

The National Ataxia Foundation 52nd Annual Membership Meeting

"Climb Every Mountain"

Seattle, Washington – March 20-22, 2009

The 2009 Annual Membership Meeting was hosted by our Seattle, WA area Ataxia Support Group and the British Columbia Ataxia Society. This was the first year that this conference has been co-hosted by an international ataxia support group. Many thanks to both support groups for all your efforts in coordinating this event and congratulations on a highly successful Annual Membership Meeting. Nearly 500 people attended the 52nd conference from around the world. Thirty-eight U.S. states were represented along with attendees from Australia, Canada, Hong Kong, and Switzerland.

Thursday, March 19, marked the arrival of the riders of Ride Ataxia III. Over 100 people gathered to welcome the riders! Congratulations to Kyle Bryant, founder of Ride Ataxia, and to all the other participants for their courageous efforts. Kyle was presented with a plaque dedicated to Ride Ataxia III and all of the riders were recognized with a medal for their participation in the bike ride, which started in Portland, OR. We would really like to thank all those that supported Ride Ataxia III in their effort to raise ataxia awareness and funds for important ataxia research.

Friday morning started out a little different this year. Instead of smaller breakouts we started our general session program this morning. The most popular or requested topics which would have been breakout sessions in the past were incorporated into our general session program. Mike Parent, NAF's Executive Director, started out the meeting with his welcome and accepted the

key to the City of SeaTac, WA from Mayor Ralph Shape on behalf of Arnie Gruetzmacher, AMM Chairman, who could not be present. Thank you so much, Mayor Shape, for your participation at our conference and for this most outstanding honor that you have given to us. Laura Ranum, PhD (University of Minnesota) then presented a general overview of ataxia and was followed by Corrie Smith, MS, CGC (University of Washington), who presented an overview of Genetics and Gene Testing. Harry Orr, PhD (University of Minnesota) gave an overview of the current ataxia research being done and was followed by S.H. Subramony, MD (University of Texas, Galveston), who gave us an update on the ataxia patient registries that are available.

The Nintendo Wii demonstration room opened Friday morning and continued on Saturday. This was a wonderful opportunity for attendees to experience the fun, interactive, physical therapy aspects of the Nintendo Wii game system.

Friday afternoon allowed attendees the opportunity to meet others by type of ataxia in smaller groups in order to get personal questions answered by ataxia investigators and to share experiences with others through the very popular Birds of a Feather sessions.

On Friday evening the Seattle Area Ataxia Support Group and the British Columbia Ataxia Society hosted a light hors d'oeuvres reception

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that was well attended. Delicious food and great company were enjoyed by all. At the reception, Theresa Zesiewicz, MD, FAAN (University of South Florida) gave an update of the clinical trial she is conducting on a compound for SCAs. Then Kyle Bryant, founder of Ride Ataxia, reflected on his own experience with ataxia and how he copes with its challenges. The work that Kyle and his fellow Ride Ataxia participants put into their cycling fundraising event is a great demonstration of his “can do” attitude. One of the goals of Ride Ataxia is to introduce cycling



NAF Executive Director Mike Parent (left) presents a plaque dedicated to the riders of Ride Ataxia III to Ride Ataxia founder Kyle Bryant

to ataxians who otherwise would never have tried it through the 2009 Ataxian Athlete Initiative. The winner of the Terra Trike Cruiser, Nadia Robertson, was announced and introduced that evening and encouraged to start her own Ride Ataxia adventure.

Ride Ataxia III raised over \$220,000 for ataxia research that will go towards a translational research grant in Kyle Bryant’s honor. Additional funds will be added by NAF and FARA.

At the reception Mike Parent, NAF’s Executive Director, presented a plaque to Dr. Michael Wilensky for his 25 years of service on the

Medical Research Advisory Board for NAF.

Saturday continued with the general session program with many new and familiar medical professionals and researchers. Thomas Bird, MD (University of Washington) started out the General Sessions by discussing the multi-discipline approach or “Seattle Experience” for an ataxia patient. Gregory Carter, MD, MS (University of Washington) talked about the rehabilitation aspects of ataxia. Kristie Spencer, PhD, CCC-SLP let us know about helpful Speech and Swallowing techniques. Michael Wilensky, MD (private practice, New Orleans, LA) then discussed medications to consider for an ataxian patient.

Saturday afternoon was filled with more general session presentations. Marek Napierala, PhD (University of Texas) presented on his study of targeting DNA structure for Friedreich’s ataxia therapy followed by Henry Paulson (University of Michigan), who presented the Poly-glutamine ataxias. Ralph Miller demonstrated wheelchair yoga. Sid Gilman (University of Michigan) then brought us up to date on sporadic ataxia.

Saturday’s banquet was a most enjoyable experience for all who attended. The 50/50 raffle was great fun with over 80% of conference attendees participating to raise more than \$2,950. Congratulations to the winners of the raffle. Thank you to everyone who donated items for the silent auction and to those that participated in this event which raised over \$5,000. Thank you so much to the Raucous Band who provided such great entertainment and dancing music!

On Sunday morning the general session program continued with Susan Perlman, MD (UCLA) who discussed how to manage your ataxia and your neurologist through a multi-disciplinary approach. David Lynch, MD (University of Pennsylvania) gave an update on the FRDA clinical trials. Timothy Maher, PhD (Massachusetts College of Pharmacy and Health Sciences & Massachusetts Institute of Technology) discussed nutrition and ataxia. ►►

Arnulf Koeppen, MD (VA Medical Center, Albany, NY) then presented on what we can learn from brain tissue donations, followed by Ryan Boudreau, PhD (University of Iowa) who discussed RNAi Research. Grisel Lopez, MD (National Genome Research Institute, NIH) then discussed the clinical trial that is currently underway for lithium treatment for patients with SCA 1. George Wilmot, MD, PhD (Emory University) gave the closing presentation of the conference with his review of what we had learned throughout the weekend.

Each day's general session was followed by a question-and-answer session facilitated by Drs. Orr, Wilensky, Gilman, and Wilmot which included the presenters of each day. Please watch future issues of *Generations*, as we publish some talks so you all can learn what they had to say. Also, you can get a copy of these presentations on our website www.ataxia.org.

This was an excellent and exciting meeting! Thank you again to the fabulous job done by the Seattle Area Ataxia Support Group and the British Columbia Ataxia Society!

A Special Thank You

The National Ataxia Foundation would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors, donors and the numerous volunteers of the NAF 2009 "Climb Every Mountain" Annual Membership Meeting held in Seattle, WA. The NAF would like to especially thank the NAF Seattle Area Ataxia Support Group and the British Columbia Ataxia Society for all their efforts. It was a pleasure working with Milly and Tony Lewendon, Louise Frank, Brenda Dixon, and Fiona Jackson on this conference.

Many thanks to Marcia Kohl, who volunteered as our on-site nurse this year. Your services are so much appreciated. We would also like to thank this year's sponsors. Thank you to the VIBE, Nintendo and Athena Diagnostics. Thank you to Milly Lewendon, who gathered items for the goody bags for this year's conference.

The "Climb Every Mountain" conference had nearly 500 attendees! We appreciate your participation in making this conference so successful. Thank you so much for the wealth of information and knowledge that was brought to the conference by all the speakers, facilitators and exhibitors. The information and skills taken away from this conference by the attendees is invaluable and worth more than any words can say.

Thank you to the Doubletree Seattle Airport Hotel and the Seattle Southside CVB for their service and hospitality throughout this event. ❖

Top Three Lists

Registrants rated their top three highlights from the 2009 National Ataxia Foundation Annual Membership Meeting:

- 1) RNAi
 - 2) Dr. Zesiewicz
 - 3) Birds of a Feather
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- 1) Meeting other "Ataxians" for the first time
 - 2) Birds of a Feather
 - 3) Q&A Sessions
-
- 1) Genetics of Ataxia
 - 2) Birds of a Feather
 - 3) Q&A Sessions
-
- 1) Birds of a Feather
 - 2) Research – SCA
 - 3) Old Friends
-
- 1) Reception & Dinner
 - 2) Informal hall meetings
 - 3) Birds of a Feather
-
- 1) Presentations
 - 2) BOF
 - 3) Auction
-
- 1) Ride Ataxia
 - 2) Seeing people I've met before
 - 3) Birds of a Feather

Here is what was said by meeting attendees...

Quotes from the 2009 NAF Annual Membership Meeting

On Birds of a Feather

“We had a great group – much sharing.”

“Excellent – Really great opportunity to connect and share.”

“As a first timer, I found the Birds of a Feather very helpful.”

On General Sessions

“Very informative and helpful.”

“All outstanding and very helpful.”

“Speakers were very well organized. I’m very appreciative of them and their time. The PowerPoint presentations were very helpful to understand what was being talked about and the PowerPoint papers were extremely nice/handy for taking organized notes and to be able to take home and share! Thank you!”

On Reception and Banquet

“Band was great!”

“Can’t say enough about Kyle.”

“Saturday was awesome! Food was amazing! Great Band! Raffle was very entertaining! J Kissies.”

“I really liked the Friday Reception menu – not messy, substantial, plentiful, with a very nice presentation... If it’s cheaper do it every year!”

General Comments

“Good Location! Major airport for easy non-stop flight availability and easy access to hotel. All meeting rooms close in. Reasonable prices in hotel. Good elevator access.”

“Great job for entire meeting.”



Annual Membership Meeting Provides Information from A to Z

From A (ataxia) to Z (Dr. Zesiewicz) the medical and research information that was presented at this year’s Annual Membership Meeting was so comprehensive that it included information that began with every letter of the alphabet. This is a list of the articles, some of which will be published in future issues of *Generations*.

Ataxia ... **B**rain tissue donations bring us closer to answers in ataxia ... **C**linical trials taking place and how to participate in a clinical trial ... **D**ysphagia, which is difficulty in swallowing, and some strategies for coping ... **E**mpowered patient needs to be an informed patient ... **F**riedreich’s ataxia research includes targeting DNA structure ... **G**enetics and gene testing ... **H**uman Genome Project was explained ... **I**debenone clinical trials for Friedreich’s ataxia

... **J**oin ataxia patient registries ... **K**nowledge is required before effective therapies are discovered ... **L**ithium clinical trials for SCA1 ... **M**edications available for treating symptoms of ataxia ... **N**eurologists and how to educate and manage them ... **O**ccupational therapy can be beneficial ... **P**olyglutamine ataxias ... **Q**uality research funded ... **R**ehabilitation strategies for those with ataxia ... **S**poradic ataxia and its many causes ... **T**argeted HDAC inhibitors to increase cellular frataxin levels ... **U**nknown dominant mutations still represent a substantial percentage of SCA (20%) ... **V**ertigo or dizziness can be treated ... **W**alking aids such as single point and quad canes and walkers ... **X**-ray beam is used in brain tissue research ... **Y**oga can be helpful for mind and body ... **Z**esiewicz.