

New Hampshire Governor's Rare Disease Advisory Council
Meeting Minutes 11/20/20
Prepared by Laura Landerman-Garber Ph.D.

-Chairman Representative William Marsh read the NH State Guidelines for official NH meetings during the COVID-19 Pandemic, including the parameters for meetings held via tele-technology

-Attendance: Present-Chairman Representative William Marsh, Dr. Sai Cherala, Ms. Krista Gilbert, Dr. Elijah Stommel, Dr. Mary Beth Dinulos, Senator Cindy Rosenwald, Dr. Laura Landerman-Garber, Dr. Angela Shepard. Guests- Ms. Elizabeth Shannon, Ms. Paula Minnehan (NH Hospital Association), Ms. Abby Rogers, Ms. Courtney Tanner (DHMC), Mr. Paul Collins (phone-identified himself by that name) Absent- Representative Richard Osborne, Dr. Richard Lafleur.

-Minutes from Meeting 10/16/20 were reviewed and accepted with one correction made by Dr. Landerman-Garber.

-Annual Report: (See Report under separate cover) Due by 12/1/20.

Chairman Marsh wished to thank Ms. Gilbert for her assistance in preparing the Report.

The Council reviewed and edited the draft of the Report.

Dr. Shepard recommended that the two Rare Disease Day events be included in the Report and she provided a narrative in this regard.

A motion was made to accept the draft of the Annual Report as presented. A Roll Call vote transpired and it was passed with no exceptions

-Data Base:

Dr. Stommel presented his recent conversations with National ALS Association (Mr. Neal Thaquer) and the CDC (Mr. Paul Mehta) regarding a National Registry. There was optimism for funding options which in turn would increase the data base on a national level. Mr. Thaquer of the National ALS Association pointed out that the US Congress might be source of funding and that in that case, the funding could possibly cover a ½ FTE in NH to collect data and share it with the CDC. There was discussion that perhaps by resubmitting to the NH

Legislature re: laws for reportable disease (ALS), it might be better received if funding was not required. Dr. Stommel planned to contact Senator Rosenwald outside the meeting to discuss filing deadlines. Dr. Shepard inquired about data availability and Chairman Marsh offered to be available to aide with legislative issues.

-Legislation:

Chairman Marsh refiled the Prior Authorization Bill
Ms. Gilbert is looking into a Direct Support Licensure Bill

-Youth Sudden Death Committee:

Dr. Dinulos reported that the next meeting is to be on December 11, 2020 and will report back to the Council at our next meeting.

-Naltrexone:

Ms. Gilbert reported that she did discuss with Dr. Lefleur about the medication, looking at indications for uses other than pain management and for use with Rare Diseases.

Dr. Lefleur will look into it with the medical community re: uses and coverage and will report back to us at our next meeting.

Ms. Gilbert will gather data about how many patients in the Rare Disease Community may be using it.

-Newborn Screenings:

Dr. Cherala reported that NH is applying for a Grant re: several genetic anomalies. A competitive field of applicants. Due Date : 11/20

Ms. Gilbert inquired about newborn hearing screenings., Dr. Cherala answered with the affirmative in that those screenings already are occurring and will connect with Ms. Gilbert outside of our meeting to discuss the issue further. It was recommended that Representative Mark Person may be a good contact within the NH Legislature.

Dr. Cherala also reported that a new F/T professional will be hired in December and will report back to us at our next meeting.

-Facebook Page:

Ms. Shannon had researched how to set up a Facebook Page
Ms. Gilbert suggested looking at other Councils for models/

Dr. Landerman-Garber, Ms. Gilbert, Ms. SHannon and Dr. Shepard hope to meet, albeit via tele-technology, prior to our next meeting.

-NORD Stakeholder Meeting:

Chairman Marsh and Ms. Gilbert

NH was highlighted as doing a good job with the Rare Disease Council activities and was noted to possibly be a model for other States as they develop their own Councils.

-CME Rare Disease

Dr. Shepard discussed the Area Health Education Center, a Federally funded program to provide health education to the workforce, especially in rural areas.

She discussed that the NHRDA will be providing a Series for health care providers re: education about Rare Diseases. For example, she hopes to provide such an education program about SMA in 2021.

Dr. Cherala recommended that the series also address other newborn diseases.

Chairman Marsh suggested that the Council contact the NH Medical Society to urge its Members to utilize these education series opportunities.

Dr. Dinulos is in contact with NERGN regarding webinar availability.

Dr. Cherala noted that NEGRN has grants to do training.

NOTE: During the course of the Council Meeting, a Zoom Bomb occurred.

Members signed out and signed back in to continue the Meeting without interruption. The appropriate authorities will be notified of this occurrence.

-The next Council meeting is scheduled for December 18, 2020 at 3:00 PM via tele-tehnology.

-The Meeting was adjourned without objection.

-Meeting Minutes respectfully submitted by Laura Landerman-Garber Ph.D. on 17 December 2020.