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

Agenda

Thursday, April 27, 2017

1:00 P.M in Room 1C of the LOB

- 1. Convene Meeting
- 2. General Announcements
 - a. Minutes (Revised from 2/2017 and 3/2017 meeting)
 - b. List of Rare Disease Patient Organizations in CT
 - c. Medicaid Waiver Information Available (Kathy Bruni from DSS—invited for upcoming meeting)
 - d. Future meetings
 - *Please fill out availability dates/times for future meeting
- 3. Newborn Screening
 - a. DPH Presentation: Adrienne Manning, Director of Newborn Screening Karin Davis form the Department's Birth Defects Program
 - b. Comments/Questions from the Task Force
- 4. Public Comments
- Closing Meeting

 Tentative Next Date: May 25, 1pm
 - b. Suggested future topics/speakers