

FGFR Syndromes Collaborative Research Network Conference

Wednesday, June 25th, 2025

9:00am - 5:00pm

**** All times listed are in Pacific Standard Time ****

Join us virtually, via Webex

<https://seattlechildrens.webex.com/seattlechildrens/j.php?MTID=m441383940125300ee8ac6290e248705f>

Webinar number:

2490 699 9703

Webinar password:

FGFR2025 (34372025 when dialing from a phone or video system)

Join by phone

1-650-479-3207 Call-in toll number (US/Canada)

Access code: 249 069 99703

Introductions

9:00 AM- 9:05 AM

Welcome

Brittany Richey

Director, Research Community Initiatives & Event Operations, Seattle Children's Hospital

9:05 AM- 9:15 AM

Introduction

Carolina Sommer

Founder and CEO, Born a Hero Research Foundation; Co-Founder, NW Rare Disease Coalition

Keynote Speaker

MC: Carolina Sommer

9:15 AM- 9:30 AM

Rise above any of Life's Challenges and Become a Victor, Not a Victim

Ben Kjar

Utah Valley University's First-Ever NCAA Division 1 Wrestling All-American; Has Represented the USA Team Internationally

International Collaborations

MC: Ellen Morgan

9:30 AM - 9:45 AM

A Midface Odyssey

Jesse A. Taylor, MD, FACS, FAAP

Peter Randall Endowed Chair and Chief, Division of Plastic, Reconstructive, and Oral Surgery, The Children's Hospital of Philadelphia

9:45 AM - 10:00 AM	Partners in African Cleft Training: Evolution of a Training Program for Interdisciplinary Cleft Team Care Anne V. Hing, MD <i>Professor, Department of Pediatrics, University of Washington School of Medicine; Faculty Member, University of Washington Division of Medical Genetics; Medical Director, Education and Academic Program and Craniofacial Genetics Program, Seattle Children's Hospital</i>
10:00 AM - 10:15 AM	Craniofacial Surgery in West Africa Solomon Obiri-Yeboah, BDS, FGCS, IFCS; <i>Consultant and Senior Lecturer, Oral and Maxillofacial Surgery; Senior Specialist/Lecturer; Kwame Nkrumah University of Science and Technology and Komfo Anokye Teaching Hospital, Kumasi, Ghana</i>
10:15 AM - 10:30 AM	African Craniofacial Anomalies Network Azeez Butali, DDS, PhD, FICD, FAMedS, FAAAS <i>Gilbert Lilly Endowed Professor of Diagnostic Sciences, College of Dentistry, University of Iowa</i>
10:30 AM- 10:45 AM	Craniofacial Surgeries in India R. Priyadharshini, MDS <i>Consultant, Cleft and Craniofacial Surgeon, GSR Institute of Craniofacial and Facial Plastic Surgery, Hyderabad, India</i>
10:45 AM- 10:55 AM	Break
10:55 AM- 11:25 AM	International Collaborations Panel Discussion and Q&A Moderator: Ellen Morgan <i>FGFR Syndromes Research Registry PI; Board Member, Born a Hero Research Foundation; President and Founder, Pros Foundation</i> Panelists: Anne V. Hing, MD <i>Professor, Department of Pediatrics, University of Washington School of Medicine; Faculty Member, University of Washington Division of Medical Genetics; Medical Director, Education and Academic Program and Craniofacial Genetics Program, Seattle Children's Hospital</i> Solomon Obiri-Yeboah, BDS, FGCS, IFCS; <i>Consultant and Senior Lecturer, Oral and Maxillofacial Surgery; Senior Specialist/Lecturer, Kwame Nkrumah University of Science and Technology and Komfo Anokye Teaching Hospital, Kumasi, Ghana</i> R. Priyadharshini, MDS <i>Consultant, Cleft and Craniofacial Surgeon, GSR Institute of Craniofacial and Facial Plastic Surgery, Hyderabad, India</i> Azeez Butali, DDS, PhD, FICD, FAMedS, FAAAS <i>Gilbert Lilly Endowed Professor of Diagnostic Sciences, College of Dentistry, University of Iowa</i>

Patient Perspective MC: Melissa McGowan	
11:25 AM- 12:05 PM	Caregiver Panel- Daily Living (Pfeiffer Syndrome) Moderator: Melissa McGowan <i>Rare Disease Mother; Board Member, Born a Hero Research Foundation</i> Panelists: Amanda Schuster <i>Caregiver; Advocate</i> Desirae Bobov <i>Caregiver; Advocate</i> Falesha Johnson <i>Caregiver; Advocate</i> Kelly Cunha <i>Caregiver; Advocate</i>
12:05 PM- 12:10 PM	Kid Presenters Delaney Cunha <i>Patient</i> Abby McGowan <i>Patient</i> Ellie Hollingshead <i>Patient</i>
12:10 PM- 1:00 PM	Lunch
Transitioning into Adulthood MC: Chanelle Cordova	
1:00 PM- 1:40 PM	Transitioning into Adulthood Panel Discussion and Q&A Moderators: Matthew Blessing, MD <i>Clinical Associate Professor, Division of Craniofacial Medicine, Department of Pediatrics, University of Washington, Seattle Children's Hospital</i> Hannah Berntson, BSN, RN, CPN <i>Craniofacial Nursing, Seattle Children's Hospital</i> Panelists: Kristine Landmann <i>Advocate; Parent of a Child with Pfeiffer Syndrome Type 3</i> Laurel Sandborn <i>Parent to Parent Vermont; Parent of a Child with Pfeiffer Syndrome</i>
1:40 PM - 2:00 PM	Transitioning from Pediatric to Adult Care Laura Tosi, MD

	<i>Orthopedic Surgeon, Children's National Hospital; Director, Bone Health Program, Children's National Hospital</i>
Cutting Edge/ New Development MC: Carolina Sommer	
2:00 PM - 2:20 PM	Craniosynostosis Intracranial Pressure Surveillance Ken K. Nischal, MD, FAAP, FRCOphth <i>Division Chief, Pediatric Ophthalmology and Strabismus; Medical Director, Digital Health UPMC Children's Hospital of Pittsburgh; Executive Vice Chair, Department of Ophthalmology; Co-Executive Officer and Co-Founder, World Society of Pediatric Ophthalmology and Strabismus (WSPOS)</i>
2:20 PM - 2:40 PM	Shaping Faces: A Story of Variation during Craniofacial Development Ralph Marcucio, PhD <i>Professor, UCSF School of Medicine; Director, Laboratory for Skeletal Regeneration, UCSF Orthopaedic Trauma Institute, San Francisco General Hospital; Co-Director, Oral and Craniofacial Science Graduate Program, UCSF, School of Dentistry</i>
2:40 PM - 3:00 PM	Exploring FGFR Inhibitors: Expanding Horizons from Cancer to Achondroplasia and Beyond Jacqueline Starrett, PhD <i>Sr Director, In Vivo Pharmacology, TYRA Biosciences</i>
3:00 PM 3:20 PM	Infigratinib: Our Path to Today and Vision for Tomorrow Rhea Daugherty, PhD, M.Ed. <i>Director, Medical Affairs, QED Therapeutics</i>
3:20 PM - 3:30 PM	Break
3:30 PM - 3:50 PM	Tracheal Sleeve: New Findings Jake Dahl, MD, PhD, MBA <i>Division Director, Division of Pediatric Otolaryngology, Children's Mercy KC</i>
3:50 PM - 4:20 PM	FGFR Update: Bench to Bedside Moderator: Jake Dahl, MD, PhD, MBA, FACS <i>Division Director, Division of Pediatric Otolaryngology, Children's Mercy Kansas City</i> Panelists: Laurie Eldredge, MD, PhD <i>Co-Director, Bronchopulmonary Dysphasia Program, Seattle Children's Center for Respiratory Biology and Therapeutics; Assistant Professor, Pediatric Pulmonology, University of Washington School of Medicine, Seattle Children's Hospital</i> Seenu Susarla, MD, FACS, FAAP <i>Division Chief, Plastic Surgery; Division Chief, Pediatric Oral and Maxillofacial Surgery; Surgical Director, Craniofacial Center, Seattle Children's Hospital</i>

Born a Hero, Research Foundation Updates

MC: Chanelle Cordova

4:20 PM - 4:40 PM	FGFR Syndromes Research Registry Carolina Sommer <i>Founder and CEO, Born a Hero Research Foundation; Co-Founder, NW Rare Disease Coalition</i> Ellen Morgan <i>FGFR Syndromes Research Registry PI; Board Member, Born a Hero Research Foundation; President and Founder, Pros Foundation</i>
4:40 PM - 4:50 PM	Resources for Families Carolina Sommer <i>Founder and CEO, Born a Hero Research Foundation; Co-Founder, NW Rare Disease Coalition</i>
4:50 PM - 5:00 PM	Closing Remarks Carolina Sommer <i>Founder and CEO, Born a Hero Research Foundation; Co-Founder, NW Rare Disease Coalition</i>

Hosted by Born a Hero and Seattle Children's Research Institute

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