

STROKE MATTERS

WINTER 2020

Minnesota Stroke Association



ONCE UPON A TIME

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Letter from the Chief Executive Officer

By David King



Dear Stroke Matters Readers,

By the time this edition of our magazine reaches your mailbox, the world will be different. The 2020 election will be over and, hopefully, done with. All 67 seats in the Minnesota State Senate and all 134 seats in the Minnesota House of Representatives will be filled. We will have begun to adjust to a state and a nation under newly elected officials. And, regardless of whether or not your hoped-for candidates won, the work you and I and the staff of the Minnesota Stroke Association do to ensure the best quality of life for people living with stroke will continue.

Because this process never ends. No matter who sits in which seat, we have to continue making our voices heard. If a politician made promises before the election, we have to make sure those promises are kept. If our bill didn't get through, if our story didn't get heard, if our hard work didn't result in a win, then we have to take a deep breath, dust ourselves off and start again.

The work never ends. And, yes, that sounds exhausting. Which is why our Public Policy staff works so hard to create a team of advocates who cheer each other on, build each other up and have each others' backs. Policy change requires a lot of energy and strength and Public Policy is great at not only helping people find their voice but helping them find that strength.

So, as you get to know our newly elected officials, know that there is work to do. And that you have the power to do it. Just call 763-553-0088 to find out how you can get involved as an advocate.

Similar to our work in Public Policy, the challenges of fundraising never end. We had a great Strides for Stroke this year, but it didn't quite get us where we need to be financially. We have a long way to go in that direction as well. So please, if you can, give to the Minnesota Stroke Association this year. We need your help. Any amount helps, so please include us in your year end giving.

Visit strokemn.org/donate today and give what you can.

We all need one another this winter. Stay safe and stay warm and I'll see you in the Spring.

Thank you for reading,
David King

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Survived ² strokes within a month



at...
28

By Phil Gonzales, Public Awareness Associate

Molly Fitzgerald is young, only 28, and is fortunate to not have the dramatic physical after-effects that linger in many people who have experienced two major strokes. But, as is often the case with stroke survivors, stroke can have effects beyond the physical. Beyond even the cognitive. Frequently, stroke survivors experience a form of acute stress disorder that, if left untreated, can form into full blown PTSD.

“For a while it was every month,” Molly says, “because there was a month in between the two events. I was waiting for the other shoe to drop. And that subsided after a couple of months. But now I’m really feeling it. Maybe it’s a combination of everything. The weather’s the same, the same stuff happening at work, they’re kind of triggers. And I have this overwhelming sense of dread that something else is going to happen again, or something’s going to happen soon. And also you’re just thinking through, like, the guilt around the shoulda, coulda, woulda. It’s kind of reliving it a bit and thinking through, ‘What was I doing a year ago?’”

It was October, 2019, and Molly had spent a week with terrible neck pain, even taking a trip to Urgent Care to see if it was anything worth worrying. Finally, she visited a chiropractor to see if they could help.

Molly didn’t realize it, but she had a vertebral artery dissection, a tear in the inner lining of the vertebral artery in the back of the neck. Blood coagulates in the tear forming a clot that can block blood flow leading to a stroke. Current research indicates that vertebral artery dissections are a leading cause of stroke in patients under the age of 45. While commonly thought of as spontaneous, new findings indicate that repeated small traumas may exacerbate the tears.

“We think the chiropractor may have pushed it all the way through.”

But, whether or not Molly’s first stroke was exacerbated by the chiropractor, she had still sought medical care in the week leading up to it and had been, essentially, missed.

“And that’s a big takeaway for me coming out of it. You really have to advocate for your own health. I think there are stereotypes and biases we all have. And I walked in as a young female; no one’s thinking stroke. And when I look back, I was like, clearly these things are posterior stroke symptoms, but their first thought was vertigo, or flu. And sometimes I wonder like, if I was a man, would people have taken it more seriously right away?”

Adding to the confusion was the fact that Molly’s symptoms didn’t line up with the Act FAST acronym.

“I looked in the mirror like my face is not drooping, my arm’s not numb. I called my mom and was talking to her and like, ‘Does my speech sound okay?’ She’s like, ‘Yeah, absolutely fine’”

Today, the Act FAST slogan is being slowly replaced with BE FAST, which accounts for the impact to Balance and Eyes found in back of the brain strokes.

“And which was 100 percent what was going on. I couldn’t see straight and I couldn’t walk straight. And, I think it’s really important that a lot of those are younger strokes, things that happen with the arteries right in the back. So that’s something I tell everyone. ‘It’s BE FAST! Don’t forget about balance and eyes!’”

Molly stayed in the hospital for three days. She still had noise and light sensitivity and dizzy spells but the more concerning persistent symptom was a recurring headache. But, doctors attributed this to a pinched nerve and continued to treat her like she was overreacting.

And then on November 16, about a month after her first stroke, Molly had her second.

“I was sitting on my bed and my left jaw felt like it locked up. And it passed, and I felt fine for probably for 20 minutes or so and ultimately decided I should go to the hospital. I called a friend to pick me up and in that five minutes I bent down to put my shoes on and all of a sudden, it’s like the world snapped. It just completely changed.

“I can barely describe it, but I felt drunk. And that makes total sense because your brain is shutting down. And my ears are ringing; the world is kind of swaying; I’m seeing green; there’s like these bubbles in my vision.



“I called 911 and within the eight minutes between when I called them and when they came, I couldn’t get up and unlock the door. And that’s when I really started to freak out. I remember it was just so bizarre. I could comprehend everything that was going on. But I couldn’t communicate back. And I couldn’t respond anymore on the left side of my mouth, my face completely drooped and my arm kind of got all curled up and I couldn’t move it. They ultimately got me into the ambulance, which was very scary with not being able to communicate. And I couldn’t breathe very well. And I was kind of throwing up a lot, kind of aspirating it, and I couldn’t communicate that. And that’s the thing I really have nightmares about still.

“I was unconscious when I arrived and this is a moment of humor for me. They were about to intubate. And for whatever reason the clot must have moved from where it was. And I was like, ‘No!’ And I was suddenly joking around and they’re like, ‘What’s going on?!’”

“And they weren’t sure that it was a stroke. They thought it might have been a migraine. And even the first MRI didn’t show a stroke at that time, because it was still happening, which is a little strange. A couple of hours later it finally showed up.”

Molly’s parents, aunt and uncle came to the hospital. She stayed in the ICU for several touch and go days. The effects of this stroke were having a profound impact on her physically and cognitively. Her limbs were numb but tingling; her heart rate would suddenly spike, causing the left side of her body to feel like it was on fire, due to what doctors could only assume was seizure activity. Eventually, she was able to begin occupational therapy and physical therapy. She

wasn’t paralyzed on her left side but was having ataxic movement where she couldn’t coordinate what her body was doing.

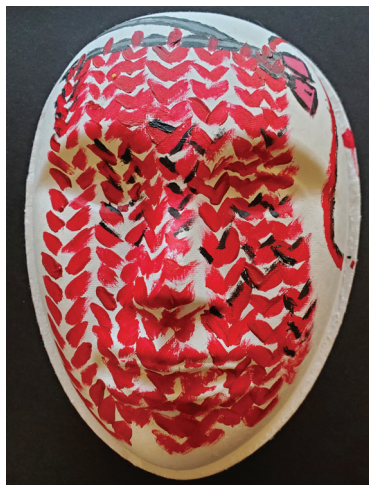
After about a week, she was moved from Edina to Riverside for inpatient rehab.

“Stroke is so crazy. It just changes so fast. You don’t know what to expect. Your brain is so complex as things change and rewire. And I get to the inpatient rehab and I start having this really nasty headache. And, the theory was your brain swells a bit to reabsorb blood after the blood clot. So that was tough. And I’m like, ‘I’m going to throw up from the pain.’ And you still had to get up and do your three to six hours of rehab a day.”

Eventually, Molly’s headaches subsided, her walking improved and she was released in time for Thanksgiving. And, today, she considers herself to be mostly recovered.

“There’s some numbness I have on my left side still and that mental fogginess. I develop migraines, which I never had before, which is a learning experience trying to figure out how to manage those and of course, then there’s the emotional recovery. This is gonna be a tough month. I’ve already started to feel really emotional about it. But if telling the story kind of helps somebody or changes the stigma, then that kind of makes me feel like I’m doing something with the experience.”

Molly participated in the Minnesota Brain Injury Alliance Unmasking Brain Injury in Minnesota project, where she made a mask to express her experience through art.



“My mask was a swatch of knitting, which is something I always like to do. And I was really, really struggling when I was in the ICU with personal suffering. And like, why these things happen to people. You hear people crying and in pain there every day. And, all these people can’t deserve this. So it’s a classic question of, ‘Why do bad things happen to good people?’ And it just really shook me up. And my friend had started knitting a sweater. And she messed up. So I said, ‘Just bring it over, I’ll kind of try to see what I can do. My hand’s not great right now, but maybe it’ll be good therapy anyway.’ And I found a bunch of mistakes, and I was going back and fixing them. And that’s when it kind of hit me that when you’re knitting, when you set out to make any project,

you don’t intend to make any mistakes or have anything go wrong. But inevitably, you make mistakes. And, you don’t just leave it, you go back and fix it or you kind of patch it and kind of make it work. But still at the end, you end up with a beautiful piece of fabric. A sweater, a scarf, a mitten, something very useful.

“And it helped me understand that you don’t have to lose faith in the world. Because bad things happen. Personal suffering may happen, but it still contributes to a bigger thing than you. You didn’t deserve it. And a lot of people went out of their way to help you keep moving forward and keep that chain of knots essentially moving forward. Yeah. And, that was what my mask was all about.”



By Phil Gonzales, Public Awareness Associate

This is a show about what happens when you have a stroke. And you have a lot of people that help you get through it and out of it. And you're able to take some advantage and talk to other people so that you can write a play, or a film, or a story about what you went through.

T

elling the story of a stroke involves telling the story of an abstracted event. For the person experiencing the stroke, perception of time, space and reality itself can be warped by the very event they are experiencing and observing.

Theater is itself an abstracted form of storytelling. The audience can never forget that they are in a room watching people enact a story. The lighting, sound design, blocking and choreography fill in the scenery, the passage of time, and the overarching themes.

In that sense, theater can serve as the perfect medium for a stroke story.

Broadstroke, a new media piece by Richard Reeder, uses the abstract medium of the stage to tell the story of Reeder's stroke from the morning of the event up through his moment of inspiration for creating the piece. It's a tale told in the abstract, with dance, poetry, vaudeville and voiceover allowing the audience to experience Richard's stroke along with him, as it happens, right in front of them.

Or, that's the idea in any case. COVID-19 had other ideas about Richard's play.

Richard Reeder, Rich to most people, and his wife Vicki Hooper live most of the time in Santa Monica, California working on available film projects. Rich graduated from the University of Minnesota in 1978 with a degree in Mass Communication. He got into filmmaking while working for the University.

"I worked there for 25 years," Rich says, "And I really wasn't in the office very much because we were doing films all the time. I spent two years working on a Hmong project when they first came to Minnesota. Then I got to go to Russia and other countries on a couple of projects. I just feel like I got the right job at the right time."

Rich's film work would also bring him back to working in the Twin Cities, as in 2014 when he created the Film In The City project, teaching filmmaking to homeless youth and helping them learn to shape their experiences into story.

By 2017, Rich and Vicki were dividing their time between the Midwest and the West Coast, traveling back and forth as work and family demanded.

"Vic and myself were, at that time, living for just two years in California. And each month, I came back to Minneapolis for a week to work on a film on dementia of all things, and also to see the two grandchildren, Ella and George and then back off to California. I was in Minneapolis. I had been out to the children's home the night before, about 25 miles away. And I drove back here that night. And, I am very, very fortunate to have lived through that situation, because it doesn't always happen, that cars can move well, while a stroke is happening."

Unbeknownst to Rich, he was in the early stages of a hemorrhagic stroke. It wasn't full blown at this point, but it had already begun affecting his ability to choose words. The next morning, he began driving out to see his grandkids again, and quickly realized something was wrong.

"Just before I got there," he says, "I didn't think I was doing well enough to go out and spend a day with the two kids. So I called their grandmother Marcel and she called my daughter, Sarah, while I was trying to get the car to their location. I got to the house, finally, and Sarah started to talk to me. She was not convinced that I was having a stroke but my messages and the words did not dwell well with her. So she said, we're going to the hospital right away. And that moment at 9:35 that morning, saved my life. If I had gone out in that car with the children, it could have been really grim."

Once he returned from the hospital and acute rehab, Rich received care at home from his therapists and the following year had surgery to repair his heart. As a result of his stroke, today Rich lives with some aphasia and cognitive issues.

But, what does this have to do with theater?

Rich had begun taking classes at the Guthrie Theater in 2015, under actor Raye Birk. Rich finally managed to resume Guthrie classes in 2018 and it was Birk who suggested Rich look into exploring his experience with his stroke as a theater piece.

"And it started with just myself, scared to death at the Guthrie class with 25 people. It was just Rich in a scene, but it got an interest. And so I talked to six people wound up being seven, in that group and those seven people stayed with this idea



Fortunately for Rich and his family, the team at Fairview Hospital was able to intervene and keep his stroke from advancing further. But, as is often the case with stroke, the causes are sometimes a bit cloudy and certain answers only raise more questions.

"It was a hemorrhagic stroke," Vicki says, "but they think it was actually caused due to an endocarditis, that it might have been triggered by a urinary tract infection that got into the bloodstream that formed this mass on his heart. So he was on this really high dosage of intravenous antibiotics for six weeks. And it was sort of interesting that once the infection went away, and the bleeding stabilized, a lot of cognition started coming back. So you know, how much was from the stroke and how much was from the serious infection?"

for a year and a half. And I kept asking them, wait a minute, are you sure you want to keep working on this? And they were like, "Well, yeah." And I was shocked and just thrilled, because they were wonderful to work with."

In that year and half, Rich, along with Vicki and his cast of seven, developed Rich's story into *Broadstroke*. *Broadstroke* tells Rich's stroke story in the abstract manner in which he experienced it. Actors portray not only Rich's family, friends and medical team, but also the voices in his head. They personify the disorientation he experienced during his stroke. Using comedy routines, they portray the seemingly absurd interactions an impaired person is expected to have with an endless array of doctors and therapists. The concept involved not only live performances, but making the show available to produce in an educational and informational capacity.

And then COVID-19 changed their plans.

“We all learned the word Zoom,” Rich says, “ And that group of seven was together almost every week. We hadn’t thought of it as a film. And yet, my background is film. So we started to work on film. And Vicki shot most of the film, not having been a filmmaker, she just stepped right in and made it happen. And it was incredible. She did a terrific job of shooting a lot of scenes. 126 to be exact, but who’s counting.”

“And then it was the Minnesota Fringe Festival,” Vicki adds, “when they said, ‘Hey, we’re going to do a virtual film festival and anybody can be in it.’ And that’s when you guys said, ‘Hey, why don’t we just try to use that as a goal?’”

helpful for you with your support group or as a stroke survivor? Rich was going to a pain management doctor who was saying that a lot of times, doctors don’t know what’s going on, what kind of effect they have on patients and what is going through their heads. And this could maybe be helpful for medical professionals, just to let them know that some of the stuff that they’re saying doesn’t quite sink in for a person having a stroke or their family.”

It was through a Fairview support group that Rich and Vicki first heard about the Minnesota Stroke Association and brought us his story.


Rich’s play and film demonstrate the importance of our core value of collaboration. Rich had a story to tell and the collaborative natures of theater and film helped, and is helping, to bring that story to a wider audience. An audience that can not only relate to, but benefit from, seeing and participating in the telling.



So, the abstract action of *Broadstroke* moved from the stage to the screen where it enjoyed a successful showing at the 2020 Minnesota Fringe Festival. The movement, voiceovers, comedy and emotion are still there, but aided by Rich’s film experience they took on an additional dimension.

“So now, we’re almost working a little bit backwards,” Vicki says, “Now that the Fringe is done, we have a piece that you can show and say, ‘Would this be

“I did not have the serious stroke, the very serious stroke that a lot of other people had. Once I started to find out how the other people had gone through this, but were willing to sit down and talk about it and share their issues or concerns. I thought, ‘Oh, this is Rich. This is what you do for a living, you’re a filmmaker! Why don’t you do something that goes into a film format that might be helpful to either medical organizations, schools, hospitals, whatever it might be universities, and let’s start to pay back what I’ve gotten.”

A close-up photograph of a hand holding a lit sparkler. The sparkler is bright and glowing, with sparks falling around it. The background is dark, making the light from the sparkler stand out. The hand is positioned in the center-right of the frame, with fingers slightly spread.

There's Magic to do

By Sue McGuigan, Development Coordinator

Who knew last year at this time, when I reflected on how the Minnesota Stroke Association was important to various members of our stroke community, that we would be living in the world we live in today? That we would be staring out the window at cold and heavy snow in October. That we would be anticipating the end of the most contentious presidential election in memory. That we would be anxious about our future access to income, school, healthcare, food, housing, transportation. That we would be able to see someone's smile only through their eyes and that handshakes and hugs would be a thing of the past. That we would be diving head first into diversity, equity, and inclusion education. That we would be conducting work, school, and social gatherings through Zoom or some other remote platform. That we would be facing Thanksgiving, Christmas, Hanukkah, and Kwanza with the prospect of missing our large, joyous family gatherings.

Who knew?

It is so easy to get overwhelmed by all of this. Just thinking about the onset of winter sends me into a panic attack.

But in the midst of this emotional, physical, and economic turmoil, there IS magic to be found. Every day, I am astounded by the kindness, generosity, creativity, compassion, humor, and optimism I see in the world. I have been inspired by young people writing letters to older adults and individuals with disabilities isolated in nursing facilities. I have been amused by the many music videos that parody every Broadway musical number in existence. I have been inspired by talking dog videos that dole out sweet words of wisdom. I have been thrilled by the efforts and excitement of so many people, particularly young people, in voting. I have been moved by people donating food, clothing and money to those adversely affected by the pandemic, riots, wildfires, and floods.

And I have been amazed by the extraordinary efforts of the Minnesota Stroke Association staff during this time. With staff members mostly working remotely, everyone has had to shift how we do our jobs. Staff members have found new ways to educate people about stroke, get people access to the services they need to live their lives with the effects of stroke, give people the chance to ask questions and talk to someone who understands stroke, and offer people the opportunity to share their stroke experiences. Our Resource Facilitators and Case Managers have been making extra calls, checking on clients' mental health and exploring whether they have access to resources to support their needs, whether they have enough food and medications, and whether they feel safe in their homes. Since the majority of outside events have been suspended and there are no volunteers in the office, Education & Community Outreach staff, the Volunteer Department, and other staff members have been finding ways to support other departments, including filing, doing data entry, processing mail, and making crucial phone calls. The support and comradery has been magical.

But for the Minnesota Stroke Association to continue to improve the quality of life for those affected by stroke, we need you to create some magic of your own. Invest in the Stroke Association with a gift that is meaningful to you. You can send us a check, donate online at strokemn.org/donate or contact Brad at bradd@strokemn.org or call 763-553-0088. Your donation will help people make it through these times. You will ensure that our staff can continue to offer support to all who need it during these challenging times. We appreciate everything and anything that you can do.

As author Roald Dahl said, "And above all, watch with glittering eyes the whole world around you because the greatest secrets are always hidden in the most unlikely places. Those who don't believe in magic will never find it."

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