

## FOR IMMEDIATE RELEASE

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## Amplifying the Voices of Wilson Disease Patients & Caregivers: Be a Part of the WDA's Virtual Externally-Led Patient-Focused Drug Development Meeting

When it comes to the future of Wilson disease (WD) treatments, patients and caregivers will now have a seat at the table. The Wilson Disease Association (WDA) invites everyone with an interest in WD to join a **virtual Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting** on **January 29, 2026**, from **10 a.m. to 3 p.m. ET**.

The **EL-PFDD program**, developed by the U.S. Food and Drug Administration (FDA), ensures that patients' experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and regulatory decision-making.

"For the first time, patients and caregivers affected by Wilson disease will have a direct voice in shaping the future of treatment. This is not just a meeting—it's a historic opportunity for the global Wilson Disease community to be heard by those who can drive real change," said **Rhonda Rowland**, President of the Wilson Disease Association. "We are thrilled to be part of this movement and encourage everyone impacted by this rare genetic liver disease to join us in making their voices count."

During this significant event, individuals impacted by WD will have the opportunity to speak directly to the **FDA, product developers, practicing physicians, and academic researchers**. A diverse group of patients and caregivers will share how Wilson disease affects daily living and treatment experiences in several ways:

- **Recorded videos and testimonials** highlighting lived experiences
- **Live "conversation starter" sessions** featuring patients and caregivers
- **Interactive participation**, including live call-ins, comment submissions, and polling

The **portal to submit written comments** opens on **December 6, 2025**, and will remain open for **30 days after the meeting**. All perspectives—shared before, during, and after the meeting—will be incorporated into a **Voice of the Patient Report**, which will be publicly available on the WDA website and shared with the FDA. This report will serve as a resource for FDA and product developers when advising on WD treatment programs and reviewing future marketing applications.

The meeting will also feature insights from leading experts in Wilson disease:

- **Dr. Michael Schilsky**, Director of the WD Center of Excellence at Yale, will provide a clinical overview.
- **Dr. Fred Askari**, Director of the WD Center of Excellence at Michigan Medicine, will discuss the current treatment landscape.
- **Dr. Aimee Magnarelli**, from the FDA's Center for Biologics Evaluation and Research (CBER), will deliver opening remarks.

Free registration for the live webcast will open soon. To receive updates and event details, **join the WDA mailing list** at [www.wilsondisease.org](http://www.wilsondisease.org). For questions, contact [events@wilsondisease.org](mailto:events@wilsondisease.org).

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The **Wilson Disease Association (WDA)** is the only U.S.-based nonprofit dedicated to supporting people affected by Wilson disease worldwide. The WDA funds research, educates patients and caregivers, and raises awareness among the public and medical professionals. Its vision is to unmask the challenges of Wilson disease and unleash the promise of a cure.

**Wilson disease** is a rare genetic disorder affecting approximately 1 in 30,000 people worldwide. It causes copper to accumulate in the liver, brain, and other organs, leading to serious health complications if untreated. Early diagnosis and treatment are crucial.