

RARE → READY

A GENETIC CONDITION COALITION



February 21, 2023

Dear Members of the Virginia General Assembly,

Rare & Ready: A Genetic Condition Coalition is a national grassroots advocacy coalition of 46 non-profit rare disease patient organizations. Included in these organizations are patients, caregivers, and advocates based in the commonwealth of Virginia. 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 Virginia have access to renown teaching hospitals and care centers right here in the Commonwealth, but it is also important to ensure they can access telehealth visits with out-of-state physicians when appropriate and necessary. For instance, when an out-of-state physician has the very specific expertise required for a rare therapy. 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 Virginia join the Interstate Medical Licensure Compact. One such bill has been introduced in the House of Delegates this session, H.B. 2073.

The Interstate Medical Licensure Compact 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, and they may have availability but may be located and licensed out-of-state. Having visits conducted virtually, where appropriate, is also critical, as many rare disease patients face increased health risks when leaving home. 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 Virginians to access the expert medical care they need when and where they need it.

Sincerely,

37 Members of the Rare & Ready Coalition

Learn more at www.rareandready.org