LOUIE'S HUWE

FOR HUWE1-RELATED GENETIC CONDITIONS

Raising awareness, supporting families and driving research into

HUWE1-RELATED GENETIC CONDITIONS

www.huwe1.org/louieshuwe

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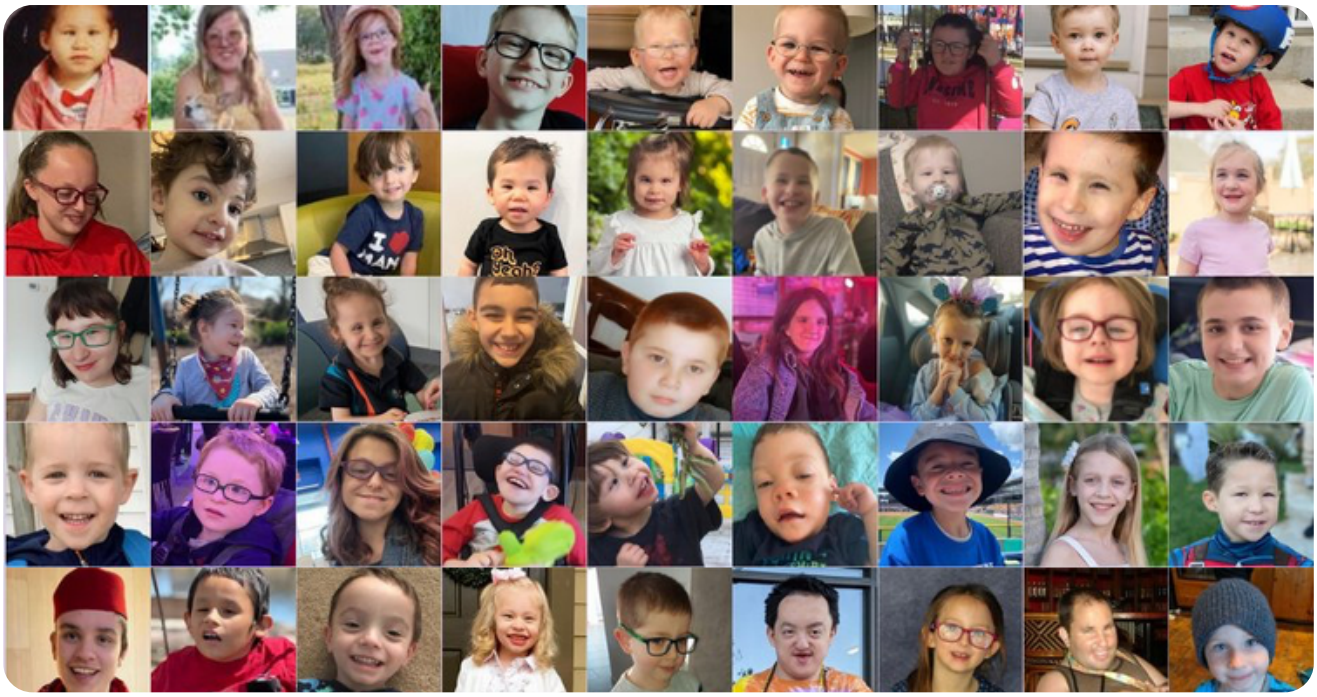
Louies Huwe is recognized by the IRS as a 501(c)(3) tax-exempt public charity (EIN: 86-1930096)
508 Crab Apple Dr., Stafford, VA 22554, United States



About HUWE1

What is HUWE1?

People with HUWE1-related genetic disorders have symptoms such as **intellectual disability, epilepsy, autism and feeding problems**

The HUWE1 gene is located on the X chromosome and encodes the HUWE1 protein. The protein is present in all cells in the human body meaning that any HUWE1 genetic variation can have significant effects throughout the body. People with HUWE1-related disorder are affected by mutations in the HUWE1 gene and have intellectual disability, epilepsy, and display autistic features as well as other medical issues.

Many children diagnosed with HUWE1 genetic variants experience intense, regular seizures, which can be one of the biggest challenges for families to manage. Others live life nonverbal, with significant intellectual disability or an autism diagnosis. One of the most dangerous features of this genetic disorder are the severe epileptic bouts individuals experience. Children and adults with HUWE1-related genetic conditions desperately need treatment options for severe epilepsy and other neurological symptoms.

HUWE1-related disorders are extremely rare but with access to genetic testing increasing, **new families are diagnosed frequently**

About us

Who are Louie's Huwe?

Partnering parents & experts

In 2021, a group of concerned and dedicated parents collaborated with a skilled physician to create a nonprofit dedicated to finding treatments for HUWE1 related genetic conditions.

Louie's HUWE is partnered with Johns Hopkins University School of Medicine and Seattle Children's Hospital and Research Institute to work towards better understanding the genetic basis of this disorder, and to develop new treatments to help these children and adults.

How we support HUWE1 families

Awareness & information
Raising awareness, sharing information on latest discoveries

Community & support
Sharing experiences, providing online events with world experts

Research into treatments
Using cutting edge science

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Scientific advisers

Our scientific advisers

Kristin W. Baranano, M.D., Ph.D.

Assistant Professor, Department of Neurology, Johns Hopkins University School of Medicine

Kristin Whitford Baranano, M.D., Ph.D. is Assistant Professor in the Department of Neurology at Johns Hopkins University School of Medicine in Baltimore, USA. She is a pediatric neurologist and neurogeneticist who specializes in the diagnosis and management of rare neurologic disorders with a genetic basis.

Brock Grill, Ph.D.

Professor, University of Washington Medical School and Seattle Children's Research Institute

Brock Grill, Ph.D. is a professor and principal investigator actively researching HUWE1. His work focuses on understanding how information is relayed within nerve cells to regulate cellular activities and animal behavior. He has been studying HUWE1's role in the nervous system for the past ten years. He is a professor at the University of Washington Medical School and at the Seattle Children's Research Institute, USA.

Our research priorities

Identifying epilepsy treatments
Targeted treatments specifically for HUWE1-related epilepsy

Understanding gene function
Better understanding of HUWE1 and its role in genetic conditions

Treating wider symptoms
Treating the many symptoms of HUWE1-related genetic conditions

Improving lives
Information, treatment pathways, quality of life

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Donate: www.huwe1.org/louieshuwe

Your support means a lot!

Donate at www.huwe1.org. Or to help us avoid processing fees, please send a check to 'Louie's Huwe' at 508 Crabapple Drive, Stafford, VA 22554.

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