

2019 NAF Annual Ataxia Conference (AAC) Preliminary Schedule and Overview

Please Note: Due to circumstances beyond our control, this conference schedule is subject to change.

The most current version of the AAC schedule can be found at:

<https://ataxia.org/2019-annual-ataxia-conference/>

The National Ataxia Foundation (NAF) Board of Directors and the National Ataxia Foundation Western Region Support Groups invite you to attend the 62nd Annual Ataxia Conference (AAC). Please join us at the Flamingo Las Vegas, NV to learn, share, network, have fun, and enjoy the sites.

Thursday, March 28

<u>Event</u>	<u>Location</u>	<u>Times</u>
AAC Registration Stop here first and get your conference program, name badge, and welcome bag.	3 rd Floor Registration	8:00 a.m. – 5:00 p.m.
Ataxia Marketplace Interested in research opportunities, accessible equipment, activities, and resources? Visit the Ataxia Marketplace to find out more about those areas of interest, participate in other activities, and attend bonus sessions. Persons under the age of 12 must be accompanied by a parent or guardian who is age 18 or older. Activities: Ataxia Rocks, Adaptive Gaming, Coloring, and more.	Twilight	12:00 p.m. – 5:00 p.m.
Fundraising Session Speaker: Joel Sutherland, NAF Development Director Anyone who is interested in learning more about organizing a fundraising event or getting involved in an Ataxia event to support the important work of the National Ataxia Foundation is encouraged to attend.	Twilight	2:30 p.m. – 3:30 p.m.
First-Time AAC Attendee Session Speaker: Dana Mauro You registered to attend the AAC. Now what? If you are wondering where to begin? What the conference is all about? How to schedule your time? What information or sessions would be the most useful to you? Network and meet others who have similar questions, then this session is for you. This session is aimed at helping anyone who may be looking for advice on how to maximize their time and get the most out of the conference. You will leave feeling more familiar with conference topics, events and breakout sessions. You'll be able to plan out a schedule and even build in some time to relax and have fun!	Twilight	4:00 p.m. – 4:30 p.m.

Friday, March 29

<u>Event</u>	<u>Location</u>	<u>Times</u>
Continental Breakfast	Sunset Ballroom Foyer	7:30 a.m. – 8:30 a.m.
AAC Registration	3 rd Floor Registration	7:30 a.m. – 5:00 p.m.
Ataxia Marketplace	Twilight	8:00 a.m. – 5:00 p.m.
General Sessions	Scenic & Vista Ballroom	8:30 a.m. - 11:30 a.m.
<u>TIME</u>	<u>TOPIC</u>	<u>SPEAKER</u>
8:30 a.m.	Welcome & NAF Update	Camille Daglio, AAC Chair <i>NAF Board Member, Hattiesburg, MS</i>
8:40 a.m.	Acknowledgements & Thanks	Joel Sutherland, NAF Development Director <i>NAF, Minneapolis, MN</i>
9:00 a.m.	Keynote Address Ataxia: A Treatable Disease	Susan Perlman, MD, NAF Medical Director <i>UCLA, Los Angeles, CA</i>
9:30 a.m.	Pioneering in Discovery Research Update	Harry Orr, PhD, NAF Research Director <i>University of MN, Minneapolis, MN</i>

10:00 a.m. Coping with the New Normal

Facilitator: Lisa Ord, PhD, LCSW
John A. Moran Eye Center, SLC, UT

Panelists: Tamara McCord, MA, LMHC, LCAC, Jane Jaffe, Alan Thomas

This panel includes a social worker, therapist, parent, and person with Ataxia.

Questions for this panel session can be sent to lori@ataxia.org.

10:45 a.m. Life Skills for Living with Ataxia

Facilitator: Jason Wolfer
*Albany Ataxia Support Group Leader,
Gervais, OR*

Panelists: Lauren Sormani, Cindy De Mint, Mark Aguilera

This panel includes persons with Ataxia, Support Group Leaders, and a parent.

Questions for this panel session can be sent to lori@ataxia.org.

11:25 a.m. Morning Wrap-Up

**Joel Sutherland, NAF Development
Director**

Lunch Concessions

Sunset Ballroom Foyer

11:00 a.m.– 2:00 p.m.

Lunch n' Learn Sessions

SCA Global Conference

Laughlin 1 & 2

11:30 a.m.– 12:30 p.m.

Opportunity to hear from International Ataxia Researchers

Speaker: Thomas Klockgether, MD

Swallowing Concerns in Ataxia

Virginia City 1

12:00 p.m. – 1:00 p.m.

Speaker: Amanda Gallagher, MA CCC-SLP

Patient Focused Drug Development

Marketplace

12:00 p.m. – 1:00 p.m.

Facilitator: Susan Hagen, NAF Patient & Research Services Director

Speakers: Pharma Representatives

Birds of A Feather (BOF)

2:00 p.m. – 4:30 p.m.

Birds of a Feather Informal Groups will meet from 2:00 – 4:30 p.m. in various conference rooms.

Please check the conference program and hall signs for your specific group's location. Paid PCAs are welcome to attend the BOF session with their client, but not required unless client requires it. Questions regarding these sessions may be directed to Sue Hagen, NAF Patient & Research Services Director susan@ataxia.org or (763) 231-2742.

*The following groups are for those who have been 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. Schut and Dr. Oz

SCA 2 BIRDS OF A FEATHER

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

Facilitator: Dr. Pulst

SCA3 BIRDS OF A FEATHER

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

Facilitator: Dr. Paulson, Dr. Moore, and Dr. Oz

SCA6 BIRDS OF A FEATHER

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

Facilitator: Dr. Khemani

ALL Other SCAs (Including SCA 5, 7, and 8) & DRPLA BIRDS OF A FEATHER

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

Facilitator: Dr. Subramony

FRIEDREICH BIRDS OF A FEATHER

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

Facilitator: Dr. Perlman

AOA BIRDS OF A FEATHER

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

Facilitator: Dr. Fogel

*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 spouses and partners to 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: Donna Neuworth, JHU Health Educator and Dr. Schmahmann

Let's Flamingle Reception

Vista & Scenic Ballroom

5:00 p.m.

All registered conference attendees are welcome to attend. Admittance to this event and the light appetizers that will be served are included with your registration fee. A cash bar will be available. You are encouraged to prepare contact cards to distribute at this event. Contact cards should only include information you wish to distribute such as your name, email address, state, and diagnosis/affiliation. Repeat attendees are encouraged to welcome a First-Time Attendee. First-Time Attendees are identified with a First-Timer Ribbon on their name badge.

Saturday, March 30

Event

Location

Times

Continental Breakfast

Sunset Ballroom Foyer

7:30 a.m. – 8:30 a.m.

AAC Registration

3rd Floor Registration

7:30 a.m. – 5:00 p.m.

Ataxia Marketplace

Twilight

8:00 a.m. – 5:00 p.m.

General Sessions

Scenic & Vista Ballroom

8:30 a.m. – 12:00 p.m.

GENERAL SESSIONS:

TIME

TOPIC

SPEAKER

8:30 a.m.

SCA Global Conference Recap:
Transforming Worldwide Research

Thomas Klockgether, MD

University Hospital Bonn, Bonn, Germany

9:00 a.m.

Ending the Diagnostic Journey:
Next-Generation Genetic Testing

Facilitator: Jeremy Schmahmann, MD

Harvard Medical School, Boston, MA

**Panelists: Matthew A. Bower, MS, CGC – University of Minnesota, Minneapolis, MN and
Brent Fogel, MD, PhD – UCLA, Los Angeles, CA**

Questions for this panel session can be sent to susan@ataxia.org

9:45 a.m.

Management of Ataxia:
Goals and Treatments

Henry Paulson, MD, PhD

University of Michigan, Ann Arbor, MI

10:15 a.m.

Physical Therapy:
Staying Strong and Balanced

Jennifer Millar, MSPT

Johns Hopkins University, Lutherville, MD

10:45 a.m. Hope and Promise for the Future
11:10 a.m. Morning Wrap-up
11:15 a.m. NAF Member Business Meeting

Jennifer Keller, PT, MS
Kennedy Krieger Institute, Lutherville, MD
Lauren Moore, PhD
University of Michigan, Ann Arbor, MI
Joel Sutherland, Development Director
NAF, Minneapolis, MN
Bill Sweeney, NAF President
NAF Board Member, Minneapolis, MN

Lunch Concessions Sunset Ballroom Foyer 11:00 a.m. – 2:00 p.m.

Lunch n’ Learn Sessions

Financial Planning and Social Security Virginia City 2 12:00 p.m. – 1:00 p.m.

Speakers: Kelly Piacenti, MassMutual SpecialCare Assistant Vice President, Jerry Hulick, CLU, ChFC, ChSNC, CLTC, Mass Mutual SpecialCare Planner, and Barbara Duckett, SSA Public Affairs Specialist

Family Planning Options Laughlin 2 12:00 p.m. – 1:00 p.m.

Speakers: Jessica Oberlin and Matthew Bower, CGC

Ataxia Advocacy: A Global Effort Marketplace 12:00 p.m. – 1:00 p.m.

Facilitator: Lori Shogren, NAF Community Program & Services Director

Panelists: Alan Thomas – Ataxia and Me.org Founder, Cory Hannan – Ataxia Mexico Founder, Kristen Angell - NORD, Lauren Sormani – NAF Under 30 with Ataxia Support Group Leader, Kyle Bryant – Ride Ataxia Founder

Birds of a Feather (BOF) 2:00 p.m. – 4:30 p.m.

Birds of a Feather Informal Groups will meet from 2:00 – 4:30 p.m. in various conference rooms.

Please check the conference program and hall signs for your specific group’s location.

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 & Research Services Director susan@ataxia.org or (763) 231-2742. Paid PCAs are welcome to attend the Birds of a Feather session with their client, but not required unless client requires it.

* 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.

Facilitator: Dr. Khemani and Matthew Bower, MS, CGC

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, MSPT

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: Stephanie Lucas, NAF Communications Manager

*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. Fogel

*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. Perlman

* The following groups have 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. For the privacy of the issues talked about in this session, we ask that those with Ataxia attend the BOF sessions for Ataxians.

Facilitator: Donna Neuworth, JHU Health Educator

Banquet

Scenic & Vista Ballroom

7:00 p.m.

We look forward to a wonderful dinner together and a fun evening of socializing. Your name badge indicating your preselected entrée choice will be required to enter this event. When you arrive at the conference, **please make sure you receive your name badge if you are attending.** The cost of the banquet is included in your registration fee. Beverages will be available at a cash bar. The banquet includes a plated dinner. Seating will begin promptly at 7:00 p.m. There will not be assigned seating. Raffle drawings will be held during the banquet program. Winners must be present to win.