

State of Connecticut  
GENERAL ASSEMBLY



PUBLIC HEALTH COMMITTEE  
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**Task Force to Study Rare Diseases**

Meeting Summary

December 8, 2017

Dr. Gulati convened the meeting at 1:15 pm with introductions of the Task Force members and the presentations.

Members Present: Dr. Tucker, Dr. Pober, Dr. Sherman, Dr. Gulati, Nancy Dupont, John Morthanos, Michelle Cotton, Dr. Spencer Manzon, Lesley Bennett, Paul Pescatello.

Others Present: Tim Boyd and Greta Stifel.

Tim Boyd, Director of State Policy for NORD Presented.



Boyd CT RD Task  
Force 12.8.pdf

Dr. Pober asked about NORD's funding sources.

Tim Boyd stated NORD receives grant funding from private and public donors, and that the company uses traditional fundraisers. He further stated that he works on the policy side and due to company policy he is not allowed to be involved in funding.

Dr. Pober asked if NORD receives state or federal funding.

Tim Boyd stated that NORD does not receive state or federal funding with the lone exception of an FDA grant.

Dr. Gulati asked what associations NORD works with in CT and has NORD offered any research grants to CT institutions or their affiliated associations.

Lesley Bennett stated that there are roughly 5 NORD members however NORD works with many other small and non-profit groups totaling about 70 associations.

Tim Boyd added that NORD works with many local chapters of national organizations as well.

Lesley Bennett of Rare Action Network presented.



Rare Disease Task  
Force\_\_Kelly\_Undiagr

Dr. Gulati asked how effective and geographically diverse is Rare Action Network's outreach programs.

Lesley Bennett stated that she has spent the last two years reaching out to various groups all over the state and the region. She further added that NORD seeks to work with as many different groups within the rare disease community as possible.

Dr. Gulati asked that Tim Boyd expand on the out of the pocket cost.

Tim Boyd stated that many rare disease meds and treatments are incredibly expensive as they are often in the highest tier which means cost sharing of up to 40%. He further states that NORD had suggested in the place that insurance companies be mandated to charge no more than \$200 per drug per month in out of pocket cost for patients. Additionally he stated the NORD is proposing a new cost sharing model where a subset 40% for example of plans has to have a copayment only model for drugs.

Dr. Barbra Pober, Staff Geneticist, Mass General Hospital presented.



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Lesley Bennett asked if Dr. Pober looked at the Children's National Model where they have opened a lifespan clinic.

Dr. Pober stated that she has not reviewed that model because nothing has been published on it yet. She further stated that she will review it going forward.

Lynne Sherman asked if the quality of care and the fact patients with rare diseases are living longer is the reason why there has been an influx of adults in need of care.

Dr. Pober stated the increase in the quality of care and the access to it has certainly increased the life span of patients with rare diseases.

John Morthanos presented on website resources.