September 15, 2023

Massachusetts Legislature
ATTN: Joint Committee on Public Health
24 Beacon St.
Boston, MA 02133

Re: H 2256 Interstate Medical Licensure Compact

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit testimony in support of H 2256 *An Act authorizing Massachusetts entry into the Interstate Medical Licensure Compact*. The EveryLife Foundation is a nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments, and cures.

During the pandemic, federal and state lawmakers issued temporary waivers under a public health emergency to allow clinicians to practice medicine across state lines, including via telehealth. Now, with the rollback of the state public health emergency declarations, many patients have lost access to their out-of-state providers. In Massachusetts, multiple providers have described instances where patients who live in bordering states needed to drive just over state lines to conduct telehealth appointments from a parking lot.[1] In January, Massachusetts' Health Policy Commission recommended the state consider policy changes, including interstate compacts, to enable providers to deliver telehealth services to out-of-state patients.[1]

Joining the Interstate Medical Licensure Compact will benefit Massachusetts physicians who see patients from all over the country and the Massachusetts residents with complex rare diseases who must travel long distances to receive care from out of state physicians if no experts are in Massachusetts. Kerry, a resident of Fitchburg, MA shared with us that she must travel to Rhode Island to receive care from one of the few specialists for her rare condition. She also visits a provider in Maryland. In her own words, "as a rare disease patient, you have to go where you'll be treated...One of my biggest challenges is people assuming that Boston has the best care for everything."

Kerry is one of many patients who must travel to receive specialty care that could benefit from Massachusetts joining the IMLC. A 2019 survey found that 39% of rare disease patients needed to travel more than 60 minutes for care. In some instances, approximately 17% of survey respondents, rare disease families face the need to permanently relocate just to be closer to the few experts for their disease.[2] This

[1] Commonwealth of Massachusetts Health Policy Commission. January 2023. Telehealth Use in the Commonwealth and Policy Recommendations.
[2] The National Organization for Rare Disorders. November 2020. Barriers To Rare Disease Diagnosis Care And Treatment In The US: A 30-Year Comparative Analysis.

travel may not be an option for patients with complex medical conditions, mobility challenges, or financial barriers.

Limited access to specialty care and financial constraints to travel long distances commonly contribute to delayed diagnoses for rare disease patients. Navigating a rare disease diagnosis can require more than 6 years and 17 medical interventions, on average, after symptoms begin, according to the National Economic Burden of Rare Disease Study. These interventions can include hospitalizations, emergency room visits, out-of-state specialist appointments, and other health-related activities.[3] Reasons for lengthy diagnostic periods include limited access and difficulty traveling to expert providers often outside of a patient's insurance network and geographic region. This diagnostic journey can also be incredibly costly for patients. An in-depth look at the diagnostic odyssey experienced across 7 diseases found the economic impact of medical costs and lost income for individuals and families ranged from $86,000 to $517,000.[4]

By joining the Interstate Medical Licensure Compact, Massachusetts can streamline the licensing process for physicians by reducing duplicative paperwork to a single application. This streamlined process provides an expedited pathway to licensure for qualified physicians and in turn increases patient access to out-of-state providers. This practice is extremely beneficial for patients in underserved or rural communities, individuals attempting to reach expert care from a distance, and patients with complex medical conditions who are unable to travel.

Expanding access and limiting the cost burden to reach expert care will help ensure patients with one or more of the estimated 10,000 rare diseases can receive the expert clinical care they need. We hope that Massachusetts will join the other 38 states and D.C. that have passed similar legislation to retain continuity of care for all patients, including those with rare diseases. **We urge you to support H 2256 and thank you for your dedication to our rare disease patient community.** If you have any questions, please contact Emily Stauffer at estauffer@everylifefoundation.org.

Emily Stauffer
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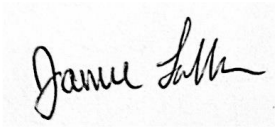

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Julia Jenkins, Executive Director, EveryLife Foundation for Rare Diseases
Frank Sasinowski, Chair of the Board, EveryLife Foundation for Rare Diseases

[3] EveryLife Foundation for Rare Diseases. April 2022. The National Economic Burden of Rare Disease in the United States in 2019.
[4] EveryLife Foundation for Rare Diseases. September 2023. The Cost of Delayed Diagnosis in Rare Disease: A Health Economic Study.