THE MANAGEMENT OF RARE DISEASES
FIFTH ANNUAL RARE DISEASE GENOMICS SYMPOSIUM

March 2 & 3, 2018
Children’s of Alabama
Bradley Lecture Center
4th Floor, Children’s Harbor Building

Friday, 8 am—4 pm: Scientific Focus
Saturday, 9 am—1 pm:
Patient & Caregiver Focus

BEYOND THE DIAGNOSIS ART EXHIBIT
“TEAGAN” BY JOTA LEAL  SCHIZENCEPHALY

GENETICS

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Friday: $35  Saturday FREE  To register, visit ChildrensAL.org/genetics
FREE Parking in the 5th or 7th Avenue Children’s Decks. Please follow the signs.
Questions? Contact Shaila Handattu at shandattu@uabmc.edu

LEARNING OBJECTIVES  (Friday, March 2)
Upon completion of this live activity, participants will be able to:
• Describe approaches to surveillance and anticipatory guidelines for patients with rare disease and their families
• Explain how increased understanding of pathogenesis is used to treat rare diseases
• Describe approaches to transition from pediatric to adult care for patients with rare diseases
• Explain the importance of coordination of care to improving outcomes for patients with rare diseases

CONTINUING EDUCATION  (Offered for Friday, March 2, ONLY)
CME
Children’s of Alabama designates this live activity for a maximum of 5.75 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Children’s of Alabama is accredited by the Medical Association of the State of Alabama to provide continuing medical education for physicians.

LEARNING OBJECTIVES  (Saturday, March 3)
Upon completion of this live activity, participants will be able to:
• Learn about resources in the state to help with advocacy and management of needs as patients and caregivers

BEYOND THE DIAGNOSIS ART EXHIBIT
Selected works from this traveling art exhibit, focusing on the rare disease patient, will be displayed at Children’s of Alabama from February 16 through March 16, 2018. Art has been used for thousands of years to successfully convey a message, whether it be a story or a glimpse into the human spirit. The purpose of this exhibit, presented by the Rare Disease United Foundation, is to encourage a look “beyond the diagnosis” to the patient. Two works from the exhibit are shown in this flyer.
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AGENDA

FRIDAY, MARCH 2
SCIENTIFIC FOCUS

8:00-8:30  Registration & Breakfast

8:30-9:00  Session 1: Genomic Medicine
~ Bruce Korf, MD, PhD
University of Alabama at Birmingham

8:30-9:00  Session 2: Treatment
Moderator
~ Matthew Might, PhD
University of Alabama at Birmingham

9:00-9:45  “Disruption Out of Desperation”
~ Emily Kramer-Golinkoff
Co-Founder, Emily’s Entourage, Philadelphia

9:45-10:30  “How Model Organism Studies Can Inform Clinical Approaches to Rare Disease”
~ Clement Chow, PhD
University of Utah, Salt Lake City, UT

10:30-10:45  Break

10:45-11:45  Keynote Speaker
~ Hudson Freeze, PhD
Sanford Burnham Prebys Medical Discovery Institute, La Jolla, CA

11:45-12:00  Break/Pick Up Lunch (Provided)

12:00-1:00  Session 3: Parent Panel
Moderator
~ Ashley Cannon, MS, PhD
University of Alabama at Birmingham

1:00-1:45  Session 4: Transition of Care
Moderator
~ Nathaniel Robin, MD
University of Alabama at Birmingham

1:00-1:45  “Transition of Care in Spina Bifida”
~ Betsy Hopson, MSHA
Children’s of Alabama and University of Alabama at Birmingham

1:45-2:30  “Not a Doorbell Ditch: Cystic Fibrosis and Transition of Care”
~ Brad Troxler, MD
University of Alabama at Birmingham

2:30-3:15  Session 5: Coordination of Care
Moderator
~ Anna C.E. Hurst, MD, MS
University of Alabama at Birmingham

2:30-3:15  “Care Coordination for Children with Special Needs”
~ Justin Schwartz, MD
Children’s of Alabama

3:15-3:35  “Care Coordination at Children’s: A Look at the Future”
~ Beth Clark, BSN, MBA
Children’s of Alabama

3:35-3:55  “Medicaid Health Home Overview”
Michael Battle
Alabama Care Plan

4:00  Adjournment

SATURDAY, MARCH 3
PATIENT & CAREGIVER FOCUS

8:30-9:00  Registration, Welcome
Continental Breakfast

9:00-9:15  Symposium Kick Off
“Update on the Genomic Health Initiative and Recent Scientific Symposium”
~ Bruce Korf, MD, PhD
University of Alabama at Birmingham

9:15-10:40  Main Lectures
~ Hudson Freeze, PhD
Sanford Burnham Prebys Medical Discovery Institute, La Jolla, CA
~ Scott Griffin, Founder, Hope for Gabe, and Parent Advocate
~ Swapna Kakani
Leader, Alabama Rare, and Patient Advocate

10:40-11:00  Break (Coffee, Tea and Snacks Provided)

11:00-12.00  Breakout Sessions (Session 1: 11:00-11:30; Session 2: 11:30-12:00; Choose 1 topic per session)
~ Bryan Douglas, Administrative Judge, United States Equal Employment Opportunity Commission
~ Carolyn Miller, LICSW, PIP, Health Systems Manager, Managed Care Division, Alabama Medicaid
~ Audrey Lampkin, Director, Children’s Harbor Family Center

12:00-12:50  Panel Discussion (featuring Breakout Session speakers)
Moderator
~ James Gallini, JD, Founder, The Gallini Group, LLC

12:50-1:00  Closing Remarks
~ Swapna Kakani
Leader, Alabama Rare, and Patient Advocate

1:00  Lunch Will Be Provided