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| FGFR Syndromes Collaborative Research Network Conference  March 17th & 18th, 2022 |

**FGFR Syndromes Collaborative Research Network Conference**

**March 17th, 8:15 a.m. to 3:30 p.m.**

***All times are listed in Pacific time***

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|  | **Join the Event**  Meeting Link: <https://seattlechildrens.webex.com/seattlechildrens/j.php?MTID=mb5869f9fef3ca12c60fb38b03022235b>  Meeting Number: 2471 648 1989  Password: conference |
| 8:15 am | **Orientation to Webex**  Brittany Richey  *Manager, Administration*  *Seattle Children’s Research Institute* |
| 8:30 am | **Introduction**  Carolina Sommer  *Founder/CEO*  *Born a Hero Research Foundation* |
| **Keynote Presentations** | |
| 8:40 am | **Introduction to Basic Science (including 5-minutes Q&A)**  Dr. David Ornitz, M.D., Ph.D.  *Alumni Endowed Professor*  *Developmental, Regenerative and Stem Cell Biology Program*  *Neurosciences Program*  *Washington University in Saint Louis* |
| 9:05 am | **Overview of Clinical Implications of FGFR Cranio Syndromes (including 5-minutes Q&A)**  Dr. Scott P. Bartlett, M.D.  *Attending surgeon in the Division of Plastic, Reconstructive and Oral Surgery*  *Director of the Craniofacial Program at Children's Hospital of Philadelphia* |
| 9:30 am | **Advances in Prenatal Detection of FGFR Conditions (including 5-minutes Q&A)**  Jessica Giordano, MS, CGC  *Assistant Professor of Genetic Counseling in obgyn*  *Columbia University* |
| 9:55am | **Keynote Presentations Q&A**  Moderator:  Dr. Joan Richtsmeier, Ph.D.  *Distinguished Professor*  *Pennsylvania State University*  Panelists:  Dr. David Ornitz  Dr. Andrew Wilkie  Jessica Giordano |
| **Musculoskeletal, Part 1** | |
| 10:25 am | **Introduction**  Delaney Cunha  *Pfeiffer Syndrome Advocate* |
| 10:30 am | **Benefits of my Daughter’s Spine Surgery (including 5-minutes Q&A)**  Synthiea Kaldi  *Parent Advocate* |
| 10:40 am | **From Bench to Beside: How to Develop Transformative Therapies for Patients with Rare Bone Disorders (including 5-minutes Q&A)**  Dr. Elvire Gouze, Ph.D.  *Founder and CEO, Innoskel* |
| 11:05 am | |  | | --- | | **Cellular Therapy for Osteogenesis Imperfecta (including 5-minutes Q&A)** |   Dr. Ivo Kalajzic, M.D., Ph.D.  *Professor, Director, Center for Regenerative medicine and Skeletal Development*  *University of Connecticut Health Center* |
| 11:30 am | **Skeletal Stem and Progenitor Cells Maintain Cranial Suture Patency and Prevent Craniosynostosis (5-minute Q&A)**  Dr. Natalina Quarto  *Senior Scientist*  *Stanford University School of Medicine* |
| 11:55 am | **Musculoskeletal, Part 1 Q&A**  Moderator:  Dr. Amy Merrill-Brugger  *Associate Professor and Chair, Department of Biomedical Sciences,*  *Ostrow School of Dentistry*  *University of Southern California*  Panelists:  Synthiea Kaldi  Dr. Ivo Kalajzic  Dr. Natalina Quarto  Dr. Elvire Gouze |
| 12:25am | **Break** (30 minutes) |
| **Musculoskeletal, Part 2** | |
| 12:55 pm | **Introduction**  Ellie Hollingshead  *Pfeiffer Syndrome Advocate* |
| 1:00 pm | **TBD, (including 5-minutes Q&A)**  Jannett Barton  *Parent Advocate* |
| 1:10 pm | **Surgeon-Orthodontist Partnership in Management of FGFR Syndromes (including 5-minutes Q&A)**  Dr. Srinivas Susarla, DMD, MD, MPH  *Associate Professor, Plastic Surgery*  *University of Washington School of Medicine*  *Oral and Maxillofacial Surgery*  *University of Washington School of Dentistry*  Dr. Hitesh Kapadia, DDS, PhD  *Chief of Craniofacial Orthodontics*  *Seattle Children's Hospital*  *Director, Fellowship Training Program in Craniofacial Orthodontics*  *Assistant Professor, Orthodontics*  *University of Washington School of Dentistry and Plastic Surgery*  *University of Washington School of Medicine* |
| 1:35 pm | **FGFR-driven skeletal dysplasias and approaches to treatment (including 5-minutes Q&A)**  Dr. Carl Dambkowski, MD  *Chief Medical Officer, QED Therapeutics*  *VP, Clinical Strategy, BridgeBio Pharma* |
| 2:00 pm | **Spine and extremities in FGFR2 related conditions: when and why to worry (including 5-minutes Q&A)**  Dr. Klane K. White, MD, MSc  *Director, Skeletal Health and Dysplasia Program*  *Medical Director, Orthopedic Research*  *Seattle Children’s Hospital*  *Professor, Orthopaedic Surgery and Sports Medicine*  *University of Washington* |
| 2:25 pm | **Musculoskeletal, Part 2 Q&A**  Moderator:  Amy Merrill-Brugger  *Associate Professor and Chair, Department of Biomedical Sciences,*  *Ostrow School of Dentistry*  *University of Southern California*  Panelists:  Jannett Barton  Dr. Srinivas Susarla  Dr. Hitesh Kapadia  Dr. Carl Dambkowski  Dr. Klane White |
| 2:50 pm | **Advocating for the Rare Disease Community (5-minute Q&A)**  Claire Ellis  *Newborn Screening and Diagnostics Policy Fellow*  *Everylife Foundation for Rare Diseases* |
| 3:15 pm | **Closing Remarks** |
| 3:25 pm | **Day 1 END** |

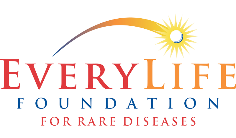
**FGFR Syndromes Collaborative Research Network Conference**

**March 18th, 8:15 a.m. to 2:30 p.m.**

***All times are listed in Pacific time***

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|  | **Join the Event**  Meeting Link:  <https://seattlechildrens.webex.com/seattlechildrens/j.php?MTID=m285ac441fa5bc49af36f0b63d3a35a93>  Meeting Number: 2470 390 4849  Password: conference |
| 8:15 am | **Orientation to Webex**  Brittany Richey  *Manager, Administration*  *Seattle Children’s Research Institute* |
| 8:30 am | **Welcome**  Carolina Sommer  *Founder/CEO*  *Born a Hero Research Foundation* |
| 8:40 am | **Multidisciplinary Team at Seattle Children’s Hospital (including 5-minutes Q&A)**  Dr. Anne Hing, M.D.  *Professor of Pediatrics*  *Department of Pediatrics*  *University of Washington*  *Associate Director, Education and Academic Programs*  *Craniofacial Center at Seattle Children’s Hospital* |
| **Neurological System** | |
| 9:05 am | **Introduction**  Avery Cooper  *Pfeiffer Syndrome Advocate* |
| 9:10 am | **Dealing with surgical anxiety (including 5-minutes Q&A)**  Whitney Hollingshead  *Parent Advocate* |
| 9:20 am | **How Pfeiffer Syndrome Affects the Nervous System (including 5-minutes Q&A)**  Dr. Ioannis Mavridis, MD, PhD, FNYAM  *Asst. Professor of Neurosurgery*  *Head, Department of Neurosurgery, Medical School, Democritus University of Thrace,*  *University General Hospital of Alexandroupolis, Alexandroupolis, Greece* |
| 9: 45 am | **Understanding Cognitive, Psychosocial, and Educational outcomes in children with Craniosynostosis (including 5-minutes Q&A)**  Dr. Hoa Schneider, Ph.D.  *Pediatric Neuropsychologist, BCH Cleft and Craniofacial Center Instructor*  *Harvard Medical School/Boston Children’s Hospital* |
| 10:10 am | **Social Work Psychosocial Care of the Child: Supporting Best Outcomes by Supporting Families (including 5-minutes Q&A)**  Cassandra Aspinall, MSW, LICSW, ACSW  *Social Worker*  *Seattle Children’s Hospital* |
| 10:35 am | **Best practices for helping an anxious child through surgery and other medical procedures (including 5-minutes Q&A)**  Dr. Cindy Ola, Ph.D.  *Acting Assistant Professor*  *Psychiatry and Behavioral Sciences*  *University of Washington School of Medicine* |
| 11:00 am | **Neurological System Q&A**  Moderator:  Ellen Morgan  *Founder/President*  *PROS Foundation*  Panelists:  Whitney Hollingshead  Dr. Ioannis Mavridis  Dr. Hoa Schneider  Cassandra Aspinall  Dr. Cindy Ola |
| 11:30 am | **Break** (30 minutes) |

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| **Respiratory System** | |
| 12:00 pm | **Introduction**  Elisa Landmann  *Pfeiffer Syndrome Advocate* |
| 12:05 pm | **The Complexities of Life with a Trach: Home Health to Insurance (including 5-minutes Q&A)**  Falesha Johnson  *Parent Advocate* |
| 12:15 pm | **Incidence and Management of Obstructive Sleep Apnea in FGFR Syndromes (including 5-minutes Q&A)** Dr. Cory M. Resnick, MD, DMD *Attending Physician, Oral & Maxillofacial Surgery Program*  *Boston Children’s Hospital*  *Assistant Professor*  *Harvard Medical School* |
| 12:40 pm | **What Parents Need to Know About Children with Tracheostomies (including 5-minutes Q&A)**  Dr. John Dahl, M.D., Ph.D., M.B.A.  *Assistant Professor*  *University of Washington*  *Otolaryngology, Head and Neck Surgery* |
| 1:05 pm | **The Role of Sleep Medicine in the Care of Children with FGFR Syndromes (including 5-minutes Q&A)**  Dr. Erin Mackintosh, M.D.  *UW fellow at the Pediatric Pulmonary Center*  *Seattle Children’s Hospital*  *UW instructor of Pediatric Pulmonary and Sleep Medicine*. |
| 1:30 pm | **Communication Considerations in Patients with FGFR Syndromes (5-minute Q&A)**  Lauren Beckett, MS, CCC-SLP  *Speech-language pathologist, Instructor*  *Oregon Health and Science University (OSHU)* |
| 1:55 pm | **Respiratory System Q&A**  Moderator:  Dr. Sarah Hofman DeYoung, MD  *Assistant Professor, Division of Pulmonary and Sleep Medicine*  *Seattle Children’s Hospital*  Panelists:  Falesha Johnson  Dr. Cory M. Resnick  Dr. John Dahl  Dr. Erin Mackintosh  Lauren Beckett |
| 2:25 pm | **Final Remarks** |
| 2:30 pm | **END** |

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