

**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, January 19, 2018

1:00 PM IN ROOM 1C OF THE LOB

1. Convene Meeting
2. Presentations:
  - I. Venice Francis-Churilov, Associate Vice President & Carrie Lebert, Manager, Intensive Care Management, Community Health Network of Connecticut (15-20 mins.)
  - II. David Guttchen, Director, Connecticut Long-Term Care Planning Committee, Office of Policy and Management (15-20 mins.)
  - III. Ted Doolittle, Healthcare Advocate, Office of the Healthcare Advocate (10-15 mins.)
  - IV. Emily L. Germain-Lee, M.D., Professor, Department of Pediatrics, UConn School of Medicine; Chief, Division of Pediatric Endocrinology and Diabetes, Connecticut Children's Medical Center (15-20 mins.)
  - V. Patient Advocates:
    - a) Mary Beth Bobik-Kadylak, Director of Patient Education & Support, Scleroderma Foundation, Tri-State Chapter (5 mins.)
    - b) Renee Sherrell, Board Member, Parent Advisory Committee, International Fox Foundation (5 mins.)
    - c) Holly LaPrade, Patient Advocate, International Fibrodysplasia Ossificans Progressiva Foundation (5 mins.)
    - d) Beth Fox, Parent and Volunteer Regional Parent Ambassador, Dravet Syndrome Foundation (5 mins.)
3. Adjournment