

New Hampshire Governor's Rare Disease Advisory Council  
Meeting Minutes 5/20/22  
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 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 official voting throughout the course of the meeting.

—Attendance:

Present: Chairman Representative Willam Marsh, Co-Vice Chairman Representative Gary Woods, Co-Vice Chairperson Mary Beth Dinulos, Ms Elizabeth Shannon, Dr. Laura Landerman-Garber, Dr. Angela Shepard , Dr. Elijah Stommel, Ms. Krista Gilbert, Dr. Lafleur, Ms Courtney Keane, Mr Nedge Pierre Louis, Ms. Guadelupe Hayley's-Mota, Ms. ALi Mahady, Ms. Paula Minnehan, Ms Audrey Gerkin, Ms Lana Joseph, Ms Tracy Williams, Representative Jim Maggiore.  
Absent: Senator Cindy Rosenwald

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

—Ms Shannon invited members from the MA RDAC in order to enhance inter-State support and to collaborate on available resources.

Ms Shannon and Chairman Marsh are closely following the Telehealth Bill and the Physician Licensure Contracts, both introduced during COVID 19.

Guests from the MA. RDAC noted that they are eager to collaborate and utilize resources. They will discuss both the Telehealth and Physician Licensure Contracts with their Members at their next meeting.

Ms. Williams reiterated her concerns and frustrations of having to take her Brother to MA, to do telehealth with his MA. Providers.

Dr. Shepard noted that being able to engage in cross-State line Telehealth and to have Providers maintain/retain their Lic Contracts would be more efficacious and easier for all involved both providers and patients. She also noted that there is an insurance reimbursement problem and that those issues vary per State. She opined that a Federal Legislative change would make it easier for everyone across the Country.

Co-Chair Woods discussed his concern about liability issues and a possible need for nationalized licensing

Dr Landerman-Garber discussed her concerns for psychotherapy patients as well, noting that MH services in regard to Licenses across State borders also have impacted treatment accessibility for patients

Ms. Williams expressed grave concern and frustration that the guidelines vary and wants to work on solution based activities.

Chairman Marsh highlighted a 6/27/22 meeting of the Telehealth Commission, inviting others to attend.

—Medical Food

Representative Maggiore expressed pleasure being present at the Meeting and is interested in helping.

Ms. Williams reported that she and Dr. Shepard met several times re: reimbursement for medical food. It is not usually nor easily reimbursed. It has been very challenging for her Brother to get coverage for his medical food, stating that the Federal Medical Food Act in Congress has been met with resistance. She has been pleased with the support from NORD and has asked for assistance with this issue for the NH Legislative process.

Dr. Shepard noted that there are separate laws for private insurance and Medicaid. Chairman Marsh added that Medical Food is covered for Pediatric Medicaid but not for Adult Medicaid.

Chairman Marsh wants to bring this to the Legislative level and Representative Maggiore opined that it would likely be supported. He posited that drafting the

language of a Bill that would likely pass would be important during planning process.

Ms Williams recommended reviewing the PA. Legislation and to customize it to fit NH needs. Dr. Shepard noted that the Nutritional Food Laws vary State to State, recommending to select ones that are most compatible to NH and to be very specific in language when composing any document. Representative Maggiore was in agreement with that and hopes to do so in a timely fashion so that NH Committees can review in September.

Chairman Marsh and Dr Shepard hope to eventually have a quorum in order to adopt an official support from the NH RDAC for such a Bill.

—ALS Database:

Dr. Stommel reviewed his work with the Council Members and guests. He reported that Maine passed the Bill to support a registry and that VT is likely to follow soon. He did note that NH has not yet done so. He also related to the Council that there is a National Registry but that it is voluntary.

Chairman Marsh recommended that it be filed in the Fall in NH.

Ms Keane inquired as to who would “own” the Registry. Co-Chair Woods said that is a concern for the NH Legislature and recommended that he and Dr Stommel meet to consult who would be best to connect in the Legislature and who might be the best person/group to sponsor the Bill for an ALS registry in NH. Chairman Marsh and Co-Chair Woods would consult in this regard and connect with Dr Stommel in the coming months.

—Youth Sudden Death:

Co-Chair Dinulos reported that there had not been a recent meeting to review although the issue of testing for all YSD cases without a clear reason for the death remains in discussion.

—Newborn Screening:

Ms Keane did not have anything to report to the Council at this time and will follow up at our next meeting.

—Community Outreach:

Ms. Gerkin noted that there is an event on June 23. She also noted that there will Children Champion Awards given to children and youth who contribute to our communities here in NH. Additionally, there will be an exhibit of Children/Youth with Chronic conditions with photos and their accompanying stories.

Ms Shannon reminded the Council of the national NORD event that is upcoming and invited all to attend.

—Direct Service Providers:

Chairman Marsh said that NH was out of compliance and legislation did not result in a way most desired. HHS Oversight will need to work on more legislation.

Dr Shepard raised the question of how can our Council support a joint venture with our NH Community Colleges for job training and job creation. She also asked Council Members to aid with the operationalization of such planning.

—Education:

A brief discussion transpired with Drs Shepard and Dinulos and Ms Keane about the need for increased education regarding newborn screening and for genetic counselors. This issue is to be discussed further at upcoming Council Meetings.

—The Council agreed to meet on August 20, 2022 at the regularly scheduled time.

-The Meeting was adjourned without objections.

Meeting minutes respectfully submitted by Laura Landerman-Garber Ph.D on 7/10/22.

