HB 237: Establishing the Rare Disease Advisory Council

Title/Introduction: AN ACT establishing the New Hampshire rare disease advisory council. This bill will help improve state policy for our community by giving patients and other members of the rare disease community a stronger voice in government.

History/Context: It is estimated that there are over 100,000 New Hampshire residents living with a rare disorder. With over 7,000 known rare diseases, it is incredibly difficult for anyone – let alone state policymakers – to have an in-depth understanding of rare diseases. Consequently, this lack of awareness contributes to some common difficulties that rare disease patients must face every day, such as delays in diagnosis, misdiagnosis, difficulty paying for treatment, and limited access to medical specialists.

The purpose of the New Hampshire Rare Disease Advisory Council is to act as an advisory body on rare diseases to the legislature and all other relevant state and private agencies. The council will coordinate with other states rare disease advisory bodies, and organizations, review any data on rare diseases in the state, and raise public awareness regarding rare diseases in New Hampshire. The council will also be responsible for reviewing any data on rare diseases in New Hampshire collected by the department of health and human services and developing strategies to raise public awareness regarding rare diseases in the state.

The Council will give rare disease patients, families, caregivers, and other stakeholders an opportunity to make formal policy recommendations to state elected officials and other state leaders about the pressing issues facing the rare disease community. Moreover, the councils’ work will be accomplished with participation from diverse stakeholders that represent the entire rare community.

Pros:

- Increase awareness of rare diseases to help reduce suffering and save lives.
- It will facilitate the sharing of information both within New Hampshire and with other states.
- It will provide a forum for making recommendations to state elected officials regarding pressing issues facing the rare disease community.
- Complaint process remains unchanged, handled by BON.

Cons:

- There is no downside to this legislation.
- Some administrative issues need to be worked out between this proposed Council and the Newborn Screening Council to insure no duplication of effort.

Committee: House Health, Human Services and Elderly Affairs

Position of the CGA: Supports HB 237.

Click here to access HB 237 on the NH General Court website.

The House HHS&EA Committee held a hearing on HB 237 on January 22, 2019. NHNA attended and signed-in in support of this bill. The bill was referred to sub-committee by the Chair to discuss and resolve concerns about potential redundancy between the proposed Rare Disease Council and the already established Newborn Screening Advisory Council. Executive session of HHS&EA is scheduled for 2-12-19, starting at 10:00 am LOB205. HHS&EA voted (22:0) ought to pass with amendment #2019-0405h.

This bill Passed with Amendment in the House on 02-28-19. This amendment add the appointment of a physician or medical researcher specializing in ALS to the Council and changes some of the responsibilities of the Council.

This bill was introduced to the Senate on 03-14-19 and referred to the Senate Health & Human Services Committee. A hearing of the Senate H&HS Committee was held on 04-02-19 and the Senate H&HS Committee voted (4:0) this bill Ought to Pass. This bill voted Ought to Pass by full Senate on 04-11-19. Bill ordered enrolled on 04-25-19 and is ready to be signed by the Governor.

HB 237 was signed by Governor Sununu on 05-15-19: Chapter Law 0024.