

Undiagnosed Diseases Network Foundation Named Patient Experience Partner for ARPA-H's Groundbreaking RAPID Program

UDNF to bring the voice and experiences of the undiagnosed community to a federal initiative aimed at transforming rare disease diagnosis.

WASHINGTON, DC, UNITED STATES, August 31, 2026 /EINPresswire.com/ -- The [Undiagnosed Diseases Network Foundation \(UDNF\)](#) today announced it has been selected as a Patient Experience Partner (PXP) for the Advanced Research Projects Agency for Health's (ARPA-H) [Rare Disease AI/ML for Precision Integrated Diagnostics \(RAPID\) program](#) — a landmark federal initiative designed to dramatically reduce the diagnostic odyssey for millions of Americans living with rare and undiagnosed diseases.



The UDNF community coming together to take action for the undiagnosed. April 2026

RAPID is built on the question of “what if we could end the rare diseases diagnostic odyssey?”. As a Patient Experience Partner, UDNF will bring the voice and experiences of the undiagnosed patient and family community to the researchers, technologists, and innovators working to solve the rare disease diagnostic challenge. UDNF will partner with [Sage Bionetworks](#) and its collaborators to ensure that the lived experience of patients informs the development and deployment of the Rare Disease Data Commons and RAPID's AI-driven solutions.

Artificial intelligence is a powerful tool, but it cannot tell you what it feels like to spend a decade without a diagnosis, or why a family in a rural community can't access the specialist their child needs. UDNF will help bridge that gap, ensuring RAPID's data resources and platform are built not just for patients, but with them.

"Serving as a Patient Experience Partner for ARPA-H's RAPID program is a profound recognition that solving the diagnostic odyssey requires more than science — it requires the voice, wisdom, and experience of the patients and families who live it every day," said Dr. Danielle Carnival, CEO, Undiagnosed Diseases Network Foundation. "UDNF exists to ensure that the undiagnosed

community is not just the subject of research, but an active force shaping the solutions that will change lives."

The Scale of the Problem

More than 10,000 unique rare diseases affect over 350 million people worldwide, including one in ten Americans. 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 finally receiving a diagnosis. The diagnostic odyssey endured by rare disease patients lasts an average of six years but can go on for decades. Each diagnostic odyssey costs an average of \$500,000 per patient and rare diseases cost the U.S. economy \$1 trillion, annually.

For families in the undiagnosed community, these numbers represent years of uncertainty, missed treatments, and an exhausting and expensive search for answers. It is estimated that half of all individuals with a rare disease remain undiagnosed or misdiagnosed, leading to inappropriate care, irreversible disease progression, and extensive medical costs.

UDNF's Role as Patient Experience Partner

As a RAPID Patient Experience Partner, UDNF will: Amplify patient and family voices to ensure that RAPID's diagnostic tools reflect the real-world needs of the undiagnosed community; Facilitate engagement by connecting RAPID program teams with patients, caregivers, and families who can provide input on research design, tool development, and deployment of new tools; Bridge the gap between cutting-edge AI research and the communities it is designed to serve, ensuring solutions are accessible, equitable, and patient-centered; Advocate for access to rare disease diagnosis, ensuring that underserved and underrepresented communities are included in RAPID's datasets and that tools are designed for use in communities across the United States

A Turning Point for the Undiagnosed Community

The RAPID program represents a pivotal moment in the fight to end the diagnostic odyssey. By harnessing the power of artificial intelligence and the scale of federal investment, RAPID has the potential to dramatically shorten the time from first symptom to accurate diagnosis — a transformation that could change the trajectory of millions of lives.

"For too long, families have navigated the diagnostic journey largely alone — moving from specialist to specialist, repeating the same tests, and waiting years for answers," said Dr. F Sessions Cole, Chair, UDNF Board of Directors. "ARPA-H's RAPID program, with patient experience at its core, represents the kind of bold, innovative thinking that is needed to make progress toward UDNF's mission to end the diagnostic odyssey."

UDNF's selection as a Patient Experience Partner builds on the organization's longstanding commitment to ensuring that patient and family voices shape the research, policy, and systems that govern rare disease diagnosis and care.

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