HD Parity Act of 2009