

2026 WDA ANNUAL CONFERENCE



September 25–26, 2026



Chicago, Illinois



WILSON DISEASE™
ASSOCIATION



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WELCOME TO CHICAGO!

Thank you for being part of the 2026 WDA Annual Conference.

We are thrilled to gather for a milestone in the history of the Wilson Disease Association (WDA): our first-ever dual-track conference, pairing a program for patients and families with a continuing medical education (CME) course for healthcare professionals. This rare opportunity allows patients, families, and clinicians to learn side by side under one roof.

Our sincere thanks go to all who have helped make this conference a reality – our co-host, the Northwestern Medicine Wilson Disease Center of Excellence, and our generous sponsors.

We are deeply grateful to our speakers. Your work advancing the understanding, diagnosis, and treatment of Wilson disease is at the heart of this conference, and we look forward to hearing your latest insights across both conference tracks.

The conference will close with our Partners in Progress focus groups, now in their third year. These sessions give attendees an important opportunity to share their experiences directly with partners developing new therapies and conducting clinical trials, helping ensure that the voices of people affected by Wilson disease remain part of the conversation about what comes next.

And, of course, thank you to all of our attendees for being here. This conference shows what is possible when patients, caregivers, researchers, healthcare professionals, and industry partners come together. Over the next two days, we will explore diagnostics, disease management, treatment options, emerging therapies, and patient support, all to build a stronger, more connected future for everyone affected by Wilson disease.

I hope each of you leaves this conference with new knowledge, renewed inspiration to advocate, and a deeper sense of community.

With gratitude,



Rhonda Rowland
President, Wilson Disease Association

YOUR CONFERENCE AT A GLANCE

The 2026 WDA Annual Conference brings the Wilson disease community together in Chicago for two days of learning, connection, and support.

Friday, September 25



The weekend begins with a Chicago River architecture cruise aboard the Odyssey Chicago River. This special community event offers attendees a chance to relax, reconnect, meet new people, and enjoy the city together before Saturday's program.

Saturday, September 26



Attendees will gather at Northwestern Memorial Hospital for a full day of patient and family programming. Sessions will explore treatment, genetics, mental health, nutrition, neurologic symptoms, pediatric transition, caregiver support, advocacy, emerging therapies, and more.



The conference is hosted in partnership with the Northwestern Medicine Wilson Disease Center of Excellence. This event brings patients, families, caregivers, clinicians, researchers, advocates, and industry partners together for a shared purpose: improving life for people affected by Wilson disease.



Wilson disease can be complicated and isolating, but no one should have to navigate it alone. This conference is a place to ask questions, hear from experts, share experiences, and see the strength of this community firsthand.

We're glad you're here.

PATIENT AND FAMILY AGENDA

Morning Program

TIME	SESSION	SPEAKER
8:00–9:00 AM	Registration and Breakfast	
9:00–9:05 AM	Welcome and Opening Remarks	Amanda C. Cheung, MD
9:05–9:15 AM	Patient Perspective: Living Well With Wilson Disease	Alpana Kharkar, MD
9:15–9:25 AM	Genetics Explained: What It Means for Your Family	Lisa Kinsley, MS, CGC
9:25–9:40 AM	Your Treatment Toolkit: Today's Options and Tomorrow's Therapies	Fred Askari, MD, PhD
9:40–9:55 AM	When Treatment Bites Back — and How to Bite Back Harder: Side Effects, Safety, and Building Habits That Last	Peter Hedera, MD, PhD
9:55–10:05 AM	Fixing the Root Cause: Gene Therapy and Gene Editing for Wilson Disease	Valentina Medici, MD, MAS, FAASLD
10:05–10:20 AM	Panel Q&A: Ask the Team	Panel
10:20–10:35 AM	Networking Break	
10:35–10:50 AM	Test Your Wilson Disease Knowledge	Alice Williams
10:50–11:00 AM	Keeping Your Liver Healthy — and What Happens if It Isn't	Amanda C. Cheung, MD
11:00–11:15 AM	Mood, Mind, and Medication: Mental Health in Wilson Disease	Reuben Heyman-Kantor, MD
11:15–11:30 AM	Rebuilding Strength and Skills: PT, OT, Speech, and Rehab in Wilson Disease	Michael R. Wilson, DO
11:30–11:45 AM	A Neurologist's Toolkit for Managing Symptoms of Wilson Disease	Danny Bega, MD, MSCI
11:45 AM–12:00 PM	Panel Q&A: Ask the Team	Panel

PATIENT AND FAMILY AGENDA

Afternoon Program

TIME	SESSION	SPEAKER
12:00–1:00 PM	Lunch Break	
1:00–1:15 PM	The Copper-Conscious Life: Real-World Nutrition Strategies That Actually Work	Stacey Beer, MPH, RD
1:15–1:30 PM	WD in Kids and Teens – Transition to Adult	Rima Fawaz, MD
1:30–1:40 PM	Navigating Insurance & Specialty Pharmacy	Alaina Slempek, RN, and Abby Mullen, PharmD, BCPS
1:40–1:50 PM	Caring for the Caregiver: You Matter Too	Emily Zivin, MSW, LCSW
1:50–2:05 PM	Panel Q&A: Ask the Team	Panel
2:05–2:25 PM	Networking Break: Peer Connections	
2:25–2:55 PM	You Are Not Alone: Finding Community and Support – What a Support Group Looks Like	Emily Zivin, MSW, LCSW (moderator); Nicole Valenzuela (caregiver); Arjun Ravichandra (patient); and Carly Albinder, LCSW, OSW-C (patient)
2:55–3:05 PM	WDA Ambassador Program	Ginta Ginaityte, RN, and Kelsey Pusillo
3:05–3:15 PM	Advocacy & Getting Involved: Wilson Disease Community	Rhonda Rowland
3:15–3:30 PM	Closing Remarks and Resources	Danny Bega, MD, MSCI
3:30–4:00 PM	Networking Break: Patients and Speakers	
3:45–5:00 PM	Partners in Progress	

MEET OUR SPEAKERS



Fred Askari, MD, PhD

Dr. Fred Askari directs the Wilson Disease Center of Excellence at the University of Michigan. Trained in gastroenterology, hepatology, genetics, and liver transplantation, he developed expertise in Wilson disease through his work with Dr. George Brewer. His research focuses on improving the diagnosis and treatment of hepatic Wilson disease, and he consults with physicians and patients worldwide on advances in Wilson disease care.



Stacey Beer, MPH, RD

Stacey is a pediatric dietitian specializing in gastroenterology, hepatology, and nutrition at Texas Children's Hospital, where she is a member of the Wilson Disease Center of Excellence and has worked with the pediatric liver transplant program for 17 years. She serves on the NATCO Nutrition Board, helped create the Certified Clinical Transplant Dietitian certification, and co-authored "The Copper Conscious Cookbook." She has received national honors for excellence in pediatric and transplant nutrition and developed a global transplant nutrition education program.



Danny Bega, MD, MSCI

Dr. Bega is a board-certified movement disorders neurologist and professor of neurology at Northwestern University Feinberg School of Medicine. He specializes in caring for patients with movement disorders, including Wilson disease, and co-directs Northwestern's Wilson Disease Center of Excellence. He also directs Northwestern's Parkinson's Disease & Movement Disorders Center, leads the neurology residency program, and serves as principal investigator for several clinical trials.

MEET OUR SPEAKERS



Amanda C. Cheung, MD

Dr. Cheung is an assistant professor of medicine at Northwestern University Feinberg School of Medicine. She specializes in both general and transplant hepatology and cares for patients with a wide range of chronic liver diseases, including Wilson disease, alcohol-associated liver disease, metabolic dysfunction-associated steatotic liver disease, viral hepatitis, and autoimmune-related liver diseases. Dr. Cheung is the co-director of the Wilson Disease Center of Excellence at Northwestern.



Rima Fawaz, MD

Dr. Fawaz is the medical director of Pediatric Hepatology and Liver Transplantation at Yale School of Medicine and a member of Yale's Wilson Disease Center of Excellence. She is a co-investigator for the Wilson Disease Registry and leads studies in pediatric liver transplantation, portal hypertension, and cholestasis. Previously, she directed the Intestinal and Multivisceral Transplant Program at Boston Children's Hospital. She twice received the Gastroenterology Attending of the Year award. She is fluent in English, Spanish, and Arabic.



Ginta Ginaityte, RN

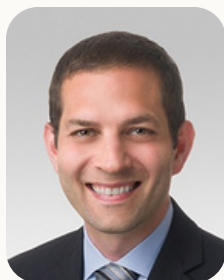
Ginta Ginaityte, RN, is an oncology nurse navigator at UChicago Medicine and was diagnosed with Wilson disease at age 23. At the Wilson Disease Association, she serves as Patient Assistance and MAP Coordinator, helping coordinate medication shipments for patients worldwide, and co-leads the WDA Ambassador Program.

MEET OUR SPEAKERS



Peter Hedera, MD, PhD

Peter Hedera, MD, PhD, is a movement disorders neurologist and medical geneticist at the University of Louisville. He specializes in inherited neurologic disorders, including Wilson disease, and has longstanding expertise in managing its neurologic manifestations. His clinical interests include movement disorders, botulinum toxin therapy, deep brain stimulation, and other advanced treatments for persistent neurologic symptoms. He is a member of the WDA Medical Advisory Committee.



Reuben Heyman-Kantor, MD

Dr. Heyman-Kantor is an assistant professor at Northwestern University, a psychiatrist who cares for patients on the inpatient service at Northwestern Memorial Hospital, and a member of Northwestern Medicine's Wilson Disease Center of Excellence. He is also a member of Northwestern's neuromodulation service, where he provides electroconvulsive therapy, transcranial magnetic stimulation, and ketamine infusion therapy.



Alpana Kharkar, MD

Dr. Kharkar is a family physician living with Wilson disease. She trained at the University of Newcastle upon Tyne in the UK. After moving to the U.S., she completed further internal medicine training at Kaiser Permanente San Francisco and practiced at Kaiser Permanente San Rafael Medical Center. She co-founded The Permanente Medical Group's Wilson disease task force to improve care and physician awareness.

MEET OUR SPEAKERS



Lisa Kinsley, MS, CGC

Lisa is a senior genetic counselor for neurology at Northwestern University and a member of Northwestern Medicine's Wilson Disease Center of Excellence team. She specializes in neurogenetics, providing counseling for patients with movement disorders and other neurologic conditions. Her work includes reviewing family histories, assessing genetic risk, educating patients about genetic testing, coordinating testing, and helping patients and families understand results.



Valentina Medici, MD, MAS, FAASLD

Dr. Medici is a professor of internal medicine in the Division of Gastroenterology and Hepatology at UC Davis School of Medicine, vice chair for research in the Department of Internal Medicine, and director of the UC Davis Wilson Disease Center of Excellence. She specializes in liver disease, with a particular clinical and research focus on Wilson disease. Her research examines copper metabolism, epigenetic changes, and liver injury in Wilson disease, and she serves as a site investigator for clinical trials evaluating emerging therapies.



Abby Mullen, PharmD, BCPS

Abby is a clinical pharmacist specializing in neurology at Northwestern Medicine Specialty Pharmacy and is board-certified in pharmacotherapy. She earned her PharmD from Purdue University and completed her residency at Northwestern Medicine. She works with the neurology department to support patients with Wilson disease, Huntington's disease, Parkinson's disease, and multiple sclerosis.

MEET OUR SPEAKERS



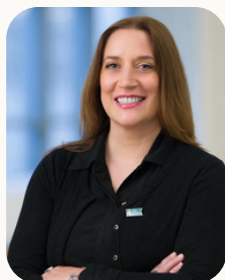
Rhonda Rowland

A career health communicator, Rhonda was diagnosed with Wilson disease after developing liver failure at age 21. She earned a degree in communication arts from the University of Wisconsin–Madison and spent 16 years in medical reporting at CNN. She later worked in freelance medical video production and consulting while raising her children. In 2020, she joined the WDA Board to help raise awareness of Wilson disease. She has served as WDA President for the past two years.



Kelsey Pusillo

At 18, Kelsey was diagnosed with Wilson disease and hemochromatosis after going into liver failure. Since then, she has navigated transplant classes, routine testing, tremors, and other challenges while building an active life in Colorado with her husband and two children. Her experience inspired her to earn a certificate in integrative health coaching and support others through the Wilson Disease Association as the Patient Ambassador Coordinator.



Alaina Slempek, RN

Alaina is a registered nurse at Northwestern Medicine with 11 years of nursing experience. She earned her nursing degree from the University of Illinois at Chicago and has a background in outpatient psychiatry and public health nursing. She is passionate about building trusting relationships with patients and providing compassionate, patient-centered care. She recently received the 2026 Northwestern Medicine Nursing Excellence Award.

MEET OUR SPEAKERS



Michael R. Wilson, DO

Michael R. Wilson, DO, is an instructor in physical medicine and rehabilitation at Northwestern University Feinberg School of Medicine. As a physiatrist, he cares for children and adults with functional limitations related to conditions such as brain and spine injuries and neuromuscular disorders. His work focuses on helping patients improve function and manage pain associated with physical limitations.



Emily Zivin, MSW, LCSW

Emily is a licensed clinical social worker. She provides outpatient clinical services at Northwestern Medicine for individuals living with Wilson disease, Huntington's disease, and atypical parkinsonism. She also provides therapy for individuals with tics, Tourette syndrome, and functional neurological disorders. In addition, Emily works with the Huntington's Disease Society of America, providing support for the National Youth Alliance.

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Prime Medicine is proud to support the
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At Prime Medicine, we're developing investigational Prime Editing approaches for serious genetic diseases.

Our mission is to expand the possibilities of what gene editing can achieve for people living with Wilson disease.

We're here to listen, learn, and connect with you. Whether you're a patient, caregiver, researcher, or advocate, your voice matters to us.

Stop by our booth at the WDA Annual Conference to:

Meet members of
the Prime Medicine
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Learn about our
research in Wilson disease

Ask questions about
Prime Editing

Share what matters most
to you and the Wilson
disease community

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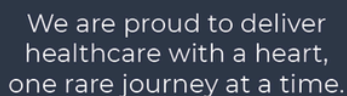
Living with Wilson disease comes with unique challenges. At Anovo, we're committed to making access to care simpler, smoother, and more personal.

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Special Thanks to Tara West

We extend our heartfelt thanks to Tara West, our conference coordinator, for the dedication, organization, energy, and care she brings to WDA events year after year. Tara has become a valued part of the WDA team, and her behind-the-scenes leadership and attention to detail have been instrumental in the success of our conferences and in bringing our community together.

Thank You

Thank you to all the donors, volunteers, medical advisors, staff, board members, clinicians, sponsors, and community members who make this work possible.

MEDICAL ADVISORY COMMITTEE

We thank the Medical Advisory Committee for its guidance on the medical and scientific aspects of Wilson disease.

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In Memoriam

Regino Gonzalez-Peralta, MD

The Wilson Disease Association remembers Dr. Regino Gonzalez-Peralta with deep gratitude for his many years of service to our community.

A pediatric gastroenterologist, transplant hepatologist, and longtime member of the WDA Medical Advisory Committee, Dr. Gonzalez-Peralta brought a special interest in pediatric Wilson disease and generously shared his expertise to help the WDA provide trusted medical information and support to individuals and families affected by Wilson disease. As a Wilson Disease Registry investigator, he contributed to efforts to deepen understanding of the disease. His knowledge, generosity, dedication to children and families, and commitment to the Wilson disease community made a lasting difference, and he will be deeply missed.



WILSON DISEASESM ASSOCIATION

Founded in 1983, the Wilson Disease Association is a global nonprofit organization dedicated to improving the lives of individuals and families affected by Wilson disease. WDA provides support, education, advocacy, and hope while advancing research, awareness, and collaboration across the Wilson disease community.

Mission

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

Vision

A future where Wilson disease is better understood, more effectively treated, and ultimately cured.

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