2017 NAF Annual Ataxia Conference (AAC)
Preliminary Schedule

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

Thursday, March 9

Event	Location	Times
NAF Registration	2nd Floor Foyer	9:00am-5:00pm
Silent Auction Item Drop-off	Lone Star C	9:00am-5:00pm
Leadership Meeting	Lone Star F	1:00-3:00pm
Fundraising Meeting	Lone Star F	4:00-5:00pm

SMALL GROUP SESSION

Fundraising Meeting: Thursday 4:00 - 5:00 pm Facilitator: Joel Sutherland, Executive Director

Many of us attending this conference are not researchers, nor are we clinicians. We are individuals seeking ways to find a cure for Ataxia. But we can play an important role by supporting the mission of the NAF and energizing our community across the country. Come and join in on the discussion on how you can play YOUR role in this effort.

Friday, March 10

Event	Location	Time
NAF Registration	2nd Floor Foyer	8:00am-5:00pm
Exhibitors	Lone Star B	8:00am-5:00pm
Silent Auction Item Drop-off*	Lone Star C	8:30am-4:00pm
Silent Auction Bidding	Lone Star C	8:30am-5:00pm
General Sessions	Lone Star A Entrance	9:00am-12:30pm
Activity Room	Bowie B	9:00am-12:00pm
Small Group Session	Lone Star A Entrance	1:00pm-2:00pm
Small Group Session	Bowie B	4:00pm-5:00pm
Lunch	On Your Own	12:30pm
Birds of a Feather (Group A)	See Conference Program	2:00-5:00pm
Southwest Meet & Greet Reception *Light appetizers*	Lone Star A Entrance	5:00pm

GENERAL SESSIONS:

TIME	*TOPIC*	*SPEAKER*
9:00am	Welcome & Announcements	**Camille Daglio, AAC Chair** *Mississippi Chapter President – Hattiesburg, MS*
9:15am	NAF Update	**Joel Sutherland, Executive Director** *NAF – Minneapolis, MN*
10:00am	Management of Ataxia through Care Teams	**Pravin Khemani, MD** *University of Texas Southwestern Medical Center*

		Dallas, TX
10:30am	From Shattered to Strength	**Jason Wolfer** *Willamette Valley Ataxia Support Group Leader* *Gervais, OR*
11:00am	Approaches to Develop Therapies for Ataxias	**Huda Zoghbi, MD** *Baylor College of Medicine – Houston, TX*
11:30am	Clinical Trial Readiness	**Henry Paulson, MD, PhD** *University of Michigan Health System* *Ann Arbor, MI*
12:00pm	Q&A Panel	
12:30pm	LUNCH	

***SILENT AUCTION**
All items being donated for the Silent Auction are due in the Silent Auction room by Friday, March 10 at 4pm.

ACTIVITY ROOM:
The Activity Room is open to all ages during scheduled Activity Room hours on Friday and Saturday 9:00am – 12:00pm. Persons under the age of 12 must be accompanied by a parent or guardian who is age18 or older. Temporary NAF Tattoos will be available during Activity Room hours. Volunteers will be on hand to help apply tattoos as needed during Activity Room hours.

Nintendo Wii: An opportunity to observe and play the Nintendo Wii game system will be available Friday and Saturday during Activity Room hours. You can try out the Nintendo Wii game system for yourself and ask questions about the Nintendo Wii system. The Nintendo Wii 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 Room hours. Coloring is a therapy recommended for handwriting. Information describing the benefits of coloring will be available.

SMALL GROUP SESSIONS
Safe Mobility Strategies; Proper Lifting/Transfers/Falls Prevention: 1:00 – 2:00pm Facilitator: Julie Walker, DPT, NCS and Marlena Casey, OT/L
Jennifer and Marlena will discuss transfer/adaptive equipment and safe strategies for mobility. Proper lifting and transfer techniques will be demonstrated.

Healing Through Writing: 4:00 - 5:00pm Facilitator: Jude Lally
Most people have a story, but for people living with Ataxia we literally have dozens. For us getting the words down on paper is an obstacle in itself. Whether you're still able to write sloppily with pen and paper, peck using a keyboard or speak into a headset via a voice recognition program, your hard work and effort should not be overlooked. Ataxians, caregivers and family members, please join us as we celebrate the fifth annual installment of Healing Though Writing, a writers' and discussion group focusing on the healing power of writing. Led by published poet, Jude Lally.

BIRDS OF A FEATHER (GROUP A): 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 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.

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

SCA1 BIRDS OF A FEATHER 2:00 – 5:00pm in Bonham E
This Birds of a Feather are for those who have been diagnosed with SCA1
Facilitator: Dr. Zoghbi, Dr. Orengo, and Dr. Schut

SCA 2 BIRDS OF A FEATHER 2:00 – 5:00pm in Mission B
This Birds of a Feather are for those who have been diagnosed with SCA2
Facilitator: Dr. Khemani and Marlena Casey, OT

SCA3 BIRDS OF A FEATHER 2:00 – 5:00pm in Bonham B
This Birds of a Feather are for those who have been diagnosed with SCA3
Facilitator: Dr. Paulson and Jessica Dileo, OTR/L

SCA6 BIRDS OF A FEATHER 2:00 – 5:00pm in Bowie C
This Birds of a Feather are for those who have been diagnosed with SCA6
Facilitator: Dr. Marvel and Dr. Jimenez-Shahed

ALL Other SCAs (Including SCA 5, SCA 7, and SCA 8) & DRPLA BIRDS OF A FEATHER 2:00 – 5:00 pm in Bonham C
For this Birds of a Feather you need to have a diagnosis of SCA other than SCA 1, 2, 3, or 6 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. Opal

OVER AGE 30 WITH FRIEDREICH BIRDS OF A FEATHER 2:00 – 5:00pm in Bowie A
Facilitator: Dr. Wilmot and Dr. Napierala

AOA 1 &2 BIRDS OF A FEATHER 2:00 – 5:00pm in Bonham A
Facilitator: Dr. Fogel

UNKNOWN WITHOUT FAMILY HISTORY – MSA, SPORADIC & GLUTEN BIRDS OF A FEATHER 2:00 – 5:00pm in Bonham D
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. Subramony, and Amanda Gallagher, CCC-SLP

Saturday, March 11

Event	Location	Time
NAF Registration	2nd Floor Foyer	8:00am-4:00pm
Exhibitors	Lone Star B	8:00am-4:00pm
Silent Auction Bidding**	Lone Star C	8:30am-1:00pm
General Sessions	Lone Star A Entrance	9:00am-12:00pm
Activity Room	Bowie B	9:00am-12:00pm
Small Group Session	Lone Star A Entrance	1:00pm-2:00pm
Small Group Session	Bowie B	4:00pm-5:00pm
Lunch	On Your Own	12:00pm
Birds of a Feather (Group B)	See Conference Program	2:00-5:00pm
Diamond Jubilee Banquet	Lone Star Ballroom	7:00pm

GENERAL SESSIONS:

TIME	*TOPIC*	*SPEAKER*
9:00am	Advances in the Genetic Diagnosis of the Cerebellar Ataxias	**Brent Fogel, MD, PhD** *UCLA – Los Angeles, CA*
9:30am	My Caregiver Story	**Terri Alessi, LPN** *Cicero, NY*
10:00am	Research Update	**Laura Ranum, PhD** *University of Florida – Gainesville, FL*
10:30am	Reproductive Strategies/Wrap-Up	**George "Chip" Wilmot, MD, PhD** *Emory University School of Medicine – Atlanta, GA*
11:00am	Q&A Panel	
11:30am	NAF Member Business Meeting	**Bill Sweeney, NAF President** *Minneapolis, MN*
12:00pm	LUNCH	

****SILENT AUCTION:**
Winners **MUST** pick-up and pay for their items on Saturday from 3-7pm.

ACTIVITY ROOM:
The Activity Room is open to all ages during scheduled Activity Room hours on Friday and Saturday 9:00am – 12:00pm. Persons under the age of 12 must be accompanied by a parent or guardian who is age18 or older. Temporary NAF Tattoos will be available during Activity Room hours. Volunteers will be on hand to help apply tattoos as needed during Activity Room hours.

Nintendo Wii: An opportunity to observe and play the Nintendo Wii game system will be available Friday and Saturday during Activity Room hours. You can try out the Nintendo Wii game system for yourself and ask questions about the Nintendo Wii system. The Nintendo Wii 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 Room hours. Coloring is a therapy recommended for handwriting. Information describing the benefits of coloring will be available.

SMALL GROUP SESSIONS
General Exercise Recommendations: 1:00 – 2:00pm Facilitator: Julie Walker, DPT, NCS
General recommendations will be discussed to help guide individuals towards establishing a safe and effective exercise program, along with suggestions for potential resources. Also, included in the discussion will be highlights of the latest research related to the exercise and motor learning in people with Ataxia, supporting the benefits of exercise.

Demystifying Feeding Tubes FAQ: 4:00 – 5:00pm Facilitator: Dianne Williamson, BSN, RN, Home Health Nurse
In the home setting, an abdominally-placed feeding tube can supplement oral intake. A feeding tube reduces risk of complications associated with frequent aspiration or choking, yet allows an individual to also eat/drink. Session is designed those who are curious about or are considering a feeding tube. It will cover the types, placement, uses, benefits and level of care.

BIRDS OF A FEATHER (GROUP B): 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 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.

* 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 2:00 – 5:00pm in Bonham A
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 race recessive ataxias.
Facilitator: Dr. Subramony and Dr. Khemani

UNDER AGE 30 WITH ATAXIA BIRDS OF A FEATHER 2:00-5:00pm in Mission B
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. Napierala, and Emily Baudin

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

PARENTS (NON- FRIEDREICH) BIRDS OF A FEATHER 2:00 – 5:00pm in Bonham C
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 2:00 - 5:00pm in Bonham D
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. Wilmot

* 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 2:00-5:00pm in Bowie C
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: John Dyer, BS, MA

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

SPOUSES & PARTNERS WITHOUT ATAXIA BIRDS OF A FEATHER 2:00-5:00pm in Bonham B
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: Dr. Marvel, Dr. Jimenez-Shahed, and Amanda Gallagher, MA, CCC-SLP