



Telehealth & Therapeutic Advances IN RARE DISEASE CARE

Friday, March 4, 2022
12:00 – 4:30 pm

via
zoom



Register now!



Children's
of Alabama®

UAB HEERSINK
SCHOOL OF MEDICINE
The University of Alabama at Birmingham

LEARNING OBJECTIVES

Upon completion of this live activity, participants will be able to:

- Integrate telemedicine into their practice
- Relate and apply lessons learned from the COVID-19 pandemic
- Prepare and plan for progressive innovations in genomic medicine to address rare diseases

CONTINUING EDUCATION

Children's of Alabama designates this live activity for a maximum of 2.5 *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.

Questions? Contact Alli Romack at alfaun@uab.edu

Telehealth & Therapeutic Advances

IN RARE DISEASE CARE

FRIDAY, MARCH 4, 2022

AGENDA

Introduction by Bruce Korf, MD, PhD

12:00- 1:30 **TELEMEDICINE:
REMOTE HEALTH CHALLENGES**

Introduction: Nathaniel
Robin, MD, FACMG

12:00- 12:30 **Keynote: Building Virtual Models
in Genetics – the Dream Home**

~ Natasha Shur, MD

12:30- 1:00 **Telemedicine Clinic Challenges**

~ Eric Wallace, MD, FASN

1:00- 1:30 **Telemedicine Panel**

~ Moderator: Anna C. E. Hurst, MD,
MS, FACMG
~ Eric Wallace, MD, FASN
~ Nathaniel H. Robin, MD, FACMG
~ Bruce Korf, MD, PhD
~ Natasha Shur, MD
~ Asiah Borden, BS

1:30- 1:45 **Break**

1:45- 3:15 **NOVEL THERAPEUTICS**

Introduction: Matt Might, PhD

1:45- 2:15 **Antisense Oligonucleotide
Therapeutics for Rare
Neurological Diseases**

~ Frank Bennett, PhD

2:15- 2:45 **Using CRISPR to Create
Precision Animal Models
of Rare Diseases**

~ Laura Lambert, PhD

2:45- 3:15 **THERAPEUTICS PANEL**

~ Moderator: Matt Might, PhD
~ Q & A Moderator:
Emily K. Johnson, BS
~ Deeann Wallis, PhD
~ Brittany Lasseigne, PhD
~ Cameron Crowder, PhD
~ Renie Moss, BS

3:15- 3:30 **Break**

3:30- 4:30 **PATIENT AND PARENT
ADVOCATE PANEL:
FINDING YOUR VOICE
THROUGH VULNERABILITY**

~ Moderator: Swapna Kakani
~ Q & A Moderator: Brooke Thomas
~ Morgan Cheek
~ Effie Parks
~ Seth Rotberg
~ Ashley Valentine

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IN RARE DISEASE CARE

SPEAKERS/MODERATORS

Natasha Shur, MD

Geneticist, Children's National Health System, Washington, DC

Eric Wallace, MD, FASN

Associate Professor of Medicine
UAB eMedicine, Medical Director
Rare Genetic Kidney Disease Clinic\Division of Nephrology Department of Medicine

Anna C. E. Hurst, MD, MS, FACMG

Associate Professor, Medical Geneticist
UAB Medicine, Department of Genetics

Renie Moss, BS

AGHI Program Director

Nathaniel H. Robin, MD, FACMG

Medical Director, Genetics
UAB Medicine
Professor, Department of Genetics

Bruce Korf, MD, PhD

Associate Dean for Genomic Medicine,
UAB Heersink School of Medicine
Chief Genomics Officer, UAB Medicine
Wayne H. And Sara Crews Finley
Endowed Chair in Medical Genetics
University of Alabama at Birmingham

Asiah Borden, BS

Clinical Administrator
Department of Genetics, UAB

Frank Bennett, PhD

Chief Scientific Officer and Neurology
Franchise Leader
Ionis Pharmaceuticals

Laura Lambert, PhD

Assistant Professor
Co-Director of UAB Transgenic
& Genetically Engineered Models Core
Department of Genetics, UAB

Matt Might, PhD

Director, Hugh Kaul Precision
Medicine Institute
Hugh Kaul Endowed Chair
in Personalized Medicine

Emily K. Johnson, BS

Genetics Researcher, UAB

Deeann Wallis, PhD

Associate Professor, Department of Genetics

Brittany Lasseigne, PhD

Assistant Professor, Department of Cell,
Developmental and Integrative Biology
Associate Scientist, Experimental Therapeutics,
O'Neal Comprehensive Cancer Center

Camerron Crowder, PhD

Assistant Director of Education, Research
and Science Communication
Hugh Kaul Precision Medicine Institute

Swapna Kakani

Founder and Director, Alabama Rare

Brooke Thomas

Alabama Rare

Morgan Cheek

Rare Disease Parent Advocate
Author and Co-Host of Grief Sown

Effie Parks

Rare Disease Parent Advocate
Once Upon a Gene Podcast Host

Seth Rotberg

Rare Disease Patient Advocate
Co-Founder of Our Odyssey

Ashley Valentin

Rare Disease Sibling Advocate
Co-Founder of Sick Cells