

The Advisory Committee on Heritable Disorders in Newborns and Children

WEBINAR

Friday, March 22, 2019 from 10:00AM to 2:00PM Eastern

TIME	TOPIC	PRESENTER
10:00AM – 10:15AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Opening Remarks • November 2018 Minutes 	<p>Joseph Bocchini, MD Committee Chair Professor and Chairman, Department of Pediatrics, Louisiana State University</p> <p>Catharine Riley, PhD, MPH Designated Federal Official Health Resources and Services Administration</p>
10:15AM – 10:45AM	Ad-Hoc Workgroup Update: Interpreting NBS Results	Mei Baker, MD Committee Member Chair, Ad-Hoc Workgroup
10:45AM – 11:00AM	Public Comment	
11:00AM – 11:30AM	RUSP Condition Nomination and Evidence Review Process: Summary of the Expert Advisory Panel Meeting	<p>Joseph Bocchini, MD Committee Chair</p> <p>Alex R. Kemper, MD, MPH, MS Lead, Evidence-Based Reviews</p>
11:30AM – 12:00PM	Lunch	
12:00PM – 12:45PM	Analyzing the Impact of Adding Conditions to the RUSP: Drafting an Approach	Alex R. Kemper, MD, MPH, MS Lead, Evidence-Based Reviews
12:45PM – 1:55PM	Resources for Facilitating Rare Disease Research - PANEL	<p>James O’Leary, MBA Strategist/Community Builder Formerly Chief Innovation Officer, Genetic Alliance</p> <p>Tiina Urv, PhD Program Director Office of Rare Diseases Research National Center for Advancing Translational Sciences National Institutes of Health</p> <p>Vanessa Boulanger, MSc Director of Research National Organization for Rare Disorders</p>
1:55PM – 2:00PM	New Topics	Joseph Bocchini, MD
2:00PM	ADJOURN	