

**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, October 20, 2017

1:00 PM IN ROOM 1B OF THE LOB

1. Opening Remarks
2. Cathleen Lutz, Ph.D. (15-20 min)  
Senior Director, Mouse Repository & In Vivo Pharmacology  
Rare and Orphan Disease Center  
The Jackson Laboratory
3. Marie Egan, MD (15-20 minutes)  
Director, Cystic Fibrosis Center (Yale)  
Professor of Pediatrics (Respiratory) and of Cellular and Molecular  
Physiology;
4. David Weinstein, MD, MSc (15-20 minutes)  
Director Glycogen Storage Disease Program, CCMC  
Professor, University of Connecticut School of Medicine
5. John Hopper (10-15 minutes)  
Executive Director, Fibrolamellar Cancer Foundation  
Founding Co-Chairman, GI Cancers Alliance
6. Community Advocacy
  - a. Adrienne Hoffman, Caregiver of individual with a rare disease(5-7 minutes)
7. Closing Remarks
  - a. Next Meeting Date: 11/17/2017
    - i. Current tentative agenda:
      1. Office of Early Childhood
      2. Department of Education
      3. Department of Insurance

4. Mustafa Khokha, MD Associate Professor of Pediatrics and of Genetics

b. Subcommittees (Review questions, interim phone call prior to 11/17/2017 meeting?)