

New Hampshire: Governor's Rare Disease Advisory Council

Minutes 5/15/20

Prepared by Laura M. Landerman-Garber, Ph.D.

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

--Attendance: Present- Chairman Representative William Marsh, Representative Richard Osburne, Dr. Sai Cherala, Dr. Richard Lafleur, Dr. Elijah Stommel, Dr. Mary Beth Dinulas, Ms. Krista Gilbert, Ms. Abigail Rogers, Ms. Audrey Gerkin, and Dr. Laura Landerman-Garber

--Minutes from Meetings (January and February 2020) were reviewed and accepted.

--UPDATES:

--DATABASE Dr. Stommel

1/10 of the USA population have a rare disease, resulting in 30 million individuals in the USA.

Dr. Stommel referenced an article in Neurology Today, and will send, via email, a link to the Council. Title: Neurologists Call for ALS Registry to Research Environmental Toxins Associated With Disease.

Re: DHMC Database, Dr. Stommel will revisit the issue with Dr. Shepard as to whether the Database reflects the overall NH Rare Disease Community.

Massachusetts ALS Registry: Still awaiting feedback from them. Possible delay secondary to COVID 19.

Dr. Stommel raised questions as to the feasibility of having an ALS NH Registry secondary to financial constraints. May need sizable donation for it to become a reality.

Dr. Lefleur raised question as to whether we could tag onto the Massachusetts registry. Dr. Stommel will address this when further contact occurs from Massachusetts.

--Representative Marsh relayed to the Council that the NH Legislature will be opening on June 11, per NH Speaker of the House. The Rare Disease Legislation will be kept on our agenda for our next meeting.

--SUDDEN DEATH COMMITTEE Dr. Denulas

A 7/10 meeting has been scheduled and she hopes to meet with Dr. Jenny Devall CME afterward the meeting date. Dr. Denulas will follow up with us in July.

--Ms. Gilbert

Sent Emails to Council Members about 5/20 NORD virtual meeting. Council Members may submit questions and are invited to join the meeting.

NH Listening Sessions: Survey is complete, and received by NH RAN NORD and will hopefully be out by mid-June.

Volunteer: Ms. Pam Becker of Community Partners, Rochester, NH. She has been an asset to this project.

Listening Sessions have been postponed due to COVID19. The population who would attend these Sessions are likely to be medically compromised and/or have family members who are compromised and therefore, the Sessions will be held off until re-opening is complete.

--NEWBORN SCREENING Dr. Cherala

Three conditions for screening have been approved for 7/1/20. The specifics of these three conditions will be included in an email to Council Members as per request of Dr. Lefleur.

Protocol establishment has been delayed by COVID19. Reviewing aspects of financial aspects of screenings.

Dr. Cherala will update us at our next meeting in July.

--Ms. Gerkin with the Youth with Chronic Conditions is working with MS. Gilbert on screenings and resources, planning to have these resources shared with parents and pediatricians. Follow up next meeting.

--Representative Marsh introduced a discussion regarding our meeting schedule. It was unanimously agreed upon that due to the complexities of COVID19, that our June meeting will be canceled and the next Advisory Council meeting will be held July 17, 2020 at 3:00 PM .

--The Meeting was adjourned without objection.

Meeting Minutes respectfully submitted by Dr. Landerman-Garber 5/26/2020