Welcome, Stroke Matters readers,

I’ve got two very exciting announcements for you that will be covered later in this issue so forgive me for spoiling the surprises. I am, however, the CEO of the Minnesota Stroke Association and that grants me certain privileges. Among those privileges is the power to spoil surprises.

First, the play A Play By Barb and Carl by Barbara Joyce-Rose Brown and Carlyle Brown will be having its in-person premier at the Illusion Theater on April 8. Barbara and Carlyle’s play was set to go up in 2020, but was derailed by COVID-19. Our organization was planning to partner with the Illusion Theater as the play explores Barbara and Carlyle’s relationship in the aftermath of her stroke. We talked with the playwrights in that season’s issue and were looking forward to the production. Now that it is back on track, we have a follow-up interview, catching up with Barbara and Carlyle and seeing how the last two years have affected their lives, and their art.

Second, the 2022 Strides for Stroke will be back to in-person participation in three locations on May 21! This is huge for us as we’ve had to make do over the last two years with virtual walks. And, while it was wonderful to see everyone’s pictures and videos, nothing is like walking in the sun with a supportive stroke community, seeing your faces and sharing the day with you. I’m very excited to see everyone at Strides for Stroke. The event will also be remote for those who don’t feel comfortable being around others.

Register at strokemn.org, today!

Finally, no more spoilers, but we do have an article by our own Nancy Christensen about Stroke Awareness Month. I don’t think I give enough attention to the fine work she does in this magazine. Wonderful writing, Nancy! We also have a very informative article on aphasia, so give that a read as well.

Thank you all so much for reading our publications and supporting the Minnesota Stroke Association. You can make a donation to our organization at strokemn.org. Every gift counts and is appreciated.

As always,
David King
CEO
When was the last time you sat down and read a helpful brochure, article or pamphlet that was informative and chock full of important facts that could be valuable in saving your own life or the life of someone else? The Minnesota Stroke Association’s publication Stroke Matters is just that!

Our Stroke Matters publication is mailed free of charge to everyone in The Minnesota Stroke Association database. We also make sure that we distribute copies to our professionals, administrators, clinics and other health care agencies that we work with so that they can pass it on to their patients, co-workers, family members and others who could benefit from reading and learning more about stroke.

But, we need more distribution! We are asking anyone that receives a copy in their mailbox to share with a friend, a neighbor, a relative, coworker or someone that might benefit in knowing more about stroke. Our hope is that we can spread the word to individuals who might be unaware of the dangers of stroke. Please take a moment and reach out to those you know and love. Why is stroke knowledge important? It’s important to know when the stroke happened because as time goes on, the treatment options become more limited. People who get medical attention early enough can receive medications and treatments to limit a stroke’s impact, or even save their life. The Minnesota Stroke Association has adopted the ACT FAST method when discussing stroke and its implications.

During Stroke Awareness month held each year for the entire month of May, the Minnesota Stroke Association wants to continue building on our mission to raise awareness about stroke and enhance the quality of life for all people dealing with its sudden and long-term effects. The Minnesota Stroke Association provides support, resources, and information to stroke survivors, their families, loved ones and the stroke professionals who work with them.
Two years ago, the world was entering a number of distinct, but related, crises. The public health crisis sat at the top of the list, but further down was the existential crisis that many public and performing arts venues were beginning to face: how do you exist when your art form depends on the presence of people? Not only people but large groups of people? And, tightly packed at that.

In the midst of this burgeoning issue, I interviewed Barbara Rose-Brown and Carlyle Brown whose play *A Play By Barb and Carl*, was gearing up for its premier at the Illusion Theater in April of 2020. The play was an exploration of Barb’s stroke and how it took her speech, affecting her personal and artistic relationships with Carlyle. Barb had met Carlyle decades earlier and quickly became his life partner as well as his dramaturg. Together, she helped Carlyle shape his plays by helping keep track of his ideas and ensuring that the story in his head made it successfully to the stage.

But, a dramaturg depends on language and Barbara found her ability to access language severely hampered by her stroke. She could no longer speak in words, only sounds, requiring her and Carlyle to reexamine and reconfigure their working relationship. As they met each new challenge Barb’s stroke presented, they examined and incorporated the experience into a growing theater work. And, out of this they created *A Play By Barb And Carl*.

In June of 2019, the Illusion Theater in Minneapolis included *A Play by Barb and Carl* as part of their Fresh Ink series and they had planned on producing it on their mainstage that following April. The Minnesota Stroke Association would be partnering with the theater to present materials at the shows and host a panel discussion. In my initial interview with Barbara and Carlyle, the focus was on the subject of communication and storytelling. Social distancing was already in effect, but the notion that theaters might shut down wasn’t even a conceivable possibility at the time. COVID was certainly presenting a challenge, but things were going to return to normal very soon.

There is an old Yiddish adage, “Mann tracht, un gott lacht” or “Man plans and God laughs.” We simply lack the ability to predict what the future will bring. And, no sooner had my interview with Barbara and Carlyle been published in the Spring/Summer edition of *Stroke Matters* than the world effectively shut down for two solid years.

We planned and God laughed.

Flash forward to 2022. The world is still more or less in turmoil but theaters are opening back up as protocols are in place to protect a greater percentage of our vulnerable populations. And, into this atmosphere of optimistic uncertainty the Illusion has again announced the mainstage appearance of Barbara and Carlyle’s. *A Play By Barb And Carl*. And, once again, the Minnesota Stroke Association
has plans to function as a source of stroke information at all of the performances and to host a panel discussion after one of the shows. Once again, we are making great plans. And, cautiously glancing up towards the heavens.

So, naturally, it made sense to check back in with the playwrights. We don’t do many follow ups in Stroke Matters, but this seemed important. How is the play doing? How optimistic are they about this production? How had the last two years affected Barb and Carl themselves?

“Well, you know, with the pandemic we’ve been isolated,” Carlyle says. “It’s just been the two of us, so it’s good that we like each other.”

Right off the bat, Carlyle is excited to talk and is effusive about the upcoming production. Barb sits next to him, quieter than the last time we spoke, but eager to leap in when the conversation veers in her direction.

“And, you know, I’ve been doing my work and there’s been sort of like, you know, difficulty in the healthcare system. And just because of all the restrictions and stuff we only did things that were essential. Just like everybody else, we’re just pretty much holed up.”

When the play was canceled in 2020, the Illusion and the Playwright’s Center held an online reading with the then-current cast. Carlyle and Barb participated in the post-show discussion. Since then, Carlyle notes, the play has stayed in pretty much the same format.

“We didn’t entirely step away from it,” he says. “But, we haven’t done any more writing. We’re pretty much ready to see it live.”

And part of the eagerness to see it live rests at the heart of theater as a form of communication. Theater isn’t a solitary exercise; it is meant to be presented and shared. To exist as a conversation with an audience.

“When we wrote the play,” Carl says, “it was kind of written in the moment. So, you know, the scenes are really about our communicating with each other. And, the purpose of art, I think, is to make sense of our lives. And so we’re going to use this to make sense of our lives. So, each of the scenes, in the moment, were like a sort of a check in for me to say, ‘Is this the way you see it? Is this what’s happening in our lives?’ I mean, in the back of our heads, we knew one day this could be a play, but its initial focus was for us to communicate with each other. And then, in the first workshop, we were engaged with people that looked into our lives and found that it had things to say to many people who were in similar situations. And so, we took it, you know, from there.”

At the time of the originally planned production, A Play By Barb And Carl was very much a play about their very recent past. But, two years had gone by since then. I wondered how it felt having that distance between their lives and the lives of the characters and if their perspective on the play itself had shifted.

“I have a play,” Carlyle says, “which is called The African Company Presents Richard III, which had its first production in 1987. And, you know, thank God, it has had a life ever since. Now, it’s a play that I wrote in the past. And, for me, personally, sometimes I would rather eat glass than to see it again. But, it still resonates with people, and they talk about it, and they do it. And, you know, it has a place in the world that has some purpose.
And, despite how I might feel about the play, I’m really sort of gratified by it. And, I guess we’re beginning to feel that way about this play. When a play is finished, when it goes into rehearsal, and you’re the writer, you walk in the room, and people look at you and are like, ‘What is he doing here?’ And so it’s kind of at that moment where it doesn’t belong to you, and it belongs to the actors. And if you’re fortunate as a writer, it belongs to the audience. So I feel like, right now directing this version, I’m just a steward of the play. People have embraced it in a way in which my job is not to mess that up.”

“There’s continued chronic pain,” Carlyle says. “We’ve made some inroads about that, you know, we went to an acupuncturist. So, we’re still exploring whatever avenues we can to make her life as independent and as enjoyable as possible. I mean, is she gonna run marathons? We know that’s unlikely but we want to go as far as we can. And, unfortunately she fell and broke her hip and other things exacerbated the chronic pain. And, she got these sudden tiredness attacks. You could see it in her face, it would just happen all of a sudden. So, these things are really intrusive because we couldn’t do as much physical exercise as we wanted to do, you know, on a regular kind of regimen. And I guess right now, if we could do something with these sleep attacks, then we could work on getting her more muscle mass, and then maybe she could get back to, you know, walking with a walker again.”

Part of Carlyle and Barb’s frustration with her recovery comes from their frustration with the medical system itself. Not the people they work with directly, but the foundations of a system that, at times, seems more concerned with raising capital than with helping people.
“If we wrote [A Play By Barb and Carl] now, maybe it’d be more like a medical play,” Carlyle says, “you know, about the healthcare system. But it would be a boring play! The pandemic has shown, you know, the fractures in the culture. And the healthcare system is not ‘people care.’ Our health care provider, she’s a wonderful person, but she’s buried underneath this draconian bureaucracy. And, it sort of seeps into all these people that really want to do the right thing but are held back by something that’s enormously capital. And, being a political guy, I’m a pain in the ass in the healthcare system. And it’s certainly more accentuated by you know, having to represent someone that doesn’t speak, they can’t speak for themselves, you know, which makes me even louder.”

Carlyle is at his most passionate when speaking about people, Barbara included, suffering under the indignities of a flawed system. His compassion, their compassion, for people comes though not only in their words, but in their play as well. At the time of our interview, rehearsals hadn’t started yet, but Barbara and Carlyle were looking forward to them.

“We’re just kind of getting ready to gear up,” Carlyle says. “The actor who plays our Carl, JoeNathan Thomas, his wife had a stroke. And, the two of them were very, very kind to us, they came to visit us and, you know, presented themselves as, you know, people who got to the next step. And he’s a great actor with a great voice, and we thought he’d be perfect for the role. And then we have Kimberly Richardson, who’s just the bomb. And she was in the first workshop, and Barb was kind of gobsmacked about how much she was like her.”

“As a culture, we often don’t look at what happens to a marriage or a family when a cherished member has a stroke,” says Bonnie Morris, Producing Director at the Illusion theater. “We have been waiting two years to share this beautiful story. Audiences who have heard Barb and Carlyle’s play tell us they feel their own story as they listen to how Barb and Carl faced the challenges of Barb’s stroke. It is raw, real and it is a beautiful love story.”

You will have the opportunity to see this incredible play for yourself April 8 through April 30. The Minnesota Stroke Association will be on hand with stroke information. Panel discussions and Q and A’s will be scheduled and available at illusiontheater.org/a-play-by-barb-and-carl. For more information on the Association’s role in the show, visit strokemn.org.
Aphasia is a condition that robs you of the ability to communicate. It can affect your ability to speak, write and understand language, both verbal and written. Aphasia does not affect your intelligence.

It typically occurs suddenly after a stroke or head injury.

Other causes include brain tumors, infections, and neurological conditions. There is also a progressive neurological form of aphasia called Primary Progressive Aphasia.

Aphasia affects an estimated 2 million people in the United States and is most commonly caused by a stroke. That is why the Minnesota Stroke Association’s work on stroke education and prevention is important work!

More than 200,000 Americans acquire aphasia each year.

Only 8.5 percent of Americans have ever heard of aphasia.

The mission of Minnesota Connect Aphasia Now (MnCAN) is to improve the life participation of individuals impacted by aphasia through comprehensive programs, education, peer connections and community support.

MnCAN serves over 120 people with aphasia and their families in Minnesota every year. It started with community conversation groups in the Twin Cities, Rochester, and out state areas. MnCAN currently operates 10 community-based conversation groups, several different care partner and young adult support groups, a Coffee Club, Gavel Toastmasters group for people with aphasia, mental health support, and a drama club focusing as an arts outlet for people with aphasia. There are also one to one opportunities for people with severe aphasia.

There is a small tuition for some groups, however, no one is turned away for inability to pay.

These have all been provided virtually to accommodate safety concerns with the pandemic and keep people connected. We look forward to gradually getting back to our community groups in person.

If you’d like more information about MnCAN or about aphasia, please contact:

Julia Halvorson, Executive Director, Minnesota Connect Aphasia Now (MnCAN) at
612-524-8802 or
julia@mncan.org
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Your donations helps to provide financial support for our programs and services that the Minnesota Stroke Association provides to individuals and family members with stroke.
Donate today at strokemn.org.
By Phil Gonzales, Public Awareness Associate

The Minnesota Stroke Association Strides for Stroke walk is returning in May to its in-person format! That means walking near other people.

**Outside.**

**In public!**

For the last two Strides for Stroke walks, we have held a Virtual Walk. People walked around their neighborhoods, playgrounds and yards and shared their experiences with us through photos and videos. Meanwhile, I’ve sat at my computer all morning intercepting those photos and videos and posting them on our social media sites. This worked out really well! People did participate!

But, I think we’re all ready to get back to the park, right? We like being outside, right?

Well, hold on to your hats because this year’s Strides for Stroke is going to be held on May 21 at 10 a.m. at Long Lake Regional Park in New Brighton. In Saint Cloud at CentraCare Plaza, and in Duluth at Miller Hill Mall. That’s three locations and three opportunities for you to put on your walking shoes and Stride for Stroke!

As we get closer to the big day, we’ll have more information available but you can go ahead and register and sign up your team today at strokemn.org. Just head to strokemn.org and get your team registered, join a team, or donate!

And, if you still want to participate virtually or you live out of state, there will be a virtual registration option at strokemn.org as well. We want this event to be accessible to everyone.

We’re so happy to have

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We can’t wait to see everyone on May 21 as we hit the trail for the 2022 Strides for Stroke!
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