

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

Wednesday, October 10, 2018

1:00 PM IN ROOM 1D OF THE LOB

1. Convene Meeting
2. Presentations:
 - I. Colleen Brunetti
 - II. Jean Kelley, Director, Brian's Hope
 - III. Dr. Myrna E. Watanabe, Harwinton, CT: Caregiver
 - IV. Kristen Angell, Associate Director of Advocacy, NORD
 - V. Erica Munn, DNP, RN
 - VI. Les Friedman, President, Mikey's Way Foundation and Mikey's Dad
 - VII. Philip Marella, Trustee, Dana's Angels Research Trust
 - VIII. David Gilford, Dup 15q Alliance Board Member and Grandfather of one of our Duppers
 - IX. Jennifer M. Iannuzzi, MSW, LCSW and Co-Founder/VP, SMS Research Foundation
3. Public Comments
4. Announcements:
 - a. Next Meeting: November 14, 2018 at 1:00pm in Room 1B of the LOB
5. Adjournment