2025 Impact Report

Support. Research. Advocacy. Hope.

WILSON DISEASE® ASSOCIATION

wilsondisease.org

A Message From Leadership

Dear Friends,

Because of you, 2025 was a year of extraordinary progress for the Wilson Disease Association (WDA). Your generosity — through donations, advocacy, and engagement — helped us expand our reach and deepen our impact for individuals and families affected by Wilson disease (WD).

We were especially encouraged by the continued growth of our core programs. Our Patient Registry expanded, building a stronger foundation for research and improved care. Our Annual Conference once again brought together patients, caregivers, clinicians, and researchers in a shared space of learning and support.

At the same time, we made meaningful progress preparing for our Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting for the U.S. Food and Drug Administration (FDA), researchers, clinicians, and drug developers — an effort that culminated in a highly successful engagement in early 2026, representing a significant milestone for our community.

In 2025, we were also honored to receive a transformational, one-time estate gift. This extraordinary contribution strengthened our financial position and will help support the long-term sustainability of our mission.

As we look ahead, we are energized by the momentum we have built. We will continue to invest in programs that deliver meaningful support to patients and families while advancing research toward better treatments — and ultimately, a cure.

None of this would be possible without you.

With gratitude,

Erol Morey

Erol Morey
Development Director, Wilson Disease Association

> *"None of this would be possible without you."*

Mission and Whom We Serve

The Wilson Disease Association (WDA) is a global nonprofit organization dedicated to improving the lives of individuals and families affected by Wilson disease. Founded by patients and families, WDA has grown into a trusted source of support, education, and advocacy for a rare disease community that often faces delayed diagnosis and limited awareness.

WDA provides support, education, and advocacy for a rare disease community that often faces delayed diagnosis and limited awareness.

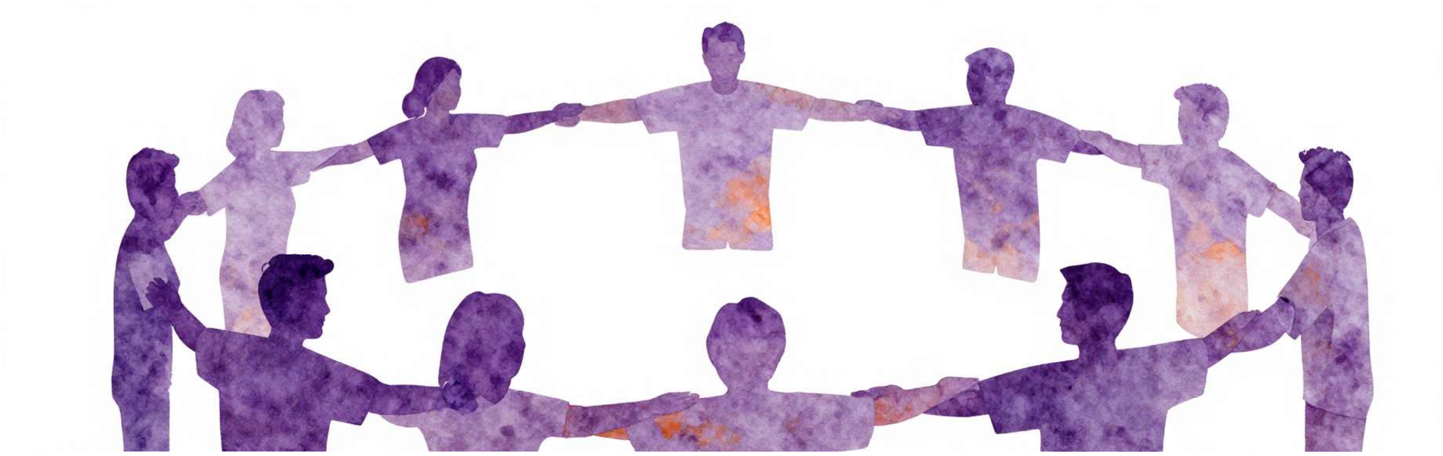
Through its programs and partnerships, WDA works to connect patients and caregivers to reliable information, provide peer support, advance research and innovation, and advocate for increased awareness across the medical, regulatory, and patient communities.

WDA increasingly serves as a connector across patients, clinicians, researchers, regulators, advocacy organizations, and industry partners working toward improved treatments and ultimately a cure.

WDA is more than an organization — it is a community of patients, families, clinicians, researchers, and industry stakeholders working together toward a shared vision: a future where Wilson disease is better understood, more effectively treated, and ultimately cured.

Our Mission

To provide support and hope so that those impacted by Wilson disease can live the best quality of life possible.



Program Impact: The Wilson Disease Registry

The Wilson Disease Registry continues to serve as a cornerstone of global research efforts, advancing understanding of the disease across its full spectrum. In 2025, the registry reached new milestones in enrollment, international collaboration, and long-term patient follow-up — strengthening its role as one of the most comprehensive prospective studies of Wilson disease worldwide. Through sustained growth and exceptional participant engagement, the registry is generating critical insights into disease progression, treatment outcomes, and patient quality of life — helping to inform better care today and accelerate research for tomorrow.

273

PATIENTS ENROLLED

across 7 international sites representing 118% growth

88.6%

RETENTION RATE

an exceptional level for a long-term rare disease study

68

PATIENTS COMPLETED 5-YEAR FOLLOW-UP

enabling critical long-term data on disease outcomes

THE IMPACT

Advances Research

Drives Global Collaboration

Improves Patient Care

Builds a Brighter Future

> *"Participating in the registry gives me hope that what I'm going through can help someone else in the future."*

Program Impact: Annual Conference

The 2025 WDA Annual Conference brought together patients, caregivers, clinicians, and researchers from across the United States and around the world for a powerful weekend of education, connection, and shared purpose. Held in Sacramento, California, the conference remains a cornerstone event for the Wilson disease community—providing access to leading medical expertise while fostering meaningful peer support and global collaboration.

Through expert-led sessions, practical resources, and community-building activities, attendees gained valuable insights into disease management, research developments, and daily living with Wilson disease. The conference also strengthened connections between patients, clinicians, and industry partners, ensuring that lived experiences continue to inform future treatments and research priorities.

> "This was the first time I met someone else with Wilson disease. I finally didn't feel alone."

2025 Conference Highlights

- Two-day conference in Sacramento, California, featuring leading experts and collaboration with the UC Davis Wilson Disease Center of Excellence
- 150 attendees, including patients, caregivers, clinicians, and industry representatives from the U.S. and international community
- Comprehensive program covering medical advances, mental health, nutrition, and caregiver support, alongside sessions connecting patients and partners to shape future therapies

150	Total Attendees
2 Days	of Programming
UC Davis	Center of Excellence Partner Institution

Program Impact: Copper Conscious Cookbook

"For the first time, I feel confident about what I can eat — and how to cook safely."

In 2025, WDA launched the “Copper Conscious Cookbook,” an important new resource designed to support individuals and families navigating the dietary challenges of Wilson disease. Developed in collaboration with registered dietitians and experts from Wilson Disease Centers of Excellence, the cookbook provides practical, evidence-based guidance to help patients confidently manage a low-copper diet.

More than a collection of recipes, the cookbook serves as a comprehensive guide—combining nutrition education, meal planning tools, and everyday strategies to empower patients to make informed food choices. By translating complex dietary restrictions into accessible, real-world solutions, this resource helps improve quality of life and reduce uncertainty for those living with Wilson disease.

What’s Inside

- Features expert-developed recipes and guidance specifically for people living with Wilson disease
- Includes copper content charts, nutrition information, and meal-planning tools to support safe and informed dietary choices
- Provides practical, everyday solutions—from cooking and grocery shopping to dining out—helping patients and families navigate daily life with confidence

Program Impact: Patient Advocacy and Global Collaboration

In 2025, WDA significantly expanded its role as a patient advocacy leader within both the rare disease and liver disease communities. Through strategic partnerships, conference participation, and collaboration with global organizations, WDA amplified the voices of patients and caregivers living with Wilson disease.

These efforts strengthened awareness of Wilson disease among researchers, clinicians, policymakers, and industry partners — while helping ensure that the lived experiences of patients remain central to research, treatment development, and access to care.

Advocacy in Action

6+

National & Global Advocacy Events

10+

Rare Disease Organizations Collaborated With

30+

Countries in WD Awareness Day

Multiple National Efforts

Legislative Initiatives Supported

Global Collaboration

- Helped strengthen the Wilson Disease Global Alliance
- Supported the Second Annual Wilson Disease Awareness Day
- Expanded international coordination among patient advocacy organizations

Rare Disease & Liver Disease Advocacy

WDA representatives participated in:

- Global Liver Institute A3 Academy
- 2025 NORD Rare Disease Summit
- Community Liver Alliance
- American Association for the Study of Liver Diseases (AASLD)
- Michigan Rare Disease Advisory Council
- American Liver Foundation / Galien Patient Summit

Patient Voice & Public Policy

- Supported legislative initiatives focused on rare disease research funding, access to life-saving medications, and improved patient access to specialized care
- Increased visibility of Wilson disease within broader rare disease advocacy efforts

Program Impact: Patient-Focused FDA Drug Development

In 2025, WDA undertook a major initiative to prepare for an Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting for the FDA, researchers, clinicians, and drug developers in January 2026 — one of the most significant advocacy and patient engagement undertakings in the organization's history.

Throughout 2025, WDA worked closely with patients, caregivers, clinicians, and regulatory experts to ensure that the lived experiences of the Wilson disease community would be accurately and effectively represented. This included extensive planning, stakeholder outreach, and the development of structured input to capture the real-world burden of the disease — spanning diagnosis, treatment challenges, and quality of life.

By elevating patient voices and aligning them with regulatory priorities, WDA helped lay the groundwork for more patient-informed drug development and evaluation processes — ensuring that future therapies better reflect the needs and experiences of those living with Wilson disease.

EL-PFDD Highlights

- Led a comprehensive, community-driven preparation effort engaging patients, caregivers, clinicians, and industry stakeholders
- Collected and synthesized patient experience data — including symptoms, treatment burdens, and quality-of-life impacts — to inform regulatory discussions
- Strengthened WDA's role as a patient advocacy leader, positioning the community to influence future drug development

Company Spotlight:
Industry Partnerships and Research Advancement

WDA continued to strengthen relationships with pharmaceutical and biotechnology partners working to improve treatments and advance research for Wilson disease. These collaborations help accelerate clinical development while ensuring patient and caregiver perspectives remain central to therapy innovation.

In addition to financial support, industry partnerships increasingly involve patient engagement, education, advisory participation, and clinical trial collaboration — reflecting the growing recognition of patient advocacy organizations as essential partners in therapy development.

Advancing Therapies Together

5
Industry Partners

Multiple
Active Clinical Programs

Ongoing
Patient Advisory & Engagement

2025
Expanded Educational Initiatives

Eton Pharmaceuticals

- Joined WDA's growing network of industry stakeholders in early 2025
- Supports efforts to improve access to Galzin® and awarenss of Wilson Disease
- Collaborating with the broader Wilson disease community

Monopar Therapeutics

- Advanced clinical development efforts in Wilson disease
- Engaged patient and caregiver perspectives during therapy development
- Supported awareness and research communications

Orphalan

- Continued support for patients living with Wilson disease
- Supported treatment access and patient assistance initiatives for Cuvrior®
- Engaged with WDA on education and community outreach

Prime Medicine

- Expanded interest in potential genetic therapies for Wilson disease
- Began engagement with the Wilson disease patient community in 2025
- Represents emerging next-generation therapeutic approaches

Ultragenyx

- Continued advancement of investigational Wilson disease gene therapies
- Supported patient education and community engagement initiatives
- Collaborated with WDA on awareness and patient-centered discussions

Program Impact: International Medication Assistance

Delivering Hope. Delivering Life.

WDA's medication assistance program reflects the organization's deep commitment to ensuring that no individual with Wilson disease goes without life-saving treatment due to financial or geographic barriers. Through a long-standing partnership with Medicine for All People (MAP) International, the program delivers essential medications to patients in underserved regions worldwide.

> **"Without this program, I would not have access to the medication that keeps me alive."**

The compassion and vision of the late Mary Graper, a long-time WDA leader, inspired the program. Nearly 20 years ago, she was contacted by the mother of a young girl in the Philippines who tragically passed away from Wilson disease due to a lack of access to treatment. Determined to prevent such loss in the future, Mary established WDA's partnership with MAP International.

In 2025, the program expanded both its reach and impact. With support from pharmaceutical partners and the Graper family, WDA coordinated the delivery of critical medications to patients across multiple continents, overcoming complex logistical challenges such as customs clearance, import regulations, and limited local infrastructure.

45

Shipments delivered to 36 patients across 11 countries, totaling approximately 398 bottles of life-saving medication

21

Additional shipments in process, reflecting growing global demand and outreach

New

Expanded treatment options through a new partnership with Orphalan, enabling distribution of Cuvrior® — an important therapy that does not require refrigeration

Dedicated

Program coordination, including the addition of a part-time coordinator with lived experience, strengthening responsiveness to patient needs

Program Impact:
Ambassador & Peer Support Programs

Building Connection. Reducing Isolation.

For many individuals and families affected by Wilson disease, one of the greatest challenges is feeling isolated while navigating a rare and often misunderstood condition. In 2025, WDA continued expanding its Ambassador Program and virtual peer support meetings to help patients and caregivers build meaningful connections, share experiences, and find encouragement from others who understand the journey firsthand.

Through one-on-one peer support, virtual group discussions, and community outreach, these programs created safe and welcoming spaces for individuals at every stage of the Wilson disease journey — from newly diagnosed patients to long-term caregivers and advocates.

Peer Support in Action

- Expanded virtual peer support meetings to 8 support groups yearly, with approximately 15 in attendance per group
- Included patients from Canada, Mexico, Pakistan, and Paraguay
- Increased demand for support groups for all ages
- Created welcoming spaces for patients, caregivers, and newly diagnosed families

Areas of Support

- Newly diagnosed patient guidance and referrals
- Caregiver connection and encouragement
- Shared lived experiences and practical advice
- Emotional support and community building
- Support for parents of young children newly diagnosed

Looking Ahead to 2026

- Launching the Ambassador Program in the fall/winter of 2026 to expand peer support, strengthen community connections, and guide patients, caregivers, and newly diagnosed families, with newly hired staff helping lay the groundwork this year
- Strengthening connections across the global Wilson disease community

8
Support Groups Yearly

~15
Attendees Per Group

Financial Overview

The Wilson Disease Association remains committed to transparency, stewardship, and the responsible use of donor support to advance our mission.

Please note that the figures shown below are approximate.

$1.7M	Total Revenue*
$650K	Total Expenses
$1.05M	Net Change in Assets
$1.8M	Total Assets at Year-End

*Includes a one-time estate gift of approximately $740,000

2025 was an exceptional year financially due to a transformational estate gift. The normalized view below — excluding the one-time gift — reflects the underlying strength of WDA's fundraising and program model.

Normalized Operating View

Core Operating Revenue	$1M
Expenses	$650K
Operating Surplus	$350K

Two-Year Financial Snapshot

	2024	2025
Revenue	$760,000	$1,700,000
Expenses	$630,000	$650,000
Net Change	$130,000	$1,050,000

Expenses by Function

Program Services	92%
Administrative	5%
Fundraising	3%

Donor Impact and Community

WDA's mission is made possible through the generosity and commitment of a diverse and growing community of donors. In 2025, we saw continued expansion in both the size and composition of our donor base, alongside sustained support from returning contributors.

194
Donors in 2025

178
Donors in 2024

38%
Repeat Donors from 2024

Revenue Composition (2025)

Source	Percentage
Pharmaceutical & Corporate Support	19%
Individual & Family Donations	32%
Foundations & Other	49%

2026 Donor Strategy

- Strengthening donor retention, particularly among first-time and mid-level donors
- Expanding the donor pipeline through deeper engagement
- Diversifying revenue sources across individual, corporate, and foundation giving
- Building long-term sustainability through recurring and multi-year support

Looking Ahead to 2026

WDA enters 2026 with strong momentum and a renewed sense of purpose, driven by the extraordinary success of the EL-PFDD Meeting on January 29.

The meeting marked a defining moment for the Wilson disease community. Nearly 350 participants from around the world joined the event — including 40 FDA regulators and senior hepatology leaders — far exceeding expectations. Most importantly, patients and caregivers shared their lived experiences with honesty and courage, ensuring their voices will directly inform how regulators and drug developers understand Wilson disease.

Building on this milestone, WDA is now developing a comprehensive “Voice of the Patient” report that will be submitted to the FDA and shared with clinicians, researchers, and industry partners.

> "Sharing my story was difficult — but knowing it could help shape future treatments made it worth it." — EL-PFDD Participant

2026 Program Priorities:

- Spring Support Symposium: Brought together 60 patients, caregivers, clinicians, and stakeholders on April 11, 2026, at the University of Michigan
- Annual Conference on September 25–26, 2026, in Chicago, Illinois: Will feature patient and family programming and our first-ever CME component — offered by Northwestern Medicine and taught by the same clinical experts presenting to patients and families
- Patient Registry: Provide ongoing support to ensure continued growth in longitudinal research data
- MAP Program: Strengthen partnerships to expand global access to life-saving medications
- Expanded Ambassador Program: Support patients as they navigate life with Wilson disease
- New staff: Operations and Program Manager, Communications Manager, and Patient Ambassador
- Patient advocacy: Raise awareness of Wilson disease and promote newborn screening efforts

Together, we are building a future where individuals with Wilson disease have access to better treatments, stronger support systems, and ultimately a cure.

Leadership and Governance

The Wilson Disease Association is guided by a dedicated group of volunteer leaders who bring professional expertise, lived experience, and deep commitment to the mission. Many members of WDA's leadership team are themselves patients or family members of those affected by Wilson disease.

Board of Directors

Name	Role
Rhonda Rowland	President
Zulma Gonzalez-Lombardo	Secretary
Carol Terry	Treasurer
Jean Perog	Past President
Rachel Albert	Registry Director
Steve Walsh	Finance Director
Alice Williams	Communications Director
Edward Tabor, MD	Medical Policy Director
Lana Escamilla	Patient Advocacy Director
Carly Albinder, LCSW	Patient Education Director
Erol Morey	Development Director

Staff

Name	Role
Nicole Brown	Operations & Program Manager
Christopher Peterson	Communications Manager
Geniquiya Merideth	Administrative Program Coordinator
Ginta Ginaityte, RN	Patient Assistance & MAP Coordinator
Kelsey Pusillo	Patient Ambassador Coordinator

Thank you to all our donors, volunteers, medical advisors, and community members who make this work possible.

WILSON DISEASE® ASSOCIATION

wilsondisease.org

Together for a future without Wilson disease.

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