

FGFR Syndromes Collaborative Research Network Conference

January 12, 2024
8:30 am – 5:00 pm

Join us for the 2024 FGFR Conference at:
To register visit [our website](#)

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Webinar code: 2630 839 0734

Password: FGFR2024

All times are listed in Pacific time.

Introductions

8:30am	Welcome Brittany Richey, <i>Manager, Administration, Seattle Children's Research Institute</i> Carolina Sommer, <i>Founder and CEO, Born a Hero Research Foundation, Co-Founder of NW Rare Disease Coalition</i>
8:50am	FGFR Syndromes Research Registry Ellen Morgan, <i>FGFR Syndromes Research Registry PI, Born a Hero Board Member, President/Founder of Pros Foundation</i>
9:10am	Mental Health Model, UK Craniofacial Team Rosanna Samuel, <i>DClinPsy, Clinical Psychologist at Oxford University Hospitals Craniofacial Unit</i>
9:40am	Patient Centered Care Emily Durham, <i>PhD, Postdoctoral fellow at Children's Hospital of Philadelphia</i>

Treatments

10:10am	Young Patient Advocate Introduction Friendship - Rosie Comprosky Moderator: Peter Taub, <i>MD, MS, FACS, FAAP, System Chief, Division of Plastic and Reconstructive Surgery at Mount Sinai Medical Center</i>
10:15am	Ultrasound Identification of Tracheal Cartilaginous Sleeve

	Jake Patrick Dahl, MD, PhD, MBA, Medical Director, Airway and Esophageal Center at Seattle Children's Hospital and Associate Professor in the Department of Otolaryngology-Head and Neck Surgery at University of Washington
10:45am	Newest Findings in Ophthalmology Ken K. Nischal, MD, FAAP, FRCOphth, Chief of the Division of Pediatric Ophthalmology and Strabismus at UPMC Children's Hospital of Pittsburgh, Director of Pediatric Program Development at the UPMC Eye Center, and Professor of Ophthalmology at the University of Pittsburgh School of Medicine.
11:15am	Non-surgical Craniosynostosis Treatment Susan M Motch Perrine, PhD, Associate Research Professor, The Pennsylvania State University, Department of Anthropology
11:45am	Barriers to Access for Patients in Colombia Marcela Cabal, MD, MS, Plastic Surgeon at Fundacion Infantil Club Noel and Centro Medico Imbanaco in Colombia
12:15pm	Break (25 minutes)
Therapies- What is on the horizon?	
12:40pm	Young Patient Advocate Introduction Savannah Smith Moderator: Ellen Morgan, FGFR Syndromes Research Registry PI, Born a Hero Board Member, President/Founder of Pros Foundation
12:50pm	Truly, Hadley, Deeply Kristy Lund, RN, AdventHealth Orlando
1:00pm	Activated Somatic Genetic Variants and Vascular Anomalies Jonathan Perkins, DO, Professor, Pediatric Otolaryngologist, University of Washington, Seattle Children's Hospital, Seattle WA
1:30pm	Novel NPR2 Variants that Affect Skeletogenesis Aris Economides, PhD, Vice President of Research at Regeneron Pharmaceuticals
2:00pm	The Value of Natural History Data in Rare Diseases Michael Bober, MD, PhD, Vice President, Clinical Development and Medical Affairs at Tyra Biosciences
2:40pm	Therapies Section Discussion Kristy Lund, RN, Jonathan Perkins, DO, Aris Economides, PhD, Mike Bober, MD, PhD
2:50pm	Break (10 minutes)
Patient Experience Session	
3:00pm	Young Patient Advocate Introduction Ashley Bock Moderator: Ellen Morgan, FGFR Syndromes Research Registry PI, Born a Hero Board Member, President/Founder of Pros Foundation

3:10pm	Perfectly Imperfect, Patient's Journey to Adulthood <u>Panelists</u> - Sabrina Seitz, <i>Montessori Toddler Teacher</i> - Lia Burton, <i>Set Designer for film & TV, Member of the Art Directors Guild</i> - Helen Webb-Prosser, <i>ED tech III at Daniel F. Mahoney Middle School</i>
3:35pm	Break (10 minutes)
Prenatal Diagnosis	
3:45pm	Young Patient Advocate Introduction Atlas Shanklin Moderator: Meng Wu, PhD, Associate Consultant, Department of Clinical Genomics, Mayo Clinic
3:55pm	Prenatal Screening for Craniosynostosis : Past, Present, and Possibly Future Panel <u>Panelists:</u> - Patricia Winters, <i>Associate Director, Medical Affairs at Illumina</i> - Rebecca Reimers, <i>MD, M.P.H, F.A.C.O.G- Maternal-fetal medicine and medical geneticist at San Diego Perinatal and Rady's Children's Hospital</i>
Close of Conference	
4:50pm	Closing Remarks Carolina Sommer, <i>Founder and CEO, Born a Hero Research Foundation, Co-Founder of NW Rare Disease Coalition</i>
5:00pm	Adjourn

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