A Year of Ups and Downs for Research

by LaVonne Goodman, M.D.

2014 was a Yin-Yang year for clinical trials in Huntington’s disease (HD), full of ups and downs. First was the disappointment in the failed trials of both coenzyme Q-10 and creatine supplements. Then in mid December, important positive results for a new formulation of tetrabenazine (name still to be decided) that is effective for treating chorea of HD, but has many fewer side effects (importantly less depression and fatigue) than that caused by the old drug.

And it is very good news for Washington State that 2015 is bringing two new drug clinical trials (PRIDE-HD and LEGATO-HD) to the Northwest, with recruitment just starting at Evergreen Neuroscience Center in Kirkland. Both of these well-designed trials are sponsored by TEVA, a big pharmaceutical company led by Dr. Michael Hayden, a scientist and physician who has been a leader in HD research for decades.

See Clinical Trials Digest on page 7 for more research news. Also, be sure to join us for the Research Symposium on Saturday, January 31, to learn about these trials and more. (Information about the symposium can be found on page 12.)
As I write this column at year’s end, I marvel at how much has been accomplished by what used to be known as the Northwest Chapter of the HDSA. We have truly had an incredible year, with several major fundraisers spread throughout the year. First, Chris Misener undertook a cross country motorcycle ride from the greater Seattle area to Key West, Florida. He spread awareness of Huntington’s Disease over approximately 3,500 miles and raised over $5,000 to support the work of the HDSA. Next, along came Jason Evans from Oregon, whose grandfather recently passed away from HD, whose mom currently suffers from it, and who himself tests as gene positive. He solo hiked the Pacific Crest Trail from Mexico to Canada, also spreading awareness of HD among fellow hikers, newspapers, and an occasional local television station. In the process, he raised almost $12,000 for the HDSA. He also went through several pairs of hiking boots and took a number of beautiful photographs of mountain vistas and wildlife. To read more about Jason’s adventures, go to http://www.firstgiving.com/fundraiser/pacific3trek/pacificcresttrekforhd and http://www.hdsa.org/about/faces-of-hd/meet-kima/meet-jason.html. Alternately, you can log onto his Facebook page, scroll down to the summer months to see numerous pictures of his hike on the Pacific Crest Trail.

Once again, Cricket and Snail, brother and sister-in-law to board member and newsletter editor John Carlson, provided a benefit concert mid-Spring, accompanied by a silent auction at One Life Community Church on 95th Street in Seattle. That fund raiser garnered several thousand dollars, and in the process, allowed for community building and sharing among friends. We also held our third Bowl-A-Thon which raised over $1,000. We held our first Pizza Party and Quarter Auction at Aly’s in Snohomish. That too raised over $1,000, with both events benefiting from supplemental grants from Lundbeck.

Our 2014 Team Hope Walk, under the able leadership and guidance of Melissa Jeng, did fabulously well, raising over $32,000. (See story on page 6) All of the foregoing indicates that 2014 was a banner year financially for your chapter.

Our chapter’s former social worker, Chris Wick, moved to Arizona with her recently retired husband. Replacing her is Vivian Foxx, M.S.W., our new chapter social worker. Due to an anonymous grant, your chapter has been able to hire a number of social workers to facilitate support groups throughout the state. We now have a total of nine support groups in Washington. If anyone should know of a location with a need for a support group, please let us know.

After much thought and deliberation, along with consultation with our national office staff, the Huntington Disease Society of America’s Northwest Chapter is ceasing to exist. In its place will be the Washington State Chapter of HDSA. Under its old banner, the chapter had been responsible for covering and providing social work support to five states: Washington, Idaho, Oregon, Western Montana, and Alaska. There was no way that we could adequately meet that obligation. Two years ago we were happy to see an affiliate emerge in southern Idaho, and attempts continue to be made by Oregon to form an affiliate there as well. While we certainly will be willing to help our neighbors where we can, we will no longer have the responsibility to do so. Instead, we will be responsible for addressing the needs of Washington (Continued on page 11)
New leadership, new year, new stories

A Note From Melissa Jeng,
New President of the
Washington State Chapter

Well, first and foremost, welcome to 2015! Hope everyone had a wonderful holiday season with family, friends and lots of joy!

So, here we go! I was asked to write a short welcoming “who am I” letter! And for those of you who may already know me, also know this is not an easy task! However, because I do enjoy telling my family’s HD story, I will start there! Just to be clear, I do not like the story itself, but like telling the story because I strongly believe it is through our collective stories that awareness and empathy are created and gained community wide!

My family’s story begins with my mother, Jeanne, who was diagnosed in November of 2010. Hence, we are still little kids in this world of Huntington’s Disease! Still learning and growing with each piece of new information we learn! Back to the story... my mother was the first one in our family to be clinically diagnosed with HD! As you all very well know, “the” diagnosis was not only shocking but also exception-

ally devastating! We were not aware that this little-monster-of-a-genetic-mishap was a trait within our family. As we have learned more, it has become very obvious that my papa Bill was the carrier! He had displayed many HD symptoms, which we simply attributed to other medical issues.

Fast forward a little and between November 2010 and September 1, 2014 my family and I went on this whirlwind roller-coaster journey with my mom! Everything we knew was turned every which way... and loose! From her care, living arrangements, finances, food choices, and everything in-between! The dynamics of her life, our lives, and our relationships were all tried, tested, re-shaped, and kept-intact!

So why is this important? Simply put, it is these experiences, these journeys that keep me motivated and give me purpose. The more stories I hear from each of you, the more I am pushed to do what I can in this fight against HD! It is the struggles in our stories that need to be heard and understood. They need to be used as the fuel in our fundraising and research efforts! We need to be able to draw a pic-

(Continued on page 11)
“If it works as predicted, this therapy will stop huntingtin protein from being made, which has the potential to slow or to halt disease progression.”

A new clinical trial just announced for 2015 aims to test a “huntingtin lowering” therapy that attacks mutant huntingtin directly. We’re extremely excited—it’s the first-ever human HD trial to fight HD at the root of the problem, and has shown great promise in animal models.

The announced clinical trial represents a collaboration between California-based Isis Pharmaceuticals, and the Swiss pharmaceutical giant Roche. The drug, called ASO-HTT-Rx, is a therapy that aims to treat HD by targeting the gene itself.

The core of the problem in HD lies in a faulty stretch of DNA—an extra-long stretch of CAG building-blocks within the huntingtin gene. The instructions contained in this mutant gene are first copied into an intermediate ‘messenger’ copy, from which the harmful protein is made. So, while the mutant gene is the root of the problem, it’s only bad because cells use the information in the gene to make a harmful protein.

The strategy behind ASO-HTT-Rx is to “shoot the messenger,” attacking the intermediate step between gene and protein by causing the destruction of the messenger copy. If it works as predicted, this therapy will stop huntingtin protein from being made—a “huntingtin lowering” strategy that, in the long term, has the potential to slow or to halt disease progression.

Every ASO (antisense oligonucleotide) has a basic structure that can be tweaked to help it stick to the right target message, ignoring the thousands of other messages in the cell. It’s a bit like when you go to the hardware store to have a key copied—the clerk selects the matching blank key and then etches the correct sequence of grooves to fit your lock, but none of your neighbors’ locks. In the case of ASOs, scientists at Isis use one of their established ‘backbone’ molecules and customize it, causing the drug to attack only the huntingtin message.

This all sounds like cutting-edge technology, but the great news is that Isis has tested ASO-based drugs in human brains before, in experimental treatments for ALS (Lou Gehrig’s, or motor neuron, disease) and SMA (spinal muscular atrophy), and there have been no reported issues with safety. One major way that ASOs differ from conventional drug treatments is that they cannot be taken orally as a pill, but must be delivered directly to the nervous system. To get into the brain, ASO-HTT-Rx will be administered via a needle inserted into the fluid-filled space below the lower spinal cord. If that sounds extreme, rest assured that this method is routinely used in many areas of medicine. A similar strategy is used by cancer doctors to deliver chemotherapy drugs to patients with brain tumors. More commonly still, many women receive similar ‘epidural’ delivery of pain drugs during child birth.

A major advantage of drugs like ASO-HTT-Rx is that researchers believe it can be administered intermittently and still be effective. Scientists have dubbed this approach to intermittent treatment in HD a ‘huntingtin holiday’: aiming to give the brain a healing break from the damage caused by the mutant Huntingtin protein.

Once injected into the spinal fluid, it takes about 4
Smarter clinical trials and groundbreaking collaboration emphasized at HSG conference

by Dr. Suman Jayadev, Director of Center of Excellence for HD, University of Washington

The topics at this year’s Huntington Study Group (HSG) conference included updates on ongoing clinical trials, previews of trials to come, training for trial investigators, and reports on new drugs from pharma representatives. HSG is an international group of clinicians and scientists committed to collaboration and open communication in a unified effort to defeat HD.

According to meeting organizers, the 2014 meeting boasted the largest attendance to date!

The HSG reception on the first evening of the meeting brought loving tributes to past investigators, field changing leaders and a rousing and moving tribute to Dr. Ira Shoulson for his transformative work along with collaborators in the HD field.

The shared understanding was that we need a cure, and fast. What was also clear is that in order to get there, we need to be engaging in sound, rational clinical trials. To that end, there were a number of very useful presentations aimed at centers that are expanding their clinical trial efforts, as well as clinics that are just entering the national and international clinical trial arena.

A very interesting theme I appreciated was the efforts to objectively measure features of HD that we wish to target for therapies. For instance, Dr. Ralf Reilmann discussed his data from the Q-Motor (quantitative motor) Assessments which involves using a small desktop tool setup to measure involuntary movements in limbs and tongue! The technique has been employed in the European TRACK-HD study and provides a way to measure physical symptoms relatively early in the progression of the disease.

In complement to designing finer motor evaluations, Drs. Karen Anderson and David Craufurd discussed the use of standardized behavioral assessments for the use in research trials. Since HD includes both behavioral and physical symptoms, being able to measure changes in behavior is critical for getting accurate data in a trial.

The keynote address for the Clinical Research Symposium date on November 8 was delivered by Kristen Powers, the inspiring young woman and creator of “Twitch,” a documentary about HD. Ms. Powers eloquently relayed an aspect of the Huntington Disease experience that rarely receives a formal audience. She spoke about how her childhood was impacted by having a symptomatic mother, and how that experience inspired her to work for HD awareness. Ms. Powers’s movie, Twitch, chronicles her own complex journey into genetic testing for HD. I found her talk to be incredibly motivating. I intend to view the film at the first opportunity.

The research symposium highlighted a number of studies on biomarkers, genetics of HD, and therapeutics.

Dr. Bonneau and group presented data regarding the use of Cysteamine, a byproduct of Cysteine, to slow motor progression in Huntington Disease. Importantly, the compound has been used clinically for more than 20 years to treat select metabolic diseases, thus has already proven its safety in use.

Vicki Wheelock and her team have meticulously designed a promising study to explore the safety and efficacy of stem cell transplantation into the brain for treatment of Huntington Disease. The procedure has been successful in animal models of HD. Dr. Wheelock presented the proof-of-concept studies as well as the goals of the pre-clinical safety and observational studies.

I came back from those three days energized, motivated, and optimistic. The molecules being discussed by academia and pharma are rational and many are proving to be safe. The strong commitment to collaboration among the international researchers was palpable with other issues taking a back seat to actually finding a cure and meaningful therapy until we do.
Well let me just admit .... I still get goose bumps just thinking about the 2014 Seattle Team Hope Walk! What a blast and what an incredible success! And none of it could have happened without all of you! Not only did we reach and exceed our goals, and have a few mishaps ... (otherwise known as learning moments)..., but we did it all in great superhero fashion with lots of smiles!

For those of us who like stats to prove our superhero -ness... we had over 200 participants and... wait for it... we raised over $32,000, super exceeding our goal of #25K! This walk included the first-ever 5k run, opening the door for people who prefer more of a super challenge. We had 40 registered runners turn out for the 5K event. We also welcomed 6 new local sponsors this year!

Speaking of sponsors, we have a few very generous and fun ones to thank! First, we know these two as major players and national sponsors, Lundbeck and Auspex! Our local sponsors were amazing, providing coffee, water and post-race snacks, kid’s activities, body align-ment analysis and back care advise, professional photos, and various postings on local and national run boards. Big thanks again to Trilogy Chiropractic (http://www.trilogychiropracticseattle.com) Caffe Vita (http://www.caffevita.com) Layton Advisory Group (http://www.conservativeplan.com) Emazing Photography, LLC (http://emazingphotographyllc.com) Quilceda Creek Manor (Adult Family Home) and Gametime (https://gametime.com).

Volunteers... they are the best! I was so fortunate to have many volunteers eagerly help out with this event! From brainstorming and planning, to day of race set-up, breakdown, clean-up, registration... and so so much more... our volunteers were awesome and encouraging!

Not to mention my friends, family, and fellow board members who had to hear a few frustrations and keep me uplifted. I can not empha-size enough how truly valuable you all were during those last few weeks while I was dealing with the death of my mom! For those of you who may not know, my mom is the reason for my continued involvement with our HD family!

As a first time Team Hope Walk coordinator all these numbers are very exciting! They are only numbers I could have (and did) dreamed of! However, they will also now be used to raise the bar for next year! Yes 2015... I am already thinking and dreaming about it! Stay tuned for save the dates and other information to come. And, if you enjoyed our Super Hero event, and have awesome ideas or suggestions for 2015, please feel free to let me know, or if you are really brave... join our planning committee! See you all next year and have an awe-inspiring new year!
Clinical Trials in the Northwest

This page highlights some clinical trials going on in our area. 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

More details at www.hdsa.org/nw-chapter/nw-clinicaltrials-update.html

PRIDE-HD (Pridopidine)

Phase 2 clinical trial to evaluate safety and efficacy of 4 different doses of pridopidine. Former trials of this drug showed benefit in motor function. It is hoped that the higher doses in the present trial will give more benefit without increasing side effects.

Location: Evergreen Neuroscience Center

Status: NOW ENROLLING

The latest research news—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.

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

More details at EnrollHD.org

LEGATO-HD

A phase 2 safety clinical trial to evaluate the efficacy and safety of laquinimod for HD. Laquinimod has positive effects in multiple sclerosis. Three different doses of the drug will be tested for HD in a one-year trial.

Location: Evergreen Neuroscience Center

Status: NOW ENROLLING

UW Muscle Study: This study is complete. Results will be shared at the January 31 Research Symposium. Larger study is coming.

FIRST-HD: This trial has completed with positive results to be shared at the January 31 Research Symposium.

There’s a lot happening in research right now! To hear the latest news, and to have a chance to get your questions answered, don’t miss the Research Symposium on Huntington’s Disease on January 31 in Kirkland, Washington. See details on page 12
Huntington’s disease doesn’t have a “Kodak moment”

by John Carlson

There was a commotion in a parking lot in the small town of Westover, WV. A passer-by with a video phone began filming a group of police officers scuffling with a man in a parking lot. What caught her attention was the sight of blood and the sound of choking. According to a story and video posted on curehd.blogspot.com, a man with HD named Jeffrey Bane was accosted and then pinned roughly on the pavement for 10 minutes, while the officers instructed him repeatedly not to move. They refused to let him stand or raise his head because of his body movements, which they interpreted as resistance to arrest, not the involuntary movements commonly caused by HD.

(http://www.curehd.blogspot.com/2014_09_01_archive.html)

Heartbreaking stories like this are reminders that the HD community still has work to do in the way of raising awareness about the realities of HD. This story, in particular, is a timely addition to the national discussion about the appropriate use of force by our police officers. Statistics, facts and slogans will not suffice to bring about change. There’s no substitute for getting our personal stories into public awareness in order to help people understand the daily reality of HD, and what they can do to make a difference.

The fact is, even if we were suddenly offered the ear of all the world for one minute to explain Huntington’s disease, we would still have a dilemma because HD is pretty complicated. While there is just one genetic cause of HD, the way the disease is expressed in each person varies tremendously. There is no single set of symptoms that everyone develops, and even within the same family there are differences in expression. The list of possible symptoms is very long, and the window for age of onset is broad. We are champions of a cause that is difficult to understand, and even harder to explain!

Some diseases are easy to understand. When you get a virus, it is clear that the virus is the “bad guy,” and the patient is the one that gets the chicken soup. Now, cancer is a bit harder to break down because the “bad guy” is the patient’s own cells. However, there’s never any doubt that, despite the growth of tumors and the difficult treatment, you can still visit the patient and talk to them and they are the same person, if somewhat fatigued.

With HD, on the other hand, (and with other neurological diseases such as Alzheimer’s,) it is pretty standard for personality changes to accompany physical onset. If you listen to enough people’s stories you will hear about family members with HD who are continually angry, or paranoid, or manipulative, or apathetic, or incarcerated, or dependent on drugs and alcohol. (Is it any wonder that many families with HD rarely talk about it, despite a trend towards “opening up” about such diseases?)

There are no character issues with HD patients, even those with “socially awkward” behaviors. HD has produced changes in their brains, and therefore also in their behavior. They are no more responsible for their symptoms than the cancer patient has “earned” their cancer.

This lack of clarity over what is character and what is disease can also make it hard to get in front of the public and do fundraising or education work for HD. The disease itself just doesn’t fit snugly into a (Continued on page 9)
Building bridges with law enforcement

by John Carlson

Are you curious or concerned about how much your local police force knows about the signs and symptoms of Huntington’s disease? Here’s something that anyone can do to help inform police officers about HD. And for every officer that understands about HD, there should be fewer of the embarrassing and dangerous misunderstandings that HD patients sometimes find themselves in. (See story on page 8.)

With the right information and some conversation, the police can be an ally instead of an adversary for HD families. With this goal in mind, the HDSA has produced some educational material specifically geared toward the law enforcement audience. Called law-enforcement toolkits, these materials can be ordered from the HDSA website from the following web page:


One copy can be sent free-of-charge to each family. Once you receive your kit, it should be taken—ideally in person—to your local police station or sheriff.

On the same web page is a second kit with information specific to families and caregivers. Also free of charge for the first copy, this kit has information about such things as interacting with law enforcement and what to do in case of arrest.

No ‘Kodak moment’ can substitute for our stories, continued

(Continued from page 8)

one minute pitch. It has too many variations, subtleties, and openings for misunderstanding.

Ah, but a picture is worth a thousand words, as they say. So maybe we can come up with exactly the right photo that shows the world what it’s like to live with HD, right? But I’m afraid even the best photos don’t really get everything across. Frankly, this disease doesn’t have a “Kodak Moment.”

However, just because HD is hard to describe doesn’t mean it’s hopeless. If a single picture isn’t enough, then let’s tell a story. But we shouldn’t just tell one family’s story, since everyone’s experience is different. We need to tell as many unique stories as possible—some heroic, some messy, some challenging, some unfinished.

With the understanding that some people’s stories are too painful to tell, I want to encourage everyone with an HD story to tell it however you can. Journal it. Blog it. Share it on social media sites such as Facebook. Tell your friends. Join a support group.

The more of us who tell our stories, and the more stories we pass around, the closer we’ll get to relating the complete picture of HD to the greater community. As a result, we will see more support for social change, research and outreach. The stories will also help those families struggling with the gritty reality of HD to feel less alone in that endeavor.
HD family praises helpful companion

The following is reprinted with permission from a letter sent to supporters of Canine Companions for Independence.

“Dear Friend,

‘Often, people would see Bob stumbling and assume he was intoxicated. They didn’t understand that he was only under the influence of Huntington’s,’ explains Nila, Bob’s wife.

“I recently told you about one of our graduates, Bob. Bob has Huntington’s disease, an inherited brain disorder that results in the progressive loss of both mental faculties and physical control. As his disease advanced, Bob lost the ability to drive, work or participate in many of the activities he enjoyed for most of his life.

“The way his Canine Companions for Independence® assistance dog, Exeter, has changed his life is amazing. Their partnership illustrates why your gift is so important to Canine Companions and the people we serve.

“Both the doctors and I can agree that Bob is doing as well as he is because of the presence of Exeter in his life,” states Nila.

“Stress hastens the progression of Huntington’s disease, but knowing that Exeter will get the phone if Bob falls and letting the public know that he has a disability has reduced stress for Bob.

“Currently there is no cure or treatment for Huntington’s disease. However, the physical and emotional benefits Exeter provides Bob slows his progression of Huntington’s disease.

“Donations from people like you [to Canine Companions for Independence] helped make it possible for them to give Exeter to Bob free of charge. With Exeter around, Nila doesn’t have to worry about Bob falling while trying to pick something up. Exeter is always there for Bob—picking up the many items Bob drops, turning on or off lights, or getting a drink from the fridge. ‘I am not sure I can even put into words really all the ways Exeter helps, but there are so many!; says Nila. ‘I can’t imagine what we would do without Exeter’s help.’

“Bob’s disability often goes unseen or is misinterpreted, going out in public was overwhelming for Bob. But thanks to Exeter, Bob has the confidence to go out with his family to eat or get coffee. One of the pair’s favorite activities is sitting by the lake and watching the eagles.

“Right now there are over 400 people on our waiting list hoping that you will make a donation to help them receive their own life-changing assistance dog. Since our last letter in June, we’ve placed an additional 52 dogs with children, adults and veterans with disabilities. I’m proud to say that means we’ve placed a total of 217 dogs so far this year! Our instructors are busy training even more dogs so we can meet the growing demand. You can help. We need your donation today to continue to provide Exceptional Dogs for Exceptional People® free of charge.”

More information: www.cci.org
Study in works for ‘gene-lowering’ treatment, continued

(Continued from page 4)

to 6 weeks for ASO-HTT-Rx to have its effect, and from animal studies we think that the silencing will then last for about 4 months. At the moment, the study is designed to have patients receive the drug treatment once a month.

Isis researchers and Prof Sarah Tabrizi, University College London and global head of the ASO-HTT-Rx study, emphasize this first clinical trial is designed purely to evaluate its safety. As exciting as this science is, the first planned trial is strictly designed to understand whether the drug is safe.

In summary, we’re excited that the first human trial of a drug that targets the root cause of HD will start as early as this year. This excitement is tempered by the realization that this first trial is all about safety, involves only a very small number of HD patients, and that many details of the study are still uncertain. We’ll be following the trial’s progress with a keen eye, so that hopefully we can provide intermittent doses of cautious optimism.

So-long and thanks, from outgoing president, continued

(Continued from page 2)

State HD families only.

This year marks the end of my third year as president of the chapter. Guidelines from our national office note that there is a three year term limit for presidents, and because of that, I have not sought a fourth term as president. Melissa Jeng stepped forward and was elected President of the board effective Jan. 1, 2015. LaVonne Veatch Goodman, M.D. was elected Vice President, Rose Benton continues as Treasurer, and I was elected to serve as Secretary to the board. The board has recently added a new member, Debra Del Castillo. Continuing to serve on the board are Marie Dunn, Erika Bjortlund, Ellen Snyder, John Carlson, and Kelly Layton. The office address of the board remains the same: 17406 Redhawk Drive, Arlington, WA 98223-5954.

In closing, I would like to thank you for your active support and attendance at our chapter events. Your willingness to give generously this past year, both of your time and financially, was inspiring and invigorating. In the four years that I have served on the chapter board, I have gotten to know many of you and your families and consider many of you to be my friend. I pray that a cure will be found sooner rather than later and that in the meantime, we continue to be a loving support community to one another. Let us all join together in supporting Melissa in her presidency. I am positive that under her leadership, we will accomplish great things.

Introduction of new chapter president, continued

(Continued from page 3)

ture of what we as patients, families, and caretakers deal with day in and day out!

Now with all that said, I look forward to serving as president of the newly re-named Washington State Chapter of the HDSA. More importantly I look forward to meeting many of you and hearing your stories!

Together we can pull from one another in order to create and increase awareness in our local communities, cities, counties and states! And by the way, if you ever want to hear the nitty gritty (those details that would make this letter way too long) of my families story, please feel free to contact me.

In closing, I would just like to encourage everyone to get involved! We have some very exciting events and volunteer opportunities coming in the future. And I would love to see more community events throughout the state. They don’t have to be big events (like the Team Hope Walk) but there are so many ideas out there I know they will be fun events! In fact, I will be anxiously waiting to meet as many of you as I can at our first big event, the Clinical Research Symposium to be held on January 31.
Registration opens at 9:00 AM. There will be an opportunity to mingle with the speakers at the end. A free box lunch and snacks are provided as well.

<table>
<thead>
<tr>
<th>Welcome and Introductions 9:30 AM</th>
<th>Jim Bridges, outgoing President, Melissa Jeng, incoming president, Vivian Foxx, chapter social worker, LaVonne Veatch Goodman, M.D., chair of education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hiking the Pacific Crest for HD and the Importance of Research</td>
<td>Jason Evans, Northwest HD Family Advocate</td>
</tr>
<tr>
<td>Research updates from the Institute of Systems Biology</td>
<td>Jocelynn Pearl, Research Scientist. Institute of Systems Biology, Graduate student University of Washington</td>
</tr>
<tr>
<td>Research Updates from Kevin Conley’s Group at the University of Washington</td>
<td>Kevin Conley, PhD, professor of biophysics and radiology at University of Washington</td>
</tr>
<tr>
<td>Clinical research updates from HSG conference</td>
<td>Suman Jayadev, M.D., director of Center of Excellence for HD at University of Washington</td>
</tr>
<tr>
<td>Enroll-HD</td>
<td>LaVonne Veatch Goodman, M.D., Chapter Board member</td>
</tr>
<tr>
<td>An hour with Jimmy Pollard</td>
<td>Jimmy Pollard, M.S Internationally known author and HD family advocate</td>
</tr>
<tr>
<td>Hot off the Press: First line Results from First-HD and ARC trials</td>
<td>David Stamler, Chief Medical Officer, Auspex Pharmaceuticals</td>
</tr>
<tr>
<td>Pride and Legato: New Drug Clinical trials enrolling at Evergreen</td>
<td>Pinky Agarwal, M.D., Evergreen Neuroscience Center</td>
</tr>
<tr>
<td>Gene lowering therapy updates</td>
<td>Nathan Goodman, PhD, Institute of Systems Biology</td>
</tr>
</tbody>
</table>