A lively crowd turned out for the Alfý’s Pizza Fundraiser and Quarter Auction on May 3 in Monroe. Proceeds from food, admission and something called a Quarter Auction went to help fight HD. “Not only did we raise money, we built friendships as well,” said auction assistant and chapter president Jim Bridges. A big thank-you to the volunteers who pitched in, and also to Alfý’s Pizza who was generous in hosting this fundraiser. And finally a high-five to Renette Davis who solicited more auction items than thought humanly possible.

**Education Day informs and encourages**

by LaVonne Goodman, M.D.

*Education Day* on May 24 was a chance for the HD community to hear research updates and attend talks on caregiving and lifestyle issues. The event was made possible by the work of the Northwest Chapter of HDSA, by generous financial support from *Lundbeck Pharmaceuticals*, and by the *Institute for Systems Biology* in Seattle for use of their auditorium. The success of the day was made possible by the estimated 75 individuals who attended.

The tone was set for the day by **Rev. Jim Bridges**, President of the Board for the Northwest Chapter of HDSA, and **Dr. Suman Jayadev**, Medical Director of the Center of Excellence (COE) at University of Washington. Rev Bridges provided updates on chapter-related fundraising and family service...
Online presence, staff turnover among changes

A Note From Jim Bridges, President of the Northwest Chapter

This past year (September through June) has been a busy one for us here in the Pacific Northwest Chapter of the Huntington’s Disease Society of America.

Our Family Services Committee, under the leadership of LaVonne Veatch Goodman, M.D., continued to provide an online resource guide for HD families on our chapter’s website. In addition, the website has highlighted various research opportunities for our community members, with the hope that many of us will sign up as research subjects. We’ve also used e-mails to highlight the local research possibilities for our membership.

Then too, we have funded our chapter’s social worker, Chris Wick, for two days per week responding to calls to the chapter’s Help Line (for those who are not patients of the Center of Excellence at the University of Washington.) She has responded to calls from all five states of our region - Washington, Oregon, Idaho, Montana, and Alaska, with an occasional call from Hawaii as well. Sadly, Chris is now in the process of moving out of state. We shall miss her.

Thanks to an anonymous grant, the chapter has been able to increase the number of professionally led support groups in the state of Washington to ten. We’ve also been able to start up a new professionally led support group in Montana, and have added an additional support group in Oregon.

The Family Services Committee has also held biannual meetings with the Center of Excellence staff to coordinate family care programs within Washington state. The chapter and the Family Services Committee, along with support from the COE staff, have continued to hold two educational events per year (Spring and Fall), funded in large part by grants from Lundbeck. Dr. Goodman and our social worker have provided outreach education for more than 100 physicians, mental health practitioners, and long term care professionals. They continue to work on developing consultative relationships with adult family assisted living and nursing home facilities so that HD patients will be accepted and experience better care in them.

We have an active website administered by Sandra Carlquist, to whom we are quite grateful! We also network through Facebook, Twitter, and e-mails, thanks to the efforts of retiring board member Jacque Stock. Then too, we now publish a semi-annual newsletter, thanks to board member John Carlson! (He also doubles as the fundraising committee chair and has designed both of our fundraising t-shirts.)

This past year we have also had a flurry of fundraising events, some large and some small. We had our Team Hope Walk, our second annual Bowling to Strike Out HD event at Evergreen Lanes.

A Fond Thank-You to Northwest Social Worker Chris Wick

In June, Chris Wick, MSW, MCSW, stepped down from her social work position For the Northwest the Chapter. She and her husband Gary, who is a retiring fire-fighter will be moving out of Washington State in the near future. Chris took on a challenging position at a time of transition and devoted much time and energy over her three-year time with the Northwest Chapter to obtain and improve services for many Huntington’s families in the Northwest. In addition to her usual duties, during the first year of her time with the chapter she created the Washington State Resource Guide for the Huntington’s Disease Community, that can be found on the NW Chapter web site. (www.hdsa.org/nw) She was also the leader in developing new professionally led support groups.
Two new social workers climb aboard

The HDSA Northwest Chapter is pleased to welcome two new social workers to the HD community. The chapter has hired Vivian Foxx as its social worker; and the UW Center of Excellence has brought Susan Reynolds on board as a clinical social worker.

Ms. Foxx (left) has extensive experience in health related social services, volunteer and paid activities. She obtained her Bachelor of Science (B.S.) degree from the University of Florida and her Master of Social Work (M.S.W.) degree from the University of Washington. Currently Ms. Foxx works at the University of Washington Medical Center, where she works with diverse patient populations to ensure they receive effective and compassionate patient care. Ms. Foxx has also begun work as a support group facilitator for the HDSA NW Chapter, and has taken over the chapter’s Help Line duties. (Her contact info is at: www.hdsa.org/nw-chapter/nw-medical-and-nonmedical-resources.html)

Susan Reynolds is a clinical social worker for the U.W. Center of Excellence, currently working half-time. Her medical social work background includes working in home health, hospice and long term care. She is passionate about her work and delighted to become part of a great team.

Chapter news, continued

in Everett, our third annual Cricket and Snail concert and art auction at OneLife Community Church, our first Pizza Party and Quarter Auction at Alfy’s in Snohomish, and an acoustic benefit concert produced by M-bibe. Additionally, we continue to sell HD t-shirts and welcome monthly pledges of financial support.

We have had two amazing efforts to raise both awareness and funds for HD this year: A motorcycle trip by Chris Misenar and a five-month hike by Jason Evans. (See related stories on p. 6)
Let’s Talk About an Important Reproductive Option: PGD

by LaVonne Goodman, M.D.

For more than a decade, couples at risk for Huntington's disease have had the option to conceive an unaffected child by utilizing the reproductive process of preimplantation genetic diagnosis (PGD). If PGD became common practice in HD, it could eliminate the majority of disease for the next generation. So if PGD has the potential to mostly "wipe out" HD for the next generation, why is it so rarely utilized?

What is PGD? First carried out in 1990, PGD is a procedure that allows genetic testing of an embryo before it is placed in the mother's uterus. Mature eggs are surgically removed during a procedure performed in the doctor's office. Then in vitro fertilization (IVF) is done by injecting each egg with sperm. Resultant embryos are grown for 5 days and a few cells are removed from each for gene analysis. Embryos that test negative for the disease gene are frozen, then subsequently implanted into the mother's uterus.

What is PGD with non-disclosure? In this PGD situation clinic staff follow procedures to prevent disclosure of gene status to those at risk for HD who have chosen not to test.

Rates of PGD use are low. How rarely is PGD used in HD? The only published studies suggest that it is very low -- even in countries where PGD for HD is covered by national health insurance. Utilization from 1995-2008 was only 0.7% in France, 1.7% in Belgium, and 1.2% in the Netherlands. Though there are no studies or reports from North America where PGD is often not covered by insurance, the rates are likely not much higher. Why so low?

Lack of Awareness/Lack of Education: Though no studies specific to HD have been done, it is likely that the vast majority of HD couples have never been given education or received counseling about PGD. In fact in a study done among internal medicine physicians, more than 90% could not explain the procedure to patients. It is doubtful that neurologists would be much better.

What about HD specialists? Though it is unknown how many have ever talked about PGD with their patients, it has not been an education topic prominently discussed in either the Huntington Study Group (HSG) or European Network of Huntington's Disease (EHDN) meetings. Though it is recommended that reproductive options be discussed during genetic testing counseling for HD, it is unclear how often this is done. Even if done for every person undergoing genetic counseling for HD, such education would reach only the minority of those at risk for the disease.

Financial Burden: Cost is in the range of $20,000 per procedure. Unfortunately for many at risk couples more than 1 cycle is needed, particularly if the mother is older than 35 years of age where 3 (or more) cycles may be needed. Only fifteen states in the U.S. have mandates for even partial coverage for PGD. A few progressive large company employers including Google, Microsoft, and Amazon provide substantial PGD benefits, but most employers do not. However,
it isn't just financial burden limiting PGD; even in those countries where PGD is covered by national insurance, at least as reported in the earlier study, fewer than 2% of couples utilized this option.

**Lack of Access/Geographical Location:** PGD is offered only in large urban areas. Because the entire procedure requires frequent visits for monitoring, multiple trips must be made to the center, making it more difficult for those who must travel long distances.

**Psychological and Physical Stress:** PGD "takes over your life" during the weeks required for all the steps related to the procedure, although studies suggest that there are no long-term adverse consequences for those who achieve a successful pregnancy using PGD.

**Religious/Ethical Reasons:** It is not known how many at risk HD couples choose not to have PGD for religious or ethical reasons.

**Acceptance or Denial of Risk for the Next Generation:** Reproductive decisions are very complex and may be subject to emotional and unconscious psychological processes, so it is likely that a published study of reproductive decision-making in those who had children while knowing of risk for HD was oversimplified. However, important themes reported are that many couples (1) "accepted" risk to children citing hope and a belief that treatment or cure for HD might occur in their children's lifetimes, or they felt optimism about their ability to care for a spouse and children if HD occurred. Others "denied" risk believing they would escape HD, and others minimized risk. It should be remembered that at the time of this study, PGD was not as readily available; however it is likely that similar thinking contributes to lower use of PGD in the present generation.

**Author's comments:** PGD is underutilized. HD doctors and HD societies do not readily increase awareness or provide adequate education. And there are geographic and financial barriers. However -- it is past time for more support and better application of PGD as a voluntary means of preventing HD in the next generation. The experts tend to agree, as is argued in a recent Nature Reviews Neurology article, "It is time for clinicians and neurological societies to consider the evidence and to formulate guidelines for the responsible integration of PGD into modern preventative neurology."

Authors of this article cite several societies for reproductive health and genetics who recommend and have guidelines for counseling of all family members afflicted by genetic disease. However, as of now, no neurological societies, including those for HD have done so. PGD has been around for more than two decades. Admittedly a sensitive topic, it is high time for the clinicians in our community to increase awareness and to provide more education to HD families.

"So if PGD has the potential to mostly "wipe out" HD for the next generation, why is it so rarely utilized?"

**BE A SUPER HERO FOR HD!**

**Join Team Hope**

See page 11

This story is also available, with references, at the author's website:

http://hddrugworks.org/index.php?option=com_content&task=view&id=336&Itemid=30
A Big Thank-you to Chris Misenar for his Cross-Country Ride for HD

by Dr. LaVonne Goodman

Chris Misenar, who lost his wife Vicky to Huntington’s disease in September of 2012 has recently completed his motorcycle ride across country from Washington State to Florida (route shown below). His goal was to help raise awareness and funds for those who live with Huntington’s disease.

After a send off by other cheering members of the Kirkland support group on May 8 (above), he rode though rain, sleet, hail, and extreme temperatures to complete this trip to Florida on May 20th. During this heroic effort, he raised more than $5,000 for HDSA, dedicated to the Northwest Chapter. Thanks Chris!

Epic Hike a Quest for HD Awareness

by Jim Bridges

Jason Evans, a self described “soft-spoken, family-oriented 37-year-old native Oregonian” set out on his most ambitious endeavor yet, “to thru-hike the 2,650-mile length of the Pacific Crest Trail (PCT); to draw attention to the sometimes devastating, life-altering effects of the genetic disorder known as Huntington’s disease, and to raise funds for research efforts to develop effective treatments and a cure.”

You can see a lot more breathtaking pictures on Facebook:
https://www.facebook.com/essive.evans

You can pledge here:
https://www.firstgiving.com/fundraiser/pacifictrek/pacificcresttrekforhd
Clinical Trials in the Northwest

This page highlights some clinical trials that are in progress or are coming soon. Of course, the long-term hope of these studies is to cure HD. But trials can’t succeed without the participation of everyone that might be eligible to take part.

by Lavonne Veatch Goodman, MD

UW Observational Study

*Muscle and brain MRI study:* This study is important for learning more about the energy problems that occur in Huntington’s.

Details: Thanks to those who participated in the pilot phase of this study earlier this year! More information will be available soon about the next phase of this study.


First-HD

*First-HD* is a Phase 3 clinical trial testing a long-acting form of tetrabenazine (Xenazine). It is hoped that the long acting preparation will be as effective for controlling chorea, but have fewer side effects and be more convenient for patients than current treatments.

*Location:* Evergreen Neuroscience Center in Kirkland and University of Washington in Seattle


CREST-E

Phase 3 clinical trial taking a high dose of the dietary supplement Creatine.

Location: Evergreen Neuroscience Center in Kirkland.


Enroll-HD

*Enroll-HD* is an international collaboration including HD patients, individuals born at risk for HD (regardless of whether they have been tested genetically), and their families.

Details: Enroll-HD requires about a half-day visit once a year. Transportation reimbursement is available. You can be in this study and take part in other trials or studies at the same time.

*Location:* Evergreen Neuroscience Center in Kirkland and University of Washington in Seattle


Keep up with research online

**www.hddrugworks.org**

HD Drug Works covers clinical study of HD symptoms and trial information

**www.hdbuzz.net**

HDBuzz covers basic science and clinical research news written in straight-forward language

PDE-10 Inhibitor Drug

*Omeros Corporation:* Phase 2 safety and tolerability clinical trial covering 3 different doses of this potential treatment.

Details: Nine site visits required, ages 18-65.

Location: Evergreen Neuroscience Center.


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Education Day informs and encourages, continued

(Continued from page 1)

activities. Dr. Jayadev first talked about the many years of dedicated service given by Dr. Thomas Bird, former director of the COE, and updated us on present staff and many services provided at the University of Washington.

The remainder of the day was split into 10 different workshops, as follows:

Clinical research updates were provided by Dr. Patrice Rious from Raptor Pharmaceuticals, and Dr. Kevin Conley from the University of Washington. Dr. Rious reported promising results using their drug in HD in an ongoing clinical trial being done in France. Preliminary review suggests that this drug can slow down progression of motor symptoms of Huntington’s disease. Dr. Conley presented preliminary results from an ongoing study of energy changes that occur mitochondria in muscle and brain in individuals with premanifest or early symptoms of disease. The hope is that this technique can be used to decrease the time needed for clinical trials of new drug. He pointed out that rapid recruitment from Northwest volunteers helped get this study done in a rapid time frame.

Arik Johnson, Doctor of Psychology from the UCLA Movement Disorder Program led 6 workshops, one on Managing Behaviors in HD, another on Care for the Caregiver. A favorite speaker for both this and the previous year, his presentations are highly lauded. He is co-author of Understanding Behavior, a new guide available by contacting HDSA at www.hdsa.org/living-with-huntingtons/publications/understanding-behavior-1.html

Dr Suman Jayadev gave a morning presentation on Cognitive Changes in HD, then was joined in the afternoon by Dr. Marie Davis, another physician from the University of Washington Center of Excellence who also provides medical care at the Veterans Hospital in Seattle for a lively “Ask the Doctors” session.

Dr. Michael Opsahl, a physician expert on PGD from POMA Fertility, in Kirkland, Washington. He taught about some of the specifics of PGD, a medical reproductive technology that can be used to select for children who will not inherit the disease gene for HD. (See related story on p. 4)

Erika Bjorklund, board member of the NW chapter, and Ian Wallace, genetic counselor from Pullman Hospital gave a lively and informative session on “Talking with Kids about HD”. They utilized and recommended information from the HDYO (HD Youth Organization) web site: http://en.hdyo.org

Dr. LaVonne Goodman and Susan Reynolds, who is the new social worker for the Center of Excellence led the Managing Late Stage HD workshop. Ms. Reynolds has extensive experience gained from being a leader in palliative and hospice care for Washington State.

Dr. Roger Carnes, HDSA Clinical Trials diplomat and Emily Freney, clinical research coordinator at the University of Washington presented “Northwest Clinical Studies and Trials”. Complete information can be found on the Northwest Chapter website: www.hdsa.org/nw-chapter/nw-clinicaltrials-update.html

Dr. LaVonne Goodman led the workshop on “The Proactive Life Style” that included discussion on the benefits of exercise, quality sleep, healthy diet, and stress reduction. More information at: www.hddrugworks.org/index.php?option=com_content&task=view&id=309&Itemid=26

Hope to see more attendees next year.
Nothing shows your support for a cause like wearing a T-Shirt! The Northwest Chapter now has 2 sharp designs to choose from. Not only will everyone know you are passionate about stopping HD, but the proceeds from these quality cotton T-shirts support the NW Chapter!

Send $25 payable to HDSA Northwest Chapter for each shirt, and specify which design and size (Men’s or Ladies “M” - “2X”). Mail to:

17406 Redhawk Drive
Arlington, WA, 98223-5954

by John Carlson

On May 23, a crowd of about 60 concert-goers had their socks charmed off by a cricket and a snail. For the third year running, the duo Cricket & Snail provided the backbone of a fun and lively event that benefited the HDSA Northwest Chapter. The evening also included an art auction and a “dessert-dash,” which together raised two-thirds of the proceeds for the night.

Many people spoke glowingly about the “euro-café” style music provided by Cricket & Snail. Attendees described the music as enchanting and mesmerizing, played with impressive musicianship. And that’s not a direct quote from the musicians’ web page. Pieces they played included traditional folk tunes arranged by the duo, some folk-oriented classical pieces, plus some original pieces that you might mistake for old folk melodies.

The auction featured a variety of fine arts contributions, including photographic prints, watercolors, oils, block-prints, ceramics, woodcrafts and more. Special thanks to all the artists who contributed to the auction. Thanks also to those volunteers who provided desserts, or set up tables, or bussed tables, or set up the auction, or helped in a hundred other ways. Finally thanks to all of you who contributed generously to the cause!
Who was the man behind the disease?

by John Carlson

I have vivid and visceral memories of visiting my Grandpa Art when my brother and I were kids. For his last couple of years, he was living in a nursing home with advanced Huntington's disease. Even before that, I remember my grandpa (through kids' eyes) as someone difficult to understand, with a mysterious and startling pattern of involuntary movements and jitters.

Sometimes I am struck by intense feelings of loss around Grandpa's illness, even though I never knew him personally. Why should those feelings be so strong, when I hardly knew him? Without really understanding the reasons, I began to piece together what Grandpa was like before HD crippled him. From recent conversations with family members, I've been happy to learn more about the man behind the disease.

As a young man he moved to Everett, Washington in the 1930's, at about the same time as my grandma's family. They had known each other in North Dakota, so perhaps it wasn't a coincidence they ended up in the same city.

Shortly after arriving in Everett they were married and before long they had 3 children, Marlynn, Teri and Bob.

During World War 2, Art found reliable work in the ship yards in Everett. After the war, however, work became harder to find. He had some experience doing bakery work, and so he picked up some part time work in another city as an early-morning baker. He worked numerous odd jobs to supplement that income. To save money, he resolved to fix any problem that sprung up around the home, including major things like digging up and repairing the sewer pipe.

The economy was bad, but at home life was good. He enjoyed spending time with his wife and kids when he could. After a few years he found a full-time job at the Boeing plant down in Renton. It was a pretty long drive in the days before I-5 was completed, but the pay was good.

Art had only been at Boeing for a few years before he began to experience a noticeable decline in concentration and eye-hand coordination. These changes began to affect his ability to do his job. Thankfully, his employer was flexible, and they moved him from assembly work to janitorial rounds.

His regular doctor and several other specialists didn't know what to make of his symptoms. Finally, he was referred to the UW Medical Center where he was diagnosed with HD in 1969. The Center of Excellence was just getting started and he was seen by Dr. Thomas Bird in his first year of clinical work. Support and follow-up were offered, but not accepted. Like many families, my grandparents valued their privacy, and they resolved to get by on their own.

Because his symptoms continued to worsen, Art took an early retirement. From that point, my grandma took care of him at home for as long as she could. And once his care required more lifting than she could manage with her slight frame, she agreed to move Art to a facility.

That's when my own story begins, with memories of Art at the nursing home and my feelings of loss. But in some ways, just knowing that there is more to his story helps me feel like I know him better. And picturing him living his life and loving his family helps relieve the feelings of pointlessness around his disease. While I didn't get to know him, he was known and loved by others. Somehow having a more complete picture of Art makes it easier to accept the part of that picture that was his disease.
Yes! You Can Be a Superhero For HD!

by Melissa Jeng

Have you ever wanted to be a Super Hero? Well now is your chance to be a Super Hero for Huntington’s Disease! I am so excited to be coordinating this year’s Team Hope Walk in Seattle!

As many of you know, the traditional Team Hope Walk consists of a simple one-mile loop. Well, this year we are also adding a 5K route! Why, you ask? Well here is the simple answer: to create more visibility and awareness for our local HD community and HDSA chapter! Adding the 5K to our traditional 1 mile loop allows us to attract runners, joggers and walkers from outside of our HD community! Getting more people involved leads to more local interest, support, and dollars … which leads to increased public awareness about HD! How awesome is that?

So… what exciting things can we expect at this year’s event? Other than some beautiful views along the waterside, we will also have various kid friendly activities, and a raffle for some fabulous prizes. You can also visit some of our generous sponsor and donor tables!

Finally… some of the fun will depend on you! And what do I mean by that? Get your costumes folks! Dress yourself, dress your kids, dress your family, dress your friends, you can even dress your dogs! Then come join us and be a Super Hero for HD!

⇒ Register you and your team today at: www.hdsa.org/thwseattle or http://www.firstgiving.com/hdsa-wa/thwseattlewa

Keep eyeing our Face Book event page (https://www.facebook.com/events/list?ref=46#!/events/710610215645458) for some exciting sponsor and activity updates! Looking forward to seeing you all there!

Quick Facts!

When? Saturday, September 13, 2014
Where? Warren G Magnuson Park, Seattle
Time? Registration opens at 8:00 am
Race begins at 9:00 am

Contact? Melissa Jeng
Secretary – HDSA NW Chapter
206-380-7336
jengmjo@gmail.com

Other regional walks
Portland: Sat, October 4
Boise: Sat, Oct. 11