2024 annual report

Undiagnosed Diseases Network Foundation

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Luke Shantz, Former UDNF Peer Member

Mission & Vision

At the Undiagnosed Diseases Network Foundation (UDNF), our mission remains steadfast: to improve access to diagnosis, research, and care for all individuals with undiagnosed and ultra-rare conditions. We are committed to advancing diagnostic strategies, expanding research opportunities, and fostering innovative treatments to bring answers where there were none before.

Our vision is to create a healthcare ecosystem that embraces the unknown—where patients are met with curiosity, urgency, and collaboration, and where scientific discovery leads to life-changing solutions. Through partnerships with healthcare professionals, researchers, advocates, and families, we strive to accelerate progress and bring hope to those navigating diagnostic uncertainty.

In 2024, we continued to build on our foundation, launched the Patient Navigation Program and support services, strengthen advocacy for sustainable funding of the Undiagnosed Diseases Network, and expanded community engagement efforts. As we move forward, we remain committed to ensuring that every individual facing an undiagnosed or ultra-rare condition has access to the answers, resources, and care they deserve.

Welcome note

Dear Friends and Supporters,

As we reflect on the past year, we are filled with gratitude for the support that has fueled the growth and impact of the Undiagnosed Diseases Network Foundation (UDNF). Our journey began in response to the pressing need for sustainability of the Undiagnosed Diseases Network (UDN) and to address the gaps in support for the undiagnosed and ultra-rare disease community. Today, thanks to your generosity and commitment, we have made strides in expanding our reach, strengthening our programs, and deepening our impact.

The UDN's work has provided a strong foundation for our work, and we remain dedicated to building upon its achievements. In 2024, we have made progress toward creating a more sustainable and equitable future for individuals affected by these conditions.

One of our milestones this year has been the launch of our Patient Navigation Program with critical support from the Chan Zuckerberg Initiative. What began as a vision in 2023 has now evolved into a support system for families navigating the diagnostic and therapeutic odyssey. We have expanded our reach to provide direct assistance to more patients and families seeking answers.

Beyond patient navigation, we continue to work alongside researchers and healthcare leaders to push for solutions that will accelerate diagnosis, improve access to care, and advance research for these conditions.
We are grateful for the dedication and expertise of our Board of Directors and growing community of partners, whose guidance has shaped our strategic direction. In 2024, we have advanced key initiatives through research collaborations and awareness campaigns, forging pathways for lasting change.

As we look ahead, your continued support is essential to our mission, and we are incredibly grateful for your partnership in this movement. With your help, we are not only expanding resources for the undiagnosed and ultra-rare disease community but also building a future where no one faces this journey alone.
Together, we are making a difference. Thank you for being part of this journey.

With gratitude,
Amy Gray

Amy Gray
Chief Executive Officer, UDNF

Strategic Plan

Guiding Our Mission Forward

We remain committed to expanding our impact for individuals and families affected by undiagnosed and ultra-rare diseases. Through strategic planning and collaboration, we continue strengthening UDNF's foundation to ensure sustainability, accessibility, and meaningful support. To guide our efforts, we have developed a strategic plan with four key pillars:

SUSTAINABILITY & GROWTH

Ensuring the long-term viability of the UDN network and our organization, expanding our reach to serve more patients.

PATIENT & FAMILY NAVIGATION

Providing personalized support and guidance to individuals navigating the complex healthcare system.

COMMUNITY OUTREACH & ENGAGEMENT

Building strong partnerships and fostering a sense of community among patients, caregivers, and healthcare providers.

PATIENT-CENTERED RESEARCH AND CLINICAL CARE

Advancing research and improving clinical care to enhance the lives of individuals with undiagnosed and ultra-rare diseases.

This strategic plan continues to serve as our blueprint for action, ensuring that our work remains patient-centered and impactful. With the ongoing support of our community, we are committed to strengthening resources, advancing research, and building a future where no one faces an undiagnosed or ultra-rare disease alone. See more here: Strategic Plan

Building Our Team in 2024

In 2024, the Undiagnosed Diseases Network Foundation (UDNF) continued to grow and evolve, strengthening our foundation to better serve individuals and families impacted by undiagnosed and ultra-rare conditions. As we expand our reach, our dedicated team remains at the core of our mission, working to improve access to diagnosis, research, and care.

Leadership and Strategy

Amy Gray leads UDNF as our Chief Executive Officer, bringing extensive experience in nonprofit leadership, strategic planning, and patient advocacy. Under Amy's leadership, we have refined our organizational priorities, expanded programs, and deepened our impact in the undiagnosed and ultra-rare disease community.

Patient Navigation and Support

Our Patient Navigation Program continues to be a vital resource for individuals and families seeking guidance through the complex medical landscape. Led by Michele Herndon and dedicated professionals with expertise in patient advocacy and healthcare navigation, our team provides personalized support, connecting patients with specialists, resources, and peer support to help them on their diagnostic journeys.

Fundraising and Outreach

With the support of a growing network of advocates, our fundraising and outreach efforts have expanded to engage more communities, build awareness, and strengthen our mission. Through strategic collaborations and donor engagement, UDNF continues to grow its capacity to serve more individuals in need.

Discover more about our dedicated team and their impact HERE.

UDNF PEER

The Undiagnosed Diseases Network Foundation (UDNF) has undergone a significant transformation, integrating the Patient Engagement and Empowerment Resource (PEER) to create a more inclusive support network for individuals and families affected by undiagnosed and ultra-rare diseases. This integration enriches the foundation's mission by uniting resources and initiatives that reflect the voices and needs of the community. One of the key goals for 2024 is to maintain the quarterly PEER newsletter, a vital communication tool that keeps the community informed on advancements, events, and resources tailored to support patients and caregivers. Additionally, the Tell Me More Series will remain a cornerstone of UDNF's efforts to share personal stories and insights from individuals on their diagnostic journeys. These programs highlight UDNF's commitment to fostering a space where patients, caregivers, and advocates can connect, learn, and find encouragement as they navigate complex healthcare challenges.

The integration of UDNF and UDN PEER marks a pivotal step in amplifying the voices of patients and families within the undiagnosed and ultra-rare disease communities. UDN PEER provides critical support by sharing resources, collaborating with researchers, and raising public awareness. This partnership will empower those affected by undiagnosed diseases with a stronger voice and the tools needed to navigate their journeys. Together, UDNF and UDN PEER will strengthen the community, offering patients and families hope for a diagnosis and research that could pave the way for treatments.

our board

MEGHAN HALLEY

Board Chair | Founding Board Member | she/her

Meghan Halley, PhD, MPH, is a Senior Research Scholar at Stanford University's Center for Biomedical Ethics, specializing in the intersection of ethics and economics in genomic technologies, with a focus on patient data sustainability, governance, and outcomes in rare disease diagnosis and pediatric care.

SIKA DUNYOH

Incoming Vice Chair | Founding Board Member | she/her

Sika Dunyoh, Senior Director of Patient Advocacy at Travere Therapeutics, brings extensive experience in patient advocacy, engagement, and education, inspired by her sister's battle with relapsing polychondritis; she previously led educational initiatives at the National Organization for Rare Disorders.

TROY EVANS

Treasurer |Founding Board Member|he/him

Troy Evans is the Owner and President of Cinch Home Loans. He is a patient of the Undiagnosed Diseases Network (UDN) and a resident of Draper, UT. He entered the UDN as a patient in 2018 at the UCLA site. Despite not yet receiving a diagnosis, his personal experience has given him a unique perspective and deep commitment to the organization's mission and sustainability.

F. SESSIONS COLE

Secretary | he/him

Dr. Cole, a neonatologist and researcher, has over 25 years of NIH-funded experience in rare disease genomics and led the Undiagnosed Diseases Network Clinical Site at Washington University. He currently co-chairs the UDN's Sustainability Working Group and leads the Therapeutic Matching Committee, focusing on therapies for rare disease patients.

our board

ANNE PARISER

Vice President Medical and Regulatory Affairs, Alltrna | she/her

Anne Pariser, VP of Medical and Regulatory Affairs at Alltrna, has over 20 years of experience in rare disease research, including roles at the NIH and FDA. She is an expert in advancing therapeutics for rare diseases through research, collaboration, and policy development.

EFFIE PARKS

Host, Once Upon a Gene Podcast | Rare Disease Community Influencer/Advocate/Storyteller | she/her

Effie is a dedicated advocate for those affected by rare genetic conditions, inspired by her child's diagnosis with CTNNB1 syndrome. As the host of the "Once Upon a Gene" podcast, she shares stories from the rare disease community to educate, connect, and amplify their voices.

GERALD SWEENEY

Retired Litigation Attorney

Gerald Sweeney, a retired litigation attorney with over 40 years of experience, has served on the boards of the Cystic Fibrosis Foundation and various entertainment companies. He has also participated in the Undiagnosed Diseases Network (UDN), bringing a wealth of legal, entertainment, and advocacy expertise to any board.

JESSICA SWANSON

UDNF PEER Co-Chair | she/her

Jessica Swanson is the founder and CEO of Summit Health Services Inc., specializing in Applied Behavior Analysis (ABA) with 20 U.S. locations. A Board Certified Behavior Analyst (BCBA), she also serves on the board of QABA and leads Redpoint Consulting Inc., advising start-ups and Pathfinder Health. As co-chair of UDNF PEER, she advocates for individuals with rare diseases. Jessica is married to an active-duty officer, has two children, and lives in Huntsville, Alabama.

BOARD OF DIRECTORS

our board

KELLY CERVANTES

Writer, Speaker, Advocate | she/her

Kelly Cervantes is an award-winning writer, speaker, and advocate, best known for her blog “Inchstones” and her upcoming book, *Normal Broken: The Grief Companion for When it’s Time to Heal But You’re Not Sure You Want to*. She has been recognized as one of "Chicagoans of The Year" and is a former Board Chair of CURE Epilepsy, where she also hosts the “Seizing Life” podcast.

LILIANA FERNANDEZ

Medical Monitor, Premier Research | she/her

Liliana Fernandez is a medical professional with 20 years of research experience, including 7 years specializing in undiagnosed and rare diseases. She worked at the Stanford Center for Undiagnosed Diseases, developing a workflow to enhance Hispanic participation, and now serves as a medical monitor for gene therapy clinical trials in rare diseases.

PARVATHY KRISHNAN

Chief Executive Officer,
Krishnan Family Foundation| she/her

Parvathy Krishnan, CEO and founder of the Krishnan Family Foundation, advocates for rare diseases following her children’s diagnoses with ultra-rare conditions. With a Master’s in Clinical Nutrition and experience as a Nutrition Support Dietitian, she engages stakeholders globally, serves on advisory councils, and brings a unique perspective to her advocacy work from her home in North Carolina.

BOARD OF DIRECTORS

our board

STEPHAN ZUCHNER

Professor of Human Genetics and Neurology, University of Miami | he/him

Stephan Zuchner, M.D., Ph.D., is a Professor at the University of Miami Miller School of Medicine, specializing in rare disease genetics. His research has identified key disease genes, and he holds leadership roles in ClinGen and several advisory boards.

STEPHANIE TOMLINSON

UDNF PEER Co-Chair | she/her

Stephanie Tomlinson has advocated for rare disease patients for over 20 years and has served on committees for early childhood special education. Formerly the Patient Support Coordinator for MitoAction, she now hosts the podcast "Energy in Action," which highlights patient stories and expert research.

TANIA SIMONCELLI

Vice President of Science in Society, Chan Zuckerberg Initiative (CZI) | she/her

Tania Simoncelli is Vice President of Science in Society at the Chan Zuckerberg Initiative, where she launched the Rare As One Project to support patient-driven research. With over 20 years in science policy, including roles at the White House and FDA, she holds degrees from Cornell and UC Berkeley and was named a 2013 “person who mattered” by Nature and an AAAS Fellow in 2021.

BOARD OF DIRECTORS

our board

TOM KELLY

Founder, UnitedHealth Group Special Needs Initiative | he/him

Tom, recently retired after 13 years as V.P. of Marketing and Innovation at UnitedHealth Group, led the creation of the Special Needs Initiative, a team of 400 focused on improving healthcare for families with children with special needs. With over 16 years of experience in rare diseases, he draws from his personal experience as a father of a child with an ultra-rare genetic disorder.

UDNF

Advisor

MAX BRONSTEIN

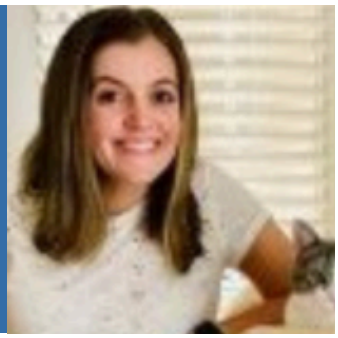
Senior Advisor to the Board of Directors | he/him

Max G. Bronstein is a health policy leader with 18 years of experience across biotech, government, and non-profits. He helped launch ARPA-H at the White House OSTP and led advocacy at Crinetics and Audentes. Max played a key role in advancing the 21st Century Cures Act and expanding newborn screening. His work appears in NEJM, Nature, and Forbes, and he founded the Journal of Science Policy & Governance. He holds degrees from the University of Michigan and Ithaca College, and enjoys hiking and diving in the Bay Area.

UDNF PEER MEMBERS

Kara Anderson | she/her

Kara Anderson is a postdoctoral fellow in Virginia who was diagnosed with a rare disease at the Duke site in 2018 and joined PEER that same year, finding the group invaluable in navigating her own condition. Outside of her work and advocacy, she enjoys cooking and dreams of turning her cat, Kit, into an Instagram influencer.



Sarah Marshall | she/her

Sarah Marshall, a UDN(F) PEER member since 2018, uses her social work background and personal experience caring for an undiagnosed child to advocate for those with rare diseases. She also supports women and children with chronic illnesses, focusing on immigrant and marginalized communities.

Christine McGarvey | she/her

Christine McGarvey and her daughter, Brigid, have been participants in the UDN at CHOP since 2021, both on diagnostic journeys. A rare disease advocate and NORD State Ambassador, Christine holds advanced degrees in Biochemistry and Cell and Molecular Biology and directs the UDNF PEER “Tell Me More” lecture series.

Nikki Patrick | she/her

Nikki Patrick, a mother of four from suburban Chicago, became involved in rare disease advocacy after her daughter Felicity passed away from an undiagnosed condition in 2020. She is dedicated to supporting families on similar journeys and hopes to find answers that may help others.

Casey Robertson | she/her

Casey Robertson, E.Ds., lives in Mississippi and has sought a diagnosis for her daughter Kylie, 17, who joined the UDN in 2022. She works in blindness research, advocates for underserved students and families, and edits the UDN newsletter.

Community Engagement & Outreach

In 2024, the Undiagnosed Diseases Network Foundation (UDNF) continued to expand its reach and impact, strengthening connections within the undiagnosed and ultra-rare disease community. Through patient support, advocacy, research, and education, we remain committed to ensuring that no individual or family faces the diagnostic journey alone.

The Patient Navigation Program has grown into a vital resource, providing guidance to individuals and families navigating the complex healthcare system. Our navigators assist with the UDN application process, helping individuals understand the criteria, apply, and, if accepted, collaborate with their UDN site. For those not accepted into the UDN or seeking additional resources, our navigators continue to provide personalized support, connecting patients with specialists, advocacy groups, and alternative diagnostic pathways.

In addition to patient support, UDNF has deepened its commitment to community engagement and outreach. In 2024, we hosted Undiagnosed. Ultra-rare. United., a UDNF community event at Washington University and Baylor College of Medicine, bringing together patients, families, researchers, and healthcare professionals to foster collaboration and awareness.

To further our mission, we expanded our team and strengthened our programs in research, education, and advocacy. By enhancing partnerships and increasing awareness, we have continued to provide critical resources to those in need.

As we look ahead, we are grateful for the dedication and expertise of our team, partners, and supporters. With continued collaboration and innovation, we are building a future where individuals with undiagnosed and ultra-rare diseases have the answers, resources, and care they deserve.

Financial Summary

Statement of Activities for the Year Ended December 31, 2024

We are committed to financial transparency and responsible stewardship of the funds entrusted to us. Every dollar we receive is used to advance our mission and make a difference in the lives of those we serve.

$	$	$
$393,955.06	**$1,423,666.90**	**$-929,823.97**
Total Revenue	Total Expenses	Change in Net Assets

Year in Review

Additional Key Achievements

2024 was a year of accomplishments for the Undiagnosed Diseases Network Foundation (UDNF). Building on the foundations laid in the previous year. Community engagement remained a key focus in 2024. Through targeted outreach and impactful events, we connected with hundreds of new community members, leading to increased donations and volunteer support. We're grateful for the growing community that has joined us on this journey, and we look forward to continuing to build these connections in the years to come.

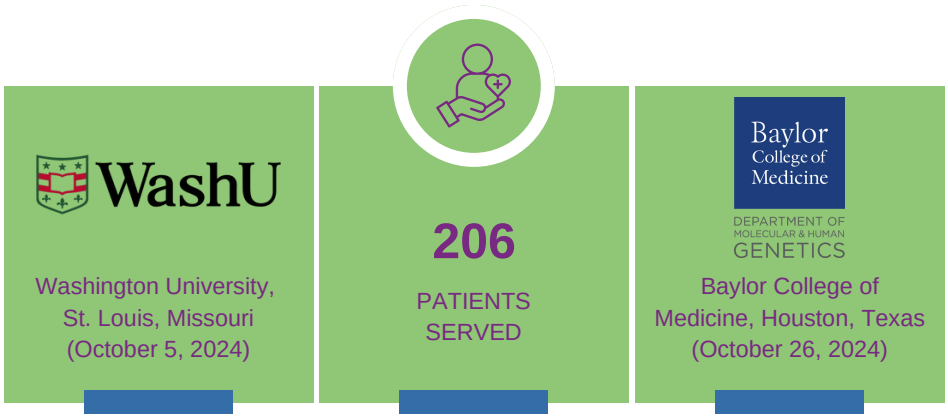
This year, we hosted several impactful webinars, including:

- Advancing Hope and Breakthroughs in Undiagnosed and Ultra-Rare Diseases (December 3, 2024): Highlighted groundbreaking research advancements and featured esteemed experts in the field.
- Growing Up Together: Recognizing and Supporting Siblings of the Undiagnosed & Ultra-Rare (July 17, 2024): Addressed the unique needs of siblings and fostered holistic family support.

You can find all webinar recordings here: https://udnf.org/webinar-recordings/
We expanded our Patient Navigator Program, with our dedicated team assisting over 206 patients, connecting them with critical resources and personalized guidance on their diagnostic journeys.

In addition, we hosted two Undiagnosed. Ultra-rare. United. community events that brought together patients, caregivers, and healthcare professionals to share knowledge and build support networks

Together, we're building a brighter future for the undiagnosed and ultra-rare disease community



Looking Ahead with Gratitude

As we reflect on 2024, we extend our deepest gratitude to everyone who has been part of our journey. To our donors, your generosity has empowered us to expand our reach and strengthen our impact. To our partners and collaborators, your expertise and commitment have driven meaningful progress in research, advocacy, and patient support. To our volunteers, your dedication has made a tangible difference in the lives of those navigating the diagnostic odyssey. And to our community, your unwavering support and advocacy continue to inspire and fuel our mission every day.

Together, we are building a future where no one faces the challenges of an undiagnosed or ultra-rare disease alone.

Stay Connected

We invite you to continue your engagement with the Undiagnosed Diseases Network Foundation. Stay up to date with our latest news, events, and initiatives by following us on social media and visiting our website.

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Thank you for your continued support. Together, we can make a difference.