



INTERNATIONAL
ANGELMAN
DAY FEB 15



For Immediate Release

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Twin Cities Buildings and Landmarks Join Others Globally to Light Up in Blue on February 15 for the 10th Annual International Angelman Day

Annual Worldwide Celebration to Raise Awareness of Angelman Syndrome, a Rare Neurogenetic Disorder that Impacts Approx. 1:15,000 Births and More Than 150 Minnesota Families

MINNEAPOLIS, Minn. (January 25, 2023) – On **Wednesday, February 15**, buildings and landmarks around the world will be lit up in blue for the **10th annual [International Angelman Day \(IAD\)](#)**, a celebration that creates awareness of **Angelman syndrome (AS)**, a rare neurogenetic disorder. Children and adults with AS typically have substantial cognitive impairment, balance issues, motor impairment and can have debilitating seizures. Some individuals never walk. Most do not speak, and many have sleep difficulties. In addition to these challenges, many individuals with AS also have unique behavioral characteristics such as a happy demeanor, characterized by frequent laughter, smiling, and excitability. February 15 is significant because February is **International Rare Disease Month** and the 15th refers to the 15th chromosome, which is the chromosome impacted by Angelman syndrome.

This year, the Twin Cities will be lit up in blue at **Capella Tower, Target Headquarters, U.S. Bancorp, 10 West End, the Lowry Avenue Bridge, and CHS Field** where the billboard will be blue. These locations will join **Yavuz Sultan Selim Bridge in Turkey (one of the tallest in the world which connects Europe and Asia); City Hall in Peterborough, ON, Canada; landmarks and buildings in both Philadelphia, PA and Brisbane, Australia;** and many other locations worldwide in a global effort to draw attention to AS and the efforts being made to find treatments and a cure.

Over the years, several Minnesota families impacted by AS have made it their mission to raise awareness and funds for research towards a cure for AS. **Meghan and Jesse Edberg** of Rosemount received a diagnosis of their son **William** in January 2020. After digesting the heartbreaking news, they started the [Will.i.CAN \(willican.org\) brand to raise awareness and provide an easy location for people to donate to help fund a cure for AS](#), which in the last 3 years, helped raise over \$510,000 for FAST. “When we learned of William’s diagnosis, it was a bittersweet day,” said Meghan Edberg. “We finally knew the cause of his delays, yet we knew nothing about Angelman syndrome and even though we can’t control this diagnosis, we can control how we react. Community fundraising and partnerships are critical for a cure to become a reality. We would love for the Minnesota business community and residents to be involved in helping cure our loved ones with Angelman syndrome.” Meghan is so committed to the cause she recently switched careers and became the Director of Community Engagement for FAST to

support these same efforts on a global scale. The Edbergs have hosted many smaller fundraising events, and this year they are excited to launch their first annual “If Will CAN, We CAN” event at Surly Brewing Co in August, with registration available at willican.org!

Todd and Karly Werner of Deephaven were also called to action after their son **Louie** was diagnosed with AS four years ago. They created the [Hopeful Halos Foundation \(hopefulhalos.org\)](http://hopefulhalos.org) and host an annual “**Links for Louie**” charity golf tournament each July, with all proceeds benefiting FAST. “When we first learned of Louie’s diagnosis, we were gutted,” said Todd Werner. “All the dreams we had for our beautiful child became sources of unimaginable grief. That year, we attended a gala for FAST and were encouraged to learn of the amazing things other AS parents were doing in their shared mission to cure AS...fast! As a single-gene mutation, AS represents a great proving ground for a variety of emerging genetic technologies.” In 2022, Todd and Karly also joined the **FAST Advisory Council** as volunteers to support FAST’s mission.

The **Foundation for Angelman Syndrome Therapeutics (FAST)**, a parent-led advocacy organization launched in 2008, is the largest non-governmental funder of Angelman syndrome (AS) research and is the reason so many in the community have so much hope to experience transformative therapies for those living with AS. The organization’s mission is to find a cure for AS through the funding of an innovative and aggressive research agenda. Since its inception, FAST has invested more than \$30 million to bring promising therapeutics to humans living with AS. Because of those efforts, today there are four active human clinical trials ongoing for AS: three using a disease modifying strategy and one targeting the downstream effects of the nonfunctional gene.

Scientists believe that AS has the greatest potential for being cured when compared to any other neurogenetic disorder.

"Angelman syndrome is a model for thousands of other genetic diseases and hundreds of other monogenetic neurodevelopmental disorders," said **Dr. Allyson Berent**, FAST Chief Science Officer. “The Angelman story will show the world that disease modifying, gene replacement, gene editing, and so many other novel and innovative modalities will have a profound impact on rare monogenetic disorders across the globe. The difference we are making for Angelman syndrome will exponentially accelerate developments for thousands of other conditions, and it's only a matter of time."

For more information about International Angelman Day and the 2023 Twin Cities Angelman syndrome events, visit <http://www.willican.org/iad>.

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