New Hampshire Governor's Rare Disease Advisory Council
Meeting Minutes 2/18/22
Prepared by Laura Landerman-Garber Ph.D.

—The meeting was held as an in-person meeting with a Zoom option for those Council Members and guests who were not able or not comfortable with meeting secondary to COVID-19. Chairman Marsh clarified to the attendees that because there was not a quorum present, that there would not be any official voting throughout the course of the meeting.

—Attendance:

Present: Chairman Representative William Marsh, Co-chairs Representative Gary WOod and Dr. Mary Beth Dinulos, Senator Cindy Rosenwald, Dr. Sai Cherala , Dr. Laura Landerman-Garber, Dr ELijah Stommel, Dr. Angela Shepard, Ms Krista Gilbert, Ms Paula Minnehan, Ms Audrey Gerkin, Ms Courtney Tapper
Absent: Ms Libby SHannon, Dr Lefleur

—Minutes:

No corrections nor addendums were offered for the minutes. Dr. Landerman-Garber is available to complete any sections of previous meeting minutes that were incomplete secondary to Zoom audio difficulties.

—Announcements re: Vacancies

Dr. Cherala is stepping down as Bureau Chief as of 3/3/22 and is beginning a new position at Massachusetts Department of Public Health. A new Council member will be replacing her position in the coming months. Unanimous support was offered to Dr Cherala for her next chapter and great appreciation was voiced by all Council Members for her work on the Advisory Council

Pending vacancies include Chairman Marsh and Co-chair Woods. Representative Woods will not be seeking reelection for his House Seat in the Fall of 2022 and Chairman Marsh will be seeking a Senate seat in his DIstrict.

The NH Speaker of the House will appoint two new House Members to the Council after the Fall elections.

Dr. Mary Beth Dinulos, in her role as current Co-chair will aid with the transition period.

Council Members offered unanimous gratitude and support for Representatives Marsh and Woods.

—Rare Disease Day

Governor Sununu signed an official Proclamation, naming 2/28/22 NH Rare Disease Day. Dr. Laura Landerman-Garber was invited to the State House to pick up the Proclamation and sent scanned copies to all Council Members.

Dr. Landerman-Garber contacted WMUR for possible coverage of RD Day with Dr Shepard as the contact person for an interview. WMUR Staff were interested in doing so but noted that availability would depend on news coverage during that time period.

Governor Sununu recorded a video for RD Day and his office staff will be sending it to Dr Landerman-Garber in a few days. It will be forwarded, along with a video introduction recorded by Dr. Landerman-Garber, to Dr Shepard to incorporate it into RD Day virtual activities.

Dr. Shepard in conjunction with several Council Members and NH RD community members have recorded videos to present for RD Day.

Dr. Shepard will facilitate RD Day virtual activities through Facebook on the NH Rare Disease Association Page. She will email Council Members an invite to share with others

Ms. Shannon has arranged for the Wolfeboro Public Library to light up the facility in recognition of RD Day.

—ALS Registry

Dr. Stommel reported that he testified before the Vermont Legislature Health and Welfare Committee. It went well, per his report, with the Committee appearing receptive for an ALS Registry in VT. He also noted that a representative from the CDC was present and was supportive. Additionally, he has been asked to testify in Maine. He is hopeful that VT and Maine will become the 2nd and 3rd States to have a Mandatory ALS Registry and that NH may be more likely to follow suit if neighboring States do so.

Chairman Marsh noted that he plans to keep this topic on the agenda.

Although Dr. Stommel is hopeful that Parkinson's and Alzheimer's Diseases would also be included in the registries, it may be more complicated as there are not yet distinct diagnostic tests, leaving it a more costly endeavor.

Dr Stommel also noted that he is often asked how such a registry would help patients and their families, especially if they live in more remote rural areas.

—Legislation:

Chairman Marsh discussed the efforts to keep our Council meetings remote secondary to COVID-19 . Although it was not approved, it can still be debated in committee. Co-Chair Woods discussed the possibility of having the quorum number reduced which would allow us to vote on items in the meetings while maintaining a hybrid style meeting attendance. Dr Cherala raised the question of whether we could continue the hybrid meetings with no physical quorum needed and Senator Rosenwald raised the possibility of whether we could be a quorum adaptation for the more critical discussion items. Chairman Marsh will revisit the option to lower the quorum for hybrid meetings and Senator Rosenwald discussed the possibilities of attaching this issue to another BIII in the Senate.

Chairman Marsh, Senator Rosenwald, and Ms. Minnehan will meet offline and report back to the Council at the next meeting.

—Youth Sudden Death Committee:

Dr. Dinulos stated that they have not met since our last Meeting but that she did meet with the NH Medical Examiner for a productive discussion on 1/31/22. Her

senior genetic counselors prepared a draft for the ME of scenarios in which they could be of assistance. It was well received. DHMC remains available to the NH ME for review of youth sudden death cases.

Dr. Dinulos also noted that she has had the pleasure to discuss RD related issues with the Utah RD Advisory Council.

—Newborn Screening:

Dr Cherala reported no new updates.

—Community Outreach:

Other than current focus on RD Day, our more formal plans for Community Outreach have been significantly interrupted by COVID-19

—Direct Service Providers:

Chairman Marsh and Senator Rosenwald plan to speak with the Chair of HHS. Ms. Gilbert reported that the Chair of HHS hopes to have the issues related to DSP and RD on the next meeting agenda.

Ms. GIlbert provided notes regarding her presentation to the Council. Please refer to the addendum.

—Education:

Dr Shepard will attempt to connect with the Newborn Screening Committee again for educational outreach opportunities and partnership

Drs. Shepard and DInulos will connect offline regarding related issues, including DHMC involvement and report back to the Council .

—Medical Foods:

Dr Shepard spoke with Ms Tracey Williams offline. There is a possiblity for legislation to mandate insurance coverage for medical nutrition.

Chairman Marsh and Senator Rosenwald discussed the urgency to work on it at the present time for next year's agenda and to explore which Legislative Committees may be appropriate for outreach and discussion

Dr Cherala suggested to contact Mr Henry Litman, Medicaid Director, to address "clear need" as well as the need to address this for the next Budget review. She raised the question of whether this needs a legislative action or is this more of a "simple fix".

—New Business:

Brief discussion about utilizing the NH Rare Disease Association Facebook Page to share additional educational, support, and advocacy opportunities. Dr Landerman-Garber discussed her willingness to share such opportunities that she has available to her through the Auto-Inflammatory Diseases (international) and Familial Mediterranean Fever Facebook pages, for example, with Dr Shepard. Dr Shepard does a wonderful job at providing opportunities for the RD community on FB.

—The Council agreed to meet on March 18, 2022 at the regularly scheduled time

—The meeting was adjourned without objections

Meeting minutes respectfully submitted by Laura Landerman-Garber on 3/6/22.

New Hampshire Department of Health and Human Services (DHHS) engaged Alvarez & Marsal (A&M) to conduct a strategic assessment of DHHS operations to (1) quantify the impact of the COVID-19 pandemic, (2) identify programmatic improvements to increase operational efficiency, and (3) improve the delivery of services during and after the public health emergency (PHE).

The Alvarez and Marsal Report (the A&M report) made the following recommendations for the DD system:

1. Conduct a 1915(c) waiver redesign by implementing tiered waivers
2. Develop tiered reimbursement rates to better align payment with level of need
3. Establish a comprehensive IT system to better manage, report, and utilize data in strategic decision-making
4. Reduce the available funding for waitlist participants "to more closely align allocated funding with trends in spending"
5. Develop an in-state network of private service providers with increased capacity for supporting individuals with intensive residential support needs

Individuals and families receiving services through the home and community based supports waiver continue to have questions and concerns that have gone unanswered.

1. Although workgroups and a steering committee have been established, there are concerns that stakeholder input will have little impact on the decisions made by BDS
2. There are no people with developmental disabilities on any of the workgroups or the steering committee.
3. We do not feel that a tiered waiver system will best meet the needs of the residents of NH.
4. We believe there is a bias in the two waiver system toward residential care.
5. The current plan to develop tiered reimbursement rates is flawed. It is based on the idea of completing an assessment of the individual that is largely deficit based operating on the medical model and then extrapolating needs to build a budget. This type of assessment cannot capture a true picture of an individual's true level of function, environmental supports and other things that must be considered when building a program that will meet someone's needs.
6. There is concern that the availability of services will be decreased. There have been discussions of A & M reviewers finding "individuals who didn't really need services", decreasing service options, and capping budgets.
7. It is not clear why outside evaluators were contracted to complete assessments for the sample data that BDS desires when CSNI has SIS evaluators available.

I've included some links below so that you can review the information. The first few links are the A&M report and their powerpoints. There is also a link to the BDS Systems Work Page. At

the bottom of that page you will find all of the committee meeting minutes and powerpoints. There are also recordings of the meetings. I feel that the minutes are a polished representation of the meetings. The last link is the proposed timeline. Though it says not for distribution it is posted on the website.

NH DHHS Operations Assessment Alvarez & Marsal Assessment November 2020 Phase 1A
https://www.dhhs.nh.gov/ocom/documents/dhhs-operations-assessment-phase-1a-report.pdf

NH DHHS Operations Assessment Alvarez & Marsal November 2020 Phase 1A powerpoint

https://www.dhhs.nh.gov/ocom/documents/dhhs-operations-assessment-phase-1a-present.pdf

NH DHHS Operations Assessment Alvarez & Marsal January 2021 Phase 1B Powerpoint

https://www.dhhs.nh.gov/ocom/documents/dhhs-operations-assessment-phase-1b-present.pdf

BDS system work waiver redesign

https://www.dhhs.nh.gov/dcbcs/bds/systems.htm

BDS systems work timeline

https://www.dhhs.nh.gov/dcbcs/bds/documents/bdssystemwrk122021timeline.pdf