



February 10, 2023

The Honorable Joy A. San Buenaventura
Chair, Hawai'i Senate Committee on Health & Human Services
Hawai'i State Capitol
415 South Beretania Street
Honolulu, HI 96813

The Honorable Henry J.C. Aquino
Vice Chair, Hawai'i Senate Committee on Health & Human Services
Hawai'i State Capitol
415 South Beretania Street
Honolulu, HI 96813

Dear Chair San Buenaventura and Vice Chair Aquino,

On behalf of the one-in-ten individuals in Hawai'i living with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for your consideration of SB 674 during today's hearing. SB 674, if passed, would allow Hawai'i to join the Interstate Medical Licensure Compact (IMLC), an agreement between participating U.S. states to work together to significantly streamline the medical licensing process for physicians who want to practice in multiple states, therefore making it possible to improve patient access to medical specialists using telehealth. NORD urges you to support SB 674 and pass it favorably out of this Committee.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. We believe that all individuals with a rare disease should have access to quality and affordable health care that is best suited to meet their medical needs.

In the United States, a rare disease is defined as any disease, disorder, illness, or condition affecting fewer than 200,000 people.¹ Unfortunately, there are often very few specialists who have expertise in any given rare disease. As a result, patients frequently travel significant distances, often across state lines, to see a medical specialist qualified to provide appropriate treatment for their condition. In a survey of rare disease patients conducted by NORD in 2019, 40% of respondents reported traveling 60 miles or greater to see a medical specialist with expertise in their rare condition.²

While rare disease patients faced serious barriers to care even before the COVID-19 pandemic, these barriers increased significantly within the rare disease community as the pandemic shocked the U.S. and global health care systems. In a survey of rare disease patients and caregivers conducted by NORD in the summer of 2020, 79% of respondents reported experiencing a canceled medical appointment due to COVID-19.³ Fortunately, 88% of survey respondents reported being offered a telehealth appointment, and 92% who accepted the offer of a telehealth visit reported having a positive experience with telehealth.⁴ Looking ahead, many patients and providers have signaled that they appreciate and have



benefitted from the expanded use of telehealth and want to see its permanent integration into our health care system.

As mentioned previously, rare disease patients are often required to travel long distances, including across state lines, to access necessary and appropriate medical care. Currently, many state's licensure laws create barriers to care by limiting providers ability to see patients across state lines. This not only complicates access for patients, but also creates additional burdens for clinicians who want to see out-of-state patients who lack access to appropriate care closer to home. This is especially relevant for people with rare disorders living in Hawai'i, as many are forced to travel by plane to see providers based in other states. This barrier to care can prove insurmountable for some due to the significant costs associated with air travel and lodging, among other expenses.

SB 674 would make it easier for providers in other states to obtain licensure in Hawai'i, allowing those providers to see patients located in Hawai'i via telehealth. This would not only expand access to out-of-state medical specialists for individuals with diagnosed rare diseases living in Hawai'i, but also to diagnostics, potentially cutting down the often-extensive diagnostic odyssey patients go through to obtain an accurate diagnosis. In passing SB 674, Hawai'i would join 37 other U.S. states, the District of Columbia, and the Territory of Guam as participants in the Interstate Medical Licensure Compact.

Once again, on behalf of the Hawai'i rare disease community, we thank you for your consideration of SB 674 and urge its swift passage. For any questions, please feel free to contact Alyss Patel at apatel@rarediseases.org.

Sincerely,

Alyss Patel
State Policy Manager, Western Region
National Organization for Rare Disorders