RARE READY

A GENETIC CONDITION COALITION

Patients living with rare and genetic disorders often have limited treatment options, with 95 percent of such conditions lacking any FDA-approved therapies. State efforts to create Prescription Drug Affordability Boards (PDABs), while intended to make drugs more affordable for health plans, can deter the development of and access to critical medical innovations. The implications are most profound for patients living with a rare disease.

What are Prescription Drug Affordability Boards, or PDABs?

PDABs are unelected boards set up by state legislators to cap prescription drug reimbursement for certain health plans in the state.

Rather than fostering cost savings and enhancing patient affordability, the outcome of a PDAB is an environment where access to innovative therapies is restricted. This unfortunate reality will predominantly impact rare disease patients.

Do PDABs Help Rare Patients?

No. PDABs do not lower patient copayments, reduce premiums, create health system transparency, or increase access to care for rare patients.

What Impact Will PDABs Have on Access to Innovative Therapies?

PDAB reimbursement caps could result in less rare disease research, fewer new treatments for patients, and restricted patient access to medicines.

What Can I Do?

- Talk to your state legislators about the unintended consequences of PDABs.
- Ask your state legislators to defeat PDAB legislation or add a critical exemption for rare disease therapies.
- Advocate for other legislative solutions to ensure medication affordability for patients:
  - Ban copay accumulators.
  - Adopt meaningful reforms for health plans and pharmacy benefit managers (PBMs).
  - Facilitate value-based purchasing arrangements.

Learn how to get involved by visiting **rareandready.org**
Join the conversation and tell your rare disease story on X **@rare_ready**

Supported by BioMarin, CSL Behring, and Sanofi