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Rare & Ready: A Genetic Condition Coalition is a national grassroots advocacy coalition of non-profit rare disease patient organizations. Included in these organizations are patients, caregivers, and advocates based in Hawaii. Our efforts are not disease- or treatment-specific; rather, we seek to address concerns of the broader rare community.

An important policy priority for Rare & Ready is to remove barriers to physician visits conducted via telehealth. Residents of Hawaii do have access to excellent hospitals and care centers right here on the islands, but it is also important to ensure they can access telehealth visits with out-of-state, mainland physicians when appropriate and necessary. For instance, when an out-of-state physician has the very specific expertise required for a rare disease. Existing licensure law means a virtual visit with a physician in another state would not currently be covered in any uniform or clear way.

To address this care gap, we urge you to support legislation to have Hawaii join the Interstate Medical Licensure Compact. SB 674 has already passed the Senate and HB 666 is awaiting consideration by the full chamber of the House of Representatives.

Interstate Medical Licensure Compact (IMLC), is an agreement among participating U.S. states to work together to significantly streamline the licensing process for physicians who want to practice out-of-state. It offers a voluntary, expedited pathway to licensure for physicians who qualify. The Compact has the potential to increase access to health care and extend the reach of physicians through telemedicine.

This is uniquely important for patients with rare conditions. There are a limited number of medical experts who truly understand and treat rare conditions, but they may be located and licensed outside of Hawaii. Residents of Hawaii should have the same access to rare disease experts as residents of the mainland. Having visits conducted virtually, where appropriate, is also critical for rare disease patients, as many face increased health risks when leaving home and getting on a flight. Additionally, many rare disease patients are children, and travel to appointments is already onerous, time-consuming, and expensive for them and their families.

Your support for Compact participation will make it easier for rare disease patients in Hawaii to access the expert medical care they need when and where they need it.

Sincerely,

39 Members of the Rare & Ready Coalition