

New Hampshire Governor's Rare Disease Advisory Council  
Meeting Minutes 11/19/21  
Prepared by Laura Landerman-Garber Ph.D.

NOTE: Dr. Landerman-Garber attended the meeting via Zoom and had some connection difficulties which will be reflected/noted in the body of these minutes.

—The meeting was held as an in-person meeting with a Zoom option for those Council Members and guests who were not able nor comfortable with meeting in person secondary to COVID-19. Chairman Marsh clarified to the attendees that because there was not a quorum present, that there would not be any voting throughout the course of the meeting

—Attendance:

Present - Chairman Representative William Marsh, Co-chair Representative Gary Woods, Dr. Sai Cherala, Dr. Elijah Stommel, Dr. Mary Beth Dinulos, Dr. Laura Landerman-Garber, Dr. Angela Shepard, Ms. Paula Minnehan, Ms. Abby Rogers, Ms. Audrey Gerkin, and Ms. Tracy Williams.

Absent - Senator Cindy Rosenwald, Ms. Krista Gilbert, and Ms. Libby Shannon

—Corrections to the Minutes:

Co-chair Representative Woods noted that HB602 was sent for interim study and not retained

Chairman Representative Marsh noted the correction and will update the minutes.

—ALS Database:

Dr. Stommel is in communication with an attorney who works with Congress and is hopeful for a Bill to pass that will create a National ALS Registry. This would in turn allow States to implement in each individual State.

Chairman Representative Marsh received getting the Bill # and that perhaps the Council could write a letter to the NH DC Delegation in support of the Bill.

Co-chair Representative Woods: UNABLE TO HEAR THE CONTENT

—Youth Sudden Death Committee:

Dr. Dinulos reported that the Committee met in mid November, discussing Program updates with hopes for an increased budget for genetic testing and additional testing for children.

Dr. Cherala noted that there is a request for \$50,000 for such testing 2023-2024. There was a question of where the funds go; the answer is to the Medical Examiner's Office.

Dr. Dinulos reported that in the meeting, they discussed two sudden deaths of teens and 5-6 infant deaths and the possible reasons for their deaths. Testing would be very informative for all child/teen deaths.

Co-chair Representative Woods referred the Council to the November 11 issue of the NE Journal of Medicine.

#### —Newborn Screening

Dr. Cherala noted that Medicaid is paying for some of the NB screening and that she and her Team are developing guidelines.

Note: further discussion by Dr. Cherala was not able to be recorded here due to connection difficulties

#### —Community Outreach:

-Ms Gerkin (Guest) reported that she signed a year contract in needs assessment to help families with issues related to chronic youth medical conditions

-Ms. Gilbert relayed through an email, an update regarding DSP:

“ The workforce shortage continues, Many individuals continue to go without services, this includes individual direct support professionals and LNA support for in-home and community care. Day programs have closed due to lack of staff. Family members have quit their jobs to stay home and to care for loved ones. Area agency staff supervisors and managers report providing direct care due to the lack of direct care staff. Family members are being hired as DSPs ( and living in poverty due to low wages) or providing 24 hour care with no pay and no respite. Family members are having to leave people with disabilities in emergency rooms and reporting that they can no longer care for them at home. We spoke last month about the BDS system redesign The update from the subcommittees relative to DSP workforce is that BDS is considering a DSP credentialing requirement in NH, They are currently gathering information from neighboring States about their credentialing requirements and curriculum. Many groups in NH have already done this work and have recommendations. I wanted to provide some links for your review of operations and programs. The link for the report is here:  
<https://www.dhhs.nh.gov/operations/documents/dhhs-operations-assessment:phase-1a-report.pdf>

A link from BDS about the system or is here: <https://www.dhhs.nh.gov/dcbcs/bds/systems.htm>.

The waiver design and steering committees meet monthly. The meetings are open to the public. The NH Council on Developmental Disabilities continues to work on the DSP workforce issue.”

Dr. Shepard expressed concern about funding and a possible push for inpatient vs at-home care.

Chairman Representative Marsh discussed the HHS Oversight Committee meeting. October 22, the HHS Commission issued/contracted for nationwide recruiting including DBS and incentive bonuses.

Dr. Cherala: Her report was not recorded here due to connection difficulties. There was some ability to hear her discuss "AHEC, Northern NH, Community Health Worker Training".

Dr Shepard supports the need for Training especially in northern NH as they have less resources.

-Dr. Shepard briefly discussed educational initiatives. She continues to work on related issues in coordination with the efforts of the Newborn Screening Committee.

-Ms Williams (Guest) discussed the topic of Medical Foods and expressed gratitude to the Council to work on these and related issues for those with Rare Diseases. She related that she has a family member (age 41) whose medical care from Mass General is covered but that his Care Team has recommended a special medical food. She is trying to get NH Medicaid to help with this from a financial perspective and is looking for guidance from the Council to guide her and her family through this challenge.

Dr Shepard offered to connect with her offline and acknowledged the difficulty here in NH, Medical foods are too often seen as less medically necessary as traditional medicines.

Dr Dinulos reported that this is a nationwide issue/problem, with the focus too often on tube feeding vs oral feeding of medical foods. The American College of Genetics is looking to advocate for Rare Disease nutritional needs.

Dr. Landerman-Garber discussed the possibilities of contacting pharmaceutical companies directly for financial assistance.

Chairman Representative Marsh suggested that the Council keep this issue on the agenda for review.

—Rare Disease Day 2022:

Dr. Shepard would like to collaborate with hospitals across NH and Governor Sununu for an official Proclamation. She discussed that Rare Disease Day events for 2022 might once again

need to be virtually delivered to the NH Community. She noted that it has gained more of a national platform of support.

Dr. Landerman- Garber will be meeting with Governor Sununu on a separate matter in early December and will work with his Staff how to obtain the Proclamation for NH Rare Disease Day,

Ms. Minnehan of the NH Hospital Association offered to help with PR for 2022 Rare Disease Day.

Chairman Representative Marsh suggests that we revisit Rare Disease Day 2022 during our January meeting as Rare Disease Day is 2/28/22.

—The Council agreed to not hold a meeting in December secondary to the complexities of scheduling during the busy Holiday Season. Our next meeting is scheduled for the third Friday in January 2022 at 3 PM.

—The meeting was adjourned without objections

—Meeting minutes respectfully submitted by Laura Landerman-Garber Ph.D. January 4, 2022.