

## **AGENDA**

### **MEETING OF THE UTAH RARE DISEASE ADVISORY COUNCIL (RDAC)**

**Date:** Friday, November 19, 2021

**Time:** 1:00 - 3:00 PM MT

**Location:** Virtual (Zoom)

**Zoom Link:** <https://us02web.zoom.us/j/86952714161>

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- I. Call to Order (Dr. Lorenzo Botto)**
  - A. Chair's remarks
- II. Welcome and Introductions (Dr. Lorenzo Botto)**
  - A. Introductions of council members/administrators
- III. Council Appointment of Vice-Chair (Dr. Lorenzo Botto)**
- IV. Review the RDAC Statute - (Kim Hart)**
  - A. Role of Utah Department of Health and BioUtah
  - B. RDAC statute - responsibilities and deadlines
- V. Discuss, Review and Approval of By-Laws - (Kelvyn Cullimore)**
- VI. Guest Speaker: Overview of Rare Disease - (NORD Representative)**
- VII. Operational Issues - (Dr. Lorenzo Botto and Kelvyn Cullimore)**
  - A. Frequency of meetings
  - B. Website
  - C. Communication modes
  - D. Work streams (use of committees)
  - E. Non-voting members (standing and non-standing; liaison; ad hoc)
- VII. Discussion Items - (Dr. Lorenzo Botto)**
  - A. Concept of a survey
  - B. RDAC scope, priorities, mission statement and work plan
  - C. Concept of rare disease coalition
- VIII. Future Meetings (Kelvyn)**