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

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)