

State of Connecticut
GENERAL ASSEMBLY



PUBLIC HEALTH COMMITTEE
LEGISLATIVE OFFICE BUILDING, ROOM 3000
HARTFORD, CT 06106-1591
TELEPHONE (860) 240-0560 FAX (860) 240-5306

TASK FORCE TO STUDY RARE DISEASES

MEETING AGENDA

Friday, September 8, 2017

1:00 PM IN ROOM 1C OF THE LOB

1. Convene Meeting (2-3 minutes)
2. Presentations:
 - I. Lynne Sherman, M.H.A., B.S.N., RN, NEA-BCM (15-20 minutes)
Director, Pediatric Specialty Centers, Yale New Haven Health (15-20 minutes)
 - II. Tracy Wodatch, RN, BSN, COS-C (15-20 minutes)
Vice President of Clinical and Regulatory Services, Connecticut Association for Healthcare at Home
 - III. Dave Marro (10-15 minutes)
President, People's Medical & Pharmacy, Respiratory Care and Medical Equipment
 - IV. Paul Pescatello JD, PhD (5-10 minutes)
Senior Counsel and Executive Director, CT Bioscience Growth Council,
President/CEO, New England Biotechnology Association, Chair, We Work for Health Connecticut
 - V. Community Advocacy (5-10 minutes)
 - a) Maryann May, Executive Director, Connecticut Hemophilia Society, Inc.
3. Rare Disease Task Force Updates
 - a. Subcommittees
 - b. Future Meetings
4. Adjournment