Sunday Life: New exhibit at Minnesota Children's Museum brings paintings to life and lets kids "step into" art. **E1**

John Shipley: Bally financial woes likely to spur MLB broadcasting shakeup. **C1**

Local: St. Paul organizations to receive $5M over 3 years as part of equity initiative. **A3**

SUNDAY
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Sunday, February 12, 2023 FACEBOOK.COM/PIONEERPRESS TWITTER.COM/PIONEERPRESS twincities.com

ST. PAUL

Anger, questions follow student's death

Police address video rumors on Harding student's stabbing; community members meet to discuss actions

By Kristi Belcamino
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As the community came together to grieve a 15-year-old Harding High School student who was fatally stabbed Friday by a fellow student, a family member started a gofundme account to help with funeral expenses.

According to the page "Help Devins Family" created by Christopher Brown, the boy who was killed is named Devin.

Brown said his "baby brother" was stabbed twice in the chest and stomach during a fight at the school.

A 16-year-old Harding High School student is in custody in connection with the death. Officers responding to a 911 call about 11:45 a.m. Friday found employees at the East Side school giving first aid to a male student with stab wounds. Paramedics took the boy to Regions Hospital, where he was pronounced dead.

Authorities did not release any new information on the homicide investigation Saturday but did address rumors about videos circulating on social media that claim to have captured the stabbing.

"We cannot comment on the validity of any videos — if they are evidence or not — just as we would not discuss facts of the case as it's an active investigation," St. Paul Police Sgt. Mike Ernster said Saturday.

Authorities asked that anyone who believes they have video of the incident call investigators at 651-266-5650.

HARDING » PAGE 12

TWIN CITIES

'MEET ANGELMAN SYNDROME'

PHOTOS BY JOHN AUTEY — PIONEER PRESS

William Edberg, 5, is held by his dad, Jesse, left, as his mom, Meghan, and brother, Henry, 3, join them on the couch, along with their dog, Puck, at their Rosemount home this month. Born with Angelman syndrome, a rare neurogenetic disorder, William has learning disabilities and does not speak. He also, like many others with the syndrome, has a happy demeanor, characterized by lots of laughing, smiling and excitability.

Rosemount boy's diagnosis spurs his family to work for awareness and a cure

By Mary Divine
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Henry Edberg dug through the play kitchen at his home in Rosemount before serving up the daily special to his older brother.

"Vegetables are healthy, so I'm giving you the vegetables," Henry, 3, told William, 5, handing him a plastic piece of broccoli, a tomato and half a carrot. "And the doughnut ... because those are healthy, too."

Meghan Edberg, the boys' mother, got two miniature muffins and a pizza.

"Are you a good big brother?" she asked Henry.

"Yes," he said. "Because I always share."

Henry — 23 months younger than William — has stepped into the role of "big little brother" because William was born with Angelman syndrome, a rare neurogenetic disorder, and has learning disabilities and does not speak. He also, like many others with the syndrome, has a happy demeanor, characterized by lots of laughing, smiling and excitability.

"He's always happy," Meghan Edberg said. "He has a good sense of humor. If he gets excited, he flaps his arms. If he's not happy, we know something is wrong."

"He makes you feel like you're the funniest person in the world," said his father, Jesse Edberg. "When you want to make yourself feel better, go see William. He's the only kid I know who laughs at all the dad jokes. He's very compassionate and loving and empathetic. When his brother is hurt or upset about something, he goes to him, and he'll try to give him a hug. He just wants harmony in the house. If you yell at the dog for eating off the table, he gets really sad because he doesn't want anyone yelling. He just wants happiness."

Angelman syndrome is caused by a loss of function in the UBE3A gene on the maternal 15th

EDBERG FAMILY » PAGE 8

William, right, gives brother Henry a face bump as the two play at home. "He's always happy," Meghan Edberg said of William.

WISCONSIN

Amid land dispute deadlock, tribe blocks streets

Tired of negotiating for overdue road fees, tribal leaders close roads crossing Lac du Flambeau reservation, disrupting neighbors' lives

By Mitch Smith
The New York Times

LAC DU FLAMBEAU, WIS. » The yellow barricades and chained-together concrete blocks went up late last month, cutting off dozens of houses from roads on the Lac du Flambeau Reservation in northern Wisconsin, where soaring evergreens and the papery bark of birch trees punctuate the skyline.

To tribal leaders, who for years tried and failed to negotiate payments for portions of those streets that cross their property, the blockades were an assertion of sovereignty, a statement that they would defend tribal land and demand respect.

To the homeowners on the wrong side of the roadblocks, many of them white, the barricades were a startling disruption to nearly every aspect of their routines, a literal barrier to getting to work or running errands.

With the tribe seeking $20 million to resolve the dispute over the four snowpacked back roads, residents have hunkered down, left town or hiked across frozen lakes to reach their cars and jobs. The standoff has prompted a visit from Wisconsin's governor and statements of concern from members of Congress.

WISCONSIN TRIBE » PAGE 11

TURKEY-SYRIA EARTHQUAKE

Rescues continue as death toll tops 28,000

Frustration grows over Turkish government's response to disaster

By Justin Spike, Abdelrahman Shaheen and Zeynep Bilginsoy
The Associated Press

LATAKIA, SYRIA » Ibrahim Zakaria lost track of time drifting into and out of consciousness while trapped for nearly five days in the rubble of his home following the massive earthquake that struck Turkey and Syria this week.

The 23-year-old cellphone shop worker from the Syrian town of Jableh survived on dirty drips of water and eventually lost hope that he'd be saved.

"I said I am dead and it will be impossible for me to live again," Zakaria, who was rescued Friday night, told The Associated Press on Saturday from his bed at a hospital in the coastal city of Latakia where his 60-year-old mother, Duha Nurallah, was also recovering.

Five days after two powerful earthquakes hours apart caused thousands of buildings to collapse, killing more than 28,000 people and leaving millions homeless, rescuers were still pulling unlikely survivors from the ruins — one of them just 7 months old.

Although each rescue elicited hugs and shouts of "Allahu akbar!" — "God is great!" — from the weary men and women working tirelessly in the freezing temperatures to save lives, they were the exception in a region blanketed by grief, desperation and mounting frustration.

More than a dozen survivors were rescued Saturday, including a family in Kahramanmaras, the Turkish city closest to the epicenter of Monday's quake. Crews there helped 12-year-old Nehir Naz Narli to safety before going back for her parents.

In Gaziantep province, which borders Syria, a family of five was rescued from a demolished building in the city of Nurdagi and a man and his 3-year-old daughter were pulled from debris in the town of Islahiye, television network Haber-Turk reported. A 7-year-old girl was also rescued in Hatay province.

In Elbistan, a district in Kahramanmaras province, 20-year-old Melisa Ulku and another person were saved from the rubble 132 hours after the quake struck.

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Full report on C8

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Edberg family

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chromosome, according to the Foundation for Angelman Syndrome Therapeutics, the largest non-governmental funder of Angelman syndrome research. It occurs in approximately one of every 15,000 births. About 157 people in Minnesota have Angelman syndrome.

Having a defective copy of the maternal UBE3A gene "affects the body's synapse function ... and makes these neurons not be able to balance each other out," Meghan Edberg said. "It's like living in a rainstorm with the wipers always going because the brain doesn't have the ability to level things out. They just can't turn off."

Other symptoms of the disorder include balance issues and having trouble getting to sleep and staying asleep.

PHOTOS BY JOHN AUTEY — PIONEER PRESS

William Edberg, left, uses his computer tablet to communicate with his mom, Meghan, as his dad, Jesse, and brother, Henry, play at their Rosemount home this month. William, 5, is on the higher end of functioning among individuals with Angelman syndrome, a rare neurogenetic disorder, but he still has cognitive challenges. He communicates by using a "talker," an app that allows him to press a button to "say" a word or name.

William smiles as he takes a bite of his favorite meal, macaroni and cheese, at home this month.

Missing milestones

William was born on Sept. 3, 2017. At his nine-month well-child visit, his doctor expressed concern that he wasn't meeting developmental milestones. "He was very quiet — not babbling or saying many words," Meghan Edberg said. "There were fine-motor delays, gross-motor delays. They did some general genetic testing, but nothing showed up there. They did an MRI, and we went to see a neurologist. Everyone was baffled."

"Everyone was like, 'Don't worry about milestones. Kids will learn when they learn,'" Jesse Edberg said.

"First-time parents," Meghan Edberg said. "Yes, everyone walks at their own pace and talks at their own pace, that's true, but had we had a neurotypical child first, I think we would have known something was wrong."

After Henry was born in July 2019, it was abundantly clear that William wasn't progressing as he should. "We even noticed William was regressing, because they say that sometimes happens when there's a second child," she said. "He had been crawling, but he stopped crawling and started scooting. This didn't seem right, so we sent an S.O.S. out to our care team for help."

The Edbergs brought William in for more testing — this time, an electroencephalogram — which showed "sparks" of seizure activity, she said. A more intense 24-hour EEG followed "just to double confirm" the seizure activity, she said.

Because seizure activity had been detected, William's neurologist recommended that he undergo genetic testing at Children's Hospital in St. Paul to focus on neurodevelopmental disorders, Meghan Edberg said. "She pointed us in a different direction, one that we hadn't gone before," she said.

In January 2020, just before the world shut down because of COVID, William was diagnosed with Angelman syndrome. "It was such a bittersweet day. We finally knew the cause of his delays, but we had no idea what Angelman syndrome was."

"My exact words, when she said he has Angelman syndrome, were, 'Is that bad?'" Jesse Edberg said. "She said, 'Well, it's not good.' I didn't know if it was a temporary thing. ... Then you start down the rabbit hole of Google and everything else, so immediately you go from 'My kid's having seizures, why?' to Angelman ('Oh, we have an answer. Great. They can fix it') to 'He's not going to walk, he's not going to talk, he's never going to live a normal or typical life,' and then everything just comes crashing down."

Sports, vocabulary

Meghan Edberg played softball at Academy of Holy Angels in Richfield and at the College of St. Benedict in St. Joseph, and the couple, who met on Match.com and married in 2017, would often talk about what sports their kids might play.

William loves to swim and has been able to play baseball thanks to Miracle League in Woodbury, said Jesse Edberg, 41, a sales accountant for a technology company based in Oklahoma. The padded baseball diamond was built for children who have disabilities.

"It's super-fun," Jesse Edberg said. "The first day, he was overwhelmed and not even engaging, but over time he was able to play to his extent, like throw the ball. Granted, he would throw the ball over the fence and make people go get it, but to him it was great. It was fun to see that transition."

William is on the higher end of functioning among individuals with Angelman syndrome, although he still has cognitive challenges. He understands simple directions and humor, his mom said, but has a harder time identifying colors, shapes and numbers, for example.

William communicates by using a "talker," an app loaded on an iPad that allows him to press a button to "say" a word or name.

"He went from a 25-button page with a key guard to 60 buttons with no key guard," Meghan Edberg said. "He can go two or three screens deep to find his words!"

When a visitor left his house last week, William grabbed his "talker" and pressed the button for "See you later, alligator."

The Edbergs and members of William's care team — he's in the special-education pre-K program at Red Pine Elementary in Eagan — continue to add new words and names of people applicable to his daily activities or a specific event. "If we're going to someone's house, we'll try to add everyone who will be there, so he can greet them," Meghan Edberg said.

William's speech therapist recently added the word "stinky" to his "talker," showed him where the button was located on the screen and taught him the context in which to use it — "like if someone passes gas or someone's feet stink," she said. "William was sitting with his caregiver Jenna (Lasserud) one day at breakfast. He passed gas and then hit the button 'stinky.'"

Meghan Edberg, 40, has a master's degree in athletic counseling, but recently switched careers to support the Angelman syndrome community. She is now the director of community engagement for the Foundation for Angelman Syndrome Therapeutics.

"I always say when we talk at a fundraiser, 'Every kiddo has something, and it's tough. Parenting is tough. This is our something, and you know every parent also has dreams for their children, and some of those dreams we can't have until we have a cure.' We want people to know there's hope," Meghan Edberg said. "This is the club no one ever thought they would be in or would want to be invited to, but here we are. In our community, there's opportunities to connect with others, there's opportunities to help and raise money and raise awareness so we can come together and cure the damn thing. It takes a lot of work."

The Edbergs are optimistic that a therapeutic option or cure for Angelman syndrome will be available in William's lifetime.

"It is a single gene disorder that can be fixed," Meghan Edberg said.

A cure would mean "freedom from the unknown, the anxieties and worries that come with having a non-verbal and developmentally delayed child," according to a post on Will.i.Can, a website the Edbergs created to raise awareness of the syndrome and to raise money to find a cure. "It would mean confidence that William can live an independent life, and the burden will not fall on his brother to support him."

Clinical trials

Angelman syndrome shares symptoms and characteristics with other disorders, including autism, cerebral palsy and Prader-Willi syndrome. Because of the common characteristics, misdiagnosis occurs often, and genetic testing isn't always available, Meghan Edberg said.

Knowing the true number of people living with Angelman syndrome will be key as therapeutics become available, she said.

"We can take that information back to our academic and pharmaceutical partners," she said. "That will help them better understand the fullness and shape of the disorder. It is important for our community to be visible so our children can live a full life, and really, as parents, that's all we want."

Four human clinical trials are underway: three using a disease-modifying strategy and one targeting the downstream effects of the nonfunctional gene, she said. Since most cases of Angelman syndrome are caused by the child's not getting a healthy copy of the UBE3A gene from their mother, or the gene's not working, one strategy involves fixing the defective copy of the UBE3A gene through gene- or protein-replacement therapy. Another strategy, paternal gene-activation therapy, works to activate the normally silent paternal gene to compensate for the underperforming or missing maternally inherited gene.

"It's called 'stopping the stop,'" Meghan Edberg said. "I joke that Dad's copy is silent. It just sits there doing nothing. It's like, 'Hello, Dad. You can make this gene. Get off your Barcalounger and make the gene.' Right now, there's something stopping Dad from being able to turn on."

The Edbergs have business cards explaining that William has Angelman syndrome; they hand them out to people they encounter. "Meet Angelman syndrome," the cards say. "A rare genetic disorder impacting 1 in 15,000 births." The cards list many of the characteristics of the disorder and a QR code that leads to their Will.i.Can site.

"We did not ask for this diagnosis, nor were we expecting it," the Edbergs write on the website. "We quickly learned we cannot control how life has turned out for our son, William, but we can control how we react. So we fight — fight for our son, our family, and the Angelman syndrome community. We are committed to providing him every opportunity to thrive in life. We will assume competence in him every day and let him tell us what he is or is not capable of."

"He's got so many barriers working against him; don't be another one," Jesse Edberg said. "Just assume he can do it. Ask the tough ask. Don't get bogged down on where he's at today; just assume competence and be hopeful."

William has helped him "restructure" who he wants to be as a person, Jesse Edberg said: "I want to be more like William. Everywhere he goes, he just brings love and joy and happiness. He's amazing."

The Edbergs have business cards explaining that William has Angelman syndrome; they hand them out to people they encounter. The cards list characteristics of the disorder and a QR code that leads to their Will.i.Can website.

To help develop his fine motor dexterity, William plays with Kinetic Sand.

INTERNATIONAL ANGELMAN DAY

International Angelman Day, a celebration to create awareness of Angelman syndrome, a rare neurogenetic disorder, is Feb. 15.

Buildings and landmarks around the metro area will be lit up in blue to mark the 10th annual event. Among the participating sites: Capella Tower, Target headquarters, U.S. Bancorp, 10 West End, the Lowry Avenue bridge, Sperry Tower, the Interstate 35W bridge and CHS Field.

Angelman syndrome was once known as "happy puppet syndrome" because of the child's sunny outlook and jerky movements. It is now called Angelman syndrome after Harry Angelman, the doctor who first investigated the symptoms in 1965. Most diagnoses are made between the ages of 2 and 5. Most people with Angelman syndrome have a standard life expectancy.

For more information about International Angelman Day and the 2023 Twin Cities Angelman syndrome events, visit will-i-can.org/iad.