



TOGETHER RARE IS NOT RARE

- There are over 10,000 different Rare Diseases
- 200+ new Rare Diseases are identified each year
- 30 million individuals in the USA have a Rare Disease
- More than 90% of Rare Diseases have no treatments
- 100% of pediatric cancers are Rare
- Rare families experience 3-5 times higher than average medical costs
- 2 out of 3 Rare Disease patients are children

**Data sources for this document include: EveryLife Foundation for Rare Diseases, Global Genes, National Organization for Rare Disorders, National Institute of Health, US Census, WI DHS*

Wisconsin Rare Disease Alliance

N85 W16110 Appleton Ave





PO Box 158

Menomonee Falls, WI 53051

info@wirare.org

www.wirare.org

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A Coalition to Advance Rare Disease in WI



Let's save and improve the lives of WI Rare Families!

Be an Ally - Join Now!!

RARE DISEASE PRIORITIES FOR WISCONSIN

ACCESS

- Advocate for policies, systems and processes that improve diagnosis, care and treatment / clinical trials for rare

EDUCATION

- Increase public awareness
- Educate decision makers
- Strengthen collaboration across rare disease stakeholders

INNOVATION

- Accelerate rare disease investment in WI
- Engage medical and health schools
- Advance science and research in rare
- Increase clinical sites and trials in WI

WISCONSIN RARE DISEASE FACTS



An est. **600,000** people live with Rare Diseases in WI.

Over **6,000** babies will be born with a Rare Disease in WI this year.

Medical costs are **3-5 times** higher in rare disease families.

ABOUT US

The Wisconsin Rare Disease Alliance is a coalition of families, clinicians, researchers, businesses, and allies interested in supporting rare diseases in WI.

We engage as a unified coalition and provide a platform to inform the public and decision makers on rare disease needs.

TIME FOR ACTION

Be an Ally and help us support WI rare disease families.

Contact us at wirare.org to learn more and get involved!

