Prior Authorization Reform

What is Prior Authorization?

Prior authorization (PA) is a cost-containment process used by insurance companies—especially pharmacy benefit managers (PBMs) and health plans—that requires patients or their healthcare providers to obtain approval before a specific medication, procedure, or treatment is covered. The goal is to ensure the treatment is medically necessary and cost-effective. However, in practice, this process can be slow, burdensome, and opaque.

Why Do Rare Disease Advocacy Groups Want Reform?

Rare disease advocacy groups are pushing for prior authorization reform because:

1. **Delays in Care Can Be Dangerous**
   For individuals living with rare diseases, delays caused by PA can lead to rapid deterioration, irreversible damage, or even death. These patients often require time-sensitive, specialized care.
2. **Administrative Burden on Families and Providers**
   Patients and caregivers already face significant emotional and logistical challenges. The time-consuming PA process adds unnecessary stress and can require repeated paperwork, appeals, and follow-ups—especially when the disease is poorly understood.
3. **Inappropriate Denials**
   Many rare diseases don't fit into standardized treatment algorithms. As a result, treatments that are evidence-based for rare conditions are frequently denied due to lack of awareness or rigid criteria that don't reflect real-world needs.
4. **Lack of Specialist Input**
   Decisions are often made by reviewers who may not have expertise in the rare disease being treated, leading to inappropriate delays or denials of medically necessary care.
5. **Barrier to FDA-Approved Treatments**
   Even when a treatment is FDA-approved specifically for a rare disease, PA can block access—either outright or by requiring patients to "fail first" on less appropriate therapies.

Bottom Line:

Prior authorization reform is critical to ensure that people living with rare diseases have timely, uninterrupted access to the treatments they need. Advocacy groups are calling for greater transparency, faster response times, streamlined processes, and input from rare disease experts in decision-making.