WI Rare Disease Patients to Rally for Improved Newborn Screening, Cole's Act

Wisconsin Rare Disease Advocacy Day to Include Beyond the Diagnosis Art Exhibit

FOR IMMEDIATE RELEASE – Sept. 8, 2025

- NOTE: Rare disease advocates will be available for media interviews on THURSDAY, SEPT. 11 at the state Capitol from 12 PM- 4 PM. Please contact Kimberly Haugstad at 414-405-7042 to arrange interviews.
- VISUAL: Art portraits of children living with rare diseases; rare disease advocates at the Capitol rally for needed legislation.

MADISON - Rare disease patients and advocates from across Wisconsin will gather at the state Capitol this Thursday, Sept. 11 for Wisconsin Rare Disease Advocacy Day, intended to bring attention to those living with a rare disease while highlighting the need for life-saving legislation.

Organized by the Wisconsin Rare Disease Alliance (WI Rare), the Advocacy Day will include an art exhibit set up in the Capitol Rotunda by Beyond the Diagnosis, which uses art to raise awareness for children living with life-altering diseases. Artists' portraits of these children will be on display from Sept. 8-12. The exhibit is free and open to the public.

The Wisconsin rare disease community will advocate on behalf of two bills currently before the state Legislature, focused on newborn screening for rare diseases and banning copay accumulators.

Senate Bill 145 would bring Wisconsin's newborn screening programs aligned with the federal Recommended Uniform Screening Panel (RUSP). The current newborn screening system is protracted and missing detectable and treatable conditions. Failing to act as soon as possible worsens outcomes.

"Half of those living with a rare disease are children. Nearly one third of those kids will not reach the age of five," WI Rare Founder Kimberly Haugstad says. "Newborn screening holds the promise of saving babies lives. We trust legislators will agree that aligning state and federal standards is a reasonable course of action to improve and even save young lives."

Senate Bill 203, also known as Cole's Act, is intended to safeguard access by ensuring that all medication copays count for patients. This is a critical need for rare diseases patients.

"Copay assistance provides direct relief to patients who need it. Other states that have passed copay accumulator bans have not seen costs rise," Haugstad notes. "Without this legislation, rare disease families may face insurmountable financial obstacles to accessing the medications they need. No one should have to make the choice of paying for your medications or paying for your groceries. Cole's Act ensures assistance is protected for those who need it the most."

About Wisconsin Rare Disease Alliance

The Wisconsin Rare Disease Alliance (WI Rare) is a nonprofit coalition dedicated to uniting patients, families, caregivers, medical providers, and advocates to improve the lives of those affected by rare diseases. WI Rare works to educate to advance research, policy, and awareness across the state.