

*The National Ataxia Foundation 2007 Annual Membership Meeting Review*

*“The Bridge to Hope”*

*Memphis, TN – March 23-25, 2007*

The 2007 Annual Membership Meeting and 50<sup>th</sup> Anniversary of NAF was hosted by our Mississippi Chapter and held in Memphis, TN. This was the 5th Annual Membership Meeting hosted by the Mississippi Chapter. Very special thanks for all your efforts and congratulations on another highly successful Annual Membership Meeting. Over 500 people attended the 50<sup>th</sup> conference from around the world.

On Thursday, March 22, was the early adult arrival and teen group outing to the Memphis Grizzlies vs. LA Lakers basketball game at the FedEx Forum. It was great fun by all who attended.

Friday morning started the breakout and workshop sessions providing several resourceful topics such as Coping Early On-Set & Late On-Set, Caregiver Coping, Exercise & Therapy, Speech and Swallowing, Genetics, Nutrition, Service Dogs, Depression, Dancing with Ataxia, and Adult Siblings. These topics were presented by individuals with either personal or professional experience. Thank you to all the presenters for the practical applications.

Kyle Bryant was recognized and presented with a plaque for his courageous bike ride to the meeting all the way from San Diego, CA at a welcome reception that was attended by many fans. Kyle raised over \$40,000.00 for ataxia research that will go towards a \$100,000.00 translational research grant in his honor. This research grant will be co-funded by NAF & FARA. Great job Kyle!!

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

Friday evening the Mississippi Chapter hosted a 50s themed hors d' oeuvres and cake “Rock Around the Clock” reception that was well attended. Delicious food and great company was enjoyed by all. At the reception, Dr. Lawrence Schut and Julie Schuur presented on the early years of NAF and their family’s struggle with ataxia. The Schut family was recognized with a plaque for all their contributions to the Foundation, which includes the formation of NAF, and was accepted by Dr. Lawrence Schut. Julie Schuur and Brant Kruen also received plaques and were recognized as original board members and for their early contributions to the foundation that continues today. David Crews was our DJ for this evening which provided endless enjoyment to this event. All joined in signing & wishing Mary Romano a Happy Birthday.

Saturday started the general session program with many new and familiar medical professionals and researchers from across the United States. Michael Wilensky (Greater New Orleans Area private practice) gave us practical advice during his presentation “Managing the Ataxia Patient”. Dr. Harry Orr (University of Minnesota ) reviewed all the research that is being done on ataxia. Dr Laura Ranum (University of Minnesota) presented us with her research of SCA 8. Dr. Sid Gilman (University of Michigan) talked to us about Sporadic ataxia. Dr. Henry Paulson (University of Iowa) gave us an update on SCA 3/Machado-Joseph disease. Saturday afternoon Dr. Meri Firpo (University of Minnesota) let us know about stem cell research as it relates to furthering ataxia research.

Dr. S.H. Subramony (Baylor University-Galveston & University of Mississippi Medical Center) told us about the uncommon causes of ataxia. Dr. Robert Wilson (University of Pennsylvania) discussed “Experimental Therapeutics for Friedreich’s ataxia. Dr. Khalaf Bushara (University of Minnesota) then explained ataxia and allergy to wheat, followed by Dr. Beverly Davidson (University of Iowa) who presented on “microRNAs in SCA1”.

Saturday’s “Fabulous 50s” banquet was a most enjoyable experience for all that attended. A special thank you to David Crews and “The Sweet Sensations” for their memorable Elvis show at this event. Michael Parent, NAF Executive Director and Arnie Gruetzmacher, NAF Annual Meeting Chairperson presented six plaques to the following: Arnie Gruetzmacher, Michael Parent, Dr. Arnulf Koeppen, DeNiece Roach, the NAF Mississippi Chapter, Charlene Danielson, for their dedicated service to the National Ataxia Foundation. The 50/50 raffle was great fun with over 70% of conference attendees participating to raise more than \$2,200.00. Congratulations to the winners of the raffle and to the Grand Prize winner who graciously donated her winnings back to NAF. Many thanks to the Memphis Downtown Marriott for their silent auction donations of two gift certificates each valid for one complimentary two night stay at the Memphis Downtown Marriott hotel. Thank you to everyone who donated items for the silent auction and to those that participated in this event which raised approximately \$3,000.00.

On Sunday morning the General Session program continued with Dr. Jeremy Schmahmann (Massachusetts General Hospital) who presented on “The Cerebellum in Behavioral Neurology and Neuropsychiatry”, Dr. Mark LeDoux (University of Tennessee Health Science Center) told us about other movement disorders that may be present in ataxia patients, Dr. Susan Perlman’s (David Geffen School of Medicine at UCLA) reviewed the non-experimental Issues of diagnosis and management for Friedreich’s ataxia, Dr. Sarah H. Ying (John Hopkins Hospital) discussed eye movement abnormalities and ataxia, Dr. Arnulf Koeppen (VA Medical Center in Albany, NY) then explained why the dominant ataxias are so different from each other, and 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. Orr, Dr. Subramony, and Dr. Koeppen which included the presenters of each day. Please watch future issues of Generations, as we publish their 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](http://www.ataxia.org).

This was an excellent & exciting meeting! Thank you again to the outstanding job done by the Mississippi Chapter!

