



February 17, 2026

Testimony Opposing SB 2933  
COMMITTEE ON HEALTH AND HUMAN SERVICES  
COMMITTEE ON COMMERCE AND CONSUMER PROTECTION

The Rare & Ready Coalition would like to express our concern with SB 2933, a bill to establish a Prescription Drug Affordability Board (PDAB) in Hawaii. While we appreciate the inclusion of a rare disease exemption in the bill, we respectfully urge you to strengthen this language to ensure meaningful protections for rare disease patients, **two-thirds of which are children.**

The Rare & Ready Coalition represents 115 non-profit organizations working to ensure rare disease patients get timely access to the care they need. We are alarmed by the devastating impact PDABs will have on access to life-saving rare disease therapies.

**One in ten people live with a rare disease.** Those living with rare, genetic diseases have extremely limited treatment options, with 95 percent of such conditions with no FDA-approved therapies. State efforts to create PDABs, while intended to make drugs more affordable for health plans, will deter access to critical medical innovations.

PDABs threaten the development of future rare disease treatments by creating pricing uncertainty for medications that serve small patient populations. Products for these vulnerable patient populations, such as plasma-derived therapies, require significant investment and depend on complex manufacturing. PDABs strip away the patient protections afforded by orphan drug designation, leaving individuals with rare conditions at greater risk of losing access to the only therapies designed to treat them.

**PDABs do not lower patient copayments, reduce premiums, or increase access to care for rare patients.** We have found that PDABs can prevent insurers and pharmacies from purchasing medications exceeding government-set prices, taking away treatment options for patients.

We urge the committee to hear directly from rare disease patients before making any decisions. We welcome the opportunity to connect you to those who are directly impacted—please reach out to the coalition administrator at [kari.lato@rx4good.com](mailto:kari.lato@rx4good.com) to schedule a meeting with **your rare disease constituents.**

Sincerely,

Rare & Ready Coalition Members