State of New Hampshire

GENERAL COURT

CONCORD

MEMORANDUM

DATE: **December 1, 2020**

TO: **Honorable Stephen Shurtleff, Speaker of the House**
Honorable Donna Soucy, 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)

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 especially want to acknowledge Robert Stoker as a tireless advocate for rare disease patients who was instrumental in passing HB237 and served on the council until he passed away. 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, 2020

Committee Membership

Representative William Marsh, Chairman	Senator Cindy Rosenwald
Representative Richard Osborne, Vice Chair	Dr. Sai Cherala
Dr. Angela Shepard	Dr. Mary Beth Dinulos
Dr. Richard Lafleur	Krista Gilbert
Dr. Laura Landerman Garber	Robert Stoker
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:

2020 was an organizational year for the Rare Disease Advisory Council. We had just gotten organized when COVID-19 hit and suspended our meetings. As Rare Disease patients obviously have preexisting conditions, we were especially hard hit. However, we successfully reorganized, meeting remotely, and resumed working on our charge listed above.

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 SB690 relative to drug formulary changes and SB685 relative to a drug importation program. The language of these bills was incorporated into HB1280, which was signed into law. We also discussed HB1623, relative to telemedicine, which was signed into law.

(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.

We met with Sharon King from the North Carolina Rare Disease Advisory Council as they were organized before us and had good suggestions about moving forward.

Dr. Stommell contacted multiple people in Massachusetts with the goal of either joining their ALS registry or establishing a NH registry. This is an ongoing goal.

Rep. Marsh discussed HB1623 at the National Organization for Rare Disease annual summit. Our bill is being used as a model for other states.

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

DHHS collects limited data at this point, however, Dr. Cherala did review with us the recent expansion of the newborn screening program.

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

Our initial plan to establish listening sessions at DHHS offices around the state was blocked by the COVID-19 pandemic. We are now exploring the idea of doing this remotely using a Facebook group.

The New Hampshire Rare Disease Advisory Council in conjunction with the NH Rare Disorders Association and NH RAN held two events for Rare Disease Day. The first was a luncheon with state legislators and other patient advocacy groups to introduce the Council and highlight rare disorders. The second event was held at a local restaurant and invited families and rare disease patients to meet council and share stories.

The New Hampshire Rare Disease Advisory Council, worked in collaboration with the New Hampshire Rare Action Network and the New Hampshire Council for Youth with Chronic Conditions to create a survey to assess the needs of families and individuals in New Hampshire. It was presented to participants online via SurveyMonkey June 2020. National and state-wide patient organizations and government programs encouraged participation through their social media and email lists. Initial findings were presented to the RDAC during the July meeting. Final results were presented during the August 2020 RDAC meeting. The summary includes information about respondents' diagnosis, insurance coverage, access to providers, transportation, prescription medication and treatment, in home supports, awareness of legislation affecting the rare community,

and quality of life. Recommendations to address the needs of families and individuals with rare disorders in NH are also included.

Respectfully Submitted,

Representative William Marsh, Chairman

Attachments:
Minutes from 2020 meetings