

New Hampshire Governor's Rare Disease Advisory Council
Meeting Minutes 8/20/21
Prepared by Laura Landerman-Garber PhD

NOTE: Dr Landerman-Garber attended the meeting via Zoom and had connection difficulties which will be noted here in the body of the 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 to meet in person secondary to COVID-19. Chairman William Marsh clarified to the attendees that because there was not a quorum present and that there would not be any voting throughout the course of the meeting.

-Attendance:

In-person: Chairman Representative William Marsh, Dr. Sai Cherala, Dr Angela Shepard, and Co-Chair Representative Gary Woods

Via Zoom: Dr. Laura Landerman-Garber. Ms. Krista Gilbert, Senator Cindy Rosenwald, Co-Chair Dr. Mary Beth Dinulos, Guests- Ms Emma Bliss and Mr John Williams

Absent: Dr. Elijah Stommel and Ms Libby Shannon

-Minutes from the last meeting were reviewed and no corrections were noted. Approval of the minutes could not be voted upon due to quorum limitations.

-ALS Database/Registry:

Dr. Shepard addressed this but due to Zoom connection difficulties, Dr. Landerman-Garber was not able to hear her statements/report.

-YSD:

Dr. Dinulos reported that the July meeting had been canceled and is to be rescheduled

Dr. Cherala noted that the meeting had been canceled due to quorum issues . She also noted that the group was looking for a facility for future meetings and was developing a hybrid model for the meetings to come in the near future.

Dr Dinulos stated that it is a large committee which makes it more challenging to meet but that she is in contact with the Medical Examiners and will arrange a Zoom meeting with them in September. She will present back to us.

Rep. Woods. And Senator Rosenwald both spoke to this issue but Dr Landerman-Garber was unable to hear due to Zoom connection issues.

-Low Dose Naltrexone:

Chairman Marsh made a statement to congratulate Ms. Gilbert for her tireless and successful work on this issue.

Ms. Gilbert noted that off label and compounded medications need to be looked at in a broader context for individuals with a rare disease.

Chairman Marsh noted that if the work can be done without the complexities of legislation, it could be very efficient and effective.

Ms Gilbert spoke about NHRDAN developing a CE on Low Dose Naltrexone to help educate about how to obtain pre-authorization for the medicine

Dr Shepard spoke about the importance of that including indicators and uses of the medication . She recommends separate CE for providers and patients/families.

Ms Gilbert has reached out to the manufacturer of the medication but has not heard back

Ms. Gilbert made a note about the importance of communication. However the rest of her statements were not heard for Dr. Landerman-Garber to record due to Zoom connection issues.

-New born Screening:

Dr Cherala did not report any new information and will provide a followup at the next meeting

-Community Outreach:

Dr. Shepard noted that there is an importance in not duplicating efforts in this area.

Chairman Marsh noted that RDAN may be taking over the social media aspect of community outreach.

Dr Shepard will be in touch with RDAN re: website and other social media platforms

Ms. Gilbert spoke to the importance of thinking ahead to Rare Disease Day 2022. She noted that the campaign to light up structures in NH with the RD colors is still on the agenda to be done

-Annual Report and Survey

Ms. Gilbert did note the upcoming Annual Report and whether or not we want to develop another Community Outreach Survey as we have done in the past.

Chairman Marsh spoke to the importance of the Survey in the past. He noted that we did not complete one in 2020 and therefore it will not be in the Annual Report but we can document that it is one of our goals for 2022.

Dr. Cherala asked if we have a good summary of the related issues in the Survey which in turn would be helpful to HHS.

Dr Cherala and Ms. Gllbert will work offline/outside the meeting and will report back to us.

Chairman Marsh noted that the Annual Report is due in November 2021 and asked that Council Members forward anything to him that might be relevant for the Report before the next meeting.

Senator Rosenwald, Co-Chair Woods, Dr Shepard, Ms Gilbert, Mr Williams, and Dr Cherala all made statements that could not be heard by Dr. Landerman-Garber due to Zoom connection issues and therefore were not able to be recorded.

-New Business:

Ms Shannon has been drafted by NORD to speak with our Congressional Delegates. The details of the proposed discussions could not be heard by Dr Landerman Garber secondary to Zoom connection issues.

Telehealth related issues were discussed by the Council with Co- Chair Woods stating that he attended a meeting about telehealth. Dr Dinulos raised the concern about future changes to reimbursement for attending telehealth sessions. Dr. Laura Landerman-Garber addressed the related issues that are impacting MH telehealth including reimbursement and the intensified need for MH accessibility during the Pandemic and as predicted for years to come as needs for MH services are skyrocketing.

Disruption then occurred whereas the Zoom connection to those attending the meeting in-person ended. Mr. Williams offered a summary to the meeting but it too was “lost” due to Zoom connection challenges

Meeting minutes respectfully submitted by Dr. Laura Landerman-Garber
on September, 12, 2021

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