

New Alliance Brings Together 1.2 Million Illinois Rare Disease Patients

A chance meeting in a DC hallway turns into a movement

SPRINGFIELD, IL, UNITED STATES, March 14, 2026 /EINPresswire.com/ -- In the world of [rare](#) diseases, finding someone who understands your journey can feel like finding a needle in a haystack. But for 1.2 million Illinoisans, that search just got a whole lot easier. The [Illinois](#) Rare Disease Alliance is a new [nonprofit](#) giving a collective voice to patients, families, advocates, researchers, and healthcare professionals across the state. Because when you are facing something rare, going it alone should not be part of the plan.

The Alliance was born from a classic D.C. moment: three Illinois advocates, standing in a hallway, waiting to meet with Senator Dick Durbin. That is where Wayne Galasek of Oak Park, Doug Butchart of Elgin, and Henry "Hank" Heren of Morton decided Illinois needed its own rare disease advocacy organization.

"While waiting for the other Illinois Advocacy Team outside the offices of Illinois Senator Dick Durbin ... along with Doug and Henry [we] decided to start an Illinois-based rare disease advocacy organization," recalls Galasek, now president of the Alliance.

Galasek knows the weight of rare disease firsthand. He is a caregiver for his wife, who lives with Huntington's disease (HD)—a fatal, inherited neurodegenerative condition with no cure and no FDA-approved treatments. Their two daughters and five grandchildren remain "at risk." As Galasek puts it, HD combines the worst of amyotrophic lateral sclerosis (ALS), Parkinson's, and Alzheimer's. All at once. No two patients have the same journey.

Butchart, one of Illinois' 3.1 million caregivers, entered the rare disease world in 2017 when his wife was diagnosed with ALS, a terminal disease with a prognosis of 2-5 years after diagnosis. "That diagnosis not only brought our family into the world of rare disease but also opened my eyes to how isolated and fragmented support can be across Illinois," he shares. Since then, he has fought for accessibility and affordable healthcare—because when you are navigating the unthinkable, insurance should not be another battle.

Then there's Heren, a rare cancer survivor who turned his diagnosis of histiocytic lymphoma into a mission. Through grassroots advocacy and a strong social media presence, Hank helps rare and ultra-rare patients and caregivers feel less alone—and more heard.

Enter Pollock, a nano-rare patient whose metabolic condition affects just 1 in 23 million people. After a 50-year diagnostic odyssey, Pollock began building their own case study and a web resource, enddenials.org, to help others facing insurance roadblocks. They also serve as chair of the Illinois Rare Disease Commission, advising state legislators on the real-world needs of patients with rare diseases. "Every patient should have access to a timely diagnosis and dignified care, whether they are rare or not," says Pollock.

The Illinois Rare Disease Alliance officially launches during Rare Disease Night & Day at the Capitol in Springfield on March 24–25, 2026. The event is free and open to the public. Registration is available at www.illinoisrare.org.

Rare people—in the right hallway—can change everything.

Maria Gross Pollock
Illinois Rare Disease Alliance
+1 773-307-5207
[email us here](#)

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