February 10, 2023

Hawai'i Senate
ATTN: Committee on Health and Human Services
415 South Beretania Street
Honolulu, HI 96813

Re: SB 674: Relating to the Interstate Medical Licensure Compact

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit testimony in support of S.B. 674 *Relating to 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, a Hawai'i executive order permitted licensed physicians to meet with patients via telehealth without an in-person consultation or a prior existing physician-patient relationship. Though this executive order is no longer in effect, the Hawai'i legislature passed S.B. 970 in 2021 which authorized the establishment of a physician-patient relationship via telehealth if the physician is licensed to practice in Hawai'i. These executive and legislative actions granted patients greater access to care via telehealth.

By joining the Interstate Medical Licensure Compact, Hawai'i can complement its previous efforts to increase patient access to expert care via telemedicine by further streamlining the licensing process for physicians. The Interstate Medical Licensure Compact reduces duplicative paperwork for physicians to a single application while retaining 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,

[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.

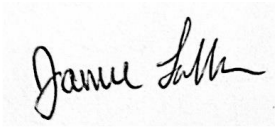
according to the National Economic Burden of Rare Disease Study.[2] Reasons for this lengthy diagnostic period include limited access and difficulty traveling to expert providers often outside of a patient's insurance network and geographic region.

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.

Thank you for the opportunity to testify in support of S.B. 674 *Relating to the Interstate Medical Licensure Compact*. We are excited at the prospect of Hawai'i 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 Hawai'i residents with a rare disease can maintain access to care across state lines.

Emily Stauffer
State Policy Manager
EveryLife Foundation for Rare Diseases



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CC:

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

[2] EveryLife Foundation for Rare Diseases. April 2022. The National Economic Burden of Rare Disease in the United States in 2019.
[3] Alliance for Connected Care. April 2022. Patients and Practitioners Agree – Telehealth Is Important for Patient Access, Health Care Workforce.