

# STROKE MATTERS

SPRING 2024

Minnesota Stroke Association



# NEVAEH ANDERSON

*Looking at the Correlation Between Type 1 Diabetes and Stroke in Children*

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# Letter from the Chief Executive Officer

By David King



Dear *Stroke Matters* readers,

Spring is in the air, and with it, a sense of renewal and hope fills the Minnesota Stroke Association. This time of year is special for us, not only because of the flowers bursting into bloom but because it heralds **Stroke Awareness Month** in May. A time when we, as a community, rally together to shine a light on stroke prevention, treatment, and recovery.

As we embrace this season of awareness, I invite you to mark your calendars for **May 18**, when we'll hit the trail for the **2024 Strides for Stroke**. This event isn't just a walk; it's a declaration of our shared commitment to combating stroke. With gatherings at Long Lake Regional Park-Twin Cities, CentraCare Plaza in Saint Cloud, and Miller Hill Mall in Duluth, we're uniting the entire Minnesota stroke community. Whether you walk in New Brighton, Saint Cloud, or Duluth, your steps echo our collective heartbeat: strong, determined, and resilient. Visit [strokemn.org/walk](http://strokemn.org/walk) to start or join a team, or to make a donation today!

But our journey doesn't stop with strides; it continues with voices. This year, we're spotlighting our **Citizen Advocacy Academy**, an initiative designed to transform personal experiences into political action. Whether you've faced a stroke head-on or walked alongside someone who has, your story has the power to enact change. By participating in training sessions, legislative meetings, and advocacy events, you'll not only find your voice but amplify it, impacting policy and shaping a better future for all affected by stroke and brain injury. Visit [braininjurymn.org/advocacy](http://braininjurymn.org/advocacy) for updates and information.

These initiatives – **Stroke Awareness Month**, **Strides for Stroke**, and the **Citizen Advocacy Academy** – are more than calendar events. They're opportunities for us to stand together, fostering a community where every person touched by stroke feels supported, heard, and empowered. But, amidst these vital initiatives, it's crucial to remember the personal stories that drive our mission forward. This issue's feature story brings to light the intertwined challenges of juvenile diabetes and stroke, areas that demand our attention and action.

Juvenile stroke presents a significant challenge for families, exemplified by Nevaeh Anderson's story in this issue. Diagnosed with Type 1 Diabetes Mellitus (T1DM), celiac disease, and Hashimoto's disease, Nevaeh's subsequent stroke highlights the critical yet overlooked link between juvenile diabetes and stroke risk. Her path from diagnosis to recovery emphasizes the urgent need for increased awareness and research. Nevaeh's resilience and her family's dedication underscore the importance of community and healthcare advocacy in managing chronic illness. Their story not only illuminates the challenges faced but also celebrates the strength found in collective support, reinforcing the importance of our mission and your ongoing sustainment.

Thank you for being a part of this journey. Your support, through participation, advocacy, or donation, fuels our purpose and brings hope to countless hearts. If you care to give to our mission, visit [strokemn.org/donate](http://strokemn.org/donate). Together, we're not just making strides; we're making a difference.

Warmest regards,

David King

CEO

Minnesota Stroke Association

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# Are Children at Risk for Stroke if They Are Diabetic?

By Nancy Christensen,  
Administrative Assistant

Is a child with type 1 diabetes at risk of having a stroke? Stroke is a relatively uncommon disorder in children, however, certain risk factors, such as a young child being diagnosed with diabetes, raise concern of the child sustaining a stroke. While research and data on the frequency of stroke in young children with diabetes are limited, recent studies are shining a new light on their potential connections.

Let's first take a look at what diabetes is and how it shows itself. According to the Mayo Clinic, in children with Type 1 diabetes (T1D), the pancreas fails to produce sufficient insulin, leading to high blood sugar levels. Symptoms of this imbalance may include blurred vision, increased hunger and thirst, and extreme fatigue. The precise cause is unclear, though factors such as family history, genetics, a higher prevalence in non-Hispanic white children, and certain viruses that may initiate autoimmune damage, all contribute to the risk of developing type 1 diabetes. Also known as juvenile diabetes or insulin-dependent diabetes, T1D requires children to supplement their insulin through injections or an insulin pump.

Diabetes can lead to various complications throughout a person's life, such as heart disease, including high blood pressure and stroke, as well as kidney and nerve damage, and retinal damage that may result in vision problems. Given that there is currently no known prevention for diabetes, working closely with a child's medical team to monitor blood sugar levels is very important. Moreover, parents or caregivers play a vital role in teaching children the significance of maintaining a healthy diet and getting plenty of regular exercise. This guidance is not merely about managing the disease in the short term; maintaining optimal blood sugar control is imperative for the long-term wellbeing of those living with diabetes.

According to The American Stroke Association, over time, excessive blood glucose levels can lead to the formation of increased fatty deposits or clots in blood vessels. These clots can narrow or completely block blood vessels in the brain or neck, cutting off blood

supply and preventing oxygen from reaching the brain, which can lead to a stroke. Consequently, diabetes increases the risk of having a stroke, which can severely damage brain tissue, leading to disability or even death. To mitigate the risk of stroke, it is essential for children with diabetes and their families and medical team to pro-actively manage not only blood glucose but also blood pressure, cholesterol, and weight ensuring a comprehensive approach to diabetes management and overall health.

Parents and loved ones of a young child with diabetes should know the signs of stroke to ensure a quick medical intervention. Because strokes are significantly more common in adults, the rarity of strokes in children can lead to delayed diagnoses. Fortunately, children do tend to recover from strokes more readily than adults, thanks to the ongoing development of their brains.

In response to this need for awareness, the Minnesota Stroke Association recently updated its stroke awareness campaign to include two additional signs that could indicate a stroke: balance or coordination issues and changes to eyesight like blurred or double vision. The BE FAST acronym – Balance, Eyes, Face, Arm, Speech, and Time – serves as a crucial reminder of the symptoms to watch for. Understanding these signs and acting swiftly at the first suspicion of a stroke can be pivotal in the outcome for anyone, especially a child (see next page).



# American Heart Association Adds to Warning Signs of Stroke

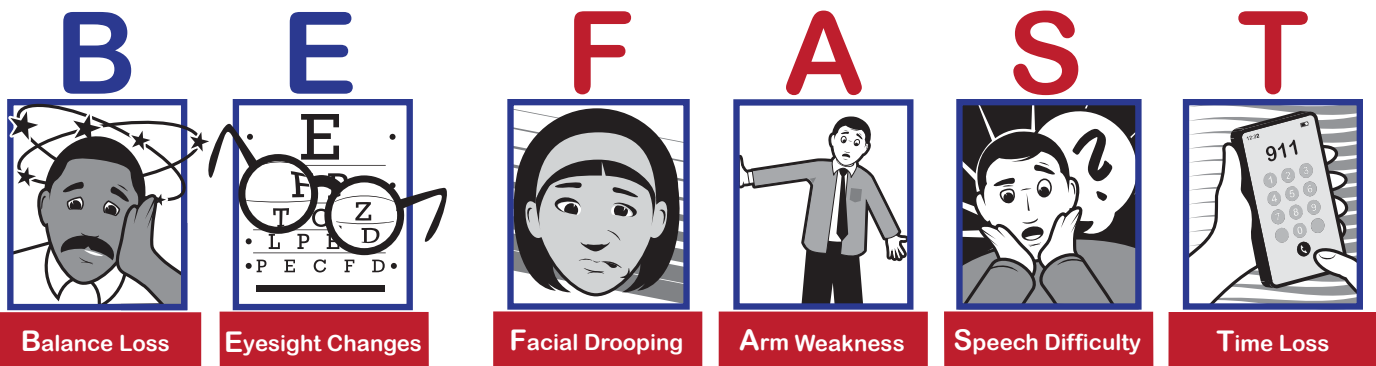
## Introducing BE FAST.

For years, the Minnesota Stroke Association has recommended using ACT FAST to remember the signs of stroke: Facial Drooping, Arm Weakness, Speech Difficult and Time to Call 9-1-1. Recently, however, the American Heart Association has begun recommending the use of BE FAST which adds Balance Loss and Eyesight Changes.

## So, why the change?

A study conducted by the AHA and published in Stroke magazine, discovered that 14 percent of patients with ischemic stroke didn't display any of the symptoms in FAST. Adding Balance and Eyesight included a substantial amount of those missed by the original acronym. And, as we know, the sooner we can identify a stroke, the sooner treatment can begin.

## BE FAST at the first sign of stroke



### Always Call 911

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- B** - Balance Loss
- E** - Eyesight Changes
- F** - Facial Drooping
- A** - Arm Weakness
- S** - Speech Difficulty
- T** - Time to Call 9-1-1.

By choosing to BE FAST, we have an inclusive and effective way of identifying potential stroke symptoms, which can lead to earlier detection and treatment, and ultimately improve outcomes for everyone.

*So, remember to BE FAST.*

**If you or someone you know is in need  
of our assistance following a stroke,  
please do not hesitate to call us  
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M Health Fairview is proud to support the Minnesota Stroke Association and its mission to serve individuals with stroke and brain injury in Minnesota.

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## Support the Minnesota Stroke Association Today

If you believe in a Minnesota where everyone recognizes stroke's causes and effects; where all individuals living with stroke are encouraged to realize their full potential; and where the greater community recognizes the intrinsic value of all people living with stroke, we hope you will give to the Minnesota Stroke Association today.

Over the past three years, the MSA has expanded its reach by offering online options for many of its services. Our teams worked hard to make sure that Minnesotans had access to opportunities and supports whether they were in our offices or at home.

***Thank you for your commitment to the Minnesota Stroke Association and for your continued support!***

We would like to make sure these opportunities remain available across Minnesota and, to help ensure that, we need **you** more than we ever have before.

**Please donate to the Minnesota Stroke Association today. A gift of \$50, \$100, \$250, or whatever is meaningful to you, can help us continue to offer educational opportunities, advocacy training, and volunteer training. YOU make a difference when you include us in your gift giving. Please, donate online at [strokemn.org/donate](https://strokemn.org/donate).**



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Let's Meet

# NEVAEH ANDERSON

By Phil Gonzales, Public Awareness Associate



All together, this was a lot for a single elementary school student to have to deal with. Nevaeh was and is an incredibly social and active kid. Suddenly, at the age of seven, she was strictly monitoring and caring for a chronic condition. This involved giving up gluten, not an easy thing for a little kid, as well as the trial and error of different insulin pumps and blood glucose monitors. Plus, the stress of being the only kid in school with a chronic illness.

“I was in a small school,” she says, “so everyone knew about it. But, now I’m in a bigger school, so no one really knows about it except my friends.”

“And when she goes swimming,” Cort adds, “because her glucose monitor is on her tummy and the insulin pump is on her leg. So, in everyday life people don’t see them but in the summer or in a swimsuit or shorts or whatever, it gets pretty noticeable.”

Nevaeh’s story at this point, that of a young kid learning to navigate life and monitor her own health, is, by itself, enough for a whole article. There have been entire Afterschool Specials based on the subject and Ann M. Martin made living with diabetes a defining characteristic as one of the *Babysitters Club*. The Anderson family, however, had little knowledge that Nevaeh’s diabetes and its comorbidities would have massive implications for her future.

A 2016 review published in *The American Journal of Medical Sciences* laid out the link between diabetes and stroke. Focusing primarily on older diabetic patients, the review underlines diabetes as a significant risk factor for both ischemic and hemorrhagic strokes, attributing this to various diabetes-induced changes in the vascular system.

And then, in 2023, a review published in the *Journal of Medicine, Surgery, and Public Health* focused on stroke in children and adolescents living with T1DM, a topic previously not extensively explored. The findings showed that young patients with T1DM are at an elevated risk for cerebrovascular diseases, including stroke. The presence of autoimmune disorders, as in Nevaeh’s case (T1DM, celiac disease, and Hashimoto’s disease), further complicates and potentially elevates the risk. Most ominous, the median age for stroke in children with T1DM was reported as 12 years old.

The Anderson family – Courtney and Ethan, their daughter Nevaeh, and their two sons Austin and Grayson – makes their home in the northwest suburbs of Minnesota. Courtney, (Cort to her friends) and Ethan grew up in the area and decided to raise their crew surrounded by extended family, friends and the conveniences of the familiar. This decision would prove to have practical benefits as they soon found their family life interwoven with the challenges and complexities of managing the unexpected twists and turns of Nevaeh’s chronic medical conditions.

In 2017, at the age of seven, Nevaeh was diagnosed with Type 1 Diabetes Mellitus (T1DM). She had been exhibiting the signs of diabetic ketoacidosis (eg., excessive thirst, frequent urination, nausea, vomiting, etc.), and after canceling out minor threats like ear infections or yeast infections, a blood test revealed her to have T1DM. Later testing revealed her to also have Celiac Disease – an immune reaction to gluten – and Hashimoto’s Disease, a condition where the immune system attacks the thyroid.



## ↑ Children's Elevators Surgery Center

"I'd never heard that," Ethan says, "until she had one, I honestly didn't even know that kids could get strokes."

In 2020, the family had just spent a relaxing December weekend with Ethan's brother's family in Kansas City. When they returned to the Twin Cities, they decided to go on a winter nature walk. Ten-year-old Nevaeh began complaining about her hand being numb, but the family didn't think it a cause for concern due to it being winter in Minnesota. Later at home, however, Cort and Ethan noticed that Nevaeh was using her other hand to lift her affected arm.

"Immediately, my first thing is like, I should Google it," Cort says. "But then it starts to like, give you all the worst things. And of course, the worst thing is a stroke. And I'm like, well, it's not that! That's like what older people get!"

Calling the nurse's help line, Cort and Ethan were told to get Nevaeh straight to the hospital.

"And they had literally everybody, a whole crew, waiting for us," Ethan says. "And they sent us to Children's Hospital down in Minneapolis, where they did a CT scan right away. And they were like, 'Well, she didn't have a stroke.' And we were like, 'Well, we didn't even know that was even an option!' But that's great! But a CT scan will only show a hemorrhagic stroke. The next day, they did the MRI. And that's when we found out that she had an ischemic stroke."

Stroke, while considered rare in children, has an incidence rate ranging from 2.3 to 13 per 100,000 children per year, with a higher prevalence of ischemic stroke. Among children and adolescents with T1DM who experience stroke, ischemic strokes are more common than hemorrhagic strokes.

After spending a week at Children's Hospital, Nevaeh started learning to walk with a walker and undergoing physical and occupational therapy (PT and OT) to regain movement, particularly on her left side, which was severely affected. Despite initial expectations that she might have to live without the use of her left arm and leg, Nevaeh's family was dedicated to her rehabilitation. They attended PT and OT sessions daily for months at the Children's Hospital. Remarkably, Nevaeh made swift progress, graduating from her projected year-long therapy programs in just six months, having regained 95 percent of her mobility. The only lingering effect was a slight delay in fast-twitch movements in her left hand compared to her right.

The stroke's impact was magnified by its occurrence during the COVID-19 pandemic, adding layers of stress and complexity to their hospital visits and the overall care process.

"Everyone was as shocked as we were by Nevaeh's stroke," Cort says, "especially because it happened during COVID, which meant our boys couldn't visit the hospital. My mom took care of the boys and our dogs for five days while we stayed at the hospital. It was so helpful."

"We have an incredible support structure around us," Ethan adds, "from both sides of our family as well as really close friends. Multiple people were, you know, doing some laundry, cleaning the house while we were gone, taking care of the kids, dropping off food, sending gift cards. Besides Nevaeh's recovery, that's the biggest thing that came out of all this as far as the positives, seeing the amount of outpouring of support from our family and friends."

After Nevaeh’s stroke, she embarked on a rigorous schedule of follow-up appointments, including regular MRI scans to monitor her recovery and ensure the stability of her condition. Initially conducted every three months, these appointments became less frequent as signs indicated that Nevaeh’s condition was stabilizing. The intervals between MRI scans eventually extended to a year.

“It was kind of a blessing in disguise that the last two MRIs that she’d had were a year apart,” Ethan says. This interval allowed medical professionals to detect a worrying trend: a part of Nevaeh’s brain, previously damaged by the stroke, was continuing to deteriorate.

This discovery prompted the medical team to perform an angiogram, a more detailed examination that would provide a clearer picture of the situation. The angiogram revealed a critical blockage: one of the four main arteries supplying blood to the brain, specifically one of the two frontal arteries, was found to be 90 percent blocked.

“And that’s the side she had her stroke on,” Cort says. “So we knew that. But then they found that the other side was 50 percent blocked. And, it was a blessing that she had this stroke that affected her left side because that

didn’t affect her memory or her speech or anything, just her motor functions. So the fact that the other part was 50 percent blocked that’s her memory and all of that. So they were like she needs brain surgery. Not on the one side, but the two. Both sides. So she did two brain surgeries and they were a month apart.”

Nevaeh underwent a specialized surgical procedure known as an EDS procedure, commonly associated with treating Moyamoya syndrome—a condition that often arises in young children following a stroke, characterized by the excessive growth of blood vessels (angiogenesis) in an area where they are not typically desired. Though relatively rare in the general population, this procedure is well-established within the neurology field, considered a standard intervention for such conditions.

Surgeons first shaved a portion of Nevaeh’s hair to access the site, then dissected the temporal artery running along the side of her head. After dissecting a significant portion of this artery, they removed a piece of her skull approximately the size of a silver dollar to gain access. The temporal artery was then inserted through this opening and stitched directly onto the brain tissue to enhance blood supply to the affected area. The surgeons made several notches in the bone





with a rash spreading across her arm, necessitating a swift change in her pain meds. Her pain was significantly less following her second surgery. Both times, however, she recovered quickly enough to be discharged from the hospital within three days.

Following both surgeries, Nevaeh spent a week at home before returning to school, resuming her studies just two weeks post-procedure. After her second surgery, adjustments were made to accommodate her recovery needs, transitioning to a hybrid learning model due to recurring headaches. The school system's supportive and accommodating stance played a crucial role in this phase, enabling Nevaeh to ease back into her routine. This flexible approach allowed her to gradually reintegrate into her school environment, balancing at-home learning with days in school to manage fatigue and headaches effectively. By the fall, she was prepared to return to full-time schooling, marking a significant milestone in her journey back to normalcy.

Cort and Ethan Anderson have woven their family's journey through health challenges into a narrative that has resonated with a wide audience online, transforming personal adversity into a shared story of resilience and support.

"My job basically is like, create content online," Cort explains. She started this journey when their first child was just a baby. Over the years, the family's experiences, from everyday moments to significant milestones and challenges, have been documented and shared, creating a "video diary" that not only captures their lives but also connects them with a global community.

This connection became a crucial source of support and information when Nevaeh faced her health crises.

"When we were going through all of this, I think the online part was super helpful," Cort recalls, especially during Nevaeh's diagnosis with diabetes and subsequent brain surgery. The outpouring of advice, support, and personal stories from their online community provided comfort and practical help at times when the family felt isolated by their circumstances.

Ethan marvels at the sense of extended family the internet has provided.

"Seeing just the outpouring from the community online, just the amount of support. I mean, it feels like another family to us," he says.

Beyond the emotional support, the tangible assistance in the form of meals, gift cards, and messages of

plug before reinserting it, ensuring the temporal artery could extend through the skull into the brain, thereby augmenting blood flow while allowing the artery to continue its normal function. This intricate procedure was performed on both sides of her brain, with the side affected by the stroke requiring additional care and time. On this side, the artery had to be embedded more deeply into healthier brain tissue to secure effective blood supply, reflecting the procedure's complexity and the surgeons' adaptability to challenging conditions.

Nevaeh's reaction to being told she needed this procedure was to be expected in a kid who'd spent most of her life treating unexpected medical anomalies. Besides the threat of being a 13 year old with a shaved head:

"It was just basically me going to sleep and waking up."

But, the response for the whole family was more profound.

"We were all crying," Cort says. "Brain surgery sounds like... I mean, obviously a stroke is a scary word. But brain surgery? I know you do a lot of these but it's my kid. So, a lot of our family came over that night and just prayed and we had dinner and they tried to make us feel a little bit better."

The first surgery, addressing the side affected by the stroke, resulted in significant swelling and discomfort with Nevaeh awakening from anesthesia in considerable pain. Then, she had an adverse reaction to her pain medication,



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encouragement underscored the depth of connection fostered through their online engagement. Ethan also highlights the reciprocal nature of this relationship, noting how their content has not only garnered support but also offered solace and companionship to others facing similar challenges. “Being able to give back just by bringing awareness on the social media platform is so cool,” Ethan adds, acknowledging the dual role their online presence plays in both receiving from and contributing to a community bound by shared experiences and mutual support.

“Once when [Cort] was having a makeup class,” Nevaeh recalls, “I was working concessions and this lady came up and she said ‘My nephew got diagnosed with diabetes, and he watches your videos every day, and it helps him so much.’”

The Anderson family’s journey through Nevaeh’s health challenges has profoundly affected their dynamics, bringing them even closer together amidst the trials of stroke, brain surgeries, and managing her diabetes.

“We’ve always been a close family,” Ethan notes. “But,” Cort adds, “this has definitely brought us closer together.”

This period of adversity has not only tested their strength but also highlighted their unwavering support for one another. Ethan adds, “It’s been a whole journey. And, just seeing both of her brothers, the way that it’s affected them and the way that they’ve supported her. And then in turn how she supports them when they’re going through something, like having each other’s backs. But you know, everybody’s really kind of rallied around the new lifestyle and adjusted to everything really well.”

Moreover, the emotional and psychological toll of their circumstances led the family to seek therapy.

“We started going to therapy,” Cort says “because we had some PTSD stuff. With anything medical, now, I get really anxious.

The therapeutic journey has been crucial for the Anderson family, offering them a space to process their emotions and begin healing.

“You don’t have time to grieve,” Ethan says, “you’re just thrown into something that’s so urgent, like all of her things have been. And so going through therapy and having that outlet to kind of work through the feelings and actually go back and actually grieve, has been really, really helpful, really important. And I think it’s something that doesn’t get talked about enough for sure.”



Now, at age 14, Nevaeh’s journey illuminates not only the resilience of one young girl and her family but also underscores the critical importance of medical research into juvenile diabetes and stroke. The advancements in treatment and care that have supported Nevaeh’s path to recovery are a testament to the ongoing need for dedicated research and innovation in these areas.

Join the Anderson family and countless others in raising awareness about the interconnected challenges of Type 1 Diabetes Mellitus and stroke in children. Share your story, educate others, and support research initiatives aimed at better understanding and managing these conditions. Together, we can build a stronger, more informed community ready to support those affected and advocate for advancements in care and treatment. Let’s make a difference; one story, one share, one donation at a time. [SM](#)

**For more information, contact the Minnesota Stroke Association at 763-553-0088 or visit [strokemn.org](http://strokemn.org).**

This article references findings from the following studies:

1. “Diabetes and Stroke: Epidemiology, Pathophysiology, Pharmaceuticals, and Outcomes” by Rong Chen, MD, MS; Bruce Ovbiagele, MD; and Wuwei Feng, MD, MS. Published in *The American Journal of Medical Sciences*, April 2016. DOI: 10.1016/j.amjms.2016.01.011. PMID: PMC5298897.

2. “Stroke in children and adolescents living with type 1 diabetes: A systematic review” by Gilbert Sterling Octavius, Felicia Harsono, and Anita Halim. Published in *the Journal of Medicine, Surgery, and Public Health*, Elsevier, Volume 2, April 2024, 100033



The Minnesota Stroke Association's annual **Strides for Stroke** event is Saturday, **May 18, 2024** and that's just around the corner! If you've never been to S4S, it's our annual fundraising event that aims to bring together stroke survivors, caregivers, and advocates in a celebration of our community to raise funds and awareness for stroke support and education.

Since its launch in 2010, Strides for Stroke has attracted thousands of participants and has been instrumental in raising crucial funds – over \$500,000 to date – for vital MSA programs that support stroke survivors and their families. Our Education and Community Outreach, Public Policy, and Volunteer programs are only able to continue their work because of these funds.

This year, Strides for Stroke is happening at three locations: Miller Hill Mall in Duluth, the CentraCare Health Plaza in Saint Cloud, and Long Lake Regional Park in the Twin Cities. Each site has been chosen for its accessibility and community presence, ensuring that the event is within reach for everyone who wants to join in the fun.

One of the key components of this year's event is the **\$1,000 Team Challenge**. The challenge encourages teams of ten to have each team member donate \$25 themselves and then each one of you ask a friend, family member, and co-worker for \$25 each – totaling \$1,000 for the team. If 50 teams meet this challenge, **together we could raise \$50,000!**

# MAY 18, 2024

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## STRIDES FOR STROKE WALK

While raising that much money might seem a monumental task, the Minnesota Stroke Association knows that our community is up to the challenge. We know this because each year we see incredible dedication and passion, not only from our walkers, but from our sponsors as well. The continued support from all of our sponsors has been an annual reminder that we're not in this alone as an organization: Presenting Sponsor M Health Fairview; Host Sponsors, CentraCare, Essentia Health; with additional support from Hennepin Healthcare, HealthPartners, and Minnesota Department of Health.

And, you're not alone either. Because Strides for Stroke is more than just a fundraising walk; Strides for Stroke is an opportunity for the stroke community to come together and let the world know "We're here and we're in this together!"

**Your participation, whether you're walking at one of the venues or supporting online, makes a difference. Registration is straightforward: visit [strokemn.org](http://strokemn.org) and follow the link to Strides for Stroke. Fill out a form, join a team or walk individually. A \$25 donation is suggested, and participants are encouraged to tackle the Team Challenge to make the biggest splash with their contributions. Let's join forces and show Minnesota that we're not just making strides; we're making a difference.**

### How to Reach Your Team Goal of \$1,000:

#### ✓ Form Your Team

Gather nine people to join you, making a team of ten walkers.

#### ✓ Team Members Contribute

Each team member (including you) contributes \$25.

#### ✓ Reach Out to Family

Each team member requests a \$25 donation from one family member.

#### ✓ Ask Friends to Support

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MAY  
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**2024 Strides for Stroke**  
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SEPT  
21

**Walk for Thought**  
Duluth • Saint Cloud • Twin Cities

OCT  
5

**Brain Injury Support  
Conference**

NOV  
21

**Statewide Stroke  
Conference**

Visit these websites for more upcoming events.

Minnesota  Stroke Association

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