



2017 FAMILY CONFERENCE AGENDA

Last Updated 6-23-17

Please be aware that the following agenda is preliminary and that talk titles, days and times are subject to change. Check back frequently for updates and additions.

CONFERENCE CO-SPONSOR



American Association for Klinefelter Syndrome Info. & Support

with additional support from Clarus Therapeutics

FRIDAY, JUNE 23

HYATT REGENCY AURORA-DENVER CONFERENCE CENTER

1:00pm – 5:00pm Meeting of the AXYS Clinic & Research Consortium at the hotel

7:00pm – 9:00pm

- Meet & Greet in the conference foyer of the hotel as the attendees and presenters arrive (Light snacks will be provided).
- Check-in and Registration at the hotel. Receive conference materials and name badges.

SATURDAY, JUNE 24

MEDICAL CONFERENCE AND EDUCATION CENTER - CHILDREN'S HOSPITAL CO

- 9:00am – 5:00pm **Adult Retreats for XXY/XYX/XXX/XXYY** (See Adult Retreat at end of main agenda.)

Morning:

- Conference Center Lobby

7:30am – 8:30am **Check-in and Registration** at the conference center. Receive conference materials and name badges.

➤ Mt. Oxford Auditorium

8:30am – 8:50am **Welcoming Remarks and Announcements**

8:50am – 10:00am **Keynote addresses:** Sharron Close, PhD and Nicole Tartaglia, MD

10:30am – 11:00am *Get to know one another!* **Guided, condition-specific socialization activities**

Break

❖ 11:10am – 12:00pm Breakout sessions

1) Topic: **Understanding Language Development and Interventions**

Variation(s): All

Speaker(s): Jacqueline Frazier, MA, CCC-SLP

Room: Princeton

2) Topic: **Independent Living Skills: Life After High School**

Variation(s): All

Speaker(s): Sharon Heller

Room: Yale

3) Topic: **First Time Attendee Panel**

Variation(s): All

Speaker(s): Susan Howell, MS, MBA, CGC and others

Room: Oxford

4) Topic: **What can animal research tell us about sex chromosome variations?**

Variation(s): XXY, XYY

Speaker(s): Arthur P. Arnold, PhD

Room: Harvard

5) Topic: **Brief Research Presentations for scientific faculty** (open to all)

Room: Columbia

Afternoon:

12:00pm – 1:00pm **Lunch** (box lunches provided)

➤ 12:00pm – 5:00pm **Teen Lounge open**

❖ 1:00pm – 1:50pm Breakout sessions

1) Topic: **Thinking about starting testosterone?**

Variation(s): XXY/XXYY/XXXY

Speaker(s): Shanlee Davis, MD

Room: Oxford

2) Topic: **Trisomy X Panel and Q&A**

Variation(s): XXX

Speaker(s): Rebecca Wilson, PsyD and others

Room: Yale

3) Topic: **Transitions to Adult Services**

Variation(s): All

Speaker(s): Cory Ellen Nourie, MSS, MLSP

Room: Princeton

4) Topic: **Male Fertility in X and Y Variations: current state-of-the art and future implications**

Variation(s): XXY

Speaker(s): Akanksha Mehta, MD and Hooman Sadri-Ardekani, MD, PhD

Room: Harvard

5) Topic: **Brief Research Presentations for scientific faculty** (open to all)

Room: Columbia

❖ 2:05pm – 2:55pm Breakout sessions

1) Topic: **Testosterone therapy for adolescents/adults with sex chromosome aneuploides: What's available and what's new?**

Variation(s): XXY/XXYY/XXXY

Speaker(s): Alan Rogol, MD

Room: Oxford

2) Topic: **What Parents Need to Know About Their Child's Development**

Variation(s): All

Speaker(s): Amy Talboy, MD

Room: Yale

3) Topic: **Mental Health: Issue and Challenges in XYY**

Variation(s): XYY

Speaker(s): Erin Torres, Nurse Practitioner

Room: Princeton

4) Topic: **Trisomy X: A group just for us**

Variation(s): XXX

Facilitator: Andrea Wilczynski

Room: Harvard

5) Topic: **Brief Research Presentations for scientific faculty** (open to all)

Room: Columbia

❖ 3:10pm – 4:00pm Breakout sessions

1) Topic: **Adult Management of Klinefelter Syndrome**

Variation(s): XXY Adults

Speaker(s): Swaytha Yalamanchi, MD

Room: Oxford

2) Topic: **Understanding Executive Functions**

Variation(s): All
Speaker(s): Jennifer Janusz, PsyD
Room: Yale

3) Topic: **Gene Function, Brain Development and Behavior**

Variation(s): All
Speaker(s): Armin Raznahan, MD, PhD
Room: Princeton

4) Topic: **Brief Research Presentations for scientific faculty** (open to all)

Room: Columbia

❖ 4:10pm – 5:00pm Breakout sessions

1) Topic: **The Inside Scoop: What families need to know about Social Media**

Variation(s): All
Speaker(s): Rebecca Wilson, PsyD
Room: Oxford

2) Topic: **IEP/504 Accommodations**

Variation(s): All
Speaker(s): Karen Riley, PhD
Room: Yale

3) Topic: **Brain and Behavioral Development in Klinefelter Syndrome**

Variation(s): XXY
Speaker(s): Allan Reiss, MD
Room: Princeton

4) Topic: **Seizures and Tremors**

Variation(s): All
Speaker(s): Elizabeth Berry-Kravis, MD, PhD
Room: Harvard

5) Topic: **Brief Research Presentations for scientific faculty** (open to all)

Room: Columbia

SUNDAY, JUNE 25

MEDICAL CONFERENCE AND EDUCATION CENTER - CHILDREN'S HOSPITAL CO

➤ 10:00am – 2:00pm **Adult Retreats for XXY/XYX/XXX/XXYY**

Morning:

8:30am – 9:00am General session with all attendees:

Presentation: **“About AXYS”**

❖ 9:00am – 9:50am Breakout sessions

1) Topic: **Disclosing the Diagnosis**

Variation(s): All

Speaker(s): Susan Howell, MS, MBA, CGC

Room: Yale

2) Topic: **Navigating the mental health system: a guide to treatment options**

Variation(s): All

Speaker(s): David Hong, MD

Room: Oxford

3) Topic: **Understanding the ABC's of Behavior in Children**

Variation(s): All

Speaker(s): Elizabeth Coan, PsyD

Room: Princeton

4) Topic: **Brief Research Presentations for scientific faculty** (open to all)

Room: Columbia

❖ 10:05am – 10:55am Breakout sessions

1) Topic: **Social Skills and Emotion Recognition**

Variation(s): All

Speaker(s): Kimberly Kuiper, MSc and Nienke Bouw, MSc

Room: Oxford

2) Topic: **Medications in X&Y Chromosome Variations: Making Medication Decisions & Strategies to Set and Monitor Treatment Goals**

Variation(s): All

Speaker(s): Nicole Tartaglia, MD

Room: Yale

3) Topic: **Government Benefits for Adults**

Variation(s): All

Speaker(s): Virginia Cover, MSW

Room: Princeton

4) Topic: **Brief Research Presentations for scientific faculty** (open to all)

Room: Columbia

➤ 11:10am – 12:00pm **Poster Session** *Interact with researchers!*

12:00pm – 1:00pm **Lunch** (box lunches provided)

❖ 1:00pm – 1:50pm Breakout sessions

1) Topic: **Working the Room: Advocacy You Can Use**

Variation(s): All

Speaker(s): Sharron Close, PhD and Dorothy Boothe, PhD

Room: Princeton

2) Topic: **Metabolic Issues in XXY**

Variation(s): XXY

Speaker(s): B. Michelle Schweiger, DO, MPH

Room: Yale

3) Topic: **Legal Issues and Challenges**

Variation(s): All

Speaker(s): Sheryl Kelly, Esq. and Gary Glissman

Room: Oxford

4) Topic: **Brief Research Presentations for scientific faculty** (open to all)

Room: Columbia

➤ 2:00pm – 3:30pm **Condition-specific and/or region-specific/Support Group meetings**

4:00pm Conference concludes

ADULT RETREAT--XXY & XYY ONLY

MEDICAL CONFERENCE AND EDUCATION CENTER-CHILDREN'S HOSPITAL

CAMERON ROOM

SATURDAY, JUNE 24

Morning:

9:00-9:10 Welcome Adults from 18-? to the Adult Retreat.
Welcoming remarks from its organizer Tom Clephane
and introducing this year's moderator, Uldis Silgailis

9:10-10:15 Hearing from each other and stating our intentions for this weekend

10:15-10:30 BREAK

10:30-12:00 SPEAKER: Allan Reiss, MD & David Hong, MD
Topics: Open discussion for Men with Klinefelter Syndrome and xxy; Mental Health challenges and Intersex Issues.

Afternoon:

12:00-1:00 LUNCH (Box Lunch Provided)

1:00-2:00 Discussions on any subject, monitored by Uldis Silgailis

2:00-3:00 SPEAKER: Virginia Cover, MSW
Topics: How to get established in a Career; Funding for job retraining or help with job placement; Going back to College in your 30's or later and getting housing and Supplemental funds; Rules for applying for SS Disability coverage.

3:30-4:00 BREAK

4:00-5:00 SPEAKER: Sharron Close, PhD, MS, CPNP-PC, FAAN
Topics: How are research projects helping adults xxy's, i.e; Patient Registry; Report from the Scientific Conference in August 2016 in Atlanta, GA; Her latest Research Projects.

SUNDAY, JUNE 25

Morning:

8:30-9:50 Welcome to those who are new. Short introductions and questions.
How is the retreat going so far? Any questions about yesterday's presentations?
Tom and Uldis will talk about the speakers scheduled for today.

9:00-9:50 MOVE TO PRINCETON ROOM
SPEAKER: Swaytha Yalamanchi, MD
Topic: Adult Management of Klinefelter Syndrome

9:50-10:00 Break

10-11:00 SPEAKERS: Robby Miller, Interim Director of AXYS and Susan Howell, Board member of AXYS.
Topics: Robby will speak about what AXYS is doing for the adults and how the organization can help us through the use of the new website, social media and support groups.
Susan will introduce us to the Axyon Patient Registry on the AXYS website, how to register, what it means to us and how research will benefit us in the future.

11:00-11:15 BREAK

11:15-12:00
SPEAKER: Swaytha Yalamanchi, MD
Topic: Swaytha will speak about Klinefelter issues and about new and old Testosterone Therapies. Questions and answers will follow.

Afternoon:

12:00-1:00 LUNCH (box Lunch Provided)

1:00-2:00 Final discussions with Tom and Uldis for future Adult Retreats, Regional meetings/Social events, etc.

2:00-3:30 Condition-specific and/or region-specific/Support Group meetings

4:00 Conference Concludes