

New Hampshire Governor's Rare Disease Advisory Council  
Minutes 8/21/20  
Prepared by Laura Landerman-Garber, Ph.D.

-Chairman, Representative William Marsh read NH State Guidelines for official NH meetings during the COVID 19 Pandemic, including the parameters for meetings held via tele-technology

-Attendance: Present-Chairman Representative William Marsh, Representative Richard Osborne, Senator Cindy Rosenwald, , Dr. Sai Cherala, Dr. Elijah Stommel, Dr. Mary Beth Dinulos, Dr. Angela SHepard, Dr. Laura Landerman-Garber, Ms. Krista Gilbert. Guests- Dr. Kimberly Phillips, Ms. ELizabeth Shannon, Ms. Heather Dainiak.

-Minutes from Meeting (17 July 2020) were reviewed and accepted.

-The news of Advisory Council Member Mr. Bob Stoker's death was shared, evoking sorrow at the passing of an inspirational leader on local, regional, and national levels. Mr. Stoker opened doors for so many to become educated about and involved in the Rare Disease Community. A letter was sent to his family on behalf of the Council. Mr. Stoker will be sorely missed by all.

## UPDATES

-Databases/Registry:

Drs. Stommel and Shepard collaboration on a pilot program possibility for a registry for Rare Diseases.

Dr. Stommel reported back about a CDC meeting with the topic being a possible mandatory ALS registry. Discussion addressed funding challenges and the possible option to include other diseases in the registry.

Drs. Stommel and Cherala collaboration on an environmental public health tracking , possibly using hospital data. Question raised if we could use the data for a pilot program for ALS registry. To further explore with Dr. Katie Bush regarding an Environmental Tracking PProgram for Neurodegenerative Diseases.

Chairman Marsh reminded Drs. Stommel and Cherala of upcoming filing deadlines but Dr Cherala clarified that it is all at the pilot program stage at this point.

Dr. Stommel is currently writing a grant to look at the Massachusetts population . The Massachusetts Registry is not complete but they do have one of the few mandatory ALS registries. These registries may eventually provide data of both genetic and environmental factors.

-Legislation:

Bills for next year are being considered and Representatives Marsh and Osborne and Senator Rosenwald are point contacts for related questions and discussion.

-Dr. Shepard:

Pharmaceutical “step” challenges for Rare Diseases. Question of whether there will be an elimination of using a series of lower cost medications prior to getting the ones that are actually needed and originally recommended. Additionally, the question of medical foods was raised in terms of availability and coverage.

-Ms. Gilbert:

Discussion was had regarding Direct Service Professional and related certification challenges. There are significant issues with education and retention for caregivers. A Certification program would be very helpful and would give them more credibility to be seen as a member of the healthcare team. Currently there are no minimum requirements for these jobs.

Dr. Phillips reported that at UNH, there has been a grant to develop such a certification program and will update us at the next meeting. Ms. Gilbert reported that she was under the impression that this above mentioned grant at UNH did not come to fruition.

Dr. Shepard raised the question whether a HS level of training would be sufficient.

Dr. Cherala raised the question as to whether the Technical College System or an equivalent on-line program would be sufficient. Ms. Gilbert, who sits on a Task Force, reports that all of these options are being considered.

-Youth Sudden Death COMmittee:

Dr. Dinulos reported that the Committee activities are currently on hold and there was nothing new to review.

-Telehealth

Dr. Dinulos addressed telehealth and the scope of practice issues such as reciprocity, fee reimbursement and whether those current flexibility and allowances will be time limited. She also raised the point that online access to telehealth is good for long distance patients vs those who do not have internet access.

Chairman Marsh reviewed current telehealth in NH and is willing to provide copies if the Bill to Council Members for review.

Dr. Cherala offered some clarifications re: the Telehealth Bill

-Ms. Gilbert Rare Disease Survey:

Ms. Gilbert provided each Council Member with results of the Survey, including the Survey topics of: Access to providers, experiences with diagnosis, transportation accessibility, RX and treatment accessibility, in-home support accessibility, NH legislation, and rare disease quality of life.

Results included:

- Difficulty getting access to providers and resources
- Need more networks and education in NH
- Need for MH resources
- Genetic Disorder got quicker dx
- Need for more communication overall
- Need for more collaboration with insurance companies
- Need for increased knowledge about rare disease resources
- Need for more transportation accessibility
- Need for enhanced coverage both in- and out- of- network
- Need for lists of providers that specifically treat rare diseases
- Need for more medication coverage
- Need for enhanced coverage and accessibility for therapy equipment

Need for enhanced coverage and accessibility for specialty pharmacy issues

Dr. Landerman -Garber shared specialty pharmacy experiences, concurring with need for improvement in NH

Guest Ms. SHannon spoke of the distinct challenges overall of obtaining medications for rare disease patients

REpresentative Osborne spoke to the challenges from a PCP/MD perspective of obtaining medications for patients with rare diseases.

Ms. Gilbert discussed the need for support of US Senator Maggie Hassan Federal Bill, the Role of Direct Support Act

-Newborn Screening Dr Cherala:

August 1, 2020 launch plan was delayed due to staffing freeze secondary to COVID-19.

August 26,2020 Screenings expected to begin and Dr. Cherala will update us at the next COUncil meeting.

-Guests:

Ms. Daniak. She shared with us the FOUndation that she founded with her Family to honor the memory of their son, Nicholas. He had Battons Disease. The Foundation, Our Promise to Nicholas, has a goal of completing research to find a treatment and ultimately, a cure for this rare disease. To date, they have held five conferences. Unfortunately, COVID-19 has led to a shut down of the labs that were in the midst of studies on Battons Disease.

Dr. Phillips does genetics research NERGEN which provides education for providers and families, connections to genetics providers for families, and telehealth in genetics health care systems.

-New Business:

Dr. Landerman-Garber addressed the current USPS challenges on political and financial levels and the related impact on the Rare Disease Community, especially those issues related to medications received through the USPS.

-Next Meeting date is September 18, 2020 at 3:00 PM via tele- technology. An invitation will be sent out to Council Members and guests and notification/announcement about the meeting date and time will be posted per NH State Guidelines.

-Chairman Marsh will extend invitations to Mr Tyler Brennan and Dr. Margaret Clifford to attend the meeting to discuss issues related to insurance and pharmaceutical needs of the rare disease community

-The Meeting was adjourned without objection

Meeting Minutes respectfully submitted by Laura Landerman-Garber  
September 10, 2020

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