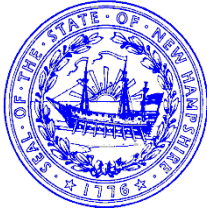


# State of New Hampshire

GENERAL COURT



CONCORD

## MEMORANDUM

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**DATE:** December 1, 2021

**TO:** Honorable Sherman Packard, Speaker of the House  
Honorable Chuck Morse, President of the Senate  
Honorable Paul C. Smith, House Clerk  
Honorable Tammy L. Wright, Senate Clerk  
Honorable Chris Sununu, Governor  
Michael York, State Librarian

**FROM:** Representative William Marsh, Chairman

**SUBJECT:** Annual Report of the Rare Disease Advisory Council.  
RSA 126-A (HB 237, Ch. 24:1) Laws of 2019)

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Pursuant to RSA 126-A (HB 237, Chapter 24:1, Laws of 2019), enclosed please find the Annual Report of the Rare Disease Advisory Council.

If you have any questions or comments regarding this report, please do not hesitate to contact me.

I would like to thank those members of the council who participated. I would also like to acknowledge all those who testified before the council and assisted the council in our deliberation.

Enclosures

cc: Members of the committee

## **ANNUAL REPORT**

### **Rare Disease Advisory Council**

**RSA 126-A (HB 237, Ch. 24:1) Laws of 2019**

**December 1, 2021**

#### **Committee Membership**

Representative William Marsh, Chairman

Senator Cindy Rosenwald

Representative Gary Woods, Vice Chair

Courtney Keane – NHDHHS

Dr. Angela Shepard

Dr. Mary Beth Dinulos

Dr. Richard Lafleur

Krista Gilbert

Dr. Laura Landerman Garber

Elizabeth Shannon

Dr. Elijah Stommel

#### **Council Charge and Purpose:**

The advisory council shall:

(a) Advise the legislature and the department of health and human services on rare diseases in New Hampshire.

(b) Coordinate with other states' rare disease advisory bodies, community-based organizations, and other public and private organizations for the purpose of ensuring greater cooperation between state and federal activities encouraging research, diagnosis, and treatment of rare diseases. Federal agencies may include, but are not limited to, the National Institutes of Health, and the United States Food and Drug Administration.

(c) Explore existing data on rare diseases in New Hampshire collected by the department of health and human services.

(d) Encourage public awareness regarding rare diseases in New Hampshire.

#### **Findings and Recommendations:**

In 2022 the Rare Disease Advisory Council continued to hold meetings in a hybrid fashion as this enabled us to do our work without putting at risk the various members of the Council whose disease or treatment has rendered them immunocompromised. Going forward, it would be most helpful if the legislature amended RSA 126-A allowing remote members to be included in quorum. As of this writing, we have been unable to convene a quorum, and our chair has drafted this report by collating input from members, and it has been approved unanimously by all members able to meet either in person or remotely.

Relevant to our charges above, the Council accomplished the following:

*(a) Advise the legislature and the department of health and human services on rare diseases in New Hampshire.*

We discussed relevant legislation, including HB1013 relative to meetings of the New Hampshire rare disease advisory council. This legislation was not passed and will need to be resubmitted. We discussed HB191, relative to prior authorizations and patient transfers under managed care group health insurance policies, which was not passed and will need to be resubmitted. We discussed three LSRs for 2023 – one by Rep. Maggiore relative to medical food, one by Rep. Berch relative to kidney donations, and a third relative to an ALS registry, which Dr. Stommel will discuss with Rep. Murphy.

We discussed the reimbursement of personal care attendants and direct support professionals, which was included in several bills, but more work may be needed in this area.

*(b) Coordinate with other states' rare disease advisory bodies, community-based organizations, and other public and private organizations for the purpose of ensuring greater cooperation between state and federal activities encouraging research, diagnosis, and treatment of rare diseases. Federal agencies may include, but are not limited to, the National Institutes of Health, and the United States Food and Drug Administration.*

Ms. Shannon participated in Project RDAC trainings. NORD's Project RDAC is designed to optimize existing RDACs and to increase the number of RDACs across the country.

In May 2022 we met with members of the Massachusetts Rare Disease Advisory Council. They are just getting organized and we offered our experience.

The RDAC has continued to develop relationships with other organizations including the Council for Youth with Chronic Conditions, the New Hampshire Occupational Therapy Association, the NH Council on Developmental Disabilities, the NH Rare Disorders Association, the NH Rare Action Network, the Youth and Sudden Death Committee with participation in council meetings and communication.

Ms. Gilbert also serves as a family representative for the BDS redesign systems work.

*(c) Explore existing data on rare diseases in New Hampshire collected by the department of health and human services.*

The issue regarding insurance coverage of low dose naltrexone was discussed. More data and education may be needed and this may be a low priority legislatively.

*(d) Encourage public awareness regarding rare diseases in New Hampshire.*

Efforts in this area continue to be hampered by Covid-19. It remains our hope to eventually revive the effort to have listening forums throughout the state about rare diseases.

Once again, this year there was a rare disease day event. Governor Sununu issued a proclamation. Multiple members of the council recorded videos for a virtual event that the NHRDA (New Hampshire Rare Disease Association) streamed on facebook for rare disease day. Dr Shepard worked with NHRDA to host a live event.

### **Specific issues addressed by members:**

#### **ALS Database / Registry**

Dr. Stommel has worked establishing a registry in Maine and Vermont and believes we can do so in NH at minimal cost to the state. This will require legislation and a more receptive legislature. Rep Murphy will work with him on this.

#### **Medical Formula and Foods**

We discussed on several occasions the lack of coverage for medical food. Rep. Maggiore has agreed to file an LSR to address this subject.

#### **Telehealth**

We discussed on several occasions the tremendous benefit of telehealth in enabling access to subspecialists that telehealth provides Rare Disease Patients, and we encourage the Telehealth Commission to maintain this access.

#### **Youth sudden death**

Dr. Dinulos is section chief of Genetics and Child Development at DHMC and a member of the NH Sudden Death in the Young (SDY) committee. This committee reviews all sudden deaths in children and infants (SUID - Sudden Unexplained Infant Death) in the state of New Hampshire. Criteria include:

- a. All cases must be residents of NH

- b. Children are less than 20 years old and have sudden and unexpected death
- c. Includes drownings in children older than age 5 years and drivers in motor vehicle accidents

This committee has resumed meeting and will have data to report.

Dr. Dinulos is advocating for genetic testing in these children with unexpected death, including comprehensive cardiac panels and comprehensive epilepsy panels. This is an item which will need to be considered as the budget for the next biennium is prepared.

### **Direct Care Workforce**

The BDS system redesign includes the revision of supports and service definitions, provider qualifications, rates for services, budgets for individuals receiving services and wages for providers. The redesign is expected to have significant impacts on the lives of many individuals living with rare disorders in NH. Individuals and families receiving services continue to voice concerns about the level of their involvement in the decision making process. Many are concerned that the plan for a two waiver system is inherently biased toward residential care. The plan to bring individuals with intensive treatment needs back to NH under the system redesign appears unwise when the needs of the current population cannot be met due to the staffing shortages and lack of capacity in NH's provider agencies, hospitals and psychiatric services.

The direct care workforce staffing crisis continues to negatively impact the health and welfare of people with rare disorders and their families. Some individuals report going without support (with the exception of their family) since before the pandemic began.

### **Vacancies**

As neither Rep. Marsh nor Rep. Woods are running for reelection, this council will have vacancies moving forward. We note Rep. Maggiore, Rep. Berch, Rep. Nutter-Upham and Rep. Booras have all had interest in this committee and attended at least once. We feel the next Speaker should take such interest into consideration.

Respectfully Submitted,

Representative William Marsh, Chairman

Attachments: Minutes from 2022 meetings