Dear [Legislator or RDAC member]:

I am writing as a member of Rare & Ready: A Genetic Condition Coalition. We are a nationwide grassroots advocacy coalition of 46 non-profit rare disease patient organizations. Our efforts are not disease- or treatment-specific; rather, we seek to address concerns of the broader rare community. As a resident of [state] I believe action must be taken to improve patient access to rare disease care and medicines.

Specifically, patients with rare and genetic disorders need and deserve access to telehealth visits with out-of-state specialists as well as timely access to medicines approved by the Food and Drug Administration (FDA).

**Coverage for Telehealth Services with Out-of-State Providers**

As you know, coverage for telehealth services was greatly expanded during the pandemic. Telehealth access particularly benefitted those with rare conditions, who may have increased health risks every time they leave their home and who often found the rare disease specialists they need to be unavailable or at capacity.

However, telehealth flexibilities during the pandemic often did not extend to *interstate telehealth* (telehealth visits with out-of-state physicians), an important and devastating gap.

With a limited number of medical experts available who truly understand and treat rare conditions, telehealth visits with out-of-stateproviders are critical to accurate diagnosis and good disease management. For rare disease patients, good treatment is oftentimes far from home, and may even be in another state. And considering many rare disease patients are children, travel out of state for them and their families is already onerous, time-consuming, and expensive.

I urge you to expand telehealth flexibilities and create exceptions to in-state physician licensure requirements when an out-of-state physician provides care to an in-state rare disease patient (or a consult to an in-state doctor) via telehealth.

**Timely, Meaningful Access to FDA-Approved Therapies**

Patients with rare and genetic disorders need and deserve timely access to FDA-approved medicines. Rare & Ready supports mitigating the programmatic access hurdles put in place by Medicaid fee-for-service (FFS) and Medicaid managed care organizations (MCOs). I encourage you to advocate for the following three key principles in our state Medicaid program:

1. Medicaid FFS and Medicaid MCOs should have an expeditious and transparent process for both clinical reviews and developing coverage criteria for new drugs for rare conditions.
2. Patient access to therapies for rare conditions in Medicaid FFS and in Medicaid MCOs must not be limited by coverage criteria that are more restrictive than the indications and usage section of the FDA-approved label.
3. Step therapy exceptions for rare disease therapies should be provided, as well as reasonable timelines for decision making and appeals.

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As a policy influencer, the decisions you make affect real people like me, who live with a life-altering rare disease or care for loved ones with these conditions. We spend countless, precious hours on the phone trying to get appointments scheduled, therapies or services approved, or exceptions granted. Some of us are parents who have children with fatal diseases. We quite literally do not have hours to waste.

As you are reviewing your policy and legislative priorities over the course of the year, I ask you to please keep the rare community in mind. Please listen to our stories and act to ensure patient access to interstate telehealth visits and life-changing therapies.

If you would like additional information or wish to talk with me or another patient or caregiver involved with Rare & Ready who can directly share their experiences with you, please contact [email].

Thank you,

[Name/email]