

Rare KC

SUMMIT '19

Kansas City Town Hall Meeting
Ewing Marion Kauffman Foundation
Conference Center
4801 Rockhill Road, Kansas City, MO
Monday, March 5th, 2018
8:00AM – 12:00PM

Agenda

- 8:00 Registration/Coffee/Networking
- 8:45 Opening Remarks – Building a Rare Home
Kelly Ranallo, Founder RareKC
- 9:00 Keynote: Breaking through the Impossible
Mark Dant, Parent Advocate – Chair Board of Directors EveryLife Foundation, Founder and Executive Director of the Ryan Foundation
- 9:45 Spot Light Discussion: The Value of a Rare Center of Excellence
- *Steven W. Stites, MD, Executive Vice President of Clinical Affairs & Chief Medical Officer The University of Kansas Health System – Cystic Fibrosis*
 - *Sally Dwyer – Program Director The ALS Association – Mid America Chapter*
 - *Michelle Pool – Parent Advocate /Turner Syndrome Global Alliance*
- 10:30 Break
- 10:45 Patient Centered Healthcare Outcomes: How do we measure success in Rare Disease?
John Spertus, MD, MPH, FACC, FAHA - Daniel Lauer/Missouri Endowed Chair and Professor University of Missouri – Kansas City Clinical Director of Outcomes Research Saint Luke's Mid America Heart Institute
- 11:15 Roundtable Workshop: Building the Center: Structure, Barriers, Resources (*All Stakeholders*)
- 12:00 Lunch
- 12:30 Learning to Speak (and Understand) Whales: Communication Challenges for Researchers and non-Researchers Alike
Dr. Kim Kimminau - Professor, Department of Family Medicine Associate Director, Frontiers: University of Kansas Clinical and Translational Science Institute University of Kansas Medical Center

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12:45 Interactive Poster Sessions

1:30 Breakout Sessions:

- *Legislative Advocacy 101 – Creating a unified voice – Moderator Mark Dant*
- *Rare Disease Research/Science Collaboration - Moderator Dr. Kim Kimminau*
- *Coordinated Care: Where do we start? - Moderator Dr. Eric Rush, MD– Geneticist
Children's Mercy Hospital*

2:45 Kansas City- A Leader in Rare Disease

Dr. Tomi Pastenin , PhD – Director of Children's Mercy Center for Pediatric Genomic Medicine

3:00 Mission Possible – The Rare Journey Rubenstein-Taybi syndrome

Dennis and Janelle Ridenour - Theo

3:30 Closing Re-Marks/Adjourn –

Angie Dunbar – RareKC Board President

Post-Event Meetings

- Ehler-Danlos Syndrome (EDS)