

New Hampshire Governor's Rare Disease Advisory Council
Meeting Minutes 1/15/21
Prepared by Laura Landerman-Garber Ph.D.

-Chairman 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. Laura Landerman-Garber, Dr. Marybeth Dinulos, Senator Cindy Rosenwald, Dr. Elijah Stommel, Dr. Richard Lafleur. Absent: Dr. Angela Shepard. Guests: Ms. Tracy Williams, Ms. Kevin Gullison, Ms. Abby Rogers, Ms. Heather Daniel, Representative Frances Nutter-Upham, Ms. Leah Stagnone, Dr. Bruce Vrooman, Ms. Pamela Becker, Ms Lynette Stebbins, Ms. Paula Minnehan, and "Alex".

-Minutes from 12/20/20 Meeting were reviewed. Approved with exception of correction provided by Dr. Cherala. The correction will be made by the next meeting and will be submitted to Chairman Marsh.

-Data Base

Dr. Stommel discussed his conversation with Ms. Ellen Morgan which was helpful to clarify the parameters of the Massachusetts ALS Registry, including how it is possible to make such a registry mandatory.

Dr. Stommel scheduled to attend a meeting (1/15/21) with Staff from the CDC to discuss the possibilities of a NH Registry (anticipation of 30-40 cases to register per year) as well as the possibilities to gain access to a more widespread, if not national database.

Vermont interested in discussion with Dr. Stommel re: database/registry before more formally addressing related issues in their Legislature.

As discussed previously, cost issues are a realistic aspect to address when considering legislative possibilities. Dr. Stommel is hopeful that costs would be minimal and therefore not prohibitive to make such a registry/database, a reality.

Chairman Marsh noted his support for Dr. Stommel's efforts and expressed interest in the possibilities of having a Bill introduced to the NH Congress, perhaps in one year's time frame.

Guest Ms. Williams offered assistance as she is an IT professional

-Guest Ms. Williams

Ms. Williams discussed her Brother's rare disease and the impact of the Pandemic on care-access and related issues. NH Medicaid coverage for metabolic disorder is limited and sought out any guidance the Council could offer her. She is connecting with NORD She would like to increase her advocacy work and offered to help in any way to support the Council's goals. Guest. Ms. Rogers offered to assist her offline.

-Legislation

Both Chairman Representative Marsh and Senator Rosenwald reported that they have not seen nor are aware of any current Bills related to Rare Disease

-Youth Sudden Death Committee

Dr. Dinulos noted that she did not have any updates except that the Committee continues to reach out to various groups for funding for genetic testing.

-Ms. Gilbert- Naltrexone

Guest Dr. Vroom is a Pain Specialist at DHMC. He noted that he initially used Naltrexone in 2008 in the treatment of a patient with MS. He continues to prescribe the medication in low doses as a compounded medication. He did report that it is difficult to obtain insurance coverage for the medication. Dr.

Vroom said that there are increases in studies about the use of low dose Naltrexone for pain but that compounding, at this time, is necessary, making it more complex for usage. He approximates that the medication is \$80.00 per month. He would like very much if there could be a pilot study of its use in NH.

Dr. Lafleur stated that from an insurance perspective, off label medication complicates coverage. He believes that any supportive information and data could lead to potential approval for individual cases.

Drs. Vroom and Lafleur will connect offline to discuss related issues.

Ms. Gilbert reported that no one from the Council's 2020 survey nor in her discussions with NH individuals in the Rare Disease Community has been able to get Naltrexone covered by their insurance.

Dr. Cherala asked about getting information in this regard from Medicaid and/or private insurance companies. Chairman Marsh requested that a representative from Medicaid be invited to attend our next meeting. Ms. Gilbert would hopefully be able to provide said Medicaid Representative, questions in advance of our meeting.

Chairman Marsh will follow up at our next meeting regarding RSA and off label medication use/coverage.

-Newborn Screenings Dr. Cherala

Dr. Cherala did not have any current issues to report but noted that the discussions on these and related issues are ongoing.

-Rare Disease Day 2021 Ms. Gilbert

Ms. Gilbert noted that Rare Disease Day is 2/28/21 and that on 2/24/21, NORD/ Rare Disease Action Network will hold a meeting from 3:00 -4:30 PM to discuss State Rare Disease Councils.

A Rare Disease Day Proclamation was requested from Governor Sununu. Guest Ms. Stebbins is working with the Governor's Office to obtain the Proclamation.

NORD is requesting that building bridges be lit up with the Rare Disease colors. Guest Ms. Daniak is working on this effort in NH

-Direct Support Provider (DSP) Ms. Gilbert

Ms. Gilbert noted that NY Bill #880 was reintroduced and that a pilot program was going to be in effect there for credentialing DSP. She also said that she is in discussions as possibilities for NH.

-Guest Ms. Gullison (OT)

Ms. Gullison shared with the Council that the NH OT Association will be holding round table discussion via tele-technology. On 2/18/21, there will be one addressing the dynamics of working with medically fragile students in home-school and in-school interventions.

She offered to make her email available to Council Members.

-Facebook Guest Elizabeth Shannon (not present), Ms. Gilbert, Dr. Shepard & Dr. Landerman-Garber

Due to illness, the group has not met but hope to do so prior to next meeting

-The next meeting is scheduled for February 19 at 3:00 PM

-The meeting was adjourned without objection

Meeting Minutes respectfully submitted by Laura Landerman-Garber Ph.D
on January 29, 2021