

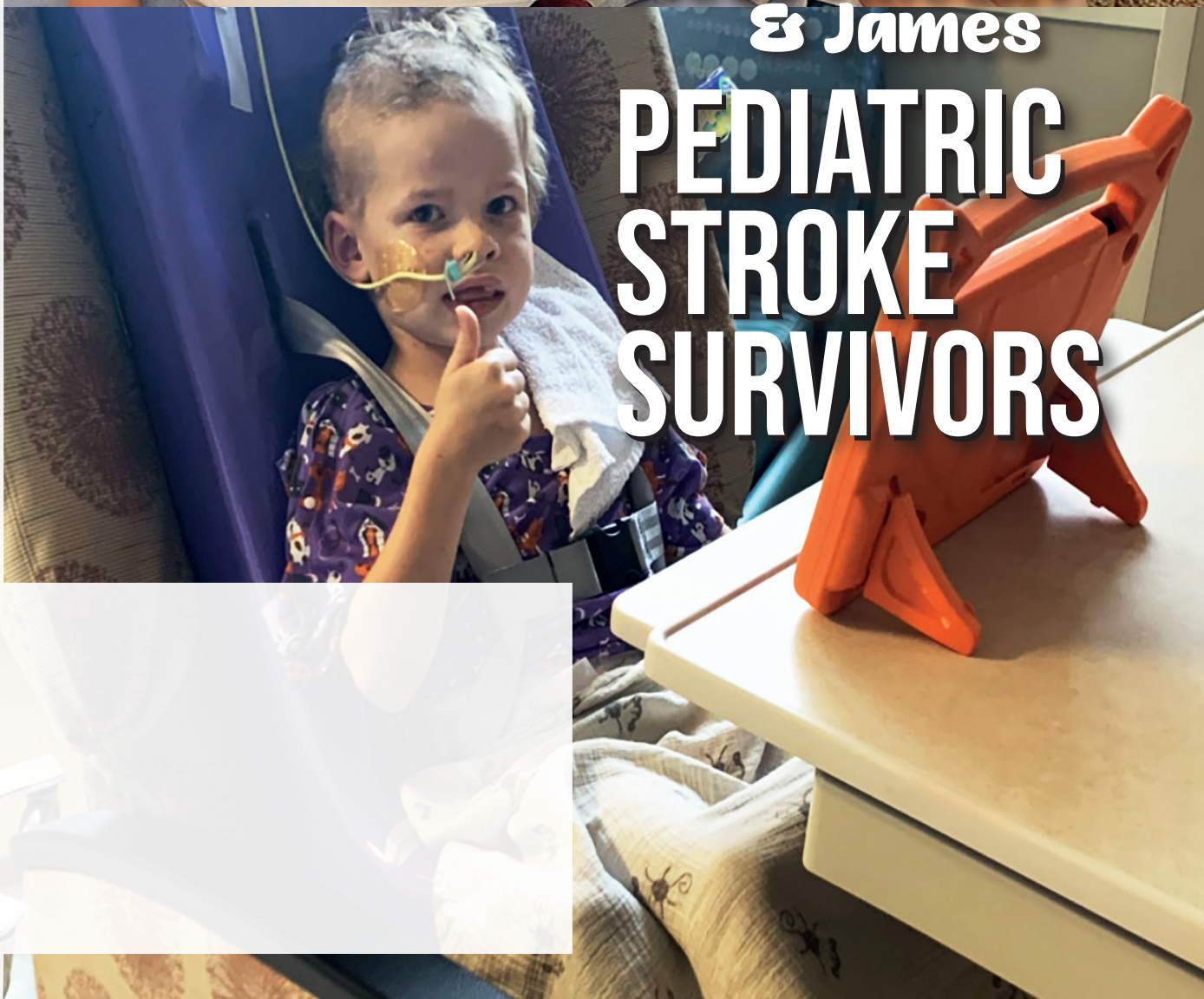
STROKE MATTERS

SPRING 2023

Minnesota Stroke Association



Meet Vincent & James



PEDIATRIC STROKE SURVIVORS

Letter from the Chief Executive Officer

By David King



Welcome, *Stroke Matters* readers,

As we approach May, Stroke Awareness month, I would like to remind everyone to take a moment to learn about stroke risk factors and symptoms. Early detection and treatment can greatly improve outcomes for stroke patients.

Katrina Meyer, our Public Relations Associate, reminds us that stroke risk factors can be divided into three categories: lifestyle risk factors, like smoking, diet, physical activity, and alcohol consumption; medical risk factors such as high blood pressure, diabetes, and heart disease; and non-modifiable risk factors, like age, gender, and family history. If you want to know more about where you might be on the risk factor scale, contact us at 763-553-0088 and talk to a Resource Facilitator. We want everyone to have

happy, healthy lives and Stroke Awareness Month is a great time to take a look at your health.

Speaking of Stroke Awareness Month, Strides for Stroke is on May 20, 2023. This annual event is a fun way to raise awareness and funds for Minnesota Stroke Association resources and programs. Whether you choose to walk or run, every stride counts in the fight against stroke. Visit strokemn.org to register. We hope to see you there!

On May 30, we will be hosting a Stroke Authors Roundtable, featuring writers who focus on stroke and who will share their insights on why they chose to write about stroke, their processes and the impact their writing has had on themselves and others. Our brain injury roundtable in March was a lot of fun. Check strokemn.org for information on the location and time of the Stroke Authors Roundtable.

Finally, I would like to take a moment to remember Greg Anderson, founder, President, and CEO of Anderson Companies, who passed away last October. Greg was a remarkable entrepreneur, philanthropist, and advocate for stroke awareness. He approached us in 2014 to partner with Anderson Companies on the Anderson Companies Annual Golf Tournament, which quickly became a major event for stroke education and awareness.

In memory of his sister Jill, who passed away from complications from a stroke, Greg committed himself to raising awareness and educating the public about stroke. He was a true friend of the Minnesota Stroke Association and the entire stroke community.

We will miss Greg dearly.

Thank you for your continued support of *Stroke Matters*, and I wish you all good health and wellness.

Sincerely,
David King
CEO, Minnesota Stroke Association

Scan here to donate!



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Letters to the Editor should be limited to 300 words. Letters may be edited for spelling, grammar and length. In order for letters to be considered, please include your name, address and the daytime phone number of the author. The Minnesota Stroke Association reserves the right to refuse letters for publication, and submission of material does not guarantee publication. Opinions expressed in Letters to the Editor are solely those of the author and do not represent the opinions or positions of the Minnesota Stroke Association.

Address editorial comments or letters to:
Public Awareness Manager
Minnesota Stroke Association
2277 Highway 36 West, Suite 200
Roseville, MN 55113-3830
763-553-0088

Advertising information contact:
Jarett Klein
Minnesota Stroke Association
2277 Highway 36 West, Suite 200
Roseville, MN 55113-3830
763-553-0088

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Baby Katie had a Stroke?

By Nancy Christensen, Administrative Assistant

Pediatric stroke is a stroke that happens in young children or adolescents. These strokes can occur even before birth (prenatal) or in the first month of life (perinatal). These types of strokes can be caused by insufficient blood flow to the brain; bleeding into the brain leading to brain cell damage; or a blood clot forming in the heart and traveling to the brain.

The effects of a stroke in a child are much the same as in an adult but often can be harder to detect with perinatal strokes often going unnoticed and undiagnosed.

to be in a high risk group as her mother was over 35 years old. Katie's mom had already been in labor for over 24 hours with lots of contractions and pain. She was given an epidural and then an IV with a Pitocin/oxytocin, which now is considered to cause risks such as slow heart beat and fetal distress. The fetal monitor placed around mom's belly observed Katie's heartbeat drop below what was considered "normal". Hard labor quickly ensued; nurses, doctors, and specialists filled the delivery room. Immediately after Katie's birth, she was brought to the newborn intensive care unit (NICU) where she stayed for several days. There was no mention of stroke.



If an infant or a young child is suspected of having a stroke, medical professionals will look for paralysis on one side of the body, cognitive and behavioral changes, and vision loss. As with an adult, immediate medical steps will be taken to help the young patient.

Pediatric stroke touched our family with my cousin's daughter, Katie. Katie's delivery story began the day before she was born. Katie was already considered

Baby Katie was finally able to go home with an IV in her skull. Visiting nurses monitored her, giving her antibiotics continually to treat her double pneumonia. While she was showing improvement, there were still many unanswered questions.

At around three months of age, one of Katie's physical therapists discovered that Katie had left side weakness both in her upper and lower body. A neurologist suggested she might have cerebral palsy,

a common diagnosis considering Katie's symptoms, but the physical therapist felt this was an incorrect diagnosis. The therapist suggested Katie possibly had a stroke during the birth process causing slow heart rate, fetal distress and meconium aspiration. Katie's stroke was confirmed later by her pediatrician.



Katie was also diagnosed with infant torticollis, shortened muscles on her left side of the neck, and damage to her lungs. This diagnosis added to her team of doctors and therapists to collaborating on her care.

For the first three years old her life, Katie had therapy three days a week to strengthen her arm; to strengthen and stretch the area in her neck; and to increase use of her left leg while learning to crawl and then walk. She had to learn to grasp and reach with her left arm and focus on turning her head to the left. When she began climbing stairs, mom would hold her right leg steady to compel her to use her left leg.

As she grew older and Katie would go to her pediatrician, they were amazed to hear her story because in all her yearly physicals Katie presented as if nothing had happened in her early years.

When I interviewed Katie's mom, she felt that the occupational and physical therapies were really what helped Katie to lead a normal and healthy life. Katie's story is what led her mom to become an occupational therapy assistant to help other children that had similar outcomes following a pediatric stroke.

As Katie grew up, she struggled in her early years in elementary school, learning something, forgetting it and having to relearn it. As she grew older and entered middle school and then high school, she participated in sports, ice skating, and cheerleading while maintaining above average grades. Katie volunteered, was on the

honor roll, and graduated with honors. She recently graduated from college with a marketing degree, has secured a position with a company and has been successful finding her way in the world.

When I asked Katie if she remembered anything from those very early years, she said, "Unfortunately, I don't remember much of it at all, only what my parents have told me. All I know is I am very grateful I was put into therapy right away otherwise I would be living a totally different life."

As difficult as it was for Katie and her family, she was lucky to have an excellent medical team and parents who were able to advocate on her behalf. Many times that isn't always the case and assistance is needed to guide, refer, answer endless questions and help families secure and obtain information to help their child. This is where the Minnesota Stroke Association can be a helpful organization. The Resource Facilitation team provides free telephone assistance to families and directs them to resources to aid in their needs.

Often times, stroke in utero, in a young infant or child is virtually unthought of. Katie and her family went through many trials, uncertainties, lots of learning, education and an appreciation for the medical team that helped them along the way. Katie's story did have a happy ending but not all children are as lucky as she was. As always, with any stroke, it's imperative to be vigilant, know the signs, and look for symptoms and work quickly to get proper care and treatment.

If you or someone you know is in need of our assistance, please do not hesitate to call us 763-553-0088

ACT FAST at the FIRST SIGN of STROKE



ALWAYS CALL 911

Minnesota Stroke Association



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.



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Why Focus on Pediatric Stroke?

By Phil Gonzales, Public Awareness Associate

Pediatric stroke is rare. Of the 793,000 people who have strokes each year in America, only about 2,000, or 0.25 percent, of them are children. A quarter of a percent is a statistical blip. It is, in the language of statistics, insignificant.

So, why talk about it?

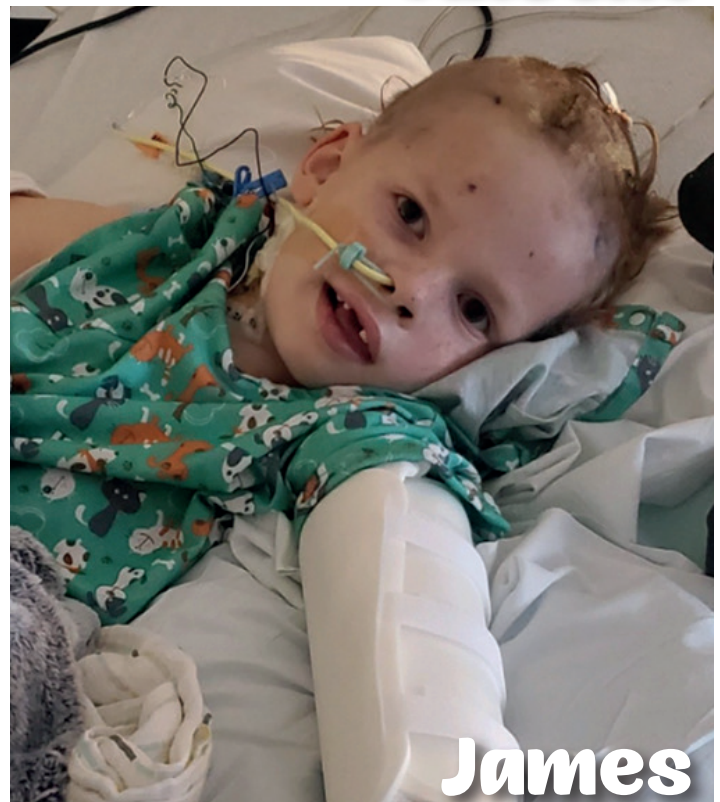
Because people aren't statistics. Each child who experiences a stroke is a person who affects the world and everyone around them. They are significant. Also, the relative rarity of pediatric stroke makes it all the more probable that the signs of its occurrence will be missed. Even by parents and professionals.

Therefore, when we shift our focus to pediatric stroke, we aren't putting it on the same point in the stroke probability curve as adult stroke; rather, we are highlighting a unique and often overlooked aspect of stroke that requires specialized attention and care and whose ramifications can affect families in unexpected ways.

Vincent Benassi and James Brandhorst are two young boys who have been impacted by pediatric stroke in very different ways. Vincent's strokes are metabolic in nature, presumably caused by a rare genetic disorder called polymicrogyria that involves excessive folding in the brain. As a result of his strokes, Vincent is blind and nonverbal, and his mental development hovers around that of a toddler. In spite of this, Vincent is an active member of his family whose contributions to the world are seen and felt by everyone who encounters him.

James Brandhorst's stroke was caused by an Arteriovenous malformation (AVM), a condition where there is an abnormal connection between arteries and veins in the brain. James has undergone multiple surgeries to remove the AVM and has been left with a permanent weakness on the left side of his body. However, James has been able to make significant progress in his recovery and continues to work towards regaining his strength and mobility. His story and Vincent's are very different from each other, but of equal importance when considering the impact pediatric stroke has in our community.

James, who was six at the time of his stroke, had bumped his head in the family playroom and reported



having a headache to his parents. Soon after, at his grandparents' house, he began slurring his words and falling over when he tried to walk. Although his bump had seemed minor, Jessica and Alan, James's mother and father, assumed he had a concussion and rushed him to Urgent Care.

Doctors were immediately concerned that James might have a brain bleed, but clearly not from his minor head bump, and had had their suspicions confirmed following

a CT scan. James was then sent to Gillette Children's where the stroke team, led by neurosurgeon Dr. Joseph Petronio, was already assembled for James's care.

"It all happened so fast," says Alan. "One minute we're playing upstairs, he has the stroke and four hours later he's having an emergency craniotomy at Children's."

James's brain had contained a ticking clock that was set to go off with little to no warning. Vincent Benassi also had a ticking clock. Polymicrogyria affects brain development and typically results in developmental delay, intellectual disability, seizures, and other neurological symptoms.

"So, we always knew there was a 90 percent chance he'd develop seizures," Vincent's mom, Joanne, explains.

In March of 2019 Vincent became ill. "He was just very lethargic," Joanne says. "He couldn't keep his eyes open, he had a fever, was vomiting. We brought him into the ER. We were there for like 12 hours. They did a full workup and even did a lumbar puncture. And found nothing. They gave him some fluids, he perked up, and we went home."

After six days of waiting for Vincent's "bug" to pass, his parents took him to a different ER where he was immediately scanned. Doctors broke the news to Joanne and Tony that Vincent wasn't sick; at the age of four, he'd had a stroke.

"I was like, this wasn't even on my top 100 list of things that Vincent would get," Joanne says. "And then, we learned that he was having seizures. And so the two kind of correlated. And, now that he's on stroke number four, we know that if we don't get the stroke to stop 'spreading' – because it is metabolic and it will continue to do damage – that his brain is going to go so out of whack we're going to start having seizures, and he's going to go into back into status [epilepticus; when there is no down time between seizures]."

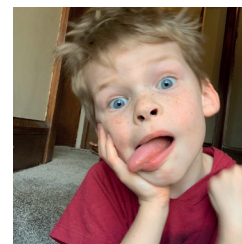
James was in a coma for about two weeks and his emergence was gradual and came in fits and starts. His speech didn't begin coming back until about a month out from his stroke. The Brandhorst family were told time and again by his stroke team that James's recovery would take a long time and that their family would have to adjust to a new routine.

"We want to just emphasize how lucky we are to have the kind of health care system that we have here for our children," Jessica says.

Vincent has been in and out of the hospital multiple times over the years. Although he is nonverbal, his family and hospital staff are keenly aware of the strong-willed child whose recovery is forever running on his own personal timeline. Whether he's mysteriously refusing to go into an induced coma, or refusing to emerge from one, Joanne and Tony have always admired Vincent's desire to have control over the limited aspects of his life that he can unequivocally govern.

Although James and Vincent's strokes have different causes, different symptoms, and different long-term ramifications, the impact on the lives of their families and communities cannot be overstated.

Vincent is one of four children. While his older and younger brothers are affected by Vincent's strokes,



they are either old enough to have some emotional distance from it or young enough to not quite grasp the implications. Vincent's older sister, Charlotte, is the sibling most affected by Vincent's condition. During his time in the hospital, Charlotte's access to Vincent was limited, something that greatly troubled her as she tends to see herself as Vincent's protector.

"She's just an emotional wreck," Joanne says. "Because she's so caring and is his best friend."

Jessica and Alan have an older son whose needs during James's hospitalization were just as important as before James's stroke. Jessica ended up taking the summer off from work so she and Alan could trade off being at the hospital and being with their other son. COVID restrictions at the time limited who and how many people could visit James. James's older brother soon grew used to James's absence and the dynamic between the two is still evolving.

"I think he missed him the first week," says Alan. "But then it was like, 'Oh, I don't have to argue over the TV!' I mean, a lot of it's just brothers being brothers, but he wants to help and James has been reluctant to accept help. And James has a lot of anger that spills over into just playtime and relationships, especially with his peers and his brother, because he's surrounded by able-bodied people all day long."

James's stroke has left him with left-sided weakness, which means he can't use his left hand and arm properly. This has affected his ability to play sports and participate in some physical activities with other children his age. While Jessica and Alan have watched his condition improve over time, it's unlikely that he'll fully recover the use of his left side. In addition, James has experienced PTSD from his stroke. He's a smart kid, and he became aware of his situation pretty quickly.

"When he was at Gillette, he would ask, why did this happen to me?" Alan says. "Why did no one catch this before? We talked with him about how this wasn't his fault. It just happened. No one's to blame. But then his question was, 'Why didn't my brother have to go through it? Why did God do this? Why did this happen?' And we would explain that God still loves you and we're going

Visit www.strokemn.org

to protect you. And, we have a pastor that kind of helped us to talk about this stuff."

"People will say, 'Oh my gosh, you guys are so strong,' says Joanne. "And, 'I don't know how you can do this and blah, blah, blah.' And it's like, I know I'm just like any other mom out there. I'm just loving my child. We all have our hard times. Mine just look different from other people's; and other people's look different from mine. So it doesn't make me any stronger. This is what I've been given. And my plate might seem full, but it doesn't overflow. This is just what I've been trusted with. And so I remind myself of that a lot and it's helpful."

Jessica and Alan and Joanne and Tony relied a lot on their faith and their church community to help them through their hard times. Jessica and Joanne each created incredibly detailed CaringBridge journals to keep people abreast of James and Vincent's progress. The journals are filled with examples of people from their respective neighborhoods and churches coming forward to cook and provide food and help for the family. This testament to the strength and generosity of their community helps reassure families that they aren't alone.



And this connection to community is vital for processing grief. Grief and trauma go hand in hand with acquired disabilities as the mind incorporates the loss, or perceived loss, of potential as it would any other form of loss. The Brandhorsts were informed early on by a hospital social worker that grief would hit them, and hit them hard, at unexpected times, but that it was natural to go through those highs and lows. However, they were told that an important part of processing their grief was

to accept help from their community. Family, friends and even relative strangers were going to reach out with offers of help and the healthiest thing they could learn to do was accept the help as it was offered even if it initially seemed overwhelming or complicated.

“At one point,” says Joanne, “we had my mom or Tony’s mom and even a family friend come down [to the hospital] one day a week. So that way he and I could be home together with the other kiddos and hang out and spend quality time as mom and dad with the other kids.”

“Oh my gosh, the amount of stuff people dropped off and the gift cards and the helping,” Jessica says. “You know, on a Saturday doing things and just supporting us so that we could have less worry. Like, I had someone offer to come do our laundry one day. You just spend



your mental energy and your physical energy being with your child. I have a hard time letting people in sometimes, but if people are offering, take them up on it.”

Three years ago, Vincent had a second stroke, one that his parents caught immediately. Then, while he was in the hospital being treated for that stroke, he had a third. And, his seizures continued. Last November, he went into the hospital again after his fourth stroke.

Despite being nonverbal, however, Vincent is a part of every moment he’s in the room.

“He has captured the hearts of so many people and has never uttered a word,” Joanne says. “Vincent just captures the hearts of everybody because he’s always

so happy. And it seems like that’s been an aspect of his personality his whole life. He’s just so laid back and easygoing and what makes him the most happy is when you talk to him. He just lights up and he doesn’t care if you’re saying, ‘Hey, you’ve got a poopy diaper.’ He’ll giggle like ‘Someone’s paying attention to me!’ That just makes me happy.”

Today, James still struggles with the mental trauma and PTSD caused by his stroke as well as his physical limitations and the anger and frustration that accompany all of those hurdles. However, Jessica and Alan have reached a place where they are able to look into James’s future and envision a happy and fulfilling life for him.

“We’re now two years in,” Alan says. “And I’m like, I can’t make his hand move. I can’t do that. As much as I want him to be able to move his hand like he used to, I can’t. That’s been the accepting part for me is that I have to get over this recovery timeline in my brain. It’s James’s recovery; it’s his timeline. So I’ve just got to be along for the ride and help him when he’s ready to recover the way he wants to recover. You know, when you’re ready to use your left hand, we’ll help, we’ll get you there.”

“Vincent is eight years old, and there is no diagnosis or reason why he continues to have these metabolic strokes,” Joanne says. “And so the most important thing is that we haven’t given up hope. And he’s just so strong and amazing. And for all that he’s been through, he still has a smile on his face. He still wakes up in the morning and he goes through his day. That’s what our main thing is, is hope and that, you know, life goes on.”

Pediatric stroke may be statistically insignificant, but each child affected by it is significant and has the potential to affect the world and everyone around them. Vincent Benassi and James Brandhorst, two young boys impacted by pediatric stroke in very different ways, are shining examples of the individual impact pediatric stroke has in our community. The impact on the lives of their families and those around them cannot be measured by mere statistics as their love is infinite and cannot be quantified. It is important to continue to raise awareness and provide support for those affected by pediatric stroke.

If you or someone you love is affected by stroke, call the Minnesota Stroke Association at 763-553-0088.



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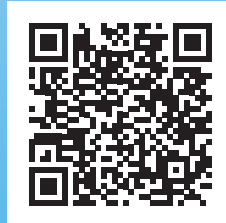
Stroke is the leading cause of death and disability in the United States and is a leading cause of death in Minnesota resulting in more than 12,000 hospitalizations in the state each year. Over 97,000 Minnesotans report having had a stroke in their lifetime.

**TO REGISTER, TO DONATE, OR FOR MORE INFORMATION
VISIT WWW.STROKEMN.ORG**

JOIN US, YOUR FAMILY, AND FRIENDS

Since 2010, more than 7,500 participants have registered for Strides for Stroke. In that time, over 400,000 has been raised by individuals, and more than \$70,000 has been raised in sponsorships which has helped support the Minnesota Stroke Association in developing programs and raising awareness across the state. Be a part of this great community!

THANK YOU TO OUR SPONSORS



Register and Donate Today!

Join us for Strides for Stroke!

ARE YOU READY TO MAKE A DIFFERENCE?

Then join us at the Strides for Stroke walk on May 20 at 10 a.m. and help support the Minnesota Stroke Association's mission to raise awareness about stroke and to enhance the quality of life for all people living with its sudden and long-term effects.

The annual Strides for Stroke event brings together the Minnesota Stroke Community to raise awareness and funds for the Minnesota Stroke Association's services and supports and to honor those who have been affected by stroke.

Strides for Stroke is also a **celebration of survivors** and a demonstration of the strength of the stroke community. As the leading cause of death and disability in the United States, stroke has impacted countless lives. In Minnesota alone, over 97,000 individuals have reported having a stroke in their lifetime. We must come together to show our support and raise awareness for this important cause.

This year, we are thrilled to be returning to an in-person format, and we need your participation to make it a success.

Invite your friends, family, and coworkers to join your team and increase your impact. The more people we have walking together, the

louder our message of support for stroke survivors will be.

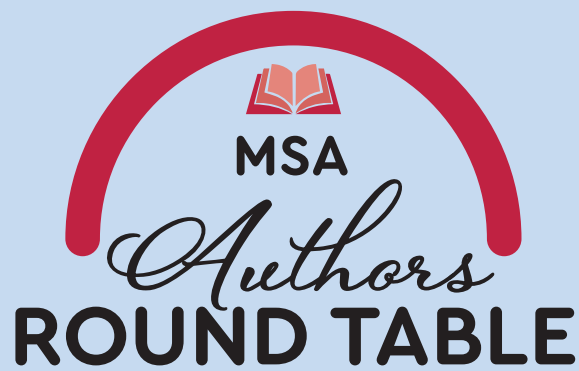
If you're unable to attend in person, we're offering virtual participation as well. No matter where you live or how you participate, your support is crucial to the success of Strides for Stroke. Also, consider donating to one of our teams at strokemn.org/stridesforstroke.

Every dollar counts, and your contribution will make a difference in the lives of those affected by stroke.

We hope you'll join us for an **unforgettable day** filled with inspiration, hope, and community. Remember, Strides for Stroke is not just a walk - it's a community of people coming together to make a difference. Register today and let's stride for stroke together! May 20 at 10 a.m. at Long Lake Regional Park in New Brighton, CentraCare Plaza in Saint Cloud, or Miller Hill Mall in Duluth. Register and donate today at strokemn.org!



Mark your
calendars!



Get your
questions
ready!

Please Join us for our
New Series –
Authors Round Table

May 30, 2023 6-8 p.m.

**Roseville Public Library
2180 Hamline Ave N Roseville 55113**

Get ready for an evening of literary enlightenment at the Minnesota Stroke Association's Stroke Authors Roundtable! Join us at the Roseville Public Library on May 30, from 6-8 p.m., for a lively discussion with some of the most talented writers in the field of stroke literature.

Don't miss this unique opportunity to gain valuable insights into the creative processes of our esteemed panelists, who will share their experiences and discuss the impact their writing has had on themselves and others. Our recent brain injury roundtable was a hit, and we fully expect this one to be just as exciting!

Mark your calendars and come prepared with your questions - this event promises to be an unforgettable experience. Visit strokemn.org for more information, and join us at the Roseville Public Library located at 2180 Hamline Ave N, Roseville, MN 55113. We can't wait to see you there!

**Minnesota  Stroke
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MINNESOTA
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UPCOMING EVENTS

Minnesota Stroke
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STRIDES FOR STROKE

SATURDAY, MAY 20, 2023 • 10 A.M.

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BRAIN INJURY AND STROKE BASICS

Learn facts about the brain, how it works,
and what happens when it's injured.

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Saturday, September 16, 2023

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