

FGFR Syndromes- Collaborative Research Network Virtual Conference

The mission of the FGFR Syndromes –Collaborative Research Network (FSCRN) Virtual Conference is to bring together basic, translational, and clinical researchers as well as patients and families to launch an innovative and impactful initiative to develop management and treatment for the complex and multisystem FGFR syndromes, including but not limited to Apert, Crouzon, Pfeiffer, and Muenke syndromes. Professionals from multiple disciplines will come together and will share and discuss how research can advance treatment approaches. International collaborative discussions will generate a strategic plan to improve research, treatment, care, and resources for individuals with FGFR syndromes.

The meeting will include presentations by clinicians, and researchers as well as focus group/workshop discussions to address the following questions:

1. What research questions are most important to answer?
2. What studies are most important to conduct to answer these key research questions?
3. What will be the impact of these studies in improving patient outcome?
4. What resources are needed to perform these key studies?
5. What collaborative groups of researchers are needed to perform these studies?
6. What is the order in which the research studies should be undertaken?
7. How can these studies be funded for targeted studies?

SCHEDULE: (On Pacific Time Zone)

8:00am- 8:05am (PT): Welcome!

Carolina Sommer, Founder/CEO/President of Born a Hero, Research Foundation

LABORATORY APPROACH

*Moderator: **Aris Economides**, Vice President of Research at Regeneron Pharmaceuticals, Inc.*

8:05am- 8:20am (PT): FGF/FGFR Signaling

David Ornitz, Alumni Endowed Professor of Developmental Biology at Washington University

8:20am- 8:35am (PT): FGF/FGFR Structural Biology and Inhibitors

Moosa Mohammadi, Professor of Biochemistry and Molecular Pharmacology at New York University

8:35am- 9:00am (PT): Panel Discussion and Question and Answer

9:00am- 9:15am (PT): Break (9:10am- 9:15am Elisa Landmann plays "Fight Song" on piano)

TRANSLATIONAL APPROACH

*Moderator – **Devaveena Dey**, Senior Staff at Uniform Services University of the Health Services*

9:15am- 9:30am (PT): Combining Molecular and Clinical Evidence, FGFR Syndromes

Amy Merrill-Brugger, Assistant Professor of Biomedical Sciences, Biochemistry and Molecular Biology at University of Southern California

9:30am- 9:45am (PT): Animal Models of FGFR Syndromes –

Ethylin Wang Jabs, Mount Sinai Professor of Developmental Genetics at Icahn School of Medicine

9:45am- 10:00am (PT): Clinical Genetics of FGFR Syndromes –

Andrew Wilkie, Nuffield Professor of Pathology at Oxford University

10:00am- 10:25am (PT): Panel Discussion and Question and Answer

10:25am- 10:40am (PT): Break (10:35am- 10:40am Abby McGowan shares poem, "Fearless")

CLINICAL APPROACH

*Moderator: **Jesse Goldstein**, Associate Professor of Plastic Surgery at University of Pittsburgh*

10:40am- 10:55am (PT): Surgical Experience of FGFR Syndromes

Jeffrey Fearon, Director of The Craniofacial Center at Children's Medical Center Dallas

10:55am- 11:35am (PT): Multidisciplinary Care of FGFR Syndromes

Multidisciplinary team of experts of the Craniofacial Center at Seattle's Children Hospital

Dr. John Dahl- Pediatric Otolaryngologist at Seattle Children's Hospital and Assistant Professor in the Department of Otolaryngology- Head and Neck Surgery at the University of Washington

Dr. Kelly Evans- MD is an attending physician at Seattle Children's Hospital and an assistant professor in the Department of Pediatrics at the University of Washington School of Medicine.

11:35am- 12:00pm (PT): *Panel and Discussion and Question and Answer*

12:00pm- 12:15pm (PT): *Break (12:05pm- 12:15pm Mariana Sommer author of "Lucy has a Baby Brother" shares her book)*

FOCUS/GROUP DISCUSSIONS AND NETWORKING

*Moderator: **Scott Mellis**, Vice President of Translational Medicine at Regeneron Pharmaceuticals, Inc.*

12:15pm- 12:35pm (PT): **KEYNOTE LECTURE**

What you can build together: Castleman Disease Collaborative Network

David Fajgenbaum, Assistant Professor of Medicine, University of Pennsylvania

12:35pm- 1:35pm (PT): Breakout groups- Basic, Translational, Clinical, Advocacy Foci

1:35pm- 1:50pm (PT): Break (1:45pm- 1:50pm Madisyn Bowers, Hula Hoop presentation)

1:50pm- 2:30pm (PT): Summary reports from each group

2:30pm- 2:55pm (PT): Q&A from summary

2:55pm- 3:55pm (PT): Next steps and how to move forward as a collaborative network

3:55pm- 4:00pm (PT): Children's Craniofacial Association (CCA) shares a video

4:00pm (PT): END

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