

JULY 15-17, 2018
Crystal Gateway Marriott
Arlington, VA

2018 Turner Resource Network Symposium "Turner Science in the 21st Century"

Join us as we promote and inspire research in Turner syndrome.

The purpose of this meeting is for clinical and basic science investigators from diverse fields to meet and discuss the molecular mechanisms, medical treatment challenges, and epidemiology of the health problems from which the girls and women who live with Turner syndrome suffer. Thus, individuals from multiple disciplines with diverse research interests will come together in order to develop an interdisciplinary strategy for advancing TS-related science.

10.75 AMA PRA Category 1 Credits™

Key discussants include:

Dr. Diana Bianchi

Dr. Scott Hawley

Dr. Carolyn Brown

Dr. Arthur Arnold

Dr. Ronald Rosenfeld

REGISTRATION

TS Symposium with meals and CME \$300
TS Symposium with CME only (no meals) \$60

TS Symposium available for individuals and family members of those directly affected by TS and includes access to all sessions only at no cost. (Does not include meals and CME credit)

For more information and to register, go to:
www.TurnerSyndrome.org/symposium

Abstracts will be considered for the poster session. Registration fees will be waived for the top three submissions. For more details go to: www.TurnerSyndrome.org/symposium



Help us launch TS Science into the future*

Turner syndrome (TS) affects only girls and women and is caused by deficiency of the second sex chromosome. Mortality rates are significantly higher than the general population. This educational symposium will bring together an international group of clinicians, clinical and basic scientists who will discuss their original research in the Turner syndrome field. Presentations will focus on how Turner syndrome predisposes affected girls and women to significant diseases that are also common in the general population including cardiovascular disease, metabolic syndrome, sensory-neural hearing loss, neuro-cognitive disorders, and infertility. In addition, working groups of scientist, clinicians and family advocates will develop strategies to deploy the patient-powered Turner Syndrome Research Registry.

Key Discussants

Dr. Diana Bianchi, Director of the National Institute of Child Health and Human Development

Dr. Scott Hawley, Member, National Academy of Sciences the leading authority on mitotic and meiotic biology

Dr. Carolyn Brown, Discovered the Xist gene providing the biological basis for the Lyon hypothesis of X-chromosome inactivation

Dr. Arthur Arnold, Editor-in-Chief Biology of sex differences and developer of the 4-core mouse model that segregates male/female chromosomal and gonadal sex gene function

Dr. Ronald Rosenfeld, internationally renowned authority on the endocrine basis of growth and the author of over 640 publications and 8 edited books



The Turner Resource Network (TRN) is a collaboration between clinicians, scientists, and advocates. TSSUS and TSGA are sponsors of this symposium.

Accreditation - This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of OHSU School of Medicine and the Turner Resource Network (TRN). The OHSU School of Medicine is accredited by the ACCME to provide continuing medical education for physicians.

Credit: OHSU School of Medicine designates this live activity for a maximum of *10.75 AMA PRA Category 1 Credits™*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

*This meeting endorses NIH directive NOT-OD-15-102 that sex must be considered as a biological variable in all NIH-funded research.



AGENDA

SUNDAY, July 15

1:00-1:10 Welcome - Paul Kruszka

Turner syndrome research: What we know and what we don't know

Goal: To identify the main challenges to advancing Turner science

1:10-1:20 Genotype versus phenotype-the 10,000 foot view - **Adrianna San Roman**

1:20-1:30 Health priorities from the clinicians point of view - **Philippe Backeljauw**

1:30-1:40 What girls and women with Turner syndrome need - **Cindy Scurlock**

Session I: *The Turner Syndrome Research Registry: Where researchers and subjects go to meet and everyone knows your name* - Moderator - **Michael Silberbach**

Goal: to discuss the TSRR

1:40-2:00 Patient-powered registries to create equipoise between scientists and subjects: Platform for Engaging Everyone Responsibly (PEER) - **Katherine Lambertson**

2:00-2:20 What 1000 girls and women with TS have told us about their research priorities - **David Sandberg**

2:20-2:40 How does the NIH promote data sharing and can it do more? - **Paul Kruszka**

2:40-4:00 Breakout (workshops/discussions)

How can we donate our bodies to science? - **Angela Lin**

How regional resource centers can mobilize the "research force" - **Kelly Ranallo**

How the TSRR works and what we can do to make it better - **Cindy Scurlock**

Creating the PEER import instrument - **Katherine Lambertson**

How the sex aneuploidy researchers and families can promote research - **Nicole Tartaglia**

4:00-5:00 Breakout summaries/action plans/group discussion - **All**

MONDAY, July 16

7:00-8:00 Breakfast

Session II: The Deep biology of Turner syndrome - Moderator - **Cheryl Maslen**

Goal: To discuss the genetics and molecular biology of TS

8:00-8:20 How understanding rare diseases offers insight into common disease mechanisms: The Turner syndrome model - **Maureen Hoatlin**

8:20-8:40 How understanding Turner syndrome genetics can help us uncover the role of the sex chromosomes in differential susceptibility to common diseases - **Adrianna San Roman**

8:40-9:00 Gonadal hormones and sex chromosomes - where do estrogens stop and transcription factors begin - **Arthur Arnold**

9:40-10:00 Escape Artists: The X Chromosome - **Carolyn Brown**

9:40-10:10 Discussion

10:10-10:30 Break

10:30-10:50 Reproductive senescence in Turner syndrome as a model of aging - **Collen Jackson-Cook**

10:50-11:10 The biology of cognition - **Rebecca Knickmeyer**

11:10-11:30 Growth hormone-beyond growth - **Ron Rosenfeld**

11:30-11:50 TIMP1 & 3/MMP axis and aortic dissection - **Cheryl Maslen**

11:50-12:00 The molecular autopsy - **Siddharth Prakash**

12:00-12:30 Discussion

12:30-1:30 Lunch

Session III: The bedside biology of Turner syndrome - Moderator - **Philippe Backeljauw**

Goal: To discuss the health challenges facing girls and women with TS

1:30-1:50 Estrogen risks and benefits - **Philippe Backeljauw**

1:50-2:10 How can we make pregnancy safe in Turner syndrome? - **Sophia Christian Maitre**

2:10-2:30 Metabolic syndrome and Turner syndrome - **Mitch Geffner**

2:30-2:50 Discussion

2:50-3:20 Break

3:20-3:40 Turner syndrome in diverse populations - **Adebowale Adeyemo**

3:40-4:00 How tissue specific mosaicism contributes to the risk for aortic dissection - **Siddharth Prakash**

4:00-4:20 Neurodevelopmental and psychosocial issues - **Nichole Tartaglia**

4:20-4:40 Sensorineural hearing loss and the X chromosome - **TBA**

4:40-5:00 Discussion

6:00-8:00 Reception

TUESDAY, July 17

7:00-8:00 Breakfast

Session IV: Keynote address and wrap-up

8:00-9:00 *Keynote:* Non-invasive prenatal testing and Turner syndrome **Diana Bianchi**

9:00-9:30 Epigenetic factors altering gene expression in Turner syndrome - **Claus Gravholt**

9:30-10:00 What have we learned and where are we going? - **Scott Hawley**

10:00-11:00 Wrap-up discussion-Action Plans **All**

11:00-11:15 Adjourn - **Paul Kruszka**

Thank you to all of the sponsors and supporters who have made this meeting possible.