

STROKE MATTERS

WINTER
2022/2023

Minnesota
Stroke
Association



REVISITING DORY 6 YEARS LATER

Minnesota Brain Injury Alliance
Minnesota Stroke Association
2277 Highway 36 West, Suite 200
Roseville, MN 55113-3830
CHANGE SERVICE REQUESTED

Letter from the Chief Executive Officer

By David King



Welcome, *Stroke Matters* readers,

We share the stories of stroke survivors for a number of reasons: to raise stroke awareness, to illustrate the different types and causes of stroke; to remind readers that they aren't alone in their stroke journeys. We also share their stories to capture a moment in time and be able to look back at where we'd been.

This issue of *Stroke Matters* is about looking back. And, to do that, we're visiting with a couple of survivors whose stories have graced our pages before.

Dorian Nelson first appeared in *Stroke Matters* in 2016. At the time, we were covering pediatric strokes, specifically in utero stroke, and Dorian's story captured the hearts of readers. He eventually threw out the first pitch at the Strike Out Stroke event in 2019 and, in recognition, we covered him again. Dorian is now a ten year old and we're taking a look at how far he's come and where his family hopes to go.

Michael McMillan appeared in 2011. A high school student, Michael's story focused on the struggle his family had convincing educators and administrators to take his stroke seriously. Now in his twenties, Michael is no longer the kid he once was. We catch up with him in this issue to see how Michael is doing and to see what affect his stroke has had on his life.

Speaking of the effects of stroke, Nancy has a great piece about mitigating stroke impact by following a careful recovery plan. She gives some great tips on recovery goals and offers perspective on setting realistic expectations.

Thank you for your continued support of the Minnesota Stroke Association. We're looking forward to a great new year and you can help it be great. Remember to keep the MSA in your end-of-the-year giving by making a donation at strokemn.org. Your gifts help keep our programs and supports funded and available all over Minnesota. Each dollar counts and every gift is appreciated. So, if you can, visit strokemn.org this winter and give a gift to the Minnesota Stroke Association.

Happy reading,
David King
CEO

Scan here to donate!



Editorial Policy

Stroke Matters is published by the Minnesota Stroke Association. The editor reserves the right to edit submitted materials for style and space. The Minnesota Stroke Association does not endorse, support, or recommend any specific method, facility, treatment, program, or support group for persons with stroke and their families. Please call for advertising rates.

Letters to the Editor Policy

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

Stroke Matters is a bi-yearly publication published by the Minnesota Stroke Association. © 2022 Minnesota Stroke Association. All rights reserved. No part of this publication may be reproduced in whole or in part in any way without the written permission from the publisher and full credit to the publication is given.

POSTMASTER: Send address changes to:
Minnesota Stroke Association
2277 Highway 36 West Suite 200
Roseville, MN 55113-3830



Minnesota Stroke Association is a proud member of Community Health Charities Minnesota. Community Health Charities Minnesota is an alliance of leading nonprofit health research and service organizations whose mission is to improve lives affected by chronic illness by investing in health research, services and education.

Have YOU met your GOALS?

By Nancy Christensen, Administrative Assistant

To a stroke survivor, the effects of stroke can be serious, life changing, frustrating and confusing. But, no evidence or recorded data can tell us exactly which effects each person will sustain. As the effects of each stroke are different, the goals set for each recovery will be different. However, there are guidelines you and your support team can follow to help make your goal setting realistic and achievable.

The immediate goals of stroke treatment are to quickly restore blood flow to the brain (with ischemic stroke) or stop the bleeding in the brain (with hemorrhagic stroke) while continuously monitoring vital signs to detect and treat stroke complications.

Following their stroke, the stroke survivor, along with their team, needs to set challenging but realistic goals that push them to their highest potential while not becoming overwhelming.

For example, a person that sustained a moderate stroke might set a goal to walk again while a person that survived a massive stroke might set out to first regain the ability to swallow. If that second person set a goal to both regain the ability to swallow and walk again, it could be overwhelming, frustrating, or discouraging.

Consider these tips when creating goals to stay motivated and realistic in your goal setting.

Be S.M.A.R.T. about it.

S.M.A.R.T. goals in stroke recovery are Specific, Measurable, Achievable, Results-focused, and Time-bound. Set your first goal. If that goal is measurable, you'll know when to set your next goal. Make sure it's an achievable goal and that you give yourself a time frame in which to accomplish it. For instance, if you can accomplish five reps of a leg exercise by the end of four weeks, then your next goal can be 10 reps by the end of the next four weeks, then 15, and so on.

Start SMALL.

Take your recovery one step at a time. For example,

if mobility is needed in your affected arm, focus on strengthening and completing the exercises as assigned by a physical or occupational therapist. Don't rush but rather focus.

Don't compare your journey to someone else's.

There is a balance between inspiration and competition. While it's okay to hear about another's story and journey, be mindful of too much comparison. If they are achieving their goals at a quick pace, it doesn't mean that your goals are any less significant. Remember, stroke recovery can happen even decades after a stroke; their time-line is not your time-line.

ACTION.

A goal means nothing unless you take action on a regular basis to meet your goals and accomplish them. Take it slow but remain consistent and vigilant.

Have you made goals? Have you achieved them? Do you need help contacting resources that can aid in your journey? The Minnesota Stroke Association Resource Facilitation team is available to listen and help you to assess your needs. We can guide you to where services are available in your area. We understand the needs of stroke survivors and we want to support and lend a hand on your journey post stroke.

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**

DORY 6 YEARS LATER, *JUST WANT HIM TO BE HAPPY*

By Phil Gonzales, Public Awareness Associate

Dorian Nelson – Dory to his friends and family – is a repeat interview for me. I’ve covered his story twice already; three or four times if you count the pieces I’ve written for promotional announcements.

When I first met Dory in 2016, he was a rambunctious four-year-old and a recent big brother to baby Livian. Being so young, I spent the interview talking with his mother, Marta. Dory had his stroke in utero, but it hadn’t been discovered until he developed seizures 20 hours after his birth. In 2016, his right side was still recovering and his family was working with him on emotional and social impulse control. Throughout the interview, Dory stayed on the periphery, darting in and out of the room and finally showing off his athletic prowess in the cul-de-sac outside.

In 2019, Dory was chosen to throw out the Twins’ opening pitch at the Minnesota Stroke Association’s Strike Out Stroke event. Once again, I sat down with Marta to talk about Dory-now six years old. He had made great physical progress, as his abilities on the pitcher’s mound more than proved. Marta was still concerned about Dory’s impulse control. However, he’d made a lot of friends and had been invited to birthday parties, so things were definitely looking up. Marta and Trent, the boys’ father, had moved the family to a large house in Lakeville. Dory had chosen once again to stay on the periphery of the conversation, finally putting in an appearance at the very end, showing off his toys and his pride in being a big brother.

When I step into the Nelson house in 2022, it all comes rushing back. I can hear Dory and Livian playing a VR game downstairs. The sunroom is bright and Marta is welcoming as always.

“The last time I interviewed you, Dorian was throwing out the pitch for Strike Out Stroke. We didn’t know at the time it was a landmark event. The final Strike Out Stroke before COVID.”

“That was the last time, yeah,” Marta responds.

“What I’d really like to know is, how has your family been handling the last few years just in general?”

“It’s been pretty hard,” she says. “I’ve made a job change. I was a Special Ed teacher for many years, and I had to cut back to just doing admin office work.”

With the COVID shutdown, Dory and Livian, who was just starting kindergarten, were in virtual classrooms. Marta found that getting them set up and properly attending class while

she was trying to teach Special Ed also over the computer was far too much to handle.

“And then Dory was in third grade, and he had a pretty difficult teacher that didn’t really understand, like, where he was at with his needs and just wasn’t very encouraging.”

The lockdown was difficult on everyone, but for parents of children with disabilities, it made gauging their progress particularly difficult. Marta and Trent were often confused as to whether Dory’s particular issues on any given day were due to his stroke, the alienating effect of virtual classrooms or him just being a kid going through physical and emotional changes.

“I definitely noticed a change in his academics,” Marta recalls. “Writing is really hard for him, and math. He’s still in third grade math and I don’t know how much it had to do with COVID or if it’s the stroke or combination. I don’t know.”

But, when he had teachers who understood his stroke, as he did in fourth and now fifth grade, things went much better. Dory is a hard worker who takes pride in his accomplishments. He’s also just a very sweet kid.

“He’s super funny,” Marta says. “He’s shy, but when he’s with people that he’s comfortable with he’s super talkative and friendly. He will surprise you with a hug out of nowhere. If he’s had a bit of a behavior, he will just come up and give you the biggest hug.

He likes being a big brother. He likes teaching Liv all the video game type things and stuff like that. But, also, he’s kind of turning into a little teenager, a little preteen.”

And, as Dory ages, I wonder to



Marta at his continued participation in MSA events. His family has attended each Strides for Stroke Walk since 2015 including the Virtual Walks. He's open and sharing about his stroke with his friends and classmates. And, the Nelsons themselves are willing to discuss their family's ups and downs as the parents of a childhood stroke survivor. What keeps them coming back?

"I think it's a good reminder to remember the gains that he's made," Marta says. "And it's good for the family and everyone to celebrate him. I know we had friends that got together when they didn't have the Walk, and they let us know that they were walking for him on that weekend in May."

And, as much as it can be tempting to act like Dory's journey is a straight line to recovery, it's important to acknowledge that he's encountered obstacles that have required new interventions.

"He's actually started having the right side weaknesses again," Marta tells me. "It's very visible when he's playing sports like catch. So he has been doing PT once a week. We were warned before COVID started that he should start PT again and then everything shut down. So he only had one appointment and then he couldn't go. So, now he's doing that years later. He's supposed to do it every day. And, it's not painful but just stuff he doesn't like to do. And it's harder for him."

In addition to his PT, Marta works with a behavior specialist five hours a week to address Dory's needs as he enters adolescence.

"We've utilized a lot of the county resources in different ways," Marta says, "now that he's on a waiver that provides more crisis services. As he's getting older, his behaviors have changed a little bit more. He is more self aware so you see that self-esteem coming out. We're dealing with some school refusal and avoidance issues. But, the specialists make sure everyone's on the same page – the therapists that he sees at school once a week and his grandparents – just so that everybody's kind of doing the same thing with him."

"You've mentioned his grandparents," I ask, "how is the family getting along? Does he still enjoy being an older brother?"

"As they both get older we're seeing how much they're different from each other," Marta tells me. "But they get along pretty good. Still lots of grandparent involvement. Lots of support there. My parents can do respite so they take Livian on Tuesday and Dory on Thursday overnight, so we can spend time with the other one. We still really don't go out much, usually. We haven't really gotten there yet. It's just kind of like, everything's opened up and I'm not used to taking them at this age now. I was used to taking them when they were a couple of years younger, but it would definitely be a two person job."

"So, what are your hopes for the future?" I ask. "I know it's a big question, but looking back on the earlier interviews, you'd focused a lot on him improving physically and making friends. When you look ahead a couple of years, now, what are your hopes for Dory?"

It doesn't take Marta long to respond.

"I just want him to be happy," she says, "and feel supported by his loved ones, his friends and family. He's still proud. He'll wear his Stroke Association shirts to school. He'll ask to wear them. Throwing out the first pitch, he still has the poster in his room the class made for him. So he likes to talk about that."

"Will the family be attending Strides for Stroke next year?"

"I hope so," Marta says. "We're probably gonna let Dory decide this year, because he's old enough to make decisions like that. It was always such a fun, nice celebration. So we'll see."

The entire time I'm talking with Marta, Dory and Liv are playing their game, their voices echoing up the stairs. Dory never says hi to me the entire time. But that's fine. Six years ago I wrote that even though he's a stroke survivor, Dory is first and foremost a great kid. And that's still true. (Even if he doesn't want to talk to an old interviewer.)



No longer a kid

By Phil Gonzales, Public Awareness Associate

My interview with Michael McMillan eleven years ago was my first, though not my last, encounter with a stroke survivor whose stroke wasn't believed.

Michael was 15 and at school when his stroke hit. Even though the stroke knocked him out, left him disoriented and unable to speak, school administration accused Michael of faking it or even worse being on drugs. By the time he was properly diagnosed, Michael's stroke had done a number on his brain. He had trouble returning to classes and his impulse control was unpredictable at best. When he finally received an IEP, he was accused by some teachers and coaches of "milking the system."

When we met, along with his mom Judy, Michael struck me as an athletic, open, forthright kid who wanted his story told in order to educate the public about juvenile strokes but also to share a story that had been so misinterpreted by the adults in his life.

Our interview ended with Michael talking about his support cat, Clay, and expressing hope to attend a two-year college and help other people. His statement, "I still don't feel like I'm back to where I was, but I don't think I'm going to be and I accept it," really hit me at the time. It showed a level of thoughtfulness I hadn't seen much in kids his age.

That was 2011. In 2022, Michael lives in Chicago and we connected over Zoom.

"I still have that cat!" he tells me. "I haven't tattooed him on me though. That's another thing; I'm all tatted up now."

Over a decade later, Michael is clearly the same upbeat and thoughtful person I met. He's no longer a kid, obviously, but he's ready to talk about his life and his stroke and where his journey has taken him.

"I got relocated to Chicago for my job," he tells me, "I've got a great opportunity down here. So, I moved in May. I think that's when Stroke Awareness Month is, I believe?"

"Yeah, it is."

"I have a one year old daughter! They were just in Chicago with me for two weeks and they just left. But, that's my life. My daughter is everything. She, like the stroke, came as a surprise but it's been great. It's been really great. I love being a father."

Michael spent most of his twenties working as a paraprofessional in a high school. He'd tried attending college after his own graduation, but found that the experience wasn't right for him.

"I was a pretty decent student before, you know, the stroke transpired," he says. "I'm not going to use the stroke as an excuse but I wasn't interested in going to college. For schooling reasons, I guess. Maybe the extracurriculars!"

Michael interviewed for the paraprofessional job and, at twenty, he was back in a high school setting working with kids not much younger than he was. He



stayed with that job for five years and only left when he realized there wasn't much hope for advancement.

"I was naive," he says. "I didn't realize how underpaid and under appreciated paraprofessionals are. You know, it's sad because those are my people, right? I love the job. But yeah, it was time to head into a different direction. Because I knew that if I wanted to advance, I would have to, like, go back to school, which I'm just not cut out for."

Throughout the conversation, Michael skirts around the subject of his stroke. He admits that he was hesitant about talking about it again, not because it didn't affect his life but because he doesn't feel it's had any lasting impact. At least, that's what he tells me in the beginning. As our talk continues, though, he seems to reveal a bit more about his reasons for downplaying his stroke.

“I’m not proud to even admit this,” he says, “but it was almost like a scapegoat in the sense that if I came up short in anything it was ‘Well, I had a stroke.’ You know what I mean? My high school career did not work out in any of the sports that I pursued. And it was just easy to say, ‘Well, I had a stroke.’ It was very, very easy to do that. And I think that’s kind of a big reason why it is something that I just kind of want to put behind me. Because I don’t want to keep going back to that. I want to persevere through it.”

Michael says that he struggled for a while with an emotional fallout that he hesitates to call PTSD. In our past interview he’d mentioned having anxiety attacks and flashbacks when he found himself back in places that reminded him of his stroke. I also recall his issues with impulse control and he’s quick to talk about it.



“Still to this day,” he says, “my impulse control when it comes to consumption is just not there. I mean, whether I’m eating food, drinking water, drinking at a pub, drinking a beer, I’m consuming it really fast still to this day. I mean, I got a Chipotle burrito last night. And I was in and out of there in five minutes. I’m just constantly wanting to consume it. Or, eat it or like, finish it or something.”

With the lingering effects of his stroke fading and his job failing to offer anything in the form of advancement, Michael began looking for a new way to earn a living.

“I had a bunch of buddies that worked in the call center for Renewal by Andersen. And, and I was like, alright, they make decent money, let’s give that a shot. And so I was an entry level agent for a year and

then, a year later, I stepped into a leadership role. And then I was like, I want to be out in the home selling. So I applied everywhere: Cleveland, Detroit, a couple Virginia markets, Los Angeles, Chicago. And nobody’s ever done that. Nobody’s ever started in the call center and then became a sales rep in the actual field. And Chicago gave me an opportunity. All that’s all transpired in about two and a half years. And I hope to retire there. I love my job. I love my company. So it’s great.”

As he settles into his new home and his new job and his new routine with his daughter, Michael the man is certainly not Michael the kid I met eleven years ago. But, as he notes, nobody is the same person they were a decade ago.

“Everybody’s going to experience everything in their own way,” he says. “I like to think I’m in a very, very good position now. And it’s just something that



I really just kind of put behind me. I haven’t even put much thought into any of this. And then my mom was like, ‘Hey, Phil, who interviewed you? He wants to do a follow up.’ And then I was like, ‘Oh, yeah, we did do that, didn’t we?’ But it’s been great. It’s nice to catch up. Because to be quite frank, I just kind of forgot about everything. And, now like starting to all come back to me. And hopefully, you know, if there’s anybody that’s gone through a situation like I’ve been in, or they’re going through currently, that hopefully I can be some sort of inspiration I guess. Just because I mean, life, now, It’s good. It’s really good. I’ve got a great opportunity here. I’m in Chicago for my job. And, being a father? It’s the coolest.”



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.



Scan here to donate!



EXPERTISE LEADS TO ASSURANCE.

Comprehensive stroke center specializing in
treatment, prevention, research and recovery.

 Hennepin
Healthcare

Hennepin Stroke Center

hennepinhealthcare.org/stroke | For more information 612-873-8712

Your all-in-one- stroke-center partner >

Get the care and support you and your family need from Minnesota's first comprehensive stroke center. We give you access to the best programs and resources to help you achieve your fullest recovery.

Stroke support groups | Communication practice groups | NeuroWell
Occupational, speech and physical therapy | Aquatic therapy
ShareGivers (peer visit volunteers) | Volunteer opportunities



American Heart Association
American Stroke Association
CERTIFICATION

Meets standards for
Comprehensive Stroke Center



Visit [regionshospital.com/rehabilitation](https://www.regionshospital.com/rehabilitation)
or call **651-254-3620** to learn more.

MINNESOTA STATEWIDE STROKE CONFERENCE



Minnesota  Stroke
Association

*Thank you for attending and making
it a great 2022 conference! Mark your
calendars for next year Fall 2023
-Stroke Association Staff*