

New Hampshire Rare Disease Advisory Council
Meeting Minutes 9/17/21

The meeting was held in-person meeting with a Zoom option for those Council Members and guests who were not able or were not comfortable to meet in person secondary to COVID-19. Chairman William Marsh clarified to the attendees that because there was not a quorum present and that there would not be any voting throughout the course of the meeting.

Attendance

In-person: Chairman Representative William Marsh, Dr. Sai Cherala, Dr Angela Shepard, Co-Chair Representative Gary Woods, Ms Libby Shannon, and a guest - Jim Shannon

Via Zoom: Dr. Laura Landerman-Garber. Ms. Krista Gilbert, Dr. Elijah Stommel, and guests -Ms Audry Gherkin and Ms Abby Rogers

Absent: Co-Chair Dr. Mary Beth Dinulos, Sen. Cindy Rosenwald, Dr. Richard Lafleur

Minutes

Minutes from the previous meeting were reviewed. A few corrections were submitted via email and will be incorporated into the appropriate draft. Approval of minutes could not be voted upon due to quorum limitations.

ALS Registry

Dr. Stommel did not have any updates. Rep. Marsh stated that there is an LSR in the works related to cyanobacteria that will be of interest to Dr. Stommel's ALS research.

Legislative Updates

Rep. Woods reported that he had a conversation with Rep. Rosemarie Rung about her proposed bill to establish a study commission related to the cyanobacteria in NH lakes. He expressed the importance of understanding the health implications. Dr. Stommel agreed that it goes beyond even the neurodegenerative issues that he is researching. Rep. Woods suggested that

perhaps it would be helpful to look at ways to link the ALS data collection with the proposed cyanobacteria study commission. He described that pursuing a legislatively mandated ALS registry at this time posed challenges. Rep Morse hoped that we might help facilitate the data collection outside of legislative action and allow the grant funding and growing research database to be managed at DHMC.

Rep. Marsh shared that he was trying to move forward legislation that would allow the Rare Disease Advisory Council to meet remotely. He feels that this is a reasonable request given that many of the individuals we serve may be immunocompromised or have other significant health or mobility issues that make in-person meetings unsafe or impractical.

YSD

No update as Dr. Dinulos is out of town.

Newborn Screening

Dr Cherala stated that they are working in collaboration with Medicaid and the hospital association to update current rules to take into account changes to the fee structure funding the program.

Community Outreach/Report on Federal Rare Disease Issues

Ms. Gilbert sent emails to the Council members about the upcoming NORD Orphan Drug Summit happening in October. She also provided a report on the SSI Restoration Act that could increase eligibility and remove penalties for people dependent on SS income. She called attention to the pending Federal Reconciliation Bill that includes Paid Family Medical Leave and limits to OOP prescription costs. Both those items could provide financial relief to rare disease patients and families.

Ms. Shannon reported that she met with the representatives from the offices of Hassan, Pappas, Kuster, and Shaheen to advocate for continued insurance reimbursement parity for telehealth care because of the value that telehealth services bring particularly to rare disease patients. Rep. Marsh related this to the work that he and Rep. Woods have been doing in response to efforts to limit reimbursement for audio only telehealth services here in the state. If the Federal

government extends the existing waiver, we will continue to have reimbursement parity in NH regardless of the proposed bill to end it.

Ms Shannon mentioned that she has been in contact with the Rare Disease Council in Massachusetts and hopes that we can collaborate with them in the future.

Annual Report

Rep. Marsh asked if the group had reviewed the draft Annual Report. He thanked Dr. Cherala and Ms. Gilbert for submitting summaries of the Council's work over the last year for inclusion in the report. Rep. Marsh reminded that the Annual Report is due in November so any suggested edits should be made promptly.

New Business

Dr. Shepard briefly updated the council about the NH Rare Disorders Association education projects. They are beginning with an LDN CME and will also CME's about the newest conditions added to the Newborn Screening panel. These course will be available online, on-demand to providers across New England at no cost.

Next meeting will be held on October 15 and will again be at 29 Hazen Drive in Concord. A Zoom invitation will be sent out prior to the meeting for those unable to attend.

Respectfully submitted,

Angela Shepard, MD, MPH