Debbie Jorde
- Parent Advocate
Debbie is an author, activist, aerobic teacher, and mother to a son and daughter both suffering from Miller syndrome.

Joseph Cramer, M.D.
- Clinical Associate Professor of Pediatrics, University of Utah and Primary Children’s Hospital
Dr. Cramer has a practice focused on care for infants, toddlers, children and adolescents. He and his partner were highly engaged in the resuscitation and care of sick newborns.

Panel Moderator: Chris Gibson, Ph.D.
- Founder and CEO, Recursion Pharmaceuticals
Chris is the co-founder and CEO of Recursion Pharmaceuticals, a biotechnology company built to leverage technology to conduct drug discovery at scale across thousands of rare genetic diseases.

Tara Newcomb, M.S.
- Clinical Research Coordinator, Pediatric Motor Disorders Program, University of Utah
Tara Newcomb is a licensed certified genetic counselor working with the Pediatric Motor Disorders Research Program at the University of Utah.

Kevin Jones, M.D.
- Associate Professor Orthopaedics and Oncological Sciences, University of Utah
Specializing in the evaluation, diagnosis, and surgical management of sarcomas, tumors arising in bone and soft-tissue, Dr. Jones sees both pediatric and adult patients.

James Bale, M.D.
- Professor of Pediatrics and Neurology, University of Utah
With advanced training and expertise in neurological infections, Dr. Bale specializes in infections of the nervous system, especially the infections that damage the developing nervous system, a group of conditions known as congenital infections.

Panel Moderator: Robert Selliah, Ph.D.
- Founder, President and CEO, American MedChem Nonprofit Corporation
Dr. Selliah has more than 18 years of experience in technology, leadership, and management in drug discovery, medicinal chemistry, and preclinical development in the United States and the global pharmaceutical and biotech sector.

Reid Robison, M.D., M.B.A.
- CEO, Tute Genomics
Dr. Robison has conducted research using next-generation sequencing technologies (i.e. whole exome sequencing) for the discovery of disease-causing genes in childhood-onset neuropsychiatric disorders such as autism.
MONDAY, FEBRUARY 29TH
Utah State Capitol Building Rotunda

2:30PM  Table Setup

3:00PM  Welcome
Gina Szajnuk
Mother to Ava, Oskar, and Lucy (Rare)

3:05PM  Speakers
Stan Summers
Box Elder County Commissioner and Father to Talan (Rare)
Jennifer Clement
Mother to Lily (Rare Angel)
Gabe Valdez
Father to Harlie with Juvenile Dermatomyositis (Rare Teen)
Josh Forsythe
Father to Calen (Rare Teen)
Catrina Nelson
Mother to Charlee (Rare Angel) Batten Disease

Panel Moderator: Justin Zanik
Parent Advocate
Justin is the father of three children, all of whom have been diagnosed with an unknown genetic dysfunction: an autonomic neuropathy.

4:15PM  Closing Remarks
Willard Dere, M.D.
Executive Director, Program in Personalized Health, University of Utah
Prior to re-joining academia, Dr. Dere was in the biopharmaceutical industry for 25 years.

4:30PM  Reception

4:35PM  Rare Teens
Introduction by Season Atwater
Jaderee Eakle
Calen Forsythe
Michael George
Ricki Jensen
Michael Lee
Katie Maguire
Katie Nuffer
Aliyah Peedle
Hailey Sampsel
Harlie Valdez
Preston Zundel

Stan Lockhart
Husband to Becky (Rare Angel) Creutzfeldt–Jakob disease
Dr. Kathryn Peterson
Doctor to Rare and Mother of son (Rare)
Michael George
(Rare Teen)

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