2025 Policy Overview

ERDC Policy Purpose

ERDC focuses it’s top policy priorities on systemic issues that impact access to care and treatments for people with rare disease. Specifically we work to:

1. Break down policy issues into bite-size education/action alerts to engage the rare disease community in advocacy.
2. Address systemic barriers that inevitable impact access for the rare disease community.

Summary

	Engage	**PBM Reform** **IRA Unintended Consequences: Orphan Cures Act, Orphan Exemption, Epic Act, Medicare Negotiations Impact on Medication Availability** **Prior Authorization Improvements** **Safe Step Act** **Social Security and Medicare Preservation** **Impact of Tariffs on Rare Disease, Medication Access and Medication Pricing**
	Support	**CMS Rules** **Telehealth Rules** **340B Reform** **Pediatric Review Voucher** **Expanded Access for Rare Disease (FDA)** **Prescription Drug Affordability Boards**

ERDC Coalition Membership

- *Save Rare Treatments Taskforce*
- *Patient Pocket Protectors*
- *Alliance for Patient Access (AfPA) Rare Disease Working Group*
- *Rare Disease Advisory Council (RDAC)*
- *BIO Advocacy*
- *Rare Action Network (NORD)*
- *FDA Rare Disease Innovation Hub*
- *State Access to Innovate Medicines Coalition (SAIM Coalition)*
- *EveryLife Foundation for Rare Disease Community*
- *MapRx*

EOSINOPHILIC & RARE DISEASE
COOPERATIVE