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| FGFR Syndromes Collaborative Research Network ConferenceMarch 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 1989Password: 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 OrnitzDr. Andrew WilkieJessica 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 |

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| **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 KaldiDr. Ivo KalajzicDr. Natalina QuartoDr. 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 BartonDr. Srinivas SusarlaDr. Hitesh KapadiaDr. Carl DambkowskiDr. 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** |

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| 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 HollingsheadDr. Ioannis MavridisDr. Hoa SchneiderCassandra AspinallDr. 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 JohnsonDr. Cory M. ResnickDr. John DahlDr. Erin MackintoshLauren Beckett |
| 2:25 pm | **Final Remarks** |
| 2:30 pm | **END** |

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