

FGFR Syndromes Collaborative Research Network Conference

March 17th & 18th, 2022

FGFR Syndromes Collaborative Research Network Conference March 17th, 8:45am to 3:30pm

All times are listed in Pacific time

	Join the Event Webex Meeting ID: Password:
8:15 am	Orientation to Webex Brittany Richey <i>Manager, Administration</i> <i>Seattle Children's Research Institute</i>
8:30 am	Introduction Carolina Sommer <i>Founder/CEO</i> <i>Born a Hero Research Foundation</i>
Introductions	
8:40 am	Basic Science Introduction (10 minutes of Q&A) Dr. David Ornitz, M.D., Ph.D. <i>Alumni Endowed Professor</i> <i>Developmental, Regenerative and Stem Cell Biology Program</i> <i>Neurosciences Program</i> <i>Washington University in Saint Louis</i>
9:05 am	Clinical Science Introduction (10 minutes of Q&A) Dr. Andrew Wilkie, M.D., Ph.D. <i>Nuffield Professor of Pathology</i> <i>Oxford University</i>
9:30 am	Advances in prenatal detection of FGFR conditions (10 minutes of Q&A) Jessica Giordano, MS, CGC <i>Assistant Professor of Genetic Counseling in obgyn</i> <i>Columbia University</i>
9:55am	Introductions Q&A Joan Richtsmeier, Ph.D. <i>Distinguished Professor</i> <i>Pennsylvania State University</i>
Musculoskeletal, Part 1	

10:25 am	Introduction Delaney Cunha <i>Pfeiffer Syndrome Advocate</i>
10:30 am	Benefits of my Daughter's Spine Surgery Synthia Kaldi <i>Parent Advocate</i>
10:40 am	Cellular therapy for Osteogenesis Imperfecta Dr. Ivo Kalajic, M.D., Ph.D. <i>Professor, Director, Center for Regenerative medicine and Skeletal Development</i> <i>University of Connecticut Health Center</i>
11:05 am	Skeletal Stem and Progenitor Cells Maintain Cranial Suture Patency and Prevent Craniosynostosis Dr. Natalina Quarto <i>Senior Scientist</i> <i>Stanford University School of Medicine</i>
11:30 am	Spine and extremities in FGFR2 related conditions: when and why to worry Dr. Klane K. White, MD, MSc <i>Director, Skeletal Health and Dysplasia Program</i> <i>Medical Director, Orthopedic Research</i> <i>Seattle Children's Hospital</i> <i>Professor, Orthopaedic Surgery and Sports Medicine</i> <i>University of Washington</i>
11:55 am	Musculoskeletal, Part 1 Q&A Amy Merrill-Brugger <i>Assistant Professor of Biomedical Sciences, Herman Ostrow School of Dentistry of USC</i> <i>Assistant Professor of Biochemistry and Molecular Biology, Keck School of Medicine of USC</i>
12:25am	Break (30 minutes)
Musculoskeletal, Part 2	
12:55 pm	Introduction Ellie Hollingshead <i>Pfeiffer Syndrome Advocate</i>
1:00 pm	The neurological effects that over 90 surgeries has had on my son and our family Dawn Brand <i>Parent Advocate</i>
1:10 pm	Surgeon-Orthodontist partnership in management of FGFR syndromes Srinivas Susarla, DMD, MD, MPH <i>Associate Professor, Plastic Surgery</i> <i>University of Washington School of Medicine</i> <i>Oral and Maxillofacial Surgery</i> <i>University of Washington School of Dentistry</i> Hitesh Kapadia, DDS, PhD <i>Chief of Craniofacial Orthodontics</i> <i>Seattle Children's Hospital</i> <i>Director, Fellowship Training Program in Craniofacial Orthodontics</i>

	<i>Assistant Professor, Orthodontics</i> <i>University of Washington School of Dentistry and Plastic Surgery</i> <i>University of Washington School of Medicine</i>
1:35 pm	FGFR-driven skeletal dysplasias and approaches to treatment Dr. Carl Dambkowski, MD <i>Chief Medical Officer, QED Therapeutics</i> <i>VP, Clinical Strategy, BridgeBio Pharma</i>
2:00 pm	From bench to bedside: how to develop transformative therapies for patients with rare bone disorders Dr. Elvire Gouze, Ph.D. <i>Founder and CEO, Innoskel</i>
2:25 pm	Musculoskeletal, Part 2 Q&A Amy Merrill-Brugger <i>Assistant Professor of Biomedical Sciences, Herman Ostrow School of Dentistry of USC</i> <i>Assistant Professor of Biochemistry and Molecular Biology, Keck School of Medicine of USC</i>
2:50 pm	Advocating for the Rare Disease Community Dylan Simon <i>Newborn Screening and Diagnostics Policy Manager</i> <i>Everylife Foundation for Rare Diseases</i>
3:15 pm	Closing Remarks
3:25 pm	END

FGFR Syndromes Collaborative Research Network Conference

March 18th, 8:30am to 3:00pm

All times are listed in Pacific time

	Join the Event Webex Meeting ID: Password:
8:15 am	Orientation to Webex Brittany Richey <i>Manager, Administration</i> <i>Seattle Children's Research Institute</i>
8:30 am	Welcome Carolina Sommer <i>Founder/CEO</i> <i>Born a Hero Research Foundation</i>
8:40 am	Multidisciplinary Team at Seattle Children's Hospital (10 minutes of Q&A) Anne Hing, M.D. <i>Professor of Pediatrics</i> <i>Department of Pediatrics</i> <i>University of Washington</i> <i>Associate Director, Education and Academic Programs</i> <i>Craniofacial Center at Seattle Children's Hospital</i>
Neurological System	
9:05 am	Introduction Avery Cooper <i>Pfeiffer Syndrome Advocate</i>
9:10 am	Dealing with surgical anxiety Whitney Hollingshead <i>Parent Advocate</i>
9:20 am	How Pfeiffer Syndrome Affects the Nervous System Ioannis Mavridis, MD, PhD, FNYAM <i>Asst. Professor of Neurosurgery</i> <i>Head, Department of Neurosurgery, Medical School, Democritus University of Thrace,</i> <i>University General Hospital of Alexandroupolis, Alexandroupolis, Greece</i>
9:45 am	Understanding Cognitive, Psychosocial, and Educational outcomes in children with Craniosynostosis Hoa Schneider, Ph.D. <i>Pediatric Neuropsychologist</i> <i>BCH Cleft and Craniofacial Center</i> <i>Instructor at Harvard Medical School/Boston Children's Hospital</i>
10:10 am	TBD Cassandra Aspinall, MSW, LICSW, ACSW <i>Social Worker</i> <i>Seattle Children's Hospital</i>
10:35 am	Best practices for helping an anxious child through surgery and other medical procedures

	Cindy Ola, Ph.D. <i>Acting Assistant Professor Psychiatry and Behavioral Sciences University of Washington School of Medicine</i>
11:00 am	Neurological System Q&A Moderator, TBD
11:30 am	Break (30 minutes)

Respiratory System	
12:00 pm	Introduction Elisa Landmann <i>Pfeiffer Syndrome Advocate</i>
12:05 pm	The Complexities of Life with a Trach: Home Health to Insurance Falesha Johnson <i>Parent Advocate</i>
12:15 pm	Incidence and Management of Obstructive Sleep Apnea in FGFR Syndromes Cory M. Resnick, MD, DMD <i>Attending Physician, Oral & Maxillofacial Surgery Program Boston Children's Hospital Assistant Professor Harvard Medical School</i>
12:40 pm	What parents need to know about children with tracheostomies John Dahl, M.D., Ph.D., M.B.A. <i>Assistant Professor University of Washington Otolaryngology, Head and Neck Surgery</i>
1:05 pm	TBD Erin Mackintosh, M.D. <i>UW fellow at the Pediatric Pulmonary Center Seattle Children's Hospital UW instructor of Pediatric Pulmonary and Sleep Medicine.</i>
1:30 pm	Communication Considerations in Patients with FGFR Syndromes Lauren Beckett, MS, CCC-SLP <i>Speech-language pathologist, Instructor Oregon Health and Science University (OSHU)</i>
1:55 pm	Respiratory System Q&A Moderator TBD
2:25 pm	Final Remarks
2:30 pm	END

SPONSORS

