

New Hampshire Governor's Rare Disease Advisory Council
Meeting Minutes 1/21/22
Prepared by Laura Landerman-Garber Ph.D.

NOTE: Dr. Landerman-Garber attended the meeting via Zoom and had some connection and audio difficulties which may be reflected 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 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 William Marsh , Co-Chairs Representative Gary Woods and Dr, Marybeth Dinulos, Senator Cindy Rosenwald , Dr. Laura Landerman-Garber, Dr. Sai Cherala, Dr. Elijah Stommel, Dr. Richard Lefleur, Ms. Krista Gilbert, Ms. Libby Shannon, Ms. Abby Rogers, and Ms, Audrey Gerkin

Absent: Dr. Angela Shepard

—Minutes

No correction nor addendums were offered for minutes from 11/19/21 meeting

—Rare Disease Day Proclamation Update:

Dr. Landerman-Garber is in close contact with Governor Sununu's Staff. They are working with the Governor on the Proclamation and will contact Dr Landerman-Garber when it is ready for pickup. Chairman Marsh, Co-Chair Woods, and Senator Rosenwald offered assistance as needed. Further discussion included whether the Governor might pre- record a reading of the Proclamation and if not, Dr Landerman-Garber is willing to do so.

—ALS Registry:

Dr Stommel provided the following update: The Governor of Maine is very interested in a mandatory registry and the discussion will go before the Maine Legislation. The Vermont Legislation will provide questions to Dr Stommel during a February Session. He reported that the Federal Government passed a Bill approving \$100 million for ALS research. Dr Stommel also discussed that he wrote an article for VT Newspaper re Cynotoxins and health risks.

Chairman Marsh noted that NH Legislature is currently stalled re the Cyanobacteria issues

Co-Chair Woods followed up with his perspective that legislative leadership is currently stalling further work in the areas of related Commission and study Committees

Dr. Stommel note that the Department of Environmental Services is already involved and that it would not be costly to continue to study these and related issues .

—Legislation:

Chairman Marsh reported that the Hearing discussion re: remote meeting allowance for RD went well with the presentation being received as legitimate rationale for such allowance . This positive reception was not necessarily evident for other committees/councils.

Co-CHair Woods presented this Bill and reported that the earliest it might be signed is Summer 2022.

Ms. Shannon inquired whether there is an intention to make the RD Council meetings optionally remote on a permanent basis. Chairman Marsh said there will be ongoing discussion in this regard.

Dr. Cherala expressed concern about the technology component of remote meetings and the need for enhancement of these options. She opined that if such enhancement occurred, the RD community would be better able to join in on the discussions

Co-Chair Dinulos continued the discussion about telehealth (TH) in both NH and across the US. She noted that TH is a positive option for RD communities, in the field of genetics and other, as patients and their families could consult with geneticists and other medical caregivers without having to travel.

Chairman Marsh serves on the Telehealth Commission. These and other related issues such as licensure are being addressed. He invited Co-Chair Dr. Dinulos to speak to the Commission

Dr Cherala raised the issue of extensions to TH allowances and that these and related issues will need to be addressed post-COVID

Chairman Marsh noted that the DHMC Legislative Liaison does attend the Commission meetings

Ms. Shannon reported that she has met with the NH DC Delegation re: the TH Modernization Act and will reintroduce this discussion in February-March 2022

Co-Chair Dinulos and Ms Shannon will meet offline and report back to the Council.

—YSD Committee

Co-Chair Dinulos reported that they met in person and a budget proposal re: genetic testing was discussed

She further reported that she will be meeting with both of the NH MER on January 31, 2022 re: testing , test results, and methods of informing families.

DHMC offers genetic counseling to the ME free of charge for complex testing, results , and family follow up.

—Newborn Screenings:

Dr. Cherala reported that there were no new nor additional medical conditions added and that the Committee continues to meet.

NOTE: Dr Cherala will provide additional notes re: NB Screenings Zoom difficulties with audio

—Community Outreach:

Ms Shannon has had contact with the Massachusetts RD Council (Ms. Glenda Thomas). They have not recently met and MS SHannon with follow up .

NOTE: Ms. SHannon discussed a new Center at Huggins Hospital and has been asked to provide a synopsis of her report to be included here.

Direct Service Providers(DSP):

HHS Oversight Committee: Chair Marsh and Senator Rosenwald can possibly present and invite Ms. Gilbert to be recognized to address the issues re to DSP.

NOTE: Ms Gilbert has been asked to provide a synopsis of her report to the Council re DSP which will be included here.

—Education:

Dr. Shepard was not present and will be asked to report on this topic at our next meeting in 2/22.

—Rare Disease Day 2/28/2022:

Ms. Gilbert reported that the RDA coordinated by Dr. Shepard is working on a virtual Program. In-person events for 2022 will not be held secondary to COVID-19. The RDA will be providing prerecorded statements and interviews that will result in a Rare Disease Day Celebration webinar.

Ms. Gilbert, on behalf of Dr. Shepard, invited Council Members to provide a recording for the webinar whether it be re: their experiences on the Council, their work with the RD community, and/or their own experiences as a person with a RD.

Chairman Marsh will prerecord a statement on behalf of the RD Council in his role as Chairman.

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

—The meetings was adjourned without objections

Meeting minutes respectfully submitted by Laura Landerman-Garber PhD