

New Hampshire Governor's Rare Disease Advisory Council  
Meeting Minutes 8/19/22  
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. He also noted that we have approximately nine meeting minutes that we have been unable to vote to approve due to a lack of a quorum.

—Attendance:

Present: Chairman Representative William Marsh, Co-Vice-Chairman Representative Gary Woods, Ms Courtney Keane, Ms Krista Gllbert, Ms Tracy Williams, Representative Booras, Representative Paul Berck, Representative Jim Maggiore, Dr. Laura Landerman-Garber, Ms Courtney Tanner, Senator Cindy Rosenwald, Dr Elijah Stommel.

Absent: Dr Angela Shepard, Ms. Elizabeth Shannon, Dr Mary. Beth Dinulos, Dr Richard Lefleur.

—No addendums nor corrections were offered for the minutes from our last meeting.

—Annual Report:

Chairman Marsh requested that Council Members send him any items to include in the Report by our next meeting. He also noted that if we do not have a quorum at our next meeting, he will sign off on the annual report at the appropriate time as Chairman of the Council.

Ms. Willaims asked if the public can submit an item for the annual report as she has been involved in our discussions on medical food, particularly for individuals who have PKU.

—Legislation:

-Rep. Maggiore expressed appreciation for attending the meeting and feeling humbled by the challenges that impact the RD communities, PKU in particular. In terms of medical food/formulas, he reported that there is an \$1800 per year cap vs what he opined should be an \$1800 per month allowance. His research revealed three PKU cases in NH whose cases should be easily covered. He is interested in presenting legislation to help people with these and other RD conditions.

Ms. Williams whose brother has PKU has \$50,000 coverage through Medicare but not that type of coverage for his medical food.

Ms Gllbert offered to help through NORD and NHRDA to work on these related issues of coverage for medical foods and will connect with Dr. Shepard as well to address these issues.

Chairman Marsh and Senator Rosenwald discussed current legislation in re: to medical food. Private insurance vs Medicaid coverage to be further discussed. Ms Williams opined that all should be covered whether through commercial/private insurance or through Medicaid.

Co-Vice-Chair Woods raised the question of what subsequent medical complications could occur if PKU is not sufficiently treated.

Ms. Gllbert raised concerns about the language of the proposed legislation as to whether it would limit this coverage only for individuals with PKU or for others in the RD community. Both CO-Vice-Chair Woods and Rep. Maggiore noted that the language at the current time is narrow.

Chairman Marsh inquired whether NHRDA and/or NORD would know if there are other diseases in this realm of legislation proposals. He also recommended that the above noted individuals, both Council members and guests, work together offline and report back at the next meeting.

-Ms. Gllbert discussed Senate Bill 430 which would provide money for family caregivers who are caring for a family member. This Bill will not be moved t this time and the language of the Bill leaves family caregivers at risk for no longer being paid for these services.

Senator Rosenwald noted that this issue may have been added to another Bill but that it addresses only personal care attendants.

Ms. Gilbert would like to keep this discussion on the agenda as does Chairman Marsh given the significant impact this could have on families in the RD community in NH. Ms. Gilbert and Senator Rosenwald will connect offline and report back to the Council at the next meeting.

-Chairman Marsh noted that he would be in favor of the Remote Meeting Bill to be refiled. One impact on the Council includes not being able to engage in voting nor approving minutes.

—ALS Registry/Data Base:

Dr Stommel met with Ms. Keane to strategize for NH ALS Registry with a need to provide feasibility. MA and VT are both providing that information to their Legislatures which could ultimately help here in NH. He is hoping to aid with MA and VT setting up their registries.

Chairman Marsh inquired as to whether Dr. Stommel is working directly with Senators/Representatives in those States.

Co-Vice-Chair Woods inquired as to whether we here in NH want to wait to see how VT and MA do with Dr Stommel replying in the affirmative.

Chairman Marsh recommended contacting Representative Murphy to aid with the process here in NH and Dr Stommel replied in the affirmative with plans to do that.

Ms Keane is currently still examining the costs of developing and consequent implementation of an ALS Registry here in NH

—Youth Sudden Death:

Per note, Co-Vice-Chair Dinulos reported that the Committee will meet next month

—Newborn Screening:

Ms. Keane noted that Disease NPS-2 will potentially be added to the list of Newborn Screenings in NH.

—Community Outreach:

It is agreed amongst Council Members that COVID-19 has profoundly impacted our abilities to engage in face-to-face community outreach, We had planned, prior to the outbreak of COVID-19, to hold outreach community meetings throughout the State to address the RD community questions/needs.

As it is a part of our charge as a Council to enhance awareness and increase education of RD in NH, we will continue to address possible opportunities to do so and plan for them in the future.

We discussed again the possibility of increasing our presence on social media.

—Dr. Shepard:

Per note, Dr Shepard announced that the NHRDA in conjunction with the NH Chiropractic Association will be holding a workshop. She also noted that she is working on the issue to increase coverage of medical foods.

—Ms Gherkin:

The Youth With Chronic Conditions has a new website. Additionally, they will providing educational support for medical foods and proposed legislation

—Ms. Gilbert:

Re: Direct Service providers. Awaiting a summary of Ms. Gllbert's discussion/report.

Chairman Marsh will keep this issue on the Council's agenda.

—Education-Dr Shepard:

As Dr Shepard was absent fro this meeting, Chairman Marsh will keep this issue on the agenda.

—The Council agreed to meet on September 16, 2022 at the regularly scheduled time, 3:00 PM.

Meeting minutes respectfully submitted by Laura Landerman-Garber Ph.D.  
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