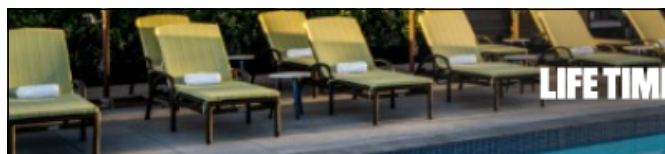


https://www.hometownsource.com/sun_thisweek/community/dakota_county/rosemount-boy-is-namesake-of-angelman-fundraiser/article_68878fbc-321a-11ee-9423-53beacd8d8de.html

Rosemount boy is namesake of Angelman fundraiser

Tad Johnson

Aug 4, 2023





The Edberg family from Rosemount are helping to organize the "If Will CAN, We CAN" benefit to raise money for Angelman syndrome research.

Photo submitted

Event to be held at Surly Brewing Co. in Minneapolis

A Rosemount boy fighting a rare disease will be the center of fundraising attention during the "If Will CAN, We CAN" benefit on Tuesday, Aug. 15, at Surly Brewing Co. in Minneapolis.

William Edberg, who was diagnosed with Angelman syndrome in 2020, is the namesake of the fundraiser and the Will.i.CAN (Cure Angelman Now) effort, which aims to fund research to find a cure for the neurogenetic disorder that leads to developmental delays in an estimated one in 15,000 births.

William was born in September 2017 and the family said early on he was not meeting developmental milestones, and doctors were struggling to identify the cause.



Premium Basics Golf Kit
250 for \$422.50



Embossed Gloss Business Cards
50 for \$15.99



Golf Balls - Case of 12
6 for \$2,241.29



Folded Hi
25 for \$

In November 2019, he was having atonic “drop” seizures, which led to focused genetic testing for neurological disorders. On Jan. 7, 2020, he was diagnosed with Angelman syndrome.

AS causes cognitive impairment, balance issues, motor impairment, and debilitating seizures.

Since his diagnosis, the family said he persists and surprises them daily with all that he is capable of. Some AS children are unable to walk and speak, but William’s mother, Meghan, said he can run and tackle most playgrounds with confidence.

“He is gaining a robust communication strategy which includes pointing, physically moving someone or an object, or using his Augmentative and Alternative Communication device to express his needs. This helps everyone around him understand what his needs are,” she said.

“Overall, he continues to be a happy, sociable, empathetic individual,” Meghan said. “However, if he cannot get his needs met, he may push, grunt, and/or resist his caregiver or friend. This is challenging now and will continue especially as he grows up and becomes stronger.”

William is behind compared to his typical peers, but the family said that does not stop him from living a full life.

Meghan said he enjoys watching YouTube, going to the swimming pool, making others laugh, following his 4-year-old brother around, being social at gatherings, and giving a lot of hugs.

William needs one-on-one attention around the clock to ensure the safety of himself and others.

He does weekly therapies for speech and occupational therapy and will be attending kindergarten at Red Pine Elementary in Eagan this fall.

Meghan said the family moved to Rosemount in April 2018 because they knew the Rosemount-Apple Valley-Eagan School District was one of the best in the state.

“It’s a bonus that their Special Ed program is also top notch since we moved here before William’s diagnosis,” she said.

After the diagnosis, Meghan said the school district connected the family with others in the district who also are raising a child with AS.

“It’s great because – because they get it,” Meghan said. “Many of us say this is the club we never wanted to be in, but we are glad we are in it with each other. Having the AS community has supported us through the day-to-day life of Angelman syndrome and helps motivate us to fight for a future, together.”

Meghan, who has a master’s degree in athletic counseling, started Will.i.CAN (Cure Angelman Now), switched careers and is the Foundation for Angelman Syndrome Therapeutics’s director of community engagement.

“There is hope for our community and it is real,” she said. “For hope to be a reality that a promising therapeutic gets from the lab to humans is a complex, expensive process. Fundraising and bringing awareness is where our family’s strength lies so that is where we put most of our energy to support the community. However, there are so many ways to support the AS community to help bring a promising therapeutic to fruition.”

Will.i.CAN has raised more than \$510,000 for FAST in the past three years.

“I’m brought to tears at every event and situation where someone steps up for our family (which isn’t easy to do as I’m usually a stoic person),” Meghan said. “I often say to our supporters that we understand that every child has something and there are causes all over the world that need support ... and we are incredibly grateful they choose us and our something to stand by.”

FAST is the largest non-governmental funder of Angelman syndrome research.

It is working with medical teams at research universities throughout the U.S. conducting three live clinical trials, with 20 more in the works.

The Edbergs will make a presentation during the event, and Dr. Allyson Berent, chief scientific officer at FAST and parent of a child with AS, will be keynote speaker to talk about these efforts and more.

Since its inception, FAST has invested more than \$30 million in AS research and therapeutics.

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

The work is showing that disease modifying, gene replacement, gene editing, and many other modalities will have an impact on rare monogenetic disorders, and the progress being made for Angelman syndrome research could accelerate developments for thousands of other conditions.

FAST has an aggressive research agenda. More information is at cureangelman.org/research#map.

Profits from the event will go toward research to support FAST's Roadmap to a cure.

"I am looking forward to this event because it is bringing together those who have been Will.i.CAN supporters since day one, old family and friends we haven't seen in years, new friends (ex: a newly diagnosed family is joining us), and new faces (friends of friends)! So, it's a bit of a hodge podge because it's a high school reunion, family reunion, networking group, and social gathering all in one. I cannot wait to feel the love, emotion, and inspiration on this special night," Meghan said.

The event is from 6-9 p.m. and includes food and craft beers, a silent auction and raffle, and a tour of buildings lit up in blue on International Angelman Day. Tickets start at \$75.

"I am looking forward to seeing William bring joy to those he has not met yet so our guests can understand all the good he brings to this world despite his diagnosis," she said.

A limited number of \$200 VIP Experience tickets are available for the 5-6 p.m. private beer/food tasting reception with a Surly staff member.

For information or to buy tickets, visit willican.org/events.html.

Tad Johnson can be reached at tad.johnson@apgecm.com.

Tad Johnson is a managing editor of Sun Thisweek and the Dakota County Tribune

Tad1234