

State of Connecticut
GENERAL ASSEMBLY



PUBLIC HEALTH COMMITTEE
LEGISLATIVE OFFICE BUILDING, ROOM 3000
HARTFORD, CT 06106-1591
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TASK FORCE TO STUDY RARE DISEASES

MEETING AGENDA

Friday, December 8, 2017

1:00 PM IN ROOM 1C OF THE LOB

1. Convene Meeting
2. Presentations:
 - I. Barbara Pober, M.D., Staff Geneticist, Massachusetts General Hospital, and Professor of Pediatrics, Emeritus, Harvard Medical School (10-15 mins.)
 - II. Tim Boyd, Director of State Policy, NORD and Lesley Bennett, Rare Action Network (25 mins.)
 - III. John Morthanos, Patient Advocate, Website Resources (5-7 mins)
 - IV. Paul Pescatello JD, PhD, Senior Counsel and Executive Director, Connecticut Bioscience Growth Council, President/CEO, New England Biotechnology Association and Chair, We Work for Health Connecticut (10-15 mins.)
 - V. Greta Stifel, STIFLE NET CANCERS FOUNDATION, INC. (10 Mins.)
3. Other Business
 - a. Subcommittees updates
 - b. Future Meetings
 - c. Drafting of Final Report
4. Adjournment