

## Wilson Disease Registry Update July 2025

The members of our registry research team would like to express their appreciation to the Wilson Disease Association and all the participants for their continuous support of both the team and the registry. Initiated in 2017, the Wilson Disease Registry (WDR) study has achieved significant progress, largely due to your collective contributions. As we enter our seventh year, we are pleased to share several key developments.

First, we thank Dr. Ayse Coskun for her hard work and dedication during her time with us at Yale. Joining in May 2019, she was a remarkable member of our team and since July 2024 is pursuing a career in psychiatry at Creighton University. While we miss her professional skills and kind spirit, Dr. Coskun remains involved in several projects initiated by the registry study during her time with us.

We are delighted to introduce Dr. Asim Ulcay as our new study director and Dr. Sefa Keserci as study coordinator. Dr. Ulcay, with his background in data analysis, will facilitate collaboration between our collected data and our biostatistical team, enabling deeper interpretation and understanding of Wilson disease (WD). Dr. Keserci will assist new and returning patients with arranging their registry visits and is involved in setting up new research protocols that align with our registry goals.

Over the past years we have expanded our registry from Yale University WD Center of Excellence to a total of eight expert centers across the globe with our most recent addition being the WD Center of Excellence at Wake Forest Baptist Health, North Carolina under the supervision of Dr. Sean Rudnick.

We are excited to announce that the registry now encompasses approximately 300 patients, including pediatric and adult patients ranging in age from 0 to 74 years. From the study data and biorepository specimens we have analyzed data that was incorporated into meeting presentations and scientific publications. Together these have expanded our understanding of the natural history of WD, shared our findings with the broader scientific community and enhanced care for patients with WD.