

## 2018 NAF Annual Ataxia Conference (AAC) Preliminary Schedule

Please Note: Due to circumstances beyond our control, this conference schedule is subject to change. Attending sessions is optional. There are no official breaks. Please review the schedule in advance to plan breaks needed for you. If there are sessions of interest to you that you are not able to attend please request that those sessions be offered again on the conference survey.

### *Wednesday, April 4*

<b>Event</b>	<b>Location</b>	<b>Times</b>
NAF Registration	5 <sup>th</sup> Floor Registration 1	9:00am-5:00pm
Silent Auction Item Drop-off	Grand Ballroom Salon A & B	9:00am-5:00pm
Leadership and Fundraising Session	Franklin 2	2:00-4:30pm
Research Poster Session	Grand Ballroom Salon F	5:15-6:45pm
SCA 6 Session	Franklin 2	6:45-7:45pm

### **SMALL GROUP SESSION**

Leadership and Fundraising Development Session: This session is for NAF Ambassadors, Chapter Presidents, Support Group Leaders, and Fundraiser Organizers. This session will provide resources and networking opportunities to those involved with providing support in their areas and raising awareness and funds to further NAF's mission. Contact [lori@ataxia.org](mailto:lori@ataxia.org) to attend this session.

Research Poster Session: This is a great opportunity for you to view research posters that are being presented at the 7<sup>th</sup> NAF Ataxia Investigators Meeting (AIM). Ataxia investigators will be present to answer questions about their posters and Ataxia research projects. Don't miss the opportunity to meet face-to-face with the Ataxia researchers from around the world.

### *Thursday, April 5*

<b>Event</b>	<b>Location</b>	<b>Time</b>
NAF Registration	5 <sup>th</sup> Floor Registration 1	8:00am-5:00pm
Exhibitors/Activity Area	Grand Ballroom Salon C & D	8:00am-5:00pm
Continental Breakfast	Grand Ballroom Foyer	8:00am-9:00am
Silent Auction Item Drop-off*	Grand Ballroom Salon A & B	8:30am-4:00pm
Silent Auction Bidding	Grand Ballroom Salon A & B	8:30am-5:00pm
General Sessions	Grand Ballroom Salon E & F	9:00am-12:15pm
Birds of a Feather	See Conference Program	2:00-5:00pm
Meet & Greet Reception <i>Light appetizers</i>	Grand Ballroom Salon E & F	5:00pm

### **GENERAL SESSIONS:**

<u>TIME</u>	<u>SESSION</u>
9:00am	Welcome & Announcements – Camille Daglio, NAF AAC Chair
9:15am	Trigriluzole: A Phase 2/3 Randomized Controlled Trial in Patients with Spinocerebellar Ataxia – Robert Berman, MD
9:35am	Clinical vs. Basic Science Research - Harry Orr, PhD and George (Chip) Wilmot, MD, PhD
10:05am	NAF Update – Bill Sweeney, NAF President

- 10:30am Living with Ataxia  
Moderator: Kyle Bryant  
Panelists: Jonas Cepkauskas, Cathy DeCrescenzo, and Linda Snider, MD  
*You are invited to submit topics or questions you would like discussed in this session.  
Submit your suggestions to [lori@ataxia.org](mailto:lori@ataxia.org).*
- 11:15am Barriers to Exercise – Jennifer Millar, MSPT and Jennifer Keller, MSPT  
*You are invited to submit your barriers to exercise or questions you would like  
discussed in this session to [lori@ataxia.org](mailto:lori@ataxia.org).*
- 11:45am 10 Basic Steps For Special Needs Caregivers – Kelly Piacenti, MassMutual  
SpecialCare Assistant Vice President and Bruce H. Sham, CLF, Special Care Planner

### **\*SILENT AUCTION**

All items being donated for the Silent Auction are due in the Silent Auction room by Thursday, April 5 at 4pm.

### **ACTIVITY AREA:**

The Activity Area is in the Exhibitor Room. Persons under the age of 12 must be accompanied by a parent or guardian who is age 18 or older. Temporary NAF Tattoos, Coloring, and Adaptive Crafts like decorating Ataxia Rocks and Planters will be available during Activity Area hours.

*Adaptive Crafts:* Get ready for the growing season by decorating your own planter! Personalize your own Ataxia Rock to post on the Ataxia Rocks Facebook Page

<https://www.facebook.com/groups/864677347039596/>. All supplies are provided while they last.

*Nintendo Wii:* An opportunity to observe and play the Nintendo Wii game system will be available Thursday and Friday during Activity Area hours. You can try out the game system for yourself and ask questions about the Nintendo Wii system. The game system is being used around the world by those with limited movement abilities who want to stay active. Please limit your time on the Nintendo Wii system so that everyone interested in this product is provided the opportunity to try it.

*Coloring:* Coloring activities will be available during Activity Area hours. Coloring is a therapy recommended for handwriting. Information describing the benefits of coloring will be available.

*Temporary Tattoos:* Get your NAF Tattoo with NAF's new logo applied to wear throughout the conference.

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

**Attention Parents:** Birds of a Feather Sessions for attendees under 30 years old are facilitated by experienced clinicians. Mature subject matter may be discussed. These sessions are not intended for those who are under 12 years old. Questions regarding these sessions may be directed to Sue Hagen, NAF Patient Services Director [susan@ataxia.org](mailto:susan@ataxia.org) or (763) 553-0020. Birds of a Feather Sessions will meet from 2 - 5pm in various meeting rooms. Please check the conference program and hall signs for your specific group's location. Paid PCAs are welcome to attend the Birds of a Feather session with their client, but not required unless client requires it.

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The following groups have been designed for those who are **affected with Ataxia:**

#### **SCA1 BIRDS OF A FEATHER**

This Birds of a Feather are for those who have been diagnosed with SCA1  
Facilitator: Dr. Orr, Dr. Wilmot, and Dr. Öz (2-3:30pm)

#### **SCA 2 BIRDS OF A FEATHER**

This Birds of a Feather are for those who have been diagnosed with SCA2

Facilitator: Dr. Rosenthal

### **SCA3 BIRDS OF A FEATHER**

This Birds of a Feather are for those who have been diagnosed with SCA3

Facilitator: Dr. Paulson and Dr. Öz (3:30-5pm)

### **SCA6 BIRDS OF A FEATHER**

This Birds of a Feather are for those who have been diagnosed with SCA6

Facilitator: Dr. Shakkottai

### **SCA7 BIRDS OF A FEATHER**

This Birds of a Feather are for those who have been diagnosed with SCA7

Facilitator: Dr. LaSpada

### **ALL Other SCAs (Including SCA 5 and SCA 8) & DRPLA BIRDS OF A FEATHER**

For this Birds of a Feather you need to have a diagnosis of SCA other than SCA 1, 2, 3, 6, 7 or DRPLA. If you do not have a diagnosis of **hereditary** Ataxia please attend the Unknown without Family History BOF session.

Facilitator: Dr. Ranum and Dr. Schmahmann

### **AOA BIRDS OF A FEATHER**

This Birds of a Feather are for those who have been diagnosed with AOA

Facilitator: Dr. Fogel

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The following group has been designed for **non-affected family members:**

### **SPOUSES & PARTNERS WITHOUT ATAXIA BIRDS OF A FEATHER**

This Birds of a Feather will be attended by only spouses and partners so they can share with other spouses and partners 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.

Facilitator: John W, Day, MD, PhD, Amanda Gallagher, MA, CCC-SLP and Donna DeLeno Neuworth, Health Educator

## *Friday, April 6*

<b>Event</b>	<b>Location</b>	<b>Time</b>
NAF Registration	5 <sup>th</sup> Floor Registration 1	8:00am-4:00pm
Exhibitors/Activity Area	Grand Ballroom Salon C & D	8:00am-4:00pm
Continental Breakfast	Grand Ballroom Salon Foyer	8:00am-9:00am
Silent Auction Bidding**	Grand Ballroom Salon A & B	8:30am-2:00pm
General Sessions	Grand Ballroom Salon E & F	9:00am-12:00pm
NAF Member Business Meeting	Grand Ballroom Salon E & F	12:00pm-12:30pm
Birds of a Feather	See Conference Program	2:00pm-5:00pm
Banquet	Grand Ballroom Salon A-F	7:00pm
<i>Plated Meal &amp; DJ</i>		

### **GENERAL SESSIONS:**

<u>TIME</u>	<u>SESSION</u>
9:00am	FRDA and other childhood ataxias – David Lynch, MD, PhD
9:30am	Genetic Testing – You need to get tested: Here's why – Jeremy Schmahmann, MD

- 10:00am Ataxia Investigators Meeting (AIM) Highlights – Gülin Öz, PhD and Albert LaSpada, MD, PhD, FACMG
- 10:30am Management of Ataxia  
Moderator: John W. Day, MD, PhD  
Panelist: Amanda Gallagher, MA, CCC-SLP, Jennifer Keller, MSPT, and Liana Rosenthal, MD  
*You are invited to submit topics or questions you would like discussed in this session. Submit your suggestions to [susan@ataxia.org](mailto:susan@ataxia.org).*
- 11:20am Home Safety Based Modifications – Jessica Wilchinski, MA, OTR/L and Marlena Casey, OTR/L, CLT
- 12:00pm NAF Member Business Meeting - Bill Sweeney, NAF President

**\*\*SILENT AUCTION:**

Winners **MUST** pick-up and pay for their items on Friday from 3-7pm.

**BIRDS OF A FEATHER: 2:00 - 5:00pm**

**Attention Parents:** Birds of a Feather Sessions for attendees under 30 years old are facilitated by experienced clinicians. Mature subject matter may be discussed. These sessions are not intended for those who are under 12 years old. Children under 12 years old should not attend a Birds of a Feather session. Questions regarding these sessions may be directed to Sue Hagen, NAF Patient Services Director [susan@ataxia.org](mailto:susan@ataxia.org) or (763) 553-0020. Birds of a Feather Sessions will meet from 2 - 5 p.m. in various meeting rooms. Please check the conference program and hall signs for your specific group's location. Paid PCAs are welcome to attend the Birds of a Feather session with their client, but not required unless client requires it.

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The following groups have been designed for those who are **affected with ataxia:**

**UNKNOWN WITH FAMILY HISTORY, EA and OTHER RARE RECESSIVES BIRDS OF A FEATHER**

This Birds of a Feather is for those who have been diagnosed with an Unknown Type of Ataxia with Family History, Episodic Ataxia, or other rare recessive ataxias.

Facilitator: Dr. LaSpada

**OVER AGE 30 WITH FRIEDREICH BIRDS OF A FEATHER**

Facilitator: Dr. Wilmot and Marlena Casey, OTR/L, CLT

**UNKNOWN WITHOUT FAMILY HISTORY – MSA, SPORADIC & GLUTEN BIRDS OF A FEATHER**

This Birds of a Feather are for those who have been diagnosed with an Unknown Type of Ataxia without Family History, including MSA, Sporadic, and Gluten Ataxia

Facilitator: Dr. Schmahmann and Jennifer Millar, DPT, NCS

**UNDER AGE 30 WITH ATAXIA BIRDS OF A FEATHER**

This Birds of a Feather session will be attended by those with any type of Ataxia who are under the age of 30.

Facilitator: Dr. Fogel

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The following group has been designed for **parents of children** who are affected with ataxia:

### **PARENTS (NON- FRIEDREICH) BIRDS OF A FEATHER**

This Birds of a Feather will be attended by parents whose child(ren) are affected by any form of Ataxia other than Friedreich's Ataxia. For this Birds of a Feather group, time will be used to listen and share experiences. This will be a powerful time for everyone.

Facilitator: Dr. Rosenthal and Jennifer Keller, PT, MS

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The following group has been designed for **parents of children** who are affected with Ataxia:

### **PARENTS (FRIEDREICH) BIRDS OF A FEATHER**

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.

Facilitators: Dr. Lynch

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The following group has been designed for **non-affected family members**:

### **FAMILY MEMBERS WITHOUT ATAXIA (other than parents, spouses, or partners) BIRDS OF A FEATHER**

This Birds of a Feather will be attended by family members (siblings, children, etc.) of those with Ataxia to share experiences and concerns. We ask that those with Ataxia attend the BOF sessions for Ataxians for the privacy of the issues talked about in this session

Facilitator: John Dyer, BS, MA and Jessica Wilchinski, OTR/L