July 26, 2023

Re: HB 681 Interstate Medical Licensure Compact

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit testimony in support of HB 681 *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, the North Carolina Medical Board issued limited emergency licenses to physicians licensed in other states to supplement the state's need for qualified physicians to provide care to its residents. These emergency licenses granted patients greater access to care via telehealth. However, with the rollback of the state public health emergency and the decision by the North Carolina Medical Board to no longer issue emergency licenses to out-of-state physicians, many patients have lost access to their out-of-state providers. This loss of access has negatively affected rare disease patients who frequently travel far to seek care, especially specialty care that is often outside their state.

Currently, North Carolina does not participate in physician licensing reciprocity with any other states, creating administrative burdens for physicians who choose to practice in the state. HB 681 would add North Carolina to the Interstate Medical Licensure Compact, reducing duplicative paperwork for physicians to a single application while retaining the states' rigorous medical licensing standards. This streamlined process provides an expedited pathway to licensure for qualified physicians and in turn increases patient access to out-of-state providers. This increased access would be extremely beneficial for patients with complex medical conditions who are unable to travel to receive care, especially specialty care that is often outside their state.

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. 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]

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

[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.

period include limited access and difficulty traveling to expert providers often outside of a patient's insurance network and geographic region.

Multiple North Carolina rare disease patients have shared with us how access to expert care has impacted them. Haley M., an Arden resident, was diagnosed with a rare condition at 26 years old. Before her diagnosis, she was unable to participate in daily life activities for months and was dismissed by several physicians who told her she was not sick. Now that she is receiving care from a specialist for her condition, she has been able to work, return to graduate school, and advocate for people with disabilities. Haley's local specialist coordinates with a neuromuscular specialist that is almost 5 hours away. Every year, Haley must undertake the financial and physical burden of traveling to see the neuromuscular specialist to receive care. During the pandemic, however, she was able to receive care virtually, requiring less travel and time away from work and school. Haley shared with us that she hopes her story will inspire her elected officials to find ways to improve access to provider care for people like her living with rare diseases.

Thank you for the opportunity to testify in support of HB 681 *Interstate Medical Licensure Compact*. We are excited at the prospect of North Carolina joining the other 40 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 Hawai'i residents with a rare disease can maintain access to care across state lines.

Emily Stauffer
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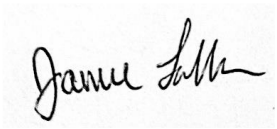

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