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

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

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

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.
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

           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
         “Congenital Disorders of Glycosylation:
                    Overview and Focal Points”
         ~ 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

           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

           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

           “Alabama Rare 2018 Plans”
           ~ Swapna Kakani
           Leader, Alabama Rare, and Patient Advocate

9:15-10:40  Main Lectures
           “Palliative Care and Coordination of Care
           in the Rare Disease Community”
           ~ M. Garrett Hurst, MD
           Assistant Professor, UAB Center for Palliative
           and Supportive Care

           “Tools to Empower Coordinated Care”
           ~ Cristina Might, President of NGLY1.org, and Parent Advocate

           “Fighting for a Cure: Growing an Organization
           and Interacting with Researchers”
           ~ Matthew Alexander, PhD
           Assistant Professor, UAB Department of Pediatric Neurology

           “Empowering the Patient—Your Voice Matters!”
           ~ Kristin Anthony, Founder, PTEN Hamartoma Tumor
           Syndrome Foundation

           ~ 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)
           “The Americans with Disabilities Act Disability
           Discrimination and Workers with Caregiving Responsibilities”
           ~ Bryan Douglas, Administrative Judge, United States
           Equal Employment Opportunity Commission

           “Alabama Medicaid Care Coordination and Waiver
           Programs”
           ~ Carolyn Miller, LICSW, PIP, Health Systems Manager,
           Managed Care Division, Alabama Medicaid

           “Overview of Children’s Harbor Services”
           ~ Audrey Lampkin, Director, Children’s Harbor Family Center

           “Advocacy, Acceptance and Understanding:
           Navigating the School Experience in a Positive Way”
           ~ James Gallini, JD, Founder, The Gallini Group, LLC

12:00-12:50  Panel Discussion (featuring Breakout Session speakers)
           Moderator
           ~ Kelly Morris
           President, Epilepsy Foundation of Alabama,
           and Parent Advocate

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

1:30  Lunch Will Be Provided