



CYSTINOSIS  
RESEARCH NETWORK

# WHAT'S YOUR 57?

**Cystinosis  
Awareness Day  
May 7th, 2026**

"57" comes from the 57kb deletion in the CTNS gene, the most common genetic cause of nephropathic cystinosis. Since it began 9 years ago, Cystinosis Awareness Day has grown into a global movement.

Join the 57 voices effort.

**What keeps you going? Why do you support the cystinosis community?**

Share your thoughts and a photo using this short form to be featured in the awareness campaign.

Together we can:

- Improve understanding of cystinosis
- Support earlier diagnosis and better care
- Strengthen support for those affected

Explore more ways to participate at [tinyurl.com/cystinosis26](https://tinyurl.com/cystinosis26).



Go to  
[tinyurl.com/57CADform](https://tinyurl.com/57CADform)  
or scan the QR code.

**Thank you for helping honor  
our 2,000+ cystinosis warriors  
worldwide.**