

## 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

Attendee 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 and 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**

	<p>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></p>
10:00 am - 10:15 am	<p><b>Craniofacial Surgery in West Africa</b>  Solomon Obiri-Yeboah, BDS, FGCS, IFCS;  <i>Consultant/ Senior Lecturer, Oral and Maxillofacial Surgery; Senior Specialist/Lecturer; Kwame Nkrumah University of Science and Technology and Komfo Anokye Teaching Hospital, Kumasi, Ghana</i></p>
10:15 am - 10:30 am	<p><b>African Craniofacial Anomalies Network</b>  Azeez Butali, DDS, PhD, FICD, FAMEDS, FAAAS  <i>Gilbert Lilly Endowed Professor of Diagnostic Sciences, College of Dentistry, University of Iowa</i></p>
10:30 am - 10:45 am	<p><b>Craniofacial Surgeries in India</b>  R. Priyadharshini  <i>MDS (Oral and Maxillofacial Surgery), Consultant, Cleft and Craniofacial Surgeon, GSR Institute of Craniofacial and Facial Plastic Surgery, Hyderabad, India</i></p>
10:45 am - 10:55 am	<b>Break</b>
10:55 am - 11:25 am	<p><b>International Collaborations Panel Discussion and Q&amp;A</b></p> <p><b>Moderator:</b>  Ellen Morgan  <i>FGFR Syndromes Research Registry PI; Board Member, Born a Hero Research Foundation; President and Founder, Pros Foundation</i></p> <p><b>Panelists:</b>  Jesse A. Taylor, MD, FACS, FAAP  <i>Peter Randall Endowed Chair, and Chief, Division of Plastic, Reconstructive, and Oral Surgery, The Children's Hospital of Philadelphia</i>  Anne 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/ 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  <i>MDS (Oral and Maxillofacial Surgery), 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></p>

<b>Patient Perspective</b> MC: Melissa McGowan	
11:25 am - 12:05 pm	<b>Caregiver Panel- Daily Living (Pfeiffer Syndrome)</b>  <b>Moderator:</b> Melissa McGowan <i>Rare Disease Mother; Board Member, Born a Hero Research Foundation</i>  <b>Panelists:</b> 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	<b>Kid Presenters</b> Ellie Hollingshead <i>Patient</i> Delaney Cunha <i>Patient</i> Abby McGowan <i>Patient</i>
12:10 pm - 1:00 pm	<b>Lunch</b>
<b>Transitioning into Adulthood</b> MC: Chanelle Cordova	
1:00 pm - 1:40 pm	<b>Transitioning into Adulthood Panel Discussion and Q&amp;A</b>  <b>Moderators:</b> 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>  <b>Panelists:</b> Karen Tamley <i>President and CEO of Access Living</i> Kristine Landmann <i>Caregiver; Advocate</i> Laurel Sandborn <i>Rare Disease Parent</i>

1:40 pm - 2:00 pm	<b>Transitioning from Pediatric to Adult Care</b> Lauri Tosi, MD <i>Orthopedic Surgeon at 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	<b>Craniosynostosis Intracranial Pressure Surveillance</b> Ken Kanwal Nischal, MD, FAAP, FRCOphth <i>Chief, Division of Pediatric Ophthalmology, Strabismus, and Adult Motility, UPMC Children's Hospital of Pittsburgh; Director of Pediatric Program Development, UPMC Eye Center; Professor of Ophthalmology, University of Pittsburgh School of Medicine</i>
2:20 pm - 2:40 pm	<b>Shaping Faces: A Story of Variation during Craniofacial Development</b> 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	<b>Exploring FGFR Inhibitors: Expanding Horizons from Cancer to Achondroplasia and Beyond</b> Jacqueline Starrett, PhD <i>Director, In Vivo Pharmacology at TYRA Biosciences</i>
3:00 pm 3:20 pm	<b>(Talk Title TBD)</b> Rhea Daugherty, PhD, M.Ed. <i>Director, Medical Affairs, QED Therapeutics</i>
3:20 pm - 3:30 pm	<b>Break</b>
3:30 pm - 3:50 pm	<b>Tracheal Sleeve- New Findings</b> Jake Dahl, MD, PhD, MBA <i>Division of Pediatric Otolaryngology  Children's Mercy KC</i>
3:50 pm - 4:20 pm	<b>FGFR Update: Bench to Bedside</b>  <b>Moderator:</b> Jake Dahl, MD, PhD, MBA, FACS <i>Division Director, Division of Pediatric Otolaryngology, Children's Mercy Kansas City</i>  <b>Panelists:</b> 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;</i>

	<i>Surgical Director, Craniofacial Center, Seattle Children's Hospital</i>
<b>Born a Hero, Research Foundation Updates</b> MC: Chanelle Cordova	
4:20 pm - 4:40 pm	<b>FGFR Syndromes Research Registry</b> 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	<b>Resources for Families</b> Carolina Sommer <i>Founder and CEO, Born a Hero Research Foundation; Co-Founder, NW Rare Disease Coalition</i>
4:50 pm - 5:00 pm	<b>Closing Remarks</b> Carolina Sommer <i>Founder and CEO, Born a Hero Research Foundation; Co-Founder, NW Rare Disease Coalition</i>
5:00 pm	<b>End of Event</b>

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

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