



Northwest Chapter HDNews

Issue 5

www.geocities.com/nwhdsa

HELPLINE 888-264-HDSA

Business line 206-464-9598

Our New NW Chapter President

Hello, my name is Liz Weber. I am the newly elected President of the board of NWHDSA. My husband and I live with our beloved dog in the Seward Park neighborhood of Seattle. Recently, I was tested for the HD gene and thankfully my test results were negative. However, HD continues to affect my family. Ted Morgan, past president, has spent the last 5 years providing strong leadership to this organization, and I'd like to thank him deeply for his devotion. My plan as President is to build on the fund-raising and awareness resources that Ted and the other members of this board have developed over the years. I look forward to working with everyone who currently serves on the board. They are a very dedicated and inspiring group of people. We are going to take a fresh look at fundraising ideas and leverage connections in the Seattle public relations arena to step up awareness of HD in the Northwest and beyond.

If you are interested in finding out how you can support us, please contact me at 206-235-5871.

Sincerely,
Liz Weber
President, Northwest Chapter



Liz Weber and her mom



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Editorial Viewpoint

March 14, 2006

Dear Editor:

Last night, after hearing Dr. Bird's presentation of the facts and possibilities of research, I have reached the conclusion that war is the most threatening danger for health.

There are two aspects to the problem. First, the deaths and injuries and lingering illnesses it causes, physical and emotional.

Secondly, and most important for our HD community, is the fact that billions go into our national budget for war purposes, while the National Institutes of Health are greatly starved of funds for critical studies.

I believe that one immediate action we can all take is to convince our legislators of those facts.

As ever,

Amelia Schultz
Ph.D., M.S.W.

If you would like to send an article or editorial viewpoint for consideration in the newsletter, please send an e-mail to: maxi@halcyon.com.

Race Across America (RAAM)

These four intrepid supporters of HDSA will be riding across America to raise funds for research and raise awareness of HD across the land. Please get in touch with Fred Taubman (ftaubman@hdsa.org) to find out how you can support them and when/how your chapter or affiliate can turn out to cheer them on.

Article Date: 02/20/2006 **“Team to Cure HD” aims to raise awareness about HD and raise funds for research.**

By Sharon Shaffer

A father’s urgent desperation to find a cure for Huntington’s disease before it strikes his little girls started the fire inside a San Diego man determined to make a difference in the lives of his family and the thousands of others afflicted with HD.

Renato Shaffer’s vision was to combine fundraising efforts with an initiative to spread awareness of this dreadful disease nationwide, quite literally from coast to coast. He believes he found the perfect venue in RAAM — Race Across America.

Joined by the team he formed in 2005 and a larger community of supporters, family, friends and generous contributors, “Team 2 Cure HD” will ride non-stop in the 2006 Insight RAAM, which extends from San Diego to Atlantic City, New Jersey.

Although the intensity of the race will far overshadow any of the team’s previous athletic endeavors, Renato instinctively knew that the serious nature of the cause would provide ample motivation to compete in RAAM. Surprisingly, the team came together relatively quickly and have spent the past year training, planning and fund-raising on behalf of their quest to assist the Huntington’s Disease Society of America (HDSA).

Three of the four men have direct connections to HD. Thankfully they all agreed this was an irresistible opportunity. As you will see, they are an amazing group and all have their own special motivation for becoming a critical part of Team 2 Cure HD.

Team 2 Cure HD consists of Renato, Scott Needle, Bryan Medrano and John Sylvester. All four have decided to make the sacrifices necessary to compete in this mammoth undertaking.

When Renato thought of riding his bike in the 2006 RAAM, he wasn’t even cycling at the time, and many years had passed since the competitive cycling days of his youth. But he had a vision.

Once the others agreed to be a part of the team, he purchased a bike and began the difficult and relentless training process. Renato does not have a fancy race resume; rather, he brings with him a pure heart and stalwart determination to make this the last generation afflicted with Huntington’s disease. With his wife recently diagnosed for HD and his two beautiful daughters looking up to him, he has all the motivation he needs. Renato and his wife have raised their girls with the cloud of HD hanging over their family. They have made HD an open subject and one that is a part of daily conversation.

They are in the fight of their lives — it is a true family affair — and they are all determined to put a face to HD by teaching others.

Scott and his wife Pam are a major force in making the idea of racing RAAM a reality. Pam’s enthusiasm and Scott’s knowledge of cycling have helped create the driving force behind Team 2 Cure HD. Scott’s can-do attitude has provided the confidence that Team 2 Cure HD will be a success. Scott married his wife knowing she was at risk for HD. Scott and Pam are excellent role models for living life to its fullest potential, a concept they regard as central to living under the specter of HD. They are both very active in the local HD community and fundraising events. They are trying to pave the way to help make this the last generation with HD.



Cheer on (from left) John, Scott, Renato, & Bryan

Race Across America (RAAM) (cont'd)

Bryan witnessed his mom struggle with HD for nearly 20 years. He is also on the board of the HDSA Northern California chapter. Several years ago Bryan decided to take the genetic test to see if he carried the defective gene. Like many others, he was devastated when he received the positive test result, learning that he too would some day develop HD. He was questioning what to do next and constantly searching himself for symptoms. Bryan, however, is a special person, endowed with remarkable strength of character. He made the decision to educate himself, and in doing so learned that if he followed a healthy lifestyle he may be able to prolong the onset of HD. He started his regimen and as he got stronger he began to participate in Xterra Off-Road triathlons. He is now an accomplished semi-professional triathlete. Bryan was honored as "Person of the Year" in 2004 by HDSA and is an inspiration and role model to America's HD community.

John is a very special edition to the team, as he does not have family members with HD. He represents our nation's citizens, those who don't have this disease but who selflessly give of themselves to help those who do. Recognizing the devastation wrought by HD, John was instantly on board when he was asked to be part of this extreme and risky adventure. John migrated to the US from Trinidad at age 15, spent his first career serving in the United States Navy for 20 years, and is a family man with a wife and two children. He enjoys cycling in his free time and has participated in multi-sport events in the past. He feels privileged to be a part of Team 2 Cure HD so he can help his friends and other families suffering from HD. He has selflessly given up valuable time with his family to prepare for the race.

On Tuesday, June 13th, Team 2 Cure HD will begin their trek through the heartland of America. It is not a stage race like the Tour De France, but a sprint from the West Coast to the East Coast. The team will ride day and night without stopping until they reach the boardwalk of Atlantic City. It's a battle for the riders to keep going while managing their pain, sleep and nutrition. There are 57 time stations along the way, where teams must check in. Team 2 Cure HD will climb 110,000 cumulative vertical feet and cross 14 states as well as 4 US time zones before arriving at the finish line on the boardwalk in Atlantic City, New Jersey. Their goal is to finish in 6 days.

The team event is more than just the four riders. A support crew of approximately ten will assist, driving the caravan of vehicles required to take this transcontinental race, helping to feed the four riders, keeping the team focused on its goal, ensuring its safety and more. It's an endurance race for these

dedicated support personnel as much as it is for the riders working in shifts in the two vans and the team RV for nearly a week without a break.

The plan is for each rider to cycle 150-200 miles per day. However, tactics will depend on terrain, time of day, weather, injuries and mounting fatigue. The riders will need to take in at least 10,000 calories per day to keep their bodies fueled and alert. Hydration is critical. Pain will be a constant.

Most importantly, however, motivation will be paramount. And, according to Renato, that's something no one on Team 2 Cure HD is lacking.

Team 2 Cure HD will need a great deal of support to compete in the Race Across America — equipment, food, support vans, gasoline, medical supplies and much more. HDSA will promote team sponsors in all publications and on our website, Team 2 Cure HD uniforms and all support vehicles.

Team 2 Cure HD is in a race a race to make this the last generation of Huntington's disease. We would like to sincerely extend an invitation for you to join our quest.

Sharon Shaffer
Team 2 Cure HD/RAAM Co-chair
Sharon.Shaffer@elan.com

Pam Foye-Needle
Team 2 Cure HD/RAAM Co-Chair
pam_dna@yahoo.com

To donate today, click on the links below!

<http://www.firstgiving.com/bryan2cure-hd>

<http://www.firstgiving.com/john2cure-hd>

<http://www.firstgiving.com/renato2cure-hd>

<http://www.firstgiving.com/scott2cure-hd>

To order RAAM t-shirts, click on the link below!

[http://www.hdsa.org/site/
PageServer?pagename=Marketplace](http://www.hdsa.org/site/PageServer?pagename=Marketplace)

This was taken from the HDSA web site. To see the link, go to:
<http://www.hdsa.org/site/PageServer?pagename=RAAM>

Our New Social Worker

Welcome to our new social worker, Donna Ross, who joined the HD Center of Excellence at UW in January, 2006 replacing Catherine Kendall. Donna is an experienced



Master's level social worker who brings extensive background with neurologically impaired populations and their caregivers. She was the full-time social worker at the Huntington's Disease Family Service Center at the University of Medicine and Dentistry in New Jersey for three years from 1998 to 2001. After moving to Seattle in

the summer of 2001, she provided comprehensive social work services to in-patients at the University of Washington's Rehabilitation Medicine Service.

Her particular areas of interest and expertise include: individual and family counseling, group facilitation and grief counseling. She has a wide knowledge of resources and services for patients and their families, both local and out of state. She is a licensed independent social worker in the State of Washington.

Donna can be reached in her office at the University of Washington by calling 206-598-8753 or the toll free helpline at 888-264-HDSA (4372).

Research Volunteers Wanted

News Flash from the Huntington's Study Group!

The Huntington Study Group (HSG) is to begin a new research study called TREND-HD (A Multi-Center, Double-Blind, Randomized, Placebo-Controlled Trial of Ethyl-EPA (Miraxion™) in Subjects with Mild to Moderate Huntington's Disease).

The sponsor, Amarin, and the HSG have just issued press releases.

The study information summary and HSG press release can be found on the HSG web site:

<http://www.Huntington-Study-Group.org/>

Amarin's press release can be found at:

<http://www.amarincorp.com/pressrelease.cfm?id=108>

There is also news of the HSG investigator/coordinator orientation meeting that can be found on Amarin's web site:

<http://www.amarincorp.com/pressrelease.cfm?id=107>

Muscle Biopsy Study in HD

Studies in HD mice have suggested the possibility of changes in the muscle. In this study, a small piece of muscle is removed under local anesthesia from persons with HD to look for markers of HD in the muscle tissue. Because measures of HD progression, such as the U.H.D.R.S., can fluctuate over time and are not consistently reliable, it is important to find other objective measures of HD progression. If you are interested in participating, please contact Hillary Lipe at 206-764-2308 or Hillary.Lipe@va.gov.

Upcoming Events

June 5 to 21, 2006 — Rock and Roll at Charitybuzz.com

Check out Charitybuzz.com from June 5 – 21 for the Last Generation Online Auction, with proceeds going to HDSA, featuring trips to see Pearl Jam concerts and other celebrity memorabilia. Be Pearl Jam's VIP Guest and experience the best of San Francisco including dinner after the July 15 show at Moose's with members of the band! Bid on other exciting items at the web site: http://www.charitybuzz.com/charityauctions_hdsa.html

Also, check out the link at Pearl Jam's web site:

<http://www.pearljam.com/news/index.php?what=News#124>



Saturday, October 21, 2006 — HD Northwest Symposium

This will be an all day event held at the University of Washington's CHDD auditorium to inform and educate people about Huntington's disease. This event is free to the public. Parking is \$5. For more information, please contact Donna Ross at 206-598-8753 or donnagr@u.washington.edu.

HD Support Groups and Contact Persons

Alaska

Marti Bradley 907-258-5665

Idaho

Bay View Peggy Webb 208-683-2704

Boise Anne Spencer 208-334-2235,
ext. 258

Coeur d'Alene Barbara Tucker 503-494-8307

Glenda Weaver 208-769-7896

Clarksfork Carolyn Vogel 208-266-0266

Sandpoint Sharon McCahon 208-265-7915

Montana

Whitefish Joanne Friedenber 406-892-3179

Patty Morris 406-862-3977

Oregon

Portland Karen Kovack 503-494-8307

CDRC Genetics 503-494-5606

Washington

Centralia Ruth Tremblay 360-736-2294

Clallam County Joan Greiger 360-683-3798

Kitsap County Angie Gordon 360-697-6870

Mukilteo Bill Pew 425-745-9468

Hans Wold 425-353-4002

Linda Dixon

Seattle Amelia Schultz 206-363-4304

Seattle Donna Ross 206-598-8753

Sequim Joan Geiger 360-683-3798

Southwest Russ Kastberg 360-425-9338

Spokane James or Patti Hook 509-276-8038

Rhea Kine 509-747-4735

Nick Suksdorf 509-838-6364

Tri-Cities –
W. Richland Carl Gallion 509-967-9161

Wenatchee Kathy Wolf 509-663-0399

509-548-7622

Washington (continued)

Vancouver Russ Kastberg 360-425-9338

Tom Gillihan 360-425-8477

Yakima Joyce Korevaar 509-225-4429

509-548-7622

HD Support Groups

- On the second Monday of each month an HD Support Group meets at the Swedish Hospital (conference room 305) in Ballard. All are welcome.

- Additionally, a neurogenetics adult support group meets the first and third Thursday of each month from 2:00-3:30 at the University of Washington CHDD building room 365.

The Northwest Chapter Can Use Your Help!

Contributions

We gratefully accept contributions. We are currently accepting donations for this year's auction, please send an e-mail to cindycrossman@yahoo.com or call her at 425-327-6887. The Huntington's Disease Society of America is a non-profit agency and all donations are tax-deductible.

Volunteers

For further information about volunteer opportunities, please call our chapter business line at 206-464-9598. You can also send us e-mail at nwhdsa@yahoo.com. If you are interested, please contact Liz Weber, our chapter president, at lweber@natlogic.com.

All telephone calls and e-mail to us will be kept strictly confidential.

You can also write to us at:

Huntington's Disease Society of America
Northwest Chapter
PO Box 33345
Seattle, WA 98133

The Northwest Huntington's News attempts to report all items of interest relating to individuals with Huntington's Disease, their families, health care professionals, and interested friends and supporters. HDSA and the Northwest 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 Northwest Chapter.

Moving or no longer want to be on our mailing list? Call our Chapter HELPLINE at 206-464-9598 or 1-888-264-HDSA. This will help us conserve paper and postage.



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Nancy L. Keller, Secretary	360-863-6183
Jerry Mickelson, Treasurer	425-828-3198

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