



Dear Colleagues,

Access to comprehensive care for people living with rare disorders has challenged us all. Insurers – both public and private – often place limits and time delays on the treatments we need. The impact of restrictive coverage policies can be devastating to our communities. In an effort to ensure that patients with rare conditions get the care they deserve, advocacy group leaders have collaborated to develop federal legislative language, **EPICrD – the Ensuring Parity through Individualized Care for Rare Disorders Act** – that comprehensively addresses disparities in Medicaid coverage of treatments, items, supports, and services for rare conditions.

We keenly appreciate that access problems extend beyond Medicaid; but, we also recognize that coalescing now around federal Medicaid policy is more politically viable and will serve as an important steppingstone toward increasingly more comprehensive reforms.

Within Medicaid, EPICrD would among other things:

- Provide coverage of therapies consistent with the use for which products were approved by the Food and Drug Administration (FDA);
- Limit prior authorization and other coverage restrictions;
- Leave determination of medical necessity in the hands of healthcare providers;
- Facilitate access to multi-disciplinary teams of specialists, including telehealth; and
- Provide coverage of other medically necessary items and services, including durable medical equipment, home infusion, medical foods, and medical supplies, that are necessary for care

This is not a bill just about drugs – it is a legislative solution that looks at all aspects of care people with rare conditions need Medicaid programs to cover. It is an approach that will have a direct impact on patients' ability to get the care they need.

To make progress on this important legislation, we need broad support from the rare disease community. We urge you to learn more (see [www.EPICrD.org](http://www.EPICrD.org)) and join us.

Your partners in advocacy,

BDSRA Foundation

Cure Sanfilippo Foundation

debra of America

Little Hercules Foundation

MLD Foundation

National MPS Society

Taylor's Tale

The National Organization of African Americans with Cystic Fibrosis