

## 2009 NAF Annual Membership Meeting Agenda

Please Note: Due to circumstances beyond our control, this meeting agenda is subject to change.

### *Wednesday, March 18<sup>th</sup>*

Event	Location	Times
NAF Registration	Northwest 1	6:00PM-9:00PM

### *Thursday, March 19<sup>th</sup>*

Event	Location	Times
NAF Registration	Northwest 1	8:00AM-9:00PM
Ride Ataxia III Arrival	Tower Entrance/Ballroom Foyer	2:00PM
Leadership Meeting	Northwest 2	3:30PM-6:00PM
Internet Group	Northwest2	7:00PM-9:00PM

### *Friday, March 20<sup>th</sup>*

Event	Location	Time
NAF Registration	Northwest 1	7:30AM-5:30PM
Exhibitors	Ballroom Foyer	8:00AM-5:30PM
General Sessions	Grand Ballroom	9:00AM-1:00PM
Nintendo Wii Demonstration	Olympic 1	10:00AM-2:00PM
Lunch	On Your Own	1:00 PM
Birds of A Feather	Various Meeting Rooms	2:00 PM-5:00PM
Reception	Grand Ballroom	7:00 PM

#### **GENERAL SESSIONS:**

<u>TIME</u>	<u>SPEAKER</u>	<u>TOPIC</u>
9:00 AM	Arnie Gruetzmacher	Welcome & Opening Remarks
9:20 AM	Ralph Shape, Mayor	Welcome to SeaTac, WA
9:30 AM	Laura Ranum, PhD	Ataxia 101
10:00 AM	Corrie Smith, MS, CGC	Genetics 101/Gene Testing
11:00 AM	BREAK	
11:30 AM	Harry Orr, PhD	Ataxia Research Review
12:00 PM	SH Subramony, MD	Ataxia Patient Registries
12:30 PM	Q&A Panel	
1:00 PM	LUNCH	

#### **BIRDS OF A FEATHER: 2:00 - 5:00 PM**

Birds of a Feather Informal Groups will meet from 2:00 - 5:00 in various meeting rooms. Please check the hall signs for your specific group's location. *Tentative room assignments* are listed below.

**SCA1 BIRDS OF A FEATHER 2:00 – 5:00 pm in the Evergreen 3 Room**

**SCA2 BIRDS OF A FEATHER 2:00 – 5:00 pm in the Cascade 13 Room**

**SCA3 BIRDS OF A FEATHER 2:00 – 5:00 pm in the Cascade 9&10 Room**

**SCA6 BIRDS OF A FEATHER 2:00 – 5:00 pm in the Cascade 12 Room**

**ALL OTHER SCAs BIRDS OF A FEATHER 2:00 – 5:00 pm in the Evergreen 4 Room**

For this Birds of a Feather you do need to know that you have a form of SCA other than SCA 1, 2, 3, or 6. If you do not know what type of ataxia you have please attend the Unknown BOF session.

**SPORADIC/MSA BIRDS OF A FEATHER 2:00 – 5:00 pm in the Northwest 3 Room**

**FA ADULTS BIRDS OF A FEATHER 2:00 – 5:00 pm in the Grand Ballroom**

A Panel of Speakers will be assembled for the first hour of this session.

**UNKOWN/EPISODIC/AOA 1&2 BIRDS OF A FEATHER 2:00 – 5:00 pm in the Northwest 2 Room**

**PARENTS BIRDS OF A FEATHER 2:00 - 5:00 PM in the Evergreen 1&2 Room**

For this Birds of a Feather group time will be used to listen and share experiences. This will be a powerful time for everyone. The session will begin with identifying some expectations of the group members and addressing their issues/concerns. Physicians will join the group for the final hour to discuss ataxia research.

**CAREGIVERS BIRDS OF A FEATHER 2:00-5:00 PM in the Cascade 3&4 Room**

This Birds of a Feather will be attended by caregivers to share with other caregivers their experiences and concerns in this most appreciated role. For the privacy of the issues talked about in this session we ask that those with ataxia attend the BOF sessions for Ataxians.

**SPOUSES BIRDS OF A FEATHER 2:00-5:00 PM in the Cascade 1&2 Room**

This Birds of a Feather will be attended by spouses to share with other spouses their experiences and concerns. For the privacy of the issues talked about in this session we ask that those with ataxia attend the BOF sessions for Ataxians.

**RECEPTION – LIGHT HORS D’OEUVRES: 7:00 PM KEY NOTE SPEAKERS:**

7:30 PM Theresa Zesiewicz, MD, FAAN

SCA Clinical Study

8:00 PM Kyle Bryant, Ride Ataxia Founder

Ride Ataxia 3 Review

## *Saturday, March 21<sup>st</sup>*

<b>Event</b>	<b>Location</b>	<b>Time</b>
NAF Registration	Northwest 1	7:30AM-5:00PM
Exhibitors	Ballroom Foyer	8:00AM-6:00PM
General Sessions	Grand Ballroom	8:30AM-12:00PM
Nintendo Wii Demonstration	Olympic 1	10:00AM-2:00PM
Lunch	On Your Own	12:00 PM
General Sessions	Grand Ballroom	1:00PM-5:00PM
Silent Auction	Northwest 2&3	3:30PM-7:30PM

Catholic Service	Cascade 9&10	6:00PM-6:45PM
Nondenominational Service	Cascade 13	6:00PM-6:45PM
NAF Banquet	Grand Ballroom	7:00 PM

**GENERAL SESSIONS:**

<u>TIME</u>	<u>SPEAKER</u>	<u>TOPIC</u>
8:30 AM	Thomas Bird, MD	Ataxia: The Seattle Experience
9:00 AM	Gregory Carter, MD, MS	Rehabilitation Aspects Of Ataxia
10:00 AM	Kristie Spencer, PhD, CCC-SLP	Speech & Swallowing
11:00 AM	Michael Wilensky, MD	Medication Considerations In Ataxia
11:30 AM	Q&A Panel	
12:00 PM	LUNCH	
1:00 PM	Marek Napierala, PhD	Targeting DNA Structure For Friedreich's Ataxia Therapy
1:30 PM	Henry Paulson, MD, PhD	Polyglutamine Ataxias
2:00 PM	Ralph Miller	Wheelchair Yoga
3:00 PM	Arnie Gruetzmacher	Financial Planning
4:00 PM	Sid Gilman, MD	Sporadic Ataxia
4:30 PM	Q&A Panel	

***Sunday March 22<sup>nd</sup>***

<b>Event</b>	<b>Location</b>	<b>Times</b>
NAF Registration	Northwest 1	7:30AM-11:00AM
Exhibitors	Ballroom Foyer	8:00AM-12:00PM
Business Meeting	Grand Ballroom	8:00 AM-8:30AM
General Sessions	Grand Ballroom	8:30AM-1:00PM

**GENERAL SESSIONS:**

<u>TIME</u>	<u>SPEAKER</u>	<u>TOPIC</u>
8:30 AM	Susan Perlman, MD	Managing Ataxia and Managing your Neurologist
9:00 AM	David Lynch, MD	FRDA Clinical Trials
9:30 AM	Timothy Maher, PhD	Nutrition And Ataxia
10:00 AM	Arnulf Koeppen, MD	Tissue Donations: What Can They Teach Us About Ataxia
10:30 AM	Ryan Boudreau, PhD	RNAi Research
11:00 AM	Grisel Lopez, MD	Lithium Treatment for Patients With SCA1 – Clinical Trial
11:30 AM	George Wilmot, MD, PhD	What We Have Learned
12:00 PM	Q&A Panel	
12:30 PM	Arnie Gruetzmacher	Closing Remarks