



UDNF Undiagnosed Diseases
Network Foundation

SUMMIT 2025: ENDING THE DIAGNOSTIC ODYSSEY

APRIL 28-30, 2025 | WASHINGTON, D.C. AREA

EVENT PROSPECTUS



**A FIRST-OF-ITS KIND COLLABORATIVE EVENT FOR
UNDIAGNOSED, ULTRA-RARE & RARE DISEASE INDUSTRY,
CLINICAL & COMMUNITY LEADERS**

HOSTED BY:



**Undiagnosed Diseases
Network Foundation**

Ending the Diagnostic Odyssey

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Chief Executive Officer

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The diagnostic odyssey for rare diseases is a significant challenge, often leaving patients and families lost in a maze of tests, misdiagnoses, missed opportunities to participate in clinical trials, and delayed treatment. Undiagnosed Summit 2025 brings together a diverse group of stakeholders – patient advocates, industry leaders, policymakers, and payers – to chart a collaborative roadmap towards a future where timely and accurate diagnoses are a reality for all with rare diseases.



Why attend

- **Gain valuable insights:** Hear from leading experts on the latest advancements in rare disease diagnostics.
- **Connect with the community:** Network with advocates, industry leaders, researchers, clinicians and policymakers dedicated to improving diagnoses.
- **Shape the future:** Participate in collaborative discussions that will shape and define the path forward for rare disease diagnosis and treatment.
- **Ignite change:** Be part of a movement that is determined to transform the lives of millions living with rare diseases.

Consensus Paper - A Roadmap to End the Diagnostic Odyssey

Undiagnosed Summit 2025 isn't just about sharing knowledge and fostering connections. It's about action. We aim to leave a lasting impact on the rare disease landscape by collaboratively creating a first-of-its-kind consensus paper - a roadmap to end the diagnostic odyssey.

This roadmap, drafted by the very stakeholders driving change – patient advocates, industry leaders, policymakers, clinicians, researchers, and payers – will be a powerful document outlining the challenges and proposed solutions for ending the diagnostic odyssey for undiagnosed, ultra-rare, and rare diseases.

Stakeholder-Specific Recommendations

The roadmap won't be a one-size-fits-all approach. It will address the specific needs and roles of each stakeholder group. Drafted collaboratively by summit delegates from all stakeholder groups, it will be a powerful testament to our unified vision. It will not only map out the key challenges we face in rare disease diagnosis, but also propose concrete solutions and recommendations tailored to each audience:

- **Patient advocates:** The roadmap will equip you with tools and strategies to advocate for earlier diagnoses within the healthcare system.
- **Biotech and pharma leaders:** Discover clear pathways for developing and implementing innovative diagnostic tools and therapies.
- **Leading researchers and clinicians:** Gain insights into how to translate scientific advancements into real-world improvements in diagnostic precision and patient care.
- **Diagnostic testing industry representatives:** Identify opportunities to develop and commercialize new diagnostic technologies that address unmet needs.
- **Policy experts:** Explore policy changes that incentivize innovation, improve access to diagnostics and clinical trials, and streamline the diagnostic journey.
- **Payers:** Understand how to ensure patients receive the diagnostic tools and expertise they need.

The Power of Collaboration

Join Us and Be Part of the Solution. Become a delegate and shape the future of rare disease diagnosis. Let's work together to make timely and accurate diagnoses a reality for all.

Who should attend

Summit 2025 brings together a unique and powerful group of stakeholders to chart a new course, including:

- **Patient Advocates:** The heart and soul of the rare disease community, sharing their perspectives and advocating for earlier diagnoses.
- **Biotech and Pharma Leaders:** Contributing their expertise to drive the discovery and development of new diagnostic tools and therapies.
- **Leading Researchers & Clinicians:** Sharing the latest in science and clinical practice and discussing new opportunities to advance diagnostic precision and reach.
- **Diagnostic Testing Industry Representatives:** Showcasing promising advancements in diagnostic technologies and future possibilities.
- **Policy Experts:** Shaping policy to incentivize innovation and improve access to diagnostics, clinical trials and targeted treatments.
- **Payers:** Ensuring patients have access to needed diagnostic tools and expertise.

Through a dynamic program of plenary sessions, panel discussions, workshops, and networking, Summit 2025 will foster collaboration across the rare disease landscape.

What to expect

- **Collaborative Discussions:** Deep-dive sessions focused on key challenges and opportunities in rare disease diagnosis.
- **Patient Perspectives:** Insightful presentations from patient advocates highlighting the human experience of the diagnostic odyssey.
- **Industry Innovation:** Advancements in diagnostic science, technologies and processes presented by leading companies and medical experts.
- **Policy & Payer Solutions:** Policy changes, implications and emerging models to incentivize and streamline rare disease diagnosis and care.
- **Networking Opportunities:** Connect with colleagues, forge new relationships, and build a collaborative network dedicated to ending the diagnostic odyssey.

Sponsorship Opportunities

Summit 2025 presents a unique opportunity to showcase your commitment to accelerating diagnoses and treatments for individuals living with rare diseases. By becoming a sponsor, you can gain significant exposure to highly engaged stakeholders, build brand awareness, and demonstrate leadership in this critical field. In addition, sponsors will support scholarship opportunities for emerging non-profit advocacy and community leaders.

Sponsorship Level	Sponsorship Amount	Sponsorship Registrations	Advocacy Scholarships
Presenting	\$100,000	6	6
Diamond	\$85,000	5	5
Platinum	\$75,000	4	4
Gold	\$50,000	3	3
Silver	\$25,000	2	2
Bronze	\$10,000	1	1
Non Profit	\$5,000	1	1

Sponsorship Benefits

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Sponsorship Level Benefits	Presenting \$100,000	Diamond \$85,000	Platinum \$75,000	Gold \$50,000	Silver \$25,000	Bronze \$10,000	NonProfit \$5,000
Social Media	6 to 8 posts	4 to 6 posts	3 posts	2 posts	1 post		
Press Release	X	X	X	X			
Website	Prominent Clickable Logo	Clickable Logo	Clickable Logo	Logo	Logo	Logo	Logo
Event Emails	X	X	X	X	X	X	
Exhibit Booth	X	X	X	X	X		X
Onsite Signage	Prominent Logo	Prominant Logo	Prominant Logo	Logo	Logo	Logo	X
Membership Meeting	2 Attendees	2 Attendees	1 Attendee	1 Attendee			X
Awareness Night Activity	6 tickets	5 tickets	4 tickets	3 tickets	2 tickets	1 ticket	
Meeting Brief	X	X	X	X	X	X	X

Event Schedule

Through a dynamic program of plenary sessions, panel discussions, workshops, and networking events, Summit 2025 will foster collaboration across the rare disease landscape. Key areas of focus will include:

- Emerging diagnostic technologies and their potential to revolutionize rare disease diagnosis.
- Strategies to overcome barriers to earlier diagnoses, including access to testing and insurance coverage.
- The critical role of patient advocacy in driving progress.
- Building a more collaborative and efficient rare disease ecosystem.
- Awareness efforts to elevate the challenges and potential solutions for patients and their families throughout the diagnostic odyssey.
- Networking and the need for more collaboration on innovative approaches.



Day 1

Alliance meetings, followed by workshops on innovation in policy, diagnosis, research and therapy development. Conference day 1 opening sessions, exhibits and Welcome reception.



Day 2

Conference day 2: Unveiling The Odyssey (state of diagnostic progress report), morning, luncheon and afternoon Keynote Sessions, exhibits and networking. Awareness night event.

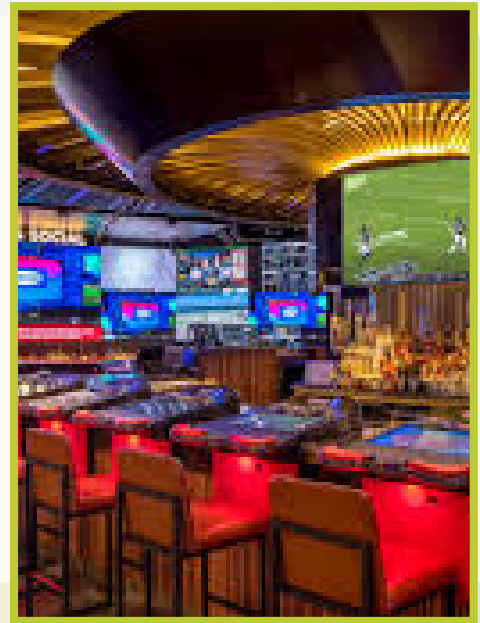
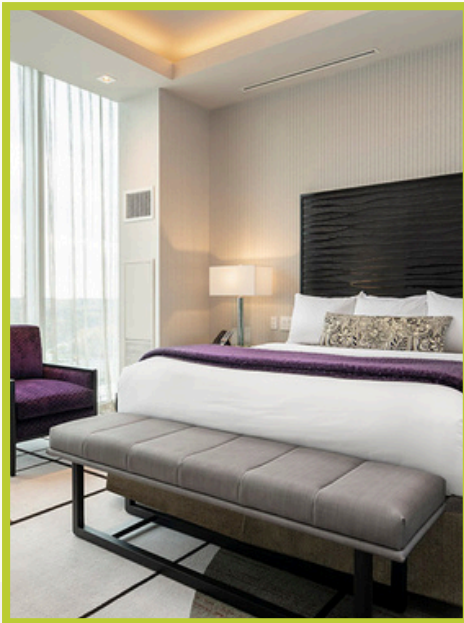


Day 3

Conference day 3: More interactive sessions, luncheon and closing Keynotes, exhibits and networking.

About the Venue

The Conference Center at the Live! Hotel in Hanover, MD is less than 10 miles from BWI Airport. The property offers a luxurious hotel boasting spacious rooms, fine dining, and a vibrant entertainment scene. Unwind and rejuvenate at the Live! Spa, offering a range of pampering treatments and relaxation services.



About the UDNF



Our mission is to improve access to diagnosis, research and care for all with undiagnosed and ultra-rare diseases. **Our vision** is healthcare that embraces the unknown and pursues clinical and research solutions for the patient well-being.

Patient & Family Navigation

We are committed to improving the speed and accuracy of diagnoses, medical management, care coordination, access to social services, support, and mental health services for patients with undiagnosed and ultra-rare diseases and their families. We also strive to enhance the patient and family experience throughout the diagnostic process and transition to therapeutics, regardless of when or whether a patient receives a diagnosis.

Community Engagement & Outreach

We are building a community by and for all patients with undiagnosed and ultra-rare diseases and their families. We serve as the leading resource for trustworthy, comprehensive and inclusive information and resources, and strive to ensure that underrepresented patients have equitable access to diagnosis, research, therapeutics, and support.

Patient-Centered Research & Clinical Care

The UDNF is committed to making diagnosis of ultra-rare diseases more accessible, equitable, accurate, and efficient. We do this by advancing the diagnosis and knowledge of these diseases through patient-centered research.

