

The National Ataxia Foundation 53rd Annual Membership Meeting

"Winds of Progress"

Chicago, Illinois – March 12-14, 2010

By Lori Shogren, National Ataxia Foundation Special Projects Coordinator

The 2010 Annual Membership Meeting was hosted by our Chicago Area Ataxia Support Group. Many thanks to the support group for your team effort in coordinating this event and congratulations on a highly successful Annual Membership Meeting. More than 600 people attended the meeting. Conference attendees came from 36 U.S. states and countries including Belgium, Canada, Ireland, Netherlands and the United Kingdom.

Thursday, March 11, was the major arrival day for most attendees outside the Chicago area. Those wanting to connect with others that they had met through social networks and ataxia chat rooms gathered together at the internet group.

Friday morning started out with our general sessions program. Arnie Gruetzmacher, NAF Annual Meeting Chair, started out the meeting with his welcome. Susan Perlman, MD (University of California - Los Angeles) started off the lectures with a general overview of ataxia followed by Wendy Galpern, MD, PhD (National Institutes of Health) who presented on the topic of therapy for ataxia. Then Allison Ebert, PhD (University of Wisconsin - Madison) talked about the latest on stem cell research followed by Martin Lavin, PhD (University of Queensland) who taught us about AOA and other recessive ataxias. Tetsuo Ashizawa, MD, PhD (University of Florida - Gainesville) gave us an update on ataxia patient registries and Joanna Jen, MD, PhD (University of California - Los Angeles) told us about episodic ataxias and the episodic

ataxia patient registry. Harry Orr, PhD (University of Minnesota) wrapped up the Friday general sessions and gave us an overview of the current ataxia research being done.

Friday afternoon gave attendees the opportunity to meet others with the same type of ataxia in smaller groups to share experiences through the very popular Birds of a Feather sessions. Friday and Saturday we offered attendees and chance to observe and try the Nintendo Wii game system. Thank you to Santhera Pharmaceuticals and Julie Braun for donating a Nintendo Wii for this demonstration.

Friday evening the Chicago Ataxia Support Group hosted a Chicago-style pizza and snack reception that was well attended. Delicious food, drink and great company were enjoyed by all. At the Friday night reception NAF recognized all the fundraisers held since the Annual Membership Meeting in 2009 that supported NAF funded research and programs. Thank you to all the supporters and organizers of these events!

Saturday continued with the general session program with many new and familiar medical professionals and researchers. Jeremy Schmahmann, MD (Harvard Medical School) started out with his presentation on cerebellar connections. Victoria Staszak, RN, MS/MBA (University of Chicago) presented on some practical aspects of ataxia and the Ataxia Center at the University of Chicago. Roger Fong, MPT (University of Chicago) talked about physical therapy for ataxia followed by SH Subramony, MD ▶▶

(University of Florida - Gainesville) who discussed ataxia medications and management techniques. Heather Connors, MS, CCC/SLP (University of Chicago) & Jennifer Legge, MS, CCC/SLP (University of Chicago) discussed speech and swallowing issues.

Kyle Bryant, Ride Ataxia Founder, started off the afternoon general sessions with his presentation on adaptive sports and fitness. Lisa Dellafave-Castillo, MS, GCC (University of Chicago) discussed genetic testing and was followed by John Rolland, MD (University of Chicago) who informed us about the psychological aspects of genetic testing. Kathryn Norcross Black, PhD (Purdue University) discussed the emotional aspects of ataxia. Then, Mary Anne Ehlert, CFP wrapped up the general sessions for the day and informed us about financial planning for persons with disabilities. Thank you to the University of Chicago Ataxia Center and other Chicago area medical professionals for your participation and support of this conference.

Saturday's banquet was a great experience for all that attended. Christopher M. Gomez, MD, PhD (University of Chicago) gave us a review of the Ataxia Investigators Meeting that was held prior to this conference. NAF recognized Mary and Wilson Romero for attending their 25th consecutive NAF Annual Membership Meeting! The 50/50 raffle was great fun with over 70 percent of conference attendees participating to raise more than \$3,500. Congratulations to the winners of the raffle. Thank you to everyone who donated items for this year's tremendous silent auction and to those that participated in this event which raised over \$5,900. Thank you to Dreamcatcher Productions who provided such wonderful dancing music!

Sunday morning started out with Michael Parent, NAF Executive Director, who discussed the 2009 highlights of NAF followed by the NAF business meeting lead by NAF Board President, DeNiece Roach. Then the general sessions continued with Laura Ranum, PhD (University of Minnesota) who gave us an update

on SCA research developments followed by Grazia Isaya, PhD (Mayo Medical Clinic) who gave us an update on FRDA research developments. Sid Gilman, MD (University of Michigan) talked about the diagnosis and management of sporadic ataxia. Hank Paulson, MD, PhD (University of Michigan) taught about RNAi research. Arnulf Koeppen, MD (Albany Medical College) talked about OPCA and developments in imaging and neuropathology. George Wilmot, MD, PhD (Emory University) gave the closing presentation of the conference with his review of what was learned throughout the weekend.

Each day's general session was followed by a question and answer session which included the presenters of each day. You can access a copy of most AMM presentations on www.ataxia.org.

A Special Thank You

The Foundation would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors and the numerous volunteers of the 2010 Annual Membership Meeting. The NAF would like to especially thank the NAF Chicago Ataxia Support Group for all their efforts. It was a pleasure working with Richard Carr, Jonas and Mary Beth Cepkauskas, Craig Lisack, Christopher Marsh, Lora Minichillo, Janet Pepitone, and Sue Woods on this conference.

Many thanks to Marcia Kohl, who volunteered as our on-site nurse again this year, your services are so much appreciated. We would also like to thank this year's sponsors. Thank you to Santhera Pharmaceuticals and Athena Diagnostics. Thank you to Sue Woods and Janet Pepitone, who gathered items for the goody bags for this year's conference. Bags were donated by SquidMarks Imprinting and the University of Chicago Ataxia Center. Contents of the welcome bags were donated by Walgreens, Chicago Botanicals Garden, Marianjoy Rehab Center and OraLabs. Also, a big thank you to David Garcia for taking such memorable pictures of this year's event. Thank you to the Hyatt Regency O'Hare and the Chicago CVB for their service and hospitality throughout this event. ❖