

New Hampshire Governor's Rare Disease Advisory Council  
Meeting Minutes 4/16/21  
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 teletechnology

-Attendance:

Present: Chairman William Marsh, Co-chairs Rep. Gary Woods and Dr. Mary Beth Dinulos, Dr. Sai Cherala, Dr. Elijah Stommel, Ms. Libby Shannon, Senator Cindy Rosenwald, Dr. Richard Lafleur, Dr. Angela Shepard, Dr. Laura Landerman-Garber. Guests: Peter Bragdar, Heidi Kroll, Abigail Rogers, Francis Nutter-Upham, Andrew Hosmer

Absent: Ms. Krista Gilbert

-Minutes from last meeting approved without objection.

-Database

Dr. Stommel discussed that there may be a National Registry meeting with Michigan interested in possibly joining in on the discussion.

Dr. Stommel discussed that Vermont remains interested in the Registry as well, noting that they likely have 30-40 cases per year and would be sharing the Database with data from NH.

Dr. Stommel is willing to make maps of toxin presence for NH Legislature when they are ready to review it and Chairman Marsh supported this plan. Note: Dr. Stommel will provide Council Members such maps (5/18/21 followup: Members received such emails from Dr. Stommel for review)

Co-Chair Woods expressed interest in connecting further with Dr. Stommel about the data maps and will do so outside of the meeting, perhaps to report back to the Council at the next meeting.

Ms. Shannon is a part of a Myasthenia Gravis registry and expressed interest in discussing this further with Dr. Stommel. They will do so outside of the meeting.

## -Legislation

Chairman Marsh reported that the Newborn Screening Bill was introduced in the Senate and the Prior Authorization Bill was retained in the House with the Continued Access Bill being tabled and possibly revised next year.

Dr. Cherala inquired about the Telehealth Bill. Chairman Marsh noted that it is to be retained, with HHS approval until December 2021.

## -Sudden Death Committee

Dr. Dinulos noted that the Committee met March 12th and reviewed CDC updates at that time.

(A synopsis of her discussion was graciously provided by Dr. Dinulos 4/16/21 for inclusion here):

Our most recent Sudden Death in the Young (SDY) Committee meeting was held on 3/12/21. CDC update noted that all cases are categorized using the SDY and SUID (Sudden Unexplained Infant Death) criteria which includes:

- A. All cases must be residents of NH
- B. Children are less than 20 years old and have sudden or unexpected death
- C. Includes drownings in children older than age 5 years and drivers in motor vehicle accidents.

Discussion was had re: genetic testing in these children, including comprehensive cardiac panels and comprehensive epilepsy panels.

This discussion prompted followup emails with Heather MacLeod, CGC who is the Senior Project manager of the SDY Registry, Dr. Mitchell Weinberg, Deputy Medical Examiner in NH, and Dr. Dinulos. All patient samples are sent to the University of Michigan biorepository for research purposes. DNA is extracted and is available to send to genetic testing labs for clinical testing. Invitae labs have a special rate for Medical Examiners - \$300.00 per test (versus the \$1,000.00 test rate at Ambry). It will be important to figure out the annual number of cases that would require genetic testing in order to put forth a budget. This data would be best obtained from the Medical Examiners. Dr. Dinulos will continue the discussion with Drs. Weinberg and Duval re: this data. In addition, Dr. Dinulos attended (virtually) the American College of Medical Genetics and Genomics (ACMG) annual meeting and will report on a presentation from the Baltimore and Boston groups re: incidence of genetic variants noted in their SDY/SUID populations.

Chairman Marsh noted that this data will be very important in terms of requesting funding for this type of testing.

Dr. Shepard noted that funding may also be available from the patient's insurance companies, even though it is atypical for insurers to reimburse for genetic testing in a deceased individual.

Drs. Dinulos and Shepard will work outside of the meeting time re: potential funding sources for this genetic testing.

Dr. Lefleur confirmed that from an insurance standpoint, post-mortem coverage is not standard.

Chairman Marsh noted that if a disease might also be present in families and is treatable, that perhaps coverage might be more possible.

-Naltrexone

Discussion was suspended until our next meeting as Ms. Gilbert was absent and is the lead source on this topic.

-Facebook Page

Drs. Landerman Garber and Shepard and Ms. Shannon reported that the creation of a Facebook Page for the Council is on hold until further notice.

It was noted however, that the Council continues to develop opportunities and pathways to raise awareness of Rare Diseases and to interface with the NH Rare Disease Community.

-Rare Disease Day

Dr. Shepard reported that the virtual NORD event that was held in collaboration with RAN was attended by 70 participants and believes that it was well received and well done, with positive feedback provided by participants.

Dr. Landerman-Garber noted that while WMUR/WZID did not participate in coverage of Rare Disease Day, that she will work with these news outlets for hopefully providing said coverage in 2022.

## -COVID-19 Vaccine

Dr. Shepard discussed the expressed fears and anxiety re: the vaccine in the NH Community and that discussions re: related fears appeared to lead to a decrease in anxieties and increase in individuals getting the vaccine. She also noted that caregivers of young children with Rare Diseases were hopefully having access to and getting the vaccine.

Ms. Shannon self reported that she had been placed in Group 1B for receiving the vaccine but was not sure how she was placed on that list. She pointed to the need for a possible registry for individuals with a Rare Disease.

Dr.. Lefleur noted that from a medical practice perspective, he felt as if it was fairly easy to obtain a vaccine for patients with a Rare Disease.

Dr. Cherala noted that from a Public Health perspective, systems were not as prepared as she would have liked, CDC Guidelines were variable, and that lessons were certainly learned in this regard. She expressed concern that if a medical condition was not on the CDC List, it complicated the ease of getting the vaccine.

Dr. Shepard expressed appreciation and gratitude for the work that Dr. Cherala has done throughout this Pandemic and her work overall in Public Health.

Chairman Marsh noted that the field of Public Health overall has become stronger and brighter for NH and the Country.

-The next Council Meeting is scheduled for Friday, May 21, 2021.

-The Meeting was adjourned without objection.

Meeting minutes respectfully submitted by Dr. Landerman-Garber on May 18, 2021.