

*The National Ataxia Foundation 2008 Annual Membership Meeting Review*

**“Blazing A Trail In Research”**

*Las Vegas, NV March 28-30, 2008*

The National Ataxia Foundation's 2008 Annual Membership Meeting was hosted by the Arizona Ataxia Support Group and held in Las Vegas. Many thanks to the Arizona Support Group for all their efforts and congratulations on a highly successful Annual Membership Meeting. Over 600 people attended the 51<sup>st</sup> meeting from around the world. Thirty-nine US states were represented along with attendees from Australia, France, United Kingdom, Germany, Switzerland, and Canada.

Thursday, March 27, was the arrival date of the riders of *Ride Ataxia II*. Over 100 people gathered to welcome the riders! Congratulations to Kyle Bryant, founder of *Ride Ataxia* and all the other participants of *Ride Ataxia II* for their courageous efforts. We thank all those that supported *Ride Ataxia II* to raise ataxia awareness and funds for important ataxia research.

Friday morning started with the breakout sessions providing several resourceful topics including Speech and Swallowing, Genetics and Genetic Testing, Dancing with Ataxia, Financial Planning, Selecting a Patient Care Attendant, Social Security and Medicare, Patient Care Techniques for Caregivers, Emotional Impact of Ataxia, Adaptive Sports, and Living with Ataxia. These topics were presented by individuals with either personal or professional experience. We thank all the presenters for their participation.

Friday afternoon attendees were given the opportunity to meet others with the same type of ataxia in smaller groups, get personal questions answered from ataxia investigators, and share experiences with others through the very popular “Birds of a Feather” sessions.

Friday evening the Arizona Support Group hosted a western-themed hors d' oeuvres reception that was well-attended. Delicious food and great company was enjoyed by all. At the reception, Dianne Blain Williamson, Northern Alabama and Southern Tennessee NAF Ambassador was recognized for her long time support of NAF and her efforts to raise ataxia awareness in her area. The Coffey Family was recognized for their long time efforts in raising funds for important ataxia research programs. The San Diego Ataxia Support Group was recognized for hosting the first Annual NAF Walk n' Roll in memory of Charlie McLaughlin. Earl McLaughlin, the San Diego Ataxia Support Group Leader, accepted the plaque on behalf of the support group and was also recognized for his outstanding leadership and commitment. Kyle Bryant, founder of *Ride Ataxia* accepted a plaque dedicated to *Ride Ataxia II*. Kyle gave a presentation of the highlights through this year's ride experience. All the riders of *Ride Ataxia II* were recognized with a medal for their participation in the bike ride which started in Sacramento and ended in Las Vegas for the NAF Annual Membership Meeting. *Ride Ataxia II* raised over \$120,000.00 for ataxia research that will go towards a Friedreich's ataxia research grant in Kyle Bryant's honor. This research grant will be co-funded by NAF and Friedreich's Ataxia Research Alliance, (FARA).

Saturday started the General Session program with many new and familiar medical professionals and researchers. Huda Zoghbi, MD (Baylor University) started out the General Sessions by discussing the translational studies being done in spinocerebellar ataxia. Christopher Gomez, MD, PhD (University of Chicago) talked about Biomarkers in ataxia. Helene Puccio, MD, PhD (INSERM) reported on what we can learn from Animal Models to further Friedreich's Ataxia research. Laura Ranum, PhD (University of Minnesota) presented a general overview of

ataxia followed by George Wilmot, MD, PhD (University of Michigan) who discussed the importance of ataxia patient registries.

Saturday afternoon was busy with more General Session presentations. Nicholas Wood, PhD, FRCP, FMedSci (University of London) presented on SCA11 followed by S. H. Subramony, MD (University of Texas) who presented on Sporadic Ataxia. Jeremy Schmahmann, MD (Boston University) discussed cognition, emotion, and the cerebellum. Harry Orr, PhD (University of Minnesota Medical School) gave a review of all ataxia research. Michael Fahey, MD (Australia) informed us about “what’s up down under.”

Saturday’s banquet was a most enjoyable experience for all who attended. The 50/50 raffle fundraiser was great fun with over 80% of conference attendees participating to raise more than \$3,700.00. 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 \$4,500.00. At the banquet, Dr. John Day gave us a review of the 2008 Ataxia Investigator’s Meeting (AIM) which was held earlier in the week. Thank you to Dr. Day and all the 2008 AIM organizers for their efforts. Michael Parent, NAF’s Executive Director, presented plaques to Dr. John Day for his organization of the 2008 AIM meeting, his years of involvement in ataxia research and service to the ataxia community, to Dr. Susan Perlman for her years of support to NAF, the ataxia community, and ataxia research, and to Dr. Larry Schut for his lifelong contributions to NAF, the ataxia community, and ataxia research.

On Sunday morning the General Session program continued with Susan Perlman, MD (UCLA) with an update on FRDA clinical trials. Arnulf Koeppen, MD (VA Medical Center – Albany, NY) then presented information on brain tissue repair in hereditary ataxia followed by Broyna Keats, PhD (Louisiana State University Health Sciences Center) who discussed RNAi Research. Armin Alaedini, PhD (Cornell University) talked about gluten sensitivity and the immune response in ataxia. Lawrence Schut, MD (CentraCare Clinic) reviewed what medication can be considered in ataxia. Dr. John Day (University of Minnesota) gave the closing presentation of the conference with his “Top 10” review of what we have learned throughout the weekend.

Each day’s General Session was followed by a question and answer session facilitated by Dr. Ranum, Dr. Orr, and Dr. Day which included the presenters of each day. Please watch in future issues of Generations, where presentations will be published so all can learn the important information that was presented. Copies of most of these presentations are available on the website: [www.ataxia.org](http://www.ataxia.org).

This was an excellent and exciting meeting! Thank you again to the outstanding job done by the Arizona Ataxia Support Group!



*The Flamingo Hotel and Casino in Las Vegas was the location of the 2008 NAF Annual Membership Meeting.*