January 26, 2022

Virginia House of Delegates
ATTN: Health, Welfare and Institutions Subcommittee 3
900 East Main Street
Richmond, VA 23219

Re: HB 2073: Interstate Medical Licensure Compact and Commission

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit testimony in support of HB 2073: Interstate Medical Licensure Compact and Commission. 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, patients have lost access to their out-of-state providers. This loss of access has significantly impacted rare disease patients who frequently travel far to seek care, especially specialty care that is often outside their state. The Interstate Medical Licensure Compact increases patient access to expert care in person and via telemedicine. 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 rare disease patients can receive the expert clinical care they need. A 2019 survey found that 39% of rare disease patients had 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.[1] Roughly every 1 in 10 people are impacted by one or more of the 10,000+ rare diseases. That's roughly 30 million people who may have experienced disruption in their care by losing convenient access to providers out of their state.

Additionally, limited access to specialty care and financial constraints to travel long distances commonly contribute to delayed diagnoses for rare disease patients. Unfortunately, the average time to receive a diagnosis from the first rare disease symptom is 6.3 years after visiting about 17 healthcare professionals, according to the National Economic Burden of Rare Disease Study.[2] Reasons for this lengthy diagnostic period include limited access and difficulty traveling to expert providers often outside of a patient's insurance network and geographic region.

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[1] The National Organization for Rare Disorders. November 2020. Barriers To Rare Disease Diagnosis Care And Treatment In The US: A 30-Year Comparative Analysis.
[2] EveryLife Foundation for Rare Diseases. April 2022. The National Economic Burden of Rare Disease in the United States in 2019.

Lastly, patients and providers alike agree that telehealth across state lines is important for patient access and treatment.[3]

- 84 percent of health care practitioners support the option to provide telehealth across state lines, along with 72 percent of patients.
- One in five practitioners surveyed has provided health care services across state lines under a waiver since the pandemic began.
- Health care providers expect that state actions to end broad access to care across state lines have had a net negative impact on patient care.

I want close by sharing with you an example from our rare disease community. Ashley is from Virginia Beach, Virginia, and was diagnosed with Lambert-Eaton myasthenic syndrome (LEMS) in 2015. LEMS is a rare condition that affects the muscles' ability to contract properly, resulting in muscle weakness and other symptoms. Ashley is fortunate because a neurologist that specialized in LEMS lived in her area when she was undergoing the diagnosis process and she received a diagnosis after only one year of waiting, much quicker than most rare disease patients. However, Ashley can no longer receive care from a LEMS specialist because the specialist that lived in her area recently moved out of the state of Virginia. Ashley told us that she is very passionate about accessibility to treatment and wishes there were more specialists for her rare disease, but if VA joins the IMLC as this bill proposes, Ashley would not have had a disruption in her care until the day comes when more VA providers have the expertise to meet her unique needs.

Thank you for the opportunity to testify on behalf of HB 2073: Interstate Medical Licensure Compact and Commission. We are excited at the prospect of Virginia joining the other 37 states that have enacted similar legislation to retain continuity of care for all patients, including those with rare diseases. We strongly encourage you to support this bill and ensure that all Virginia residents with a rare disease can maintain access to care across state lines.

Emily Stauffer
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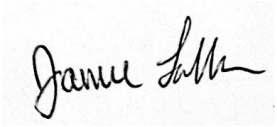

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CC:

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Annie Kennedy, Chief of Policy, Advocacy and Patient Engagement, EveryLife Foundation for Rare Diseases

[3] Alliance for Connected Care. April 2022. Patients and Practitioners Agree – Telehealth Is Important for Patient Access, Health Care Workforce.