



THE HDSA WISCONSIN UPDATE

THE NEWSLETTER FOR THE HUNTINGTON'S DISEASE SOCIETY *of* AMERICA— WISCONSIN CHAPTER

Winter 2008

www.hdsawi.org

Volume I, Number 3

My HD Manifesto

When I agreed to become editor of the HDSA-Wisconsin Chapter newsletter, Shana Martin explained to me that readers nearly unanimously requested one thing: personal stories. I decided to take this opportunity to introduce myself, my family, and something that until recently I may not have shared—my father's struggle with HD.

You see, for most of my adult life—I just turned 30—I have held the monster that is HD at bay. I did so through both physical distance (I moved from my hometown shortly after high school) and emotional guardedness. For years, I kept my family's secret from even my best friends. For me, the topic brought shame, fear, uncertainty, and anger, to name only a few emotions those at risk for HD often experience.

While I was largely ignorant of specifics, I became acquainted with HD early; my grandfather was stricken with dementia by the time I was born. I remember him sitting in his recliner, forever laughing to himself or humming a tune. The disease took him before I was ten.

My father's malady set in slowly, first manifesting itself in aggressive behavioral patterns, then the inability to retain a job. Whether my parents suspected HD I cannot say, but my father's behavior caused much family turmoil and my parents divorced when I was 12. For me, it was a welcome relief. Shortly thereafter, my father was officially diagnosed with HD. Sadly, I knew little about HD other than that it frightened me, and I

didn't learn much more during the years that followed. My family did not deal with HD directly, at least not in a way I could perceive at that age.

The emotional fallout of the years that followed is a topic on which I could write volumes—perhaps one day I will. For now, it is safe to say that sweeping HD under the proverbial rug helped no one, my father included. I regret that I did not have the insight as a young man to delve more deeply into HD, to confront the problem head-on. I hope my family's approach to the disease did not cause my father additional suffering, though I fear that is not the case.

After all, this is about my father. It is about my grandfather, and about your loved ones suffering from HD. While the disease is devastating on many levels to those around the HD patient, we must never forget our duty to those truly living it.

I am happy to write to you today as a man who has decided to meet the challenge of HD. While I am not a billionaire or a scientist, I am committed to using the tools I have to help the HDSA work toward the best possible outcome. It is in that spirit that I challenge each of you—perhaps some who shared an experience similar to mine—to put fear aside, to disregard uncertainty, and become a vocal advocate for our HD families. Whether you stage a rally or write an e-mail, it is up to you to help make a few voices become many.

You could start by sharing your story with us in this newsletter. To do so, contact me at willmclain@yahoo.com.



HDSA-Wisconsin Chapter
2008 Board of Trustees

President
Shana Martin

Vice President
Carla DeLucca

Secretary
Tom Mueller

Treasurer
Liz Molitor

This newsletter is a forum for learning about new research, social services, events and individual stories affecting the HD community in Wisconsin and throughout the United States. If you have any ideas, articles, photos, words of wisdom, questions, or anything else you would like to see in this newsletter, please contact Will McClain, editor, at willmcclain@yahoo.com.

Disclaimer: HDSA and the Wisconsin Chapter do not provide medical advice; nor do they promote, endorse or recommend any product, therapy or institution. Please check all drugs, treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA, Inc. and the Wisconsin Chapter.



**HDSA-Wisconsin Chapter
Information Line**

toll free: 877-330-2699
In Wisconsin: 414-257-9499

**HDSA-National
Information Line**
Toll free: 800-345-HDSA

3rd Annual Hootenanny a Success

The Huntington's Disease Society of America-Wisconsin Chapter held its 3rd Annual Woody Guthrie Hootenanny on Saturday, November 22 at The Coffee House in Milwaukee. The event was a great success, with 55 paying guests in attendance, up slightly from the previous two years.

Running just under three hours, the event was divided into two sets, with an introduction on Huntington's Disease, the HDSA, and its connection to Marjorie and Woody Guthrie by the evening's MC, Tom Muller. The Coffee House provided a warm, intimate atmosphere for the event, during which the audience enjoyed three or four songs from each of the four performers: Madison folkie Frank Simpson; Maggie "Catfish" Friedrich of California and Madison; Larry Penn, well-known Milwaukee troubadour, and 14-yr-old sensation Macyn Taylor.

The performances were interspersed with sections from Woody's autobiography Bound for Glory, read by Macyn's mother, Jean. The music was a mix of traditional Guthrie songs, other folk tunes, children's songs, and original numbers, including "Madison Boogie" by Ms. Friedrich and "Frozen in Time" by Larry Penn.

Woody Guthrie, author of "This Land is Your Land" and widely considered to be the Father of American Folk Music, died of Huntington's Disease forty-one years ago. His widow, Marjorie Guthrie, founded the organization that became the HDSA. All proceeds from the event go to the HDSA research fund.

Attention Brown County Residents

This past summer we created The Brown County Huntington's Disease Charity (BCHDC) to help HD families in the Green Bay area. Over the next year, the organization hopes to start a quarterly support group and support various fundraisers in the area. If you would like to join their mailing list or receive more information about their new support group, please contact President **William Richards** at (920) 371-3333 or e-mail bchdc@yahoo.com.

Swimsuits and Formal Wear: Not Your Typical Fundraiser

Last fall, students from Ripon College's communication department hosted the first annual **Mr. Ripon Pageant** to benefit HDSA. Filled with the drama and glamour of a traditional beauty pageant, judges rated contestants on talent, swimwear, eveningwear, Q&A, and their fundraising contribution.

The project began in 2007, when the applied communication class received the task of raising money for HDSA. After much debate, the students decided to host Ripon's first-ever "man pageant."

Nine contestants participated in the event, which provided Ripon College students and community members an enjoyable and entertaining night while prompting awareness for Huntington's Disease. Participants had to raise a minimum donation amount to enter the pageant and spent several nights prior to the event practicing.

The evening's competition began with swimwear; the men strutted their stuff in Hawaiian trunks, beach towels, inflatables, and Speedos. During the talent portion of the evening, contestants displayed unique skills including singing, dancing, juggling, and dribbling a soccer ball. After narrowing the contestants to five, the remaining participants each received the same question: "In thirty seconds, tell us why you should be Mr. Ripon." After the scores came in, first-year Ross Lewis earned the titles second runner-up, Biggest Donor, and Mr. Congeniality. First year Sam Ewig was first runner-up, and Senior Adam Schmitz was named Mr. Ripon.

The pageant was a hit with the crowd—the applied communication class has already discussed ideas for next year's pageant. Overall, the pageant raised more than \$1,500 for HDSA. Congratulations to the participants and the communication department for their hard work.

LETTER FROM THE PRESIDENT

Hello everybody, and Merry Christmas!

I'm sure by now most of you have heard the exciting news about the approval of Tetrabenazine by the FDA. The advocacy efforts of HD families across the country helped make this a reality. Although it is but a small step toward a cure, this FDA approval continues to give hope to us all. As long as we continue to work together as a team, a cure is within reach.

A few months ago, I was elated to win a United Way Community Volunteer Award. I had the honor of standing on stage with Wisconsin First Lady Jessica Doyle and some of the most amazing volunteers in Dane County. This award would not have been possible without the help of the rest of the HDSA Wisconsin Board, and all of the amazing HD families in the state of Wisconsin. Thank you, everybody.

With all of the exciting chapter events on the schedule over the past few months, I hope you all had a chance to meet one another and help us raise money to care for patients and cure HD. If you were unable to attend our spring and summer events, we hope you were able to attend the Hootenanny in Milwaukee, hosted by HDSA Wisconsin Secretary Tom Mueller, or our second annual Reindeer 5K Run Walk in Madison.

As always, I am honored to be president of an amazing organization representing the strongest people I know. Let's stick together to make a cure a reality!



Shana Martin
President
HDSA Wisconsin Chapter

Midwest Log Rolling Championships

Madison, WI (Shana Martin Tourney Director)
June 21, 2008

On June 23, 2008, amateur and professional log rollers from across the Midwest turned out for a fun day of competition and fundraising.

Congrats to our top fundraiser, **Evie Lynch**, who raised \$1,090.00! Evie won the grand prize—a #4 log rolling log donated by Lumberjack Enterprises.

Thank you, thank you, thank you to all competitors and volunteers! Together we rose close to \$5,000 for the Huntington's Disease Society of America!

We had amazing weather and a wonderful turnout of competitors and volunteers. Thanks again to our sponsors: Lumberjack Enterprises, Trader Joes, Duluth Trading Company, Smart Scion, Flad Architects, The UPS Store of Monona, Ben and Jerry's Ice Cream, and Budget Bicycle Center.

And our amazing volunteers: George Martin (my right-hand daddy), Larry Waite, Alex Waite, Corkey Waite, Scott Greene, Phil Olsen, John and Kathy Berard, Pat Burns, Bob Swanson, Jeff and Jackie Steinhauer, Fiona Cahill, Olivia Judd, the amazing Rick family (thanks for staying so late to clean up), Kurt Weber, and Matt Schmidt.

As always, this tournament would not have been possible without all of your help and hard work.

Results:

U7 Coed

1st Evie Lynch

U10 Girls

1st Rachel Ellis

U10 Boys

1st Tanner Hallett

U13 Girls

1st Leah Burns

U13 Boys

1st Garrick Olsen

U17 Girls

1st Fiona Cahill

U17 Boys

1st Alec Christopherson

Adult Novice

1st Kurt Weber

Elite Men Log Rolling

1st Jacob Rick

Elite Women Log Rolling

1st Jenny Atkinson

Men's Boom Run

1st Jacob Rick

13.95

Women's Boom Run

1st Shana Martin

14.67

Genetic Testing for HD

If you are considering genetic testing, please call the help line for assistance. A no-cost pre-genetic testing counseling session is available from our social worker. Call **Jean Morack**, the HDSA WI social worker at 414-257-9499 or e-mail her at info@hdsawi.org for more information.

Pacin' Parson Walks 13,000 Miles for HD

On April 26, 2008, **Don Stevenson**, aka “The Pacin' Parson,” completed an epic 13,000 mile walk to build awareness for Huntington's Disease and raise money to support HDSA programs.

The 72-year-old Stevenson crossed the George Washington Bridge with several supporters and made his way across Manhattan to the Terence Cardinal Cooke Healthcare Center, where he was greeted by Barbara Boyle, HDSA CEO, and Laura Gaffney, Executive Director of the Terence Cardinal Cooke Center, as well members of the HDSA New York Metro and New Jersey chapters, HDSA staff, Terrence Cardinal Cooke patients, family members, and staff members.

Among the crowd of well-wishers were Liz Weber and Pearl Jam's Stone Gossard, who played a welcoming concert with Vince Mira the night before, with proceeds donated to the walk fund.

The Pacin' Parson's walk raised over \$25,000, and educated many people along the way about Huntington's Disease and the need to support efforts to eradicate it.

Stevenson completed the first 10,000 miles of his walk that began in January 2007 in Auburn Washington, and then set out from Seattle's Space Needle for New York in March of 2008. He walked in honor of a close friend who had lost several family members to Huntington's Disease, and dedicated it to all those who suffer the disease's effects.

After the reception at the Cooke Center, Stevenson was back on the road, heading downtown to the Empire State Building, the end of his journey.

Don is currently making his way back to Seattle, where plans are underway to host a welcoming for him. He plans to climb Mt. Rainier for HD.

We will post information on the next phase of the Pacin' Parson's amazing journeys as soon as it is available.

The Fight Continues

Earlier this year, Congressman Bob Filner [D-CA] introduced H.R. 6259, **The Huntington's Disease Parity Act**. If passed, this important legislation will require the Social Security Administration to update their outdated disability listing for HD and provide a waiver for the 2-year Medicare waiting period to people disabled by HD.

Delays and unnecessary reapplications for Social Security Disability Insurance (SSDI) are far too common and you don't have to go far within the HD community to find someone that has struggled or is still struggling to obtain benefits. After they begin receiving benefits, people with HD often face a gap in health coverage due to the Medicare eligibility waiting period, at a time when their medical needs are only increasing.

This is an issue affecting everyone in our community and we've gained a lot of ground this year in bringing about these much needed changes. After Bob Filner introduced the legislation, devoted advocates across our network contacted their Congress Members and were able to rally support in the form of 8 co-sponsors.

See sponsors and learn more at <http://tinyurl.com/6pocvl>

With every co-sponsor, we come one step closer to our goal. When the new Congress convenes in early 2009, we'll need to push forward with our efforts of making all of our Congress Members supporters and advocates of HD.

UPDATE FROM THE MEDICAL ADVISOR.

The main utility of **stem cell research** is tissue growth for the transplant of needed tissue like bone marrow, pancreas, or liver. Huntington's Disease, Alzheimer's, and Parkinson's Disease are complicated neural system diseases where transplantation is not a solution. The solution comes from stopping the process. In many ways transplants in these three diseases are poorly timed. In **Parkinson's Disease** from carbon monoxide poisoning, the disease process was a single hit of the poison. Since the residual brain is not deteriorating, transplants have very effective utility. The thrust of clinical research is directed at stopping the cause, and this in HD must be very early neuroprotection. Of course with effective neuroprotection, transplants would be unnecessary. If we get behind the early detection idea and

encourage the HD researchers to do early neuroprotection, we will be reaching a realistic goal.

Dr. Paulsen and I are pursuing the **JHD Scale Initiative**. Children with JHD cannot be assessed with the UHDRS and need their own scale, which is age specific and considers degeneration of function unique to the developing brain. We have a JHD Category Listing (forms of JHD vary more than adult HD) and a JHD Scale ready for testing. We are now looking for two sites to test 30-50 children each: Ulm Germany and Milwaukee/Chicago. Jane is pursuing federal funding options. We will present the initiative at the November HSG meeting in West Palm Beach.

Dr. Norman Reynolds,
Medical Advisor.

Training for Health Care Professionals Offered

On August 22, 2008, medical professionals presented a three-hour **"Caring for the Huntington's Disease Patient"** session at the Milwaukee Athletic Club in downtown Milwaukee.

Karen Blindauer, MD, associate professor of neurology, Medical College of Wisconsin, provided an overview of Huntington's Disease and symptomatic treatment. Gwen Johnson, nurse manager, and Jessica Hancock, social worker, from Good Samaritan Medical Center, Huntington's Unit, Minneapolis, spoke to the audience about practical methods for managing HD behaviors within a residential setting.

Attendees included nursing staff, physical therapists, social workers, residential care workers, and administrative staff.

The HDSA-WI chapter would like to express thanks to Dr Blindauer, Gwen Johnson, and Jessica Hancock for the helpful education they provided.

Volunteers Needed!

HDSA Wisconsin cannot function without your help! Here are some options for getting involved:

Holiday Amaryllis Sales: Every holiday season we sell beautiful Amaryllis bulbs in a kit. They sell for \$10 each, and with each flower sold HDSA receives \$5. We need people to sell these flowers or give them as gifts.

Hearts For Huntington's: We seek motivated high school students, fraternity and sorority members, or folks involved in the community to start a "Hearts For Huntington's" campaign in their area! We need you to find schools and businesses willing to sell these hearts at the point of purchase.

For details visit www.hdsawi.org/donate.html

If you are interested in helping out with either of these opportunities, e-mail chapter president Shana Martin at: shana@shanamartin.com

HDSA Thanks

HDSA thanks the following people and organizations for their generous support:

Amy Winter
William Fkinke
Ellen Pfenninger
Mary Arthur
Ann Blazek
John & Lenora Eull
Patricia Ebli
J. Merac
Pieper Electric

Gifts in Honorarium and Memoriam

In Memory of Ervin Joecks from Lynne Babich, Michelle/Ruben Perz, Mark/Becky Babich, Kevin/Dawn Kroneberg, Dean/Sue Weltman

In Memory of Bev Christensen Diederich from Sarah/Christopher Worley

In Memory of Joel Mueller from Sandra Faber, Sonia Neuberger

In Memory of Barbara Cucinello from Robert DeGroot, John/Mary Borman, Patrick Levenhagen, David/Christine Carpentier, Ignatius/Nancy Bartolotta, Lorraine Berndt, Geraldine Accetta, Geprgia Cuninello, Theresa A LaLicata, Frances Orlando, John/Nancy Cucinciolo, Julius/Barbara Fomotor, Mary Mueller

In Memory of Sharon Lanphier from Sean Lanphier

In Memory of Lois Sheffler from Ellen Bauer

In Memory of Emily Schillinger from Barbara/Karl Muske, Nancy/Herb Lienenbrugger, Vito Garfolio

In Memory of Leona Berger from Jos/Geriann Heath, Brian Berger

In Memory of Keith Brisky from Employees at Wagreens

In Memory of Charles Larkin from Kathleen Kelly, Lynn O'Connell, John/Roseann Granca, M. Koss

In Memory of Mary Jane Moe from Wayne/Paula Whitton

In Memory of Bob Hansen from Betty Rich, Barbara Luther, Dale/Susan Mork, Jerry/Carol Bressler, Pamela Teigen, Betty/Simon Olson, Frances Bessler, Ann Mense, Elizabeth Specken, Susan/Sam McCrary, Floyd/Pearl Ninas, Richard/Cheryl Lowery, Deborah Johnson, Richard Peterson

In Memory of Dale Hansen from Vivan Heinz

In Memory of Robert Blattner from Patricia/Edw Roszkowski, David Thompson, Lou Jean/Ludwig Erzens, Carrie/Jim Dessecker, Yvonne/Nick

Buyiazis, Jim/Penny Blattner & Family, Robert/Diane Dettlaff, Wayne/Loretta Wite, Mr./Mrs. Jesse Clarkson, Joyce O'Brien, Robt/Nancy Blattner, Daniel/Kathleen Mejac, Mrs. Robt Blattner

In Memory of Carl Hueppchen from Katherine Hueppchen

In Memory of Jeff Harnisch from Elise Harnisch, Steven Hedgcoth, Marla/Donald Wagner Holmen, Robt Marilee Wuensch

In Memory of Ron Heinz from Diane Bergler, Mari McKeeth, Vivan Heinz, Marit Salvesson, Dan/Marilyn McKeeth, Karen Byrns, Dolores Waggoner, Anna/Lois Spaulding, Geraldine Easley

In Honor of the wedding of Garry Schoemanns & Mary Flynn from Larry & Anne Schoenemann

In Honor of Wade Mueller from Helen Drexler

While the Wisconsin chapter makes every effort to ensure accurate spelling of donor and honoree names, please remember that some errors may be unavoidable.

Wisconsin Monthly Support Groups

Milwaukee

When: Third Saturday of every month
10:30 a.m.-12:00 p.m.

Where: Froedert Hospital
West Clinics, lower level, Conf Rm A/B
9200 W. Wisconsin Avenue
Milwaukee, WI

Madison

When: Second Saturday of every month
10:30 a.m.-12:00 p.m.

Where: Attic Angels
8301 Old Sauk Road
Middleton, WI

Two Rivers

When: January 10, February 21, April 18
10:30 a.m.-12:00 p.m.

Where: Aurora Hospital
5000 Memorial Drive
Two Rivers, WI

Oshkosh

When: January 17, February 28, April 4

Where: Aurora Clinic
Conference Room B
855 N Westhaven Dr.
Oshkosh, WI

For more information, contact WI chapter social worker **Jean Morack** at 877-330-2699 or 414-257-9499. If you are new to attending a support group, we suggest you call Jean first to verify meeting dates.

We are attempting to start support groups in both Brown and Walworth counties. Contact Jean if you have an interest in either location.

DO AS I DO
BECOME A VOLUNTEER

The Wisconsin Chapter of HDSA is looking for volunteers. If you are interested in working on one of our committees, sitting on our board, or becoming a speaker on our behalf, please contact Shana Martin at shana@shanamartin.com.