

# FGFR Syndromes- Collaborative Research Network Symposium

SAVE THE DATE  
**SEPTEMBER 10,**  
**2020**

**New Seattle Children's Research Institute- Building Cure (1920 Terry Ave, Seattle, WA 98101)**

**Start @ 9:00am (end time will be in the evening,TBD) Lunch and Dinner are provided.**

Questions please contact Carolina Sommer at [carolina@bornahero.org](mailto:carolina@bornahero.org)

**The mission of the FGFR Syndromes - Collaborative Research Network (FSCRN) Symposium is to bring together basic, translational, and clinical researchers as well as patients and families to launch an innovative and impactful initiative to develop management and treatment for the complex and multisystem FGFR syndromes, including but not limited to Apert, Crouzon, Pfeiffer, and Muenke syndromes. Professionals from multiple disciplines will come together and will share and discuss how research can advance treatment approaches. International collaborative discussions will generate a strategic plan to improve research, treatment, care, and resources for individuals with FGFR syndromes.**

The meeting will include presentations by families, clinicians, and researchers as well as focus group/ workshop discussions to address the following questions:

- What research questions are most important to answer?
- What studies are most important to conduct to answer these key research questions
- What will be the impact of these studies in improving patient outcome?
- What resources are needed to perform these key studies?
- What collaborative groups of researchers are needed to perform these studies?
- What resources and facilities are needed to perform these studies?
- How feasible will it be to conduct these studies (e.g. logistically or technically).
- What is the order in which the research studies should be undertaken?
- How can these studies be funded for targeted studies?

#### HOSTED BY:

Dr. Ethylin Wang Jabs- Vice Chair of the Department of Genetics & Genomics Science at the Icahn School of Medicine at Mount Sinai

Dr. Aris Economides- Vice President of Regeneron Pharmaceuticals

Brittany Richey- Manager, Research Institute Administration at Seattle Children's

Carolina Sommer- CEO/President/Founder of BORN A HERO, Research Foundation

**REGENERON**  
SCIENCE TO MEDICINE®



**ultragenyx**



**Seattle Children's®**  
HOSPITAL • RESEARCH • FOUNDATION

Research Institute