

Event Agenda | USH Connections Conference

Friday, July 19, 2024

12:00 PM - 2:00 PM

Registration/Check-In

Location: Ballroom Terrace

2:00 PM - 2:15 PM

Welcome/Housekeeping

Location: Ballroom

2:45 PM - 4:30 PM

Connecting with our sense of TOUCH (IN-PERSON ONLY)

Location: Monroe

Speakers: Roberto Cabrera, Yashaira Romilus

2:45 PM - 3:30 PM

Self-Advocacy – Because It Matters (IN-PERSON ONLY)

Location: Henrietta A-D

Speakers: Ashley Benton, Nicole Alleman

2:45 PM - 3:30 PM

Navigating the Overwhelm: Starting Points and FAQs for Parents of Children with Usher Syndrome in IEPs

(IN-PERSON ONLY)

Location: Ontario

Speaker: Lane McKittrick

3:45 PM - 4:30 PM

Success in Higher Education (IN-PERSON ONLY)

Location: Henrietta A-D

Speakers: Katrina Stanley, Caroline Cerilli

3:45 PM - 4:30 PM

USHvoices Advocacy Fair (IN-PERSON ONLY)

Location: Ontario

USHmentor: Ava Bullis, Ethan Morrobel, Gavin Morrobel

6:00 PM - 7:30 PM

Young Adult Conversation (IN-PERSON ONLY)

Location: Trellis Lounge

Facilitators: Megan Lengel, William Wilkerson

Event Agenda | USH Connections Conference

Saturday, July 20, 2024

7:00 AM - 8:00 AM

Check-In and Breakfast

Location: Ballroom Terrace

8:00 AM - 8:15 AM

Welcome Address

Location: Ballroom

8:30 AM - 9:00 AM

Keynote Speaker: Defying the Odds

Keynote Speaker: Jasmine Simmons, AuD

9:00 AM - 9:15 AM

Usher 101: Realities, Resources, and Research Location:

Speaker: Jennifer Lentz, PhD

9:15 AM - 9:30 AM

Atypical Usher Syndrome and Usher Syndrome type 4: Do they really exist?

Speaker: Margaret Kenna, MD, MPH

9:30 AM - 9:45 AM

Progress and Promise of Usher Syndrome Society Sponsored Research

Speaker: Jeffrey Holt, PhD

9:45 AM - 10:00 AM

NAC Attack Clinical Trial for RP

Speaker: Susie Trotochaud

10:00 AM - 10:30 AM

BREAK

10:30 AM - 10:45 AM

A First-In-Class Revolutionary Platform: jCell® Retinal Progenitor Cells (RPC) Restoring Vision in Patients with Blinding Diseases

Speaker: John Sholar

10:45 AM - 11:00 AM

Clinical Trials: Options, Decisions, and Expectations

Speaker: Alex Levin, MD

11:00 AM - 11:20 AM

More than meets the eye: Current and future applications of stem cell technology in Usher syndrome

Speaker: David Gamm, MD, PhD

11:20 AM - 12:30 PM

USH Research Panel Q&A

Moderator: Jeffrey Holt **Panelists:** John Sholar, Jennifer Lentz, Margaret Kenna, David Gamm, MD, PhD, Alex Levin, Susie Trotochaud

12:30 PM - 2:00 PM

Lunch

2:00 PM - 2:15 PM

Low Vision Rehabilitation and Resources

Speaker: Jennifer Krech, OD

2:15 PM - 2:30 PM

Updates on Hearing Assistive Technology From a DeafBlind Audiologist

Speaker: Jasmine Simmons, AuD

2:30 PM - 2:45 PM

Genetic Testing in Usher Syndrome

Speaker: Celeste Wyman

2:45 PM - 3:00 PM

USH DCP: Community-Driven Data Science

Speaker: Karmen Trzupsek

3:00 PM - 3:15 PM

Addressing the Mental Health Needs of the Usher Community: Step 1 and Beyond

Speaker: Rebecca Alexander

3:15 PM - 3:30 PM

Clinical Trials: Perspective from Participants

Speakers: Cory Dorfman, J.J. Dorfman

3:30 PM - 4:45 PM

Living with Usher Syndrome - Panel Discussion

Moderator: Rebecca Alexander

Panelists: Jasmine Simmons, AuD, Nicki Boccia, Roberto Cabrera, Cory Dorfman, J.J. Dorfman, Katie Fromholt

4:45 PM - 5:00 PM

Closing

5:15 PM - 5:45 PM

Virtual Young Adult Conversation

Location: Zoom

Facilitators: William Wilkerson, Megan Lengel

6:00 PM - 8:00 PM

Evening Social

Location: Ballroom