

A GENETIC CONDITION COALITION

Patients with Rare and Genetic Disorders Deserve Timely Access to Care by Medical Experts

Many states do not allow patients with rare conditions to use telehealth to access physician specialists who practice medicine in other states.

Rare & Ready: A Genetic Condition Coalition fights for policies that will ensure patients with rare conditions get the care they need. With a limited number of medical experts in their rare conditions, telehealth across state lines is critical to accurate diagnosis and good disease management.



Patients with Rare Conditions Need Expert Medical Care

- If you or your loved one is living with a rare condition, you know finding healthcare providers who really understand the disease is difficult.
- Often, good treatment is far from home and may even be in another state.



Telehealth Improves Patient Access to Care

- The COVID-19 pandemic ushered in state flexibilities with regard to telehealth, and we learned just how much virtual medical visits help patients especially those with rare conditions get the care they need.
- Laws that expanded the availability of telehealth should be extended past the pandemic to ensure these services continue to be covered.



Where You Live Should Not Be an Impediment to Expert Care

- Some states make it hard for out-of-state providers to become licensed to provide care to in-state residents.
- Without a license to practice medicine in the state where the patient lives, a physician cannot provide care and consult (even virtually).
- Since physician licensure rules are not uniform, patient access to virtual physician visits across state lines varies dramatically across the country.



Let's Fix the Problem

- States should adopt policies exempting out-of-state physician experts (who are licensed and in good standing in their own states) from secondary in-state licensure requirements when they are providing care via telehealth for patients with rare disorders.
- All states should consider joining the Interstate Medical Licensure Compact to provide physicians an easier path toward licensure so they can provide care to patients from out-of-state.

If you agree with these principles, **join the Rare & Ready Coalition today!**Join the conversation and tell your rare disease story on X @rare ready

