

New Hampshire: Governor's Rare Disease Advisory Council

Minutes 7/17/20

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. Abigail Rogers, Senator Cindy Rosenwald, Dr. Angela Shepard, Ms. Paula Minnehan, and Dr. Laura Landerman-Garber Absent: Ms. Krista Gilbert and Mr. Robert Stoker.

--Minutes from Meeting (15 May, 2020) were reviewed and accepted.

UPDATES:

--ALS/RARE DISEASE REGISTRY (Drs. Stommel and Shepard)

Dr. Shepard: Secondary to impact of COVID19, there was nothing new to report at this time.

Dr. Stommel: Agreed that impact of COVID19 has delayed the process of moving forward on this topic.

Dr. Stommel had an opportunity to appear on the Dave Grahm Radio Show (WDEB) to discuss in a public forum venue, the potential for improvement in research and treatment by having a registry for ALS and rare diseases. It also would allow citizens of a State in which they live, to promote Legislative attention to rare diseases, a topic too often minimized. Dr. Stommel was also able to address bacteria blooms, especially regarding tourism during the Pandemic. Chairman Representative Marsh confirmed the economic risks in this regard and Dr. Shepard fully supported expanding this discussion. Representative Osburne reported that DES in Hampton has funding for studies of bacterial blooms and related impacts. Dr. Stommel discussed with the Council, the desire to further utilize radio presentations to promote the Registry concept, believing that it may also lead to financial support through donations from listeners. Suggestions were made about possible venues such as NHPR and Manchester Radio Group (Ms. Marga Bessette), Eye on New Hampshire.

Dr. Stommel reported that Massachusetts General Hospital was able to start a clinical trial to study neurodegenerative disease after a substantial donation was made in memory of a family member who had suffered through such an illness. The Council discussed the trend that occurs in fund raising when someone is personally touched by a rare disease.

Dr. Cherala suggested that there are Legislative Commissions that may be helpful to support the development of a Registry, including HHS's interest in the long-term impact of illness on costs, including prevention and treatment. She will report back to the Council at upcoming meetings in this regard.

Dr. Stommel had formally proposed the development of such a Registry in Vermont a number of years ago; the proposal was turned down secondary to financial constraints.

It was agreed by Council Members that if sufficient funds were available, that the Legislature would likely be fully supportive.

--LEGISLATION

Chairman Representative Marsh reported that SB 690,685 and 685 were being monitored in terms of possible passage. Representatives Marsh and Osborne reported that HB 1280 containing their language was signed by the Governor on 16 July, 2020. Additionally, HB 1623 addressing TeleHealth is believed to have support by Governor Sununu and is to be signed in the near future. This latter Bill addresses the expansion of TeleHealth and related issues such as, telephone sessions, billing, parity, treatment sites, providers and reimbursement .

--NORD ANNUAL MEETING:

Chairman Representative Marsh was invited to speak at the NORD National Convention in Fall, 2020 about telemedicine.

--NORD SURVEY/LISTENING SESSIONS:

Ms. Gilbert was unable to attend today's meeting. The Council acknowledged that she has been doing an amazing job at creating and disseminating both the Survey and the gathered information. Dr. Landerman-Garber was able to address briefly the findings from the Survey regarding Transportation of individuals/families with rare diseases. It appeared from the preliminary data that survey-takers self-report that they have good access to transportation when needed for issues related to their rare disease treatment.

The Council will look forward to Ms. Gilbert's reports at the next scheduled meeting.

--INFANT/YOUTH SUDDENT DEATH (IYSD)

Dr. Denulas reported that any meetings regarding IYSD were postponed and no review of cases were being reviewed at this time.

Dr. Cherala noted that those meetings were going to be on hold until a leadership position on that Committee was filled; this delay is secondary to the Pandemic and hiring freeze due to the COVID19 Emergency Order.

The Council officially encouraged the continuation and importance of the IYSD Committee.

--NEWBORN SCREENING PROGRAM

Dr. Cherala reported that there is a need to further develop and establish a protocol and that the impact of COVID19 has delayed this process. Professional positions still need to be filled and Dr. Cherala added that they are awaiting the Governor's approval for hiring.

Dr. Cherala noted that the screenings do add significant costs for hospitals and that much gratitude is given to the NH Hospital Association for their support. Ms. Minnehan supports the screenings and raised concerns about long term finances.

Starting 1 August 2020, three newborn screenings will be added to the protocols.

--NEW BUSINESS:

Dr. Shepard wanted to note that she truly appreciated all of the efforts made during the Pandemic, to address the needs of those with Rare Diseases. She is proud to be a part of the Rare Disease Council and extended Community. Council Members were appreciative of her statements and agreed that they will continue to address these issues.

--NEXT MEETING DATE

Per discussion with Council Members, it was agreed that the next Council meeting will be held Friday, 21 August 2020 at 3 PM.

--The Meeting was adjourned without objection.

Meeting Minutes respectfully submitted by Dr. Landerman-Garber 24 July 2020