

FGFR Syndromes: Collaborative Research Network Conference

Day One: Thursday, March 17, 2022
8:15 a.m. to 3:30 p.m.

Click to Join the Event on Day One:

<https://seattlechildrens.webex.com/seattlechildrens/j.php?MTID=mb5869f9fef3ca12c60fb38b03022235b>

Day One Meeting Number: 2471 648 1989

Day One Password: conference

All times are listed in Pacific time

- 8:15 a.m. **Orientation to Webex**
Brittany Richey, *Manager, Administration, Seattle Children's Research Institute*
-
- 8:30 a.m. **Introduction**
Carolina Sommer, *Founder and CEO, Born a Hero Research Foundation*

Keynote Presentations

- 8:40 a.m. **Introduction to Basic Science**
Dr. David Ornitz, *Alumni Endowed Professor, Developmental, Regenerative and Stem Cell Biology Program, Neurosciences Program, Washington University in Saint Louis*
-
- 9:05 a.m. **Overview of Clinical Implications of FGFR Cranio Syndromes**
Dr. Scott P. Bartlett, *Attending Surgeon, Division of Plastic, Reconstructive and Oral Surgery, Director of the Craniofacial Program, Children's Hospital of Philadelphia*
-
- 9:30 a.m. **Advances in Prenatal Detection of FGFR Conditions**
Jessica Giordano, *Assistant Professor of Genetic Counseling in OB/GYN, Columbia University*
-
- 9:55 a.m. **Keynote Presentations Q&A**
Moderated by Dr. Joan Richtsmeier, *Distinguished Professor, Pennsylvania State University*

Musculoskeletal, Part 1

- 10:25 a.m. **Introduction**
Delaney Cunha, *Pfeiffer Syndrome Advocate*
-
- 10:30 a.m. **Benefits of my Daughter's Spine Surgery**
Synthia Kaldi, *Parent Advocate*
-
- 10:40 a.m. **From Bench to Beside: How to Develop Transformative Therapies for Patients with Rare Bone Disorders**
Dr. Elvire Gouze, *Founder and CEO, Innoskel*
-
- 11:05 a.m. **Cellular Therapy for Osteogenesis Imperfecta**
Dr. Ivo Kalajzic, *Professor, Director, Center for Regenerative Medicine and Skeletal Development, University of Connecticut Health Center*
-
- 11:30 a.m. **Skeletal Stem and Progenitor Cells Maintain Cranial Suture Patency and Prevent Craniosynostosis**
Dr. Natalina Quarto, *Senior Scientist, Stanford University School of Medicine*
-
- 11:55 a.m. **Musculoskeletal, Part 1 Q&A**
Moderated by Dr. Amy Merrill-Brugger, *Associate Professor and Chair, Department of Biomedical Sciences, Ostrow School of Dentistry, University of Southern California*
-
- 12:25 p.m. **Break (30 minutes)**

Musculoskeletal, Part 2

12:55 p.m.	Introduction Ellie Hollingshead, <i>Pfeiffer Syndrome Advocate</i>
1:00 p.m.	TBD, Jannett Barton, <i>Parent Advocate</i>
1:10 p.m.	Surgeon-Orthodontist Partnership in Management of FGFR Syndromes Dr. Srinivas Susarla, <i>Associate Professor, Plastic Surgery, University of Washington School of Medicine; Associate Professor, Oral and Maxillofacial Surgery, University of Washington School of Dentistry</i> Dr. Hitesh Kapadia, <i>Chief of Craniofacial Orthodontics, Seattle Children's; Director, Fellowship Training Program in Craniofacial Orthodontics, Assistant Professor, Orthodontics, University of Washington School of Dentistry and Plastic Surgery and University of Washington School of Medicine</i>
1:35 p.m.	FGFR-driven Skeletal Dysplasias and Approaches to Treatment Dr. Carl Dambkowski, <i>Chief Medical Officer, QED Therapeutics; VP, Clinical Strategy, BridgeBio Pharma</i>
2:00 p.m.	Spine and Extremities in FGFR2-related Conditions: When and Why to Worry Dr. Klane K. White, <i>Director, Skeletal Health and Dysplasia Program, Medical Director, Orthopedic Research, Seattle Children's; Professor, Orthopedic Surgery and Sports Medicine, University of Washington</i>
2:25 p.m.	Musculoskeletal, Part 2 Q&A Moderated by Amy Merrill-Brugger, <i>Associate Professor and Chair, Department of Biomedical Sciences, Ostrow School of Dentistry, University of Southern California</i>
2:50 p.m.	Advocating for the Rare Disease Community Claire Ellis, <i>Newborn Screening and Diagnostics Policy Fellow, EveryLife Foundation for Rare Diseases</i>
3:15 p.m.	Closing Remarks
3:30 p.m.	Day One Adjourn

Thank you to our event sponsors!



FGFR Syndromes: Collaborative Research Network Conference

Day Two: Friday, March 18, 2022
8:15 a.m. to 2:30 p.m.

Click to Join the Event on Day Two:

<https://seattlechildrens.webex.com/seattlechildrens/j.php?MTID=m285ac441fa5bc49af36f0b63d3a35a93>

Day Two Meeting Number: 2470 390 4849

Day Two Password: conference

All times are listed in Pacific time

- 8:15 a.m. **Orientation to Webex**
Brittany Richey, *Manager, Administration, Seattle Children's Research Institute*
-
- 8:30 a.m. **Welcome**
Carolina Sommer, *Founder and CEO, Born a Hero Research Foundation*
-
- 8:40 a.m. **Multidisciplinary Team at Seattle Children's Hospital**
Dr. Anne Hing, *Professor of Pediatrics, Department of Pediatrics, University of Washington; Associate Director, Education and Academic Programs, Craniofacial Center at Seattle Children's*

Neurological System

- 9:05 a.m. **Introduction**
Avery Cooper, *Pfeiffer Syndrome Advocate*
-
- 9:10 a.m. **Dealing With Surgical Anxiety**
Whitni Hollingshead, *Parent Advocate*
-
- 9:20 a.m. **How Pfeiffer Syndrome Affects the Nervous System**
Dr. Ioannis Mavridis, *Assistant Professor of Neurosurgery, Head, Department of Neurosurgery, Medical School, Democritus University of Thrace, University General Hospital of Alexandroupolis, Greece*
-
- 9:45 a.m. **Understanding Cognitive, Psychosocial, and Educational Outcomes in Children with Craniosynostosis**
Dr. Hoa Schneider, *Pediatric Neuropsychologist, BCH Cleft and Craniofacial Center Instructor, Harvard Medical School/Boston Children's Hospital*
-
- 10:10 a.m. **Social Work Psychosocial Care of the Child: Supporting Best Outcomes by Supporting Families**
Cassandra Aspinall, *Social Worker, Seattle Children's*
-
- 10:35 a.m. **Best Practices for Helping an Anxious Child Through Surgery and Other Medical Procedures**
Dr. Cindy Ola, *Acting Assistant Professor, Psychiatry and Behavioral Sciences, University of Washington School of Medicine*
-
- 11:00 a.m. **Neurological System Q&A**
Moderated by Ellen Morgan, *Founder and President, PROS Foundation*
-
- 11:30 a.m. **Break (30 minutes)**

Respiratory System

- 12:00 p.m. **Introduction**
Elisa Landmann, *Pfeiffer Syndrome Advocate*
-
- 12:05 p.m. **The Complexities of Life with a Trach: Home Health to Insurance**
Falesha Johnson, *Parent Advocate*

12:15 p.m.	Incidence and Management of Obstructive Sleep Apnea in FGFR Syndromes Dr. Cory M. Resnick, <i>Attending Physician, Oral & Maxillofacial Surgery Program, Boston Children's Hospital; Assistant Professor, Harvard Medical School</i>
12:40 p.m.	What Parents Need to Know About Children with Tracheostomies Dr. John Dahl, <i>Otolaryngologist, Seattle Children's; Assistant Professor, Department of Otolaryngology – Head and Neck Surgery, University of Washington</i>
1:05 p.m.	The Role of Sleep Medicine in the Care of Children with FGFR Syndromes Dr. Erin Mackintosh, <i>Acting Assistant Professor, Pediatric Pulmonary and Sleep Medicine, University of Washington, Seattle Children's</i>
1:30 p.m.	Communication Considerations in Patients with FGFR Syndromes Lauren Beckett, <i>Pediatric Speech Language Pathologist, Instructor, Oregon Health and Science University</i>
1:55 p.m.	Respiratory System Q&A Moderated by Dr. Sarah Hofman DeYoung, <i>Assistant Professor, Division of Pulmonary and Sleep Medicine, Seattle Children's</i>
2:25 p.m.	Closing Remarks
2:30 p.m.	Day Two Adjourn

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- Download the [Webex meetings app desktop version](#)
- Plan to participate in the event from a laptop or desktop computer. Do not download the mobile version.
- If you are joining from an international location or from a location that has high security firewalls in place, we recommend working with your IT department to ensure the Webex app will function properly.