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TTY: 771
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February 6, 2025

The Honorable Susan R. Donovan, Chair
House Committee on Health and Human Services
State House
82 Smith St.
Providence, RI 02903

RE: H 5023 – An Act Relating to Health and Safety – Rare Disease Advisory Council

Dear Chair Donovan:

Please accept this letter regarding H 5023, legislation that would establish a Rare Disease Advisory Council within the Rhode Island Department of Health (RIDOH). The act would take effect upon passage.

Although RIDOH applauds the intent of the proposed legislation, this bill would have a significant financial impact on RIDOH. RIDOH would need adequate staffing resources to meet the requirements of H 5023. Specifically, RIDOH would require a 0.5 FTE at an initial annual cost of \$63,310 (salary and fringe) to collaborate with the Council Chair to fulfill the functions of the Council, including, but not limited to, the following: recruiting individuals to serve on the Council; collecting the information needed for the Council to review; convening any public hearings and/or soliciting comments from the general public; organizing, taking minutes, and posting meeting agendas and minutes; preparing annual reports, protocols, and recommendation documents; conducting any relevant research needed for Council's review; coordinating relevant meetings with stakeholders; and developing and updating the Council's website.

Other states have established Rare Disease Advisory Councils that have staff and funding attached to the Council. For instance, in FY23, the Minnesota Rare Disease Advisory Council operated with 1 FTE and an annual appropriation of \$150,000. In Colorado, for FY23, an Act appropriated \$80,567 from the general funds to support the Colorado Department of Health for administration and support costs associated with the Council.

Although Rhode Island would not be an outlier among states nationally or regionally if H 5023 were enacted, RIDOH would have difficulty supporting and staffing the activities outlined in the bill without adequate funding to hire the necessary staff to manage the work of the council and potentially to support patient and caregivers' travel and time spent at meetings and doing Council work.

I thank you for the opportunity to comment on the proposed legislation and would be happy to work with the sponsors and members of the Committee to identify the financial resources needed

to implement the provisions in H 5023.

Sincerely,

A handwritten signature in black ink that reads "Jerome M. Larkin". The signature is written in a cursive style with a long horizontal flourish extending to the right.

Jerome M. Larkin, MD
Director

CC: The Honorable Members of the House Committee on Health and Human Services
The Honorable Brian Patrick Kennedy
Nicole McCarty, Chief Legal Counsel
Lynne Urbani, Director of House Policy