Author Jimmy Pollard Inspires Caregivers

by Christina Wick, MSW, LICSW

HDSA-NW was fortunate to host longtime HD advocate Jimmy Pollard at an all-day event held on Saturday, November 16th, 2013 at the Evergreen Health auditorium in Kirkland. Pollard helped listeners have better compassion with HD patients by leading strategic thought exercises. He also led a discussion panel about the upcoming wave of clinical research trials.

Jimmy Pollard is well known to people with Huntington’s disease and their families in the United States and around the world. He has been an invited speaker at national meetings in Ireland, Scotland, England, and the United States. He has worked in HD specialty care programs in nursing homes, assisted living, and hospital settings for over twenty years. A licensed nursing home administrator, he holds a Master’s degree in Special Education and has taught Special Education at the graduate level for several years.

Pollard gave two talks; the first titled Hurry Up and Wait which gave the audience a very good depiction of what it is like to think as a person with HD. His second presentation, Making It Yesterday, addressed the

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As of January 1st, my second year serving as President of the Board of Directors for the Northwest Chapter of the HDSA came to an end. I believe it has been a rather busy, productive year. We held two chapter-wide educational events - the Northwest’s annual Spring convention at the Institute of Systems Biology in Seattle, and the visit by Jimmy Pollard at Evergreen Hospital in November. Both received positive comments by attendees.

We witnessed a change in leadership of the University of Washington Center of Excellence (COE). We salute the former director, Dr. Thomas Bird, for his many years of service provided to our Huntington’s community. Assuming the directorship of the COE is Dr. Suman Jayadev. We also welcome two additional Center physicians: Doctors Ali Sami and Marie Davis. Twice during the year, the Chapter’s COE Review Committee met with the COE leadership and established a cooperative relationship, with focus placed upon delivery of quality patient care by all parties.

Last year, the chapter received an anonymous grant for expanding our support groups throughout the Northwest. We added three professionally led support groups, two new ones to start this January, with several more set up to begin this coming year in Washington. We also hope to increase the number of groups meeting in Oregon, Idaho, and Montana this coming year.

This past year also saw the beginning of what we call the Outreach Program - in which the chapter, in conjunction with the COE, provides education to commu-

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CONTINUED: President’s Letter, A Busy Year

They now include our annual Team Hope Walk, a dinner concert featuring Cricket & Snail, and a small bowl-a-thon held mostly for people attending the Everett Support Group and their friends. My effort to encourage people to make a monthly pledge to the chapter has slowly grown as well, and we now have roughly 20 people making monthly contributions. While our Team Hope Walk did not do as well this past year compared to two years ago, the dinner concert increased in attendance and proceeds. The bowl-a-thon brought in close to twice as much money as the prior year.

For our next year, we plan on continuing with these fund raisers, as well as with our educational events. Plus we hope to add a new Team Hope Walk in Spokane (in addition to the one in Seattle) and hold a gala dinner event. It is awkward for me always to have to talk about money - but it must be done. The Northwest Chapter has not carried its own weight financially. We need to raise roughly $85,000 annually to cover our own expenses. (That includes $50,000 to cover the grant which the national HDSA gives to our Center Of Excellence and another $30,000 for salary for our own two day a week social worker, plus related office expenses, etc.) We are not yet one-half of the way towards covering our expenses. That doesn’t mean we cannot do it - it just means that we must work harder and get everyone to contribute to the effort!

Suman Jayadev, MD, recently stepped into leadership of the Northwest Center of Excellence.
CONTINUED: Pollard Brings New Insights to Caregivers

Several doctors joined Pollard for the panel discussion on research: Left, Dr Suman Jayadev of the UWMC; Above, Dr. LaVonne Veatch Goodman (Left) and Dr. Marie Davis of the UWMC.

advances in research and new opportunities to participate in local research studies. Two physicians from the University of Washington and our own Dr. LaVonne Veatch Goodman joined Pollard in sharing about new clinical research, and how very important it is to participate.

Jimmy Pollard’s noted book, *Hurry Up and Wait* (available in paperback), examines the characteristics of thinking for a person with Huntington’s disease. He began his presentation by explaining that his objective was not to teach us what we may already know, but to perhaps help us see things in a new way, and allow us to teach others.

Pollard accomplished this as he invited the audience to participate in exercises that actually simulate features of thinking like a person who has HD. The exercises involved the use of a pen and paper and following his thorough instructions. He also enlisted volunteers to perform tasks which he precisely directed them through. As the exercises were completed, the distinct challenges in characteristics of thinking such as slower thinking, recognition vs. recall, the ability to focus, organizing, and impulse control were very clearly understood by all.

Pollard is an engaging speaker who involves his audience. His compassion and care for the HD community is evident as he conveys his knowledge of HD and the related challenges that people face. He travels throughout the country supported by funding from CHDI, making a valuable contribution to HD communities who are always pleased to hear him speak. Approximately 75 people from NW Chapter support groups attended the event. Food and beverage was provided by a grant from Lundbeck.

Does your doctor want to learn more about HUNTINGTON’S DISEASE?

The HDSA offers Outreach Education for Huntington’s Disease, to help community-based physicians in their care of HD patients. Continuing Education credit is offered. Staff at long-term care facilities can receive specialized training as well.

For more information contact Jacquie Stock: jacquieleestock@gmail.com
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!

Show Your Support With A T-Shirt!

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

Similarly, HD research has been “off soundings” since it began, delving into brand-new areas of research such as genetics and systems biology. By adding more and more soundings to the chart of human biology, we’re not only coming closer to curing HD, but shedding light on the function of other diseases as well.

Finally, the name is a nod to the most familiar body of water in the Northwest, Puget Sound. Like many people who grew up in the Northwest, I’ve spent a lot of time rowing, sailing, yachting, going somewhere on a ferry and kicking around on a beach. What brings people of the Northwest together is their love of water, as well as a passion to take care of the waterways.

I would love to see that same community spirit and Northwest activism come to fruition in the name of curing Huntington’s disease. We’ve got a lot of great people doing their part for the Northwest Chapter. But there is room for much-needed growth in both membership and regular giving. Please consider Jim’s plea on page 3 of this newsletter to pledge your regular support to the Northwest HDSA.

Thanks for your time.
Ordinary Good Deeds Launch Extraordinary Friendship

by LaVonne Veatch Goodman, MD

A short while ago a patient of mine died after a long struggle with Huntington's disease. Here I tell the uplifting story about him and the last four years of his life. This story would not have been the same—for him or for me—without Elizabeth, our mutual and ordinary/extraordinary friend.

The Story Begins: During the latter years of my patient's illness he had fallen on hard times and turned to alcohol. He was estranged from family, and trusted no one. He spent too many days in bars and too many nights out on the streets. He was in and out of shelters when there was room and food. Near the end of his days on the street he sought refuge in a portable toilet.

Then about 4 years ago his luck changed. On a rainy and cold night on her way to a local restaurant, a woman walked by my soon-to-be patient sitting in the doorway of an adjacent shop. She had seen him in this neighborhood before, when he had seemed angry and threatening. However on this night, when she walked past him again later on her way back to her car, she could see that he was very thin and looked sick.

After a few minutes debating with herself, she walked back to this homeless man, asking if he was hungry. To which he replied "yes", and that he really would like a pizza with everything on it from a shop around the corner, "extra cheese, no olives". After getting the requested pizza, she delivered it to him, but she didn't leave immediately. Instead she patiently stood there silently for several uncomfortable moments till he introduced himself. They exchanged names, and then after several more uncomfortable minutes of silence while waiting to eat, he asked if she'd be back next week. "Yes" she said and went to her car and drove away.

Then next week, at the same time and place, she was there with his pizza.

The Story Continues: For the next four years as his trust for her grew, this woman became his advocate and a true friend. She soaked up all the information she could find about Huntington's disease. She helped get him off the street and into an Adult Care Family Home. She convinced him to allow medical attention and brought him to see me. And though his disease progressed and his last years were not easy; they were some of the best years of his life because he had a friend who helped him through. A friend that brought diverse gifts from warm socks to cigarettes to reuniting him with his nieces and cousins. Each respected the other, and they enjoyed the others' company.

She made all the difference.

Ordinary or Extraordinary? Over the years as I watched this mutually caring relationship evolve, I learned things about both my patient and his advocate and friend Elizabeth, who has since become my friend.

From my patient, I learned that even at his end-stage of Huntington's disease, his mind could grow and change, he could learn to trust again, make a new friend, and be a true friend. He early on accepted rules she set, and though he kept his own opinions, he respected, trusted and he complied with her rules. And over time, he increasingly gave of himself, opening up with stories of his life. And no matter what the weather, and as long as he physically could, he always looked forward to and enjoyed their occasional excursions. When he could no longer go out, he would smile when she came. And with her there, his dying was not as hard.

From Elizabeth, I watched and learned about how to live a more beautiful life. Her answer to me when I asked her why she had befriended my patient? "Because anyone can help just one other person." Of course, as I would learn later, this good lady has helped a lot more than just one other person. She has helped many homeless persons in Seattle for a lot of years. However, the important point she was making was that an ordinary person can help just one other person. It shouldn't be extraordinary.

Imagine what a different and wonderful world it would be if every person helped one other.

"Anyone can help just one other person."
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

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.

Details: Participants must have moderate to severe chorea. They must have never taken tetrabenazine (Xenazine), and must not be on an antipsychotic drug (like olanzapine or risperidone or others). Study length is 4 months, with 8 in-person visits and 7 by telephone. There is 50/50 chance of getting drug or placebo, but at the end of the trial, drug will be given to all participants in follow-up study for 1 year. Transportation reimbursement is available.

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

Contact: http://www.hdsa.org/nw-chapter/nw-clinicaltrials-update.html

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

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. This study is vital to the more rapid development of treatments for HD therapeutics and completion of clinical trials.

Details: Enroll-HD requires about a half-day visit once a year. Transportation is reimbursement 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

Contact: http://www.hdsa.org/nw-chapter/nw-clinicaltrials-update.html

Coming Soon

Muscle and brain MRI study: This study is important for learning more about the energy problems that occur in Huntington’s, and may be a useful technique for speeding the time needed for new drug clinical trial completion.

Details: Participants have tested positive for H.D and either have no symptoms or early symptoms. Requires 2 visits 1 week apart, each taking most of the day. University of Washington

Contact: http://www.hdsa.org/nw-chapter/nw-clinicaltrials-update.html

Coming Soon

Omeros Corporation will be sponsoring the testing of a new drug for Huntington’s disease. Details are pending.

Location: Evergreen Neuroscience Center.

Contact: http://www.hdsa.org/nw-chapter/nw-clinicaltrials-update.html
Alive & Well Documentary Takes HD to the Masses

by John Carlson

Alive & Well is not your typical documentary about a disease. Rather than focusing on the discovery of the disease, or on the breadth of impact that a disease can have, the film-makers have chosen to tell the stories of seven individuals who face the reality of Huntington’s disease in their lives.

Consequently, Alive & Well is compelling for a diverse audience, because at the end of the day, the struggle with HD is not that different from the mortal struggles by which people everywhere are challenged. This movie is engaging whether you are familiar with HD, or whether you had not heard of it before walking into the theater.

Alive & Well offers some surprisingly intimate glimpses into these people’s lives. The listener can’t help but be moved by these stories of heartbreak, bravery and pluck. By the end, the name of Huntington’s is transformed from an abstraction into a sobering future for seven new acquaintances.

The director is Josh Taft, an accomplished video and TV director who is best known locally for his music videos for Pearl Jam, Alice in Chains and Stone Temple Pilots. The music score for the documentary lists some savvy contributions from the Northwest music scene.

Alive & Well was well-received at its premier at the 2013 Seattle International Film Festival (SIFF). It was awarded a screening in the “Best of SIFF” film series, and was nominated for Best Documentary at SIFF.

The filmmakers are currently showing the film “on-demand” using the Gathr film service. Through this web site you can see which showings are being offered in your area, and which screening are still waiting for a GreenLight. You can even submit a request for a new showing in your area. (See the following websites for details.)

http://aliveandwelfilm.com/
http://gathr.us/films/alive-and-well

“We made this film to honor the people who trusted us with their stories, to have this film seen by as many people as possible, and to raise awareness of Huntington’s disease.” (From the Director’s Statement, aliveandwelfilm.com)

You do it for public radio.
You do it for political causes.
Why Not Pledge Your Monthly Support to the NW Chapter of the HDSA?

https://www.hdsa.org/nw-chapter/nwchap.html
Catching Up With HDSA on Social Media

by Jacquie Stock

How do you find support and information about living with Huntington’s disease, or news and events about Huntington’s disease? If you asked a group of people this question, you would get many different answers. Not everyone starts with the phone book anymore, or even Google.

Huntington’s Disease Society of America Northwest Chapter (HDSANW) offers several ways to communicate with us and other people who are at risk for or have HD, have a family member or friend with HD, or are interested in HD. Yes, we do have email and traditional support groups, but we are also on Facebook at www.facebook.com/hdsanw and we Tweet from @hdsanw.

Whether you are a regular on Facebook or you think an “app” is something you fill out for a new job, it can be interesting and useful to know which groups of people might use Facebook to learn about or share with others who have a similar interest. People use Facebook for different reasons. Our HDSANW page posts and links to news, events, human-interest stories, literature, movies, research updates about HD as well as sharing inspirational material. The HDSANW Facebook page is also a place where people who choose to can interact and ask questions.

As with all Facebook pages, HDSANW Facebook page can view basic descriptive information about people who “Like” our page. From the data Facebook shares with us, (without us having to calculate it ourselves,) we can learn that at last analysis, 76% of our fans were women and 23% were men. Our users ranged in “age groups” from 13-17 years old to 65 years old and older.

Our 730-some HDSANW Facebook users come from all over the United States, Africa, Asia, Central and South America, Europe, Australia and New Zealand, and speak many different languages. Yet, the one thing that holds us all together is our bond of HD.

Our @HDSANW Twitter feed is increasingly followed by people who use Twitter for personal or professional interest. HDSANW at last count had 133 people or organizations who read our Tweets about news and information related to HD. A review of our Twitter followers reveals a variety of individuals, scientists, other HD organizations, and news organizations.

So, whether social media is something you grew up with or something you have not yet tried, we would love to welcome you to simply keep informed or share with others through our HDSANW social media options.

Save the Dates

for this year’s HDSA National Convention! Don’t miss this opportunity to meet people from all over the country (world, really) who are passionate about stopping HD. Hear the latest research results and hear first-hand what new studies are coming next.

June 20-23, 2014

Louisville, Kentucky