UDNF Undiagnosed Diseases Network Foundation

UDNF Talking Points

Updated 9/16/2025

For use by staff, volunteers, patients, families, and community partners

---

Who We Are

- The **Undiagnosed Diseases Network Foundation (UDNF)** is a nonprofit organization dedicated to individuals living with **rare and undiagnosed conditions.**
- Our mission is **to improve access to diagnosis, research, and care** for all individuals with undiagnosed and ultra-rare conditions.

Why It Matters

- An estimated **25 million Americans** live with a rare disease. Many stay **undiagnosed for years**, some for life.
- Without a diagnosis, patients often have **no treatment plan, no coordinated care, and limited access to support systems.**
- Undiagnosed patients and their families and caregivers often face **medical, emotional, and financial hardship**, made worse by isolation and uncertainty.
- The UDNF helps undiagnosed and ultra-rare patients **get answers, access care, and connect to research.**

What We Do

1. **Patient, Caregiver, & Family Support**
   - We provide resources, peer support, and community connections.
   - We help individuals navigate the complex medical system.
2. **Awareness & Advocacy**
   - We amplify the stories of rare and undiagnosed individuals to raise public and medical awareness.

   - We advocate for policies that improve access to diagnostic testing, specialist care, and rare and undiagnosed disease research.

3. **Research Collaboration**
   - We work with the Undiagnosed Diseases Network (UDN), a research program that connects patients with expert medical teams to find answers.
   - We connect patients with the UDN and other research entities working to unlock medical mysteries.
   - Our community helps researchers better understand the scope and impact of undiagnosed conditions.
4. **Funding & Philanthropy**
   - We raise funds to:
     - Support patients through our **patient navigation and assistance programs.**
     - Expand **access to diagnostics**.
     - Advance **research and therapeutic development**.

Our Impact

- **First-of-its-kind Navigation Program:** Created the only dedicated Patient Navigation program for UDN participants, and also serving the broader undiagnosed and ultra-rare community.

- **Direct Support via the Patient Assistance Fund:** Offering financial relief and services that improve access to care.

- **Partners in Research:** Support and facilitate patient-centered research connecting undiagnosed and ultra-rare patients with scientific collaborators.

- **Therapeutic Matching & Discovery Initiative:** Unite ultra-rare patient advocates and researchers to explore and develop novel treatment pathways.

UDNF Undiagnosed Diseases Network Foundation

Boilerplate

The Undiagnosed Diseases Network Foundation (UDNF) is a patient-driven nonprofit that fosters community, support, innovation, and action for families navigating the uncertainty of rare and undiagnosed conditions. Together, we can deliver on the hope for connection, answers, and improved outcomes.

For people facing a rare disease, the journey to a diagnosis is long, isolating, and costly. Families encounter more barriers than pathways and more questions than answers. Patients may see dozens of doctors and undergo countless tests before receiving a diagnosis. Even then, many rare and ultra-rare diseases have no known treatment. The impact is widespread; an estimated 25 million Americans are living with rare and undiagnosed conditions.

The UDNF is here to help. We are home to a community of support, where people can connect with others who understand their journey. We provide access to professional navigators, resources, and information, giving patients guidance through the complex healthcare system and more. We connect patients to research in rare and ultra-rare disease diagnosis and treatment, driving progress toward answers and potentially cures. And we take action with the rare and undiagnosed community to improve their experience and outcomes.