

New Hampshire Governor's Rare Disease Advisory Council  
Meeting Minutes 2/9/2021  
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 teletechnology.

-Attendance:

Present- Chairman Representative William Marsh, Dr. Sai Cherala, Dr. Elijah Stommel, Ms. Krista Gilbert, Representative Gary Woods, Ms. Libby Shannon, Senator Cindy Rosenwald, Dr. Mary Beth Dinulos, Ms. Paula Minnehan, Sr. Angela Shepard, Dr. Laura Landerman-Garber  
Guests- Ms. Betty Gay, Ms Abby Rogers, Ms. Courtney Tanner Absent- Dr. Lefleur

-Minutes from last meeting approved

-Reappointed Council Members/Chair

Representative Marsh will continue as Chairman of the Council, renominated and approved by Council

Representative Woods will be Co-Chair along with Dr. Dinulos, both nominated and approved by Council

Ms. Libby Shannon has been appointed by the Governor to the vacancy left by the death of Mr. Robert Stoker

-Database

Dr. Stommel provided a general review of this topic to new Members and guests.

Dr Stommel is discussing and collaborating with others re: creative ideas on decreasing costs of such a database in hopes of a reintroduction to Legislature. He is optimistic that it can be done for NH/VT

Chairman Marsh is supportive and will reintroduce to the Legislature once the infrastructure is in place.

Representative Woods inquired about whether there are federal programs that might ease the costs

Dr. Shepard inquired as to what kind of infrastructure might exist for multiple medical conditions and the possibilities of data-sharing, regional study groups vs Legislature, secondary to that there are few cases which might ease the data sharing idea. She noted that there is already some infrastructure in place for data-sharing.

Senator Rosenwald raised the question that if individuals own their own medical information in their records in NH, then wouldn't it be up to the individuals to make a decision in this regard.

Dr. Shepard raised the possibility of looking in HIPPA Guideline allowance for at the time of consents signed at intake, whether individuals could agree for data-sharing

Senator Rosenwald pointed out the possibility of a Claims-based data sharing

Chairman Marsh suggested that the info /data could perhaps be obtained from CPT Codes.

Dr. Stommel raised concern that those without insurance /Medicare would not be included in the data-sharing and why other illnesses are mandatory.

Ms. Shannon posited that it would be very helpful, as it is for her, to have a registry and raised an additional issue regarding the possibility of COVID Vaccine registry/data-sharing

These and related issues to Database will be revisited at the next Council meeting

#### -Legislative Updates

Chairman Marsh updated us on HB 600, HB 191 and HB 62. He will continue to update the Council on Legislative activities.

Dr. Dinulos inquired about the Prior Authorization Bill including how long the pre-auth takes and how long it will last

Ms. Minnehan, in response to Dr Dinulos, raised related issues/questions such as: 1) What is the COVID impact? 2) Will there be an extension of how long it takes and how long it lasts including cases of medical necessity

Dr. Cherala raised questions about HB 600 Newborn Screenings. Chairman Marsh, Dr. Cherala, and Ms. Minnehan will follow up outside of the meeting and get back to the Council.

Ms. Gilbert raised a question about HB 104 and was referred to Representative Smith for clarification and consult

Dr. Shepard raised the concern about the complexity of ID-ing/tracking Bills other than the Website.

Council Members agreed that the complexity makes it difficult and Dr Shepard offered to look in to the matter and get back to the Council at our next meeting

#### -Youth Sudden Death Committee

Dr. Dinulos provided a general review of this topic to new Members and guests

Dr. Dinulos discussed that she is interested in the genetic component and in working with the State Medical Examiner, Dr. Duvall. Raised the issues re: fundings/consent. Dr. Dinulos recently discussed with Dr. Duvall that the numbers of unexplained deaths in NH are few and whether the funding could cover those genetic tests.

Dr. Dinulos reviewed Infant SID re: data and whether the review of that data would reveal other underlying disease issues. She believes that it would be informative if they would be able to thoroughly test infants but both funding and what to test are issues that will need to be reviewed.

Dr. Shepard has looked at research and would support a small Panel to understand the deaths from a broader perspective while still maintaining original and overall goals.

Drs. Dinulos and Shepard will work together outside of the Council meetings and will report back to Members.

Dr. Cherala noted care to be taken to examine expectations and what is feasible

Representative Woods recommended that cardiac and brain disruptions be looked into in this regard as well

-Facebook

Ms. Shannon, Ms. Gilbert, Drs. Landerman-Garber, and Shepard discussed the related issues of creating a Facebook page for the Council. Some concerns were raised about whether it would be information based, the stage of the Council's development, consideration of other options, and whether or not it would replicate NORD and RDAN social media.

At this point in time, the Council agreed that such a development is not necessary but will be kept in mind for possible future development

-Rare Disease Day

Ms. Gilbert reminding the Council of the 2/24/21 3-4:30 PM Virtual Event NORD Sponsored

Dr. Landerman-Garber offered to contact WMUR and ABC, The View Producers for possible coverage.

-Naltrexone

Ms. Gilbert offered to revisit this issue at the next meeting,

Dr. Shepard raised the question of a possible clinical benefit for impact on the lungs from COVID and treatment with low dose Naltrexone

Ms. Gilbert was referred to Representative Merchant re: this and other issues related to Naltrexone

-The next Council meeting is scheduled for April 16, 2021

-The meeting was adjourned without objection

Meeting Minutes respectfully submitted by Laura Landerman-Garber on April 9, 2021