Allina Health

ABBOTT NORTHWESTERN HOSPITAL
Neuroscience Institute

Grey Matters

Newsletter of Givens Brain Tumor Center

SUMMER 2022

IN THIS ISSUE

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Dr. John Trusheim

MEDICAL DIRECTOR

Hello! As I write this column, it is late May and we continue to have coolish weather and recent flooding in areas around the state of Minnesota from a long, cold winter. Here in Minnesota, we covet our summers so we can be at the cabin, or swim in the lake, or attend the many summer activities in our communities. We know how to celebrate summer!

This Grey Matters issue is once again overflowing with stories from our patients and interesting information from our neuroscience partners. Our research nurses describe the innovative clinical trials available for patients diagnosed with glioblastoma (GBM) and the Primary CNS Lymphoma (PCNSL) evaluative study started by our Advance Practice RN, Patti Bruns.

You will learn more about the neuropathologist, a specialized pathologist, and their critical role in the diagnosis of brain and spinal cord tumors which helps direct patient care. Take Dr. McDonald's neuropathology challenge! Dr. Wasilewski, our succeeding clinical Medical Director, and Dr. White from the Minnesota Epilepsy Group, educate us about seizures and brain tumors.

And we have so much more to share about nutrition and other community resources, such as CaringBridge, available to support you and your loved ones who are living with a brain or spinal cord tumor.

In addition to my own retirement this summer, we say "Good Luck in your Retirement" to our Social Worker, Margaret Callan, who has been with our clinic for 15 years. She will be leaving us the beginning of June.

As I prepare for retirement, I have been reflecting upon my years as a physician for 40 years as well as my role as a neuro-oncologist most of those years. Over that amount of time the treatment of brain tumors has progressed from a small group of individuals trying to adopt drugs or other therapies from other tumor types, through more targeted therapies, to immunotherapy development, and increasing refinement of distinguishing tumor types through molecular analysis.

All of these steps seem logical in retrospect, though at the time, each was a sort of breakthrough.

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Meet staff at the Givens Brain Tumor Center

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I am certain that the future of treatment and management of these most difficult tumors will continue to improve. Already we have more efficient and effective trials using adaptive statistical methods (such as the ongoing AGILE Trial) to more quickly and cost effectively find therapies, even if some drugs may only help a very targeted group of patients.

I am so proud of the multidisciplinary team which we have developed at the Givens Brain Tumor Center. We are looked upon as a model of patient care throughout the nation and consistently use methods and approaches generally reserved only for elite institutions.

All this has been accomplished in a relatively few years, with many more advancements in the wings. The Givens Center will remain at the forefront of these advancements.

I know we will achieve success as we continue the fight against brain tumors. Thank you for the privilege of helping to care for you and your loved ones.

Dr. John Trusheim

Welcome Dr. Wasilewski!

MEDICAL DIRECTOR, GIVENS BRAIN TUMOR CENTER

It has been an exciting first few months for me at the Givens Brain Tumor Center. The staff here are wonderful and it has been an incredible privilege to meet and care for so many of you. I want to acknowledge the retirement of Dr. Trusheim and commend him for the legacy he built and leaves behind. He will certainly be missed as he heads into his well-deserved retirement.

I look forward to continuing to provide the highest level of multidisciplinary, specialized care for all our patients with brain tumors and their caregivers. In the months to come I look forward to continuing to grow our research and clinical trials program while expanding the center to address additional conditions such as brain metastases and neurologic complications of cancer. There is so much to be excited for in the months to come!

On a personal note, I cannot wait to explore Minnesota in the summer and look forward to picnics on the lake and long walks in the many parks. I wish you all a happy and successful summer and hope that you enjoy all that this beautiful state has to offer. Remember to stay safe and apply your sunscreen!

Dr. Wasilewski

The Givens Family

Mike and Linda Givens

Mike Givens, who lost his battle with brain cancer in 2015, was a hero in every sense of the word. He and his wife, Linda, co-founded the 501(c)3 MG Charities, which held fundraising events around the country. Mike and Linda were self-made entrepreneurs in the Midwest and the driving force behind raising and donating over $10 million to charities around the country over the past 20+ years.

Since 2016, MG Charities has donated $1.85 million to the Givens Brain Tumor Center. Their annual Mind Over Matter charity golf event has been held at the Wayzata Country Club during previous summers, raising money to benefit brain cancer research and patients currently being treated for brain cancer. Mike's legacy lives on through the charity work that continues in his honor. Mike and Linda's daughter, Megan Givens Laatsch, continues their legacy of service as a member of the Abbott Northwestern Hospital Foundation.

Welcome to Gray Matters

Editor's Column

DEBORAH JONES,

LIFECOURSE CARE GUIDE

We are so excited for summer here in Minnesota. This summer edition is full of news and information with something valuable and helpful for each of you!

There are stories from 2 patients who describe the moment they learned about their brain tumor diagnosis and another who talks about her anniversary of surviving 5 years. We also have photos from a patient's family lake place in New Hampshire, which has been a very meaningful part of her life.

We feature an article about CaringBridge who is celebrating their 25th anniversary this year! Their beginning is a fortunate one and has served many of our patients and families during those years. More than 300,000 people use their private and ad-free platform every single day sharing health updates, rallying around loved ones, and offering and asking for support. Michael Bischoff, one of our patients and mentioned in the article, had a very active relationship with CaringBridge. When he was diagnosed with glioblastoma in 2017, one of his passions was encouraging patients and providers to share their stories, particularly in the health care setting. He was a key contributor in developing the CaringBridge "How We Heal" series, produced in collaboration with National Geographic photographer David McLain. Take a peek: https://www.caringbridge.org/resources/healing/.

And we are proud to share news about a new book, Reconnected: Stories from Spinal Cord Tumor Survivors. The book, by Dawn Standera, who collaborated with Kim Wallgren from the CERN Foundation and Kathy Kuhl from walktalkconnect.org, is a series of stories from spinal cord tumor survivors. Standera previously wrote her book ReWired: A Story of Recovery from Spinal Cord Tumor Surgery, in 2017, about her experience of diagnosis, treatment, and rehabilitation as a spinal cord tumor survivor. Kathy Kuhl, a patient at the Givens Brain Tumor Center, also a spinal cord tumor survivor, contributed her story to the book.

As I write this, our community within Allina Health and outside our doors is remembering the 2nd anniversary of the murder of George Floyd - May 25, 2020. It is Allina Health's continued commitment to be a steady presence in the communities we serve. We are learning more about how we can provide culturally-informed, equitable and welcoming care and employment to all.

And I want to recognize both Dr. John Trusheim and Margaret Callan, Social Worker, who are moving into retirement this summer. Their contributions and hard work creating and maintaining the excellent team who serves you and your loved ones will always be a part of the fabric of this brain and spinal cord tumor community. Thank you Dr. Trusheim and Margaret!

Please tell us what you want included in this newsletter. I would love to hear from you.

Stay safe and stay strong!

Deborah

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Staff Announcement

Good bye and thank you!

Dear Patients and Families,
June 3 was my last day as your Social Worker with Givens Brain Tumor Center. After 15 years of working with our remarkable team, I have decided to join my husband in retirement. It has been an honor to serve you, offering hope and support and hopefully helping along this journey. You are a courageous group and I will carry your stories with me.

Thank you for allowing me to be a part of your journey.

With Gratitude,

Margaret Callan
Social Worker, LSW, ACM

Patient stories

Noelle Kane

There is very little in my life I have control over

My name is Noelle and I am 27 years old. My husband, Elijah, and I got married the end of June 2019. 2020 began with my husband and I celebrating my birthday by staying at a local hotel in Qingdao, China. It was the beginning of Lunar New Year celebrations so the international school I worked at was on a two week break. After getting back to our apartment we received word that a virus was spreading in Wuhan and that if we are able to go back to our home country we should. So my husband and I boarded a plane a couple days later to America.

As the weeks turned into months, I went to see my primary doctor about some issues I was having with my right ear. This led to the discovery of a 7cm tumor on my right temporal lobe. While talking with my neurosurgeon I explained that I was having weird deja-vu, but not deja-vu type visual episodes, that started in November of 2019. I had no idea what they were and honestly thought I was going crazy. But then my surgeon told me that these episodes were actually temporal seizures. I was both relieved and concerned, since I had three of these episodes that very day.

Fortunately, I was able to have surgery to remove 95% of my tumor. I then completed 6 1/2 weeks of chemotherapy and radiation followed by another year and a half of chemotherapy. I am now finally done with treatment. However, my husband and I will not be returning to our home in China. Instead, we are adjusting back to life in America and seeing where God leads us. I am currently working at my church as the children's ministry director and my husband got a job working as a carpenter. I am so grateful to have been able to be surrounded by friends and family during such a challenging season in my life. During the last few years I have learned that there is very little in my life that I have control over. I have relied heavily on my faith in God to give me the strength to get through this.

Qingdao, China where Noelle and Elijah lived

Ollie Frost

Déjà vu?

My Name is Ollie Frost and I'm 45 years old, married to Farrah for 12 years, with an 8 year old son Charlie. In the Summer of 2020 I was joking with Farrah that I was experiencing déjà vu, music in the shower as an example, that I couldn't recall where I had heard before. I would walk past her saying "deja vu", and she would say "you should get that checked out" and of course I would dismiss it and go about my day.

When working from home during COVID and on zoom calls, I would get a minor shudder, which ultimately lead me to talk with my local doctor. She suggested an MRI as the shuddering could be seizures. 10 minutes after the MRI, I got a call from my doctor explaining the situation.

Later the surgeon explained it was a grade 2, possibly grade 3 astrocytoma and reasonably easy to work on as it's on the right side of my brain. I said, "I'm a lefty." He proceeded to explain that I may have made this a little more complicated! He did a fantastic job. I woke up from surgery with what I would consider no issues that could have been short or longer term due to the complexity of using that part of my brain.

Radiotherapy coupled with the chemo shrunk the remaining 15% to almost nothing, and the 12 cycles of continued monthly chemo has kept things at bay. We are now in the early stages of seeing how things go with no chemo and every 3 month MRI check-ups.

I continue to do what I love such as sailing and bike riding. I've been a sailor since I was young, competing nationally and moving into bigger boats in my early 20s for competitive offshore racing. Due to being part of a strong team, I won a number of sailing races and accolades. I am on the board of directors for Wayzata Sailing providing a voice in how to grow support and engagement in the local community whilst pushing the competitive edge for those kids that want to race locally and sometimes a little further afield. I believe sailing provides team spirit and personality traits such as confidence, independence, and rapid strategic thinking, which kids don't realize they have acquired until they get a little older.

I share my status on social media, typically after the check-ups and scans. I think people like to read and keep up to speed on how it's going. I have had a number of friends reach out telling me they have had medical challenges, some of the same level of concern, some less. Some even tell me that my stories or posts provide perspective and help them to lift themselves up.

I can either sit on the couch and worry about the future, or get up, stay active and continue what I believe will ultimately be seen as appreciated skills and support for the next generation. Although tough at times, I've ultimately chosen the latter.

Ollie sailing in J/22 fleet sailing regatta, Wayzata Yacht Club, Lake Minnetonka

Ollie's son Charlie sailing Opti

Patient stories

Jennifer D. Arbuckle, Survivor

5 Years – Really?

I fancy myself a writer of sorts and have shared a ton of stuff from my experiences with "Mulligan," my Oglioblast-o-matic brain boo boo (oligodendroglioma) and the resulting roller coaster ride of a lifetime! So, when I was asked to do something on my anniversary for the Grey Matters Newsletter, I loved the idea. You see, it seems brain and spinal cord tumors are serious business and when you toss in "cancer" the whole situation makes life a bit complicated. Maybe, that's why we so passionately celebrate the milestones as we come to them. I have tried but for some, my reaction takes me by surprise.

February 16, 2022 was the fifth anniversary of my going under the knife. Now, don't get me wrong, I count my blessings daily and have an enthusiasm for life that drives people nuts. This anniversary evoked the most bizarre feelings. Much like when Dr. Trusheim said, "no known active cancer", I struggled with "what now?" That sounds terrible, I know! I'm the luckiest duck on the planet to be alive and that's the truth. I don't think the human condition is meant to keep things that cut and dry though. Not mine anyway. I wanted to write this on the actual date of the surgery but found myself lost in a spiral, going neither up nor down. I was stuck to sort out why it felt so odd before I could ever form the words.

One of my worst struggles, as a 5 year survivor, is I sometimes feel as though my wheels are spinning as I go nowhere. That's when I take a step back. It's common for me to overthink things…everything…so I often have to look in a time machine, not the mirror, too see where I am or rather "who" I am five years after the weirdest day I hope to ever experience.

After considerable thought to understand why I didn't feel reason to celebrate, I realized the core of my problem. My expectations were completely out of whack. "Normal." That's what I expected with the "no known active cancer" and certainly after five years, it's the least I should get. What am I talking about? I had a chunk of brain taken out! There's nothing normal about that! "Normal" left with Mulligan.

In five short years, I've learned more about myself than I ever would have without my brain surgery and subsequent physical disability. Granted, I'd rather skip that part and be happy in my oblivion but I'm pretty sure that's not going to happen. So, one does what one can and learns which super powers to fine tune and which to accept as history. I fight acceptance and probably always will, but the past five years are worth celebrating as are all of the milestones for each warrior in this highly exclusive and far from "normal" club.

Ann B. Sidwell, MD

On Golden Pond

One year after a craniotomy for Glioblastoma Multiforme (GBM), Ann B. Sidwell, MD is able to return to Squam Lake in New Hampshire (featured in the movie On Golden Pond) to kayak. She has regained enough balance to do so, is wearing a life jacket in her boat due to seizure risk. Her shaved head holds an Optune device containing transducer arrays for ongoing treatment to her brain at least 85% of the time. She takes chemotherapy having followed a period of radiation therapy.

Dr. Sidwell's vocation was primary care for complex patients, adults and children with a variety of specialists, helping them focus on their healing goals and potential. To increase her ability to provide chronic care and end of life care, she recently completed a year long course in Community Hospice and Palliative Care -- only to discover the information is more helpful to her and the support groups she attends, as she has had to retire due to her own brain tumor.

Ann (front of canoe) with her cousin Mary, a retired speech pathologist, on Squam Lake, NH

For more patient stories and to see previous issues of our newsletter visit us online at **allinahealth.org/givens**

Neuropathology: Hidden from View, Vital to Care

By William McDonald, M.D.

Most professions have specialists whose integral role is unclear or even unknown to all but other insiders. In the theater, for instance, the artistic director plays an essential part in crafting a performance, but outside of the stage community, few people really understand that role. Nonetheless, the results of excellent artistic direction are enjoyed by the whole audience. In neurology and neurosurgery, a neuropathologist is such a specialist.

Neuropathology is the branch of pathology that specializes in diseases of the brain, spinal cord, muscles, and nerves. In the United States, neuropathologists are physicians, usually MD's or MD/PhD's, trained in laboratory methods and the biology of the human nervous system. We classify disease, determine prognosis, or predict response to therapy.

Pathologists have been called "doctor's doctors," since we work mostly with other physicians and health care providers, laboring behind the scenes so that others can focus on the bedside, examination room, or operating theater. If a surgeon is identified by scalpel and suture, or an internist by stethoscope and medications, then a pathologist is firmly associated with the microscope.

To see a microscopic slide of a brain tumor and experience a real-life problem in neuropathology, follow this link to a Neuropathology Challenge: **https://tinyurl.com/yeyumfub** or scan the QR code. The slide shows a sample prepared by smearing a small piece of brain tumor between two glass slides and staining the cells with a combination of hematoxylin and eosin (H&E). It is examined during neurosurgery in order to guide the neurosurgeon, and to prepare for additional informative testing. What do you see? What might you be able to tell the neurosurgeon about the tumor? Is it benign or malignant? (click the arrows in the menu bar of the path finder link for the answer!)

While the microscope remains an invaluable tool for pathologists today, exciting recent developments in testing technology, such as massive parallel sequencing of tumor DNA and DNA methylation profiling, are augmenting and improving our diagnoses. At the same time, new statistical tools--often referred to as machine learning--are helping to make sense of the mountains of data now generated. Neuropathology is at the forefront of this expansion of the diagnostic toolkit.

Neuropathologists also teach trainees, neurosurgeons, neurologists, radiologists, oncologists, and other pathologists the fundamentals of neuroscience, and disseminate important advancements in biology and medicine that impact neurological medicine.

Neuropathology is the interface between neuroscience and neurological medicine, the foundation upon which neurosurgical intervention is based, and the doorway to modern targeted therapy. A neuropathologist works offstage to translate recent advances in science into practical elements that optimize and direct patient care.

Neuro-Oncology Research

Allina Health's Neuroscience Research Department supports Neuro-Oncology research at Givens Brain Tumor Center. Through our current research, patients diagnosed with grade 4 astrocytoma/glioblastoma (GBM) have access to multiple cutting-edge radiotherapy, drug, and device treatment trials. Trials are aimed to treat patients with primary and recurrent brain tumors and are focused on individualized medicine protocols with adaptive platforms in order to bring our patient the most innovative treatments available.

Our current available clinical trials include:

- GBM AGILE (ClinicalTrials.gov Identifier: NCT03970447
- Denovo Biopharma DB102-01 (ClinicalTrials.gov Identifier: NCT03776071)
- TRIDENT EF-32 (ClinicalTrials.gov Identifier: NCT04471844)
- STaRT Registry (GammaTiles) (ClinicalTrials.gov Identifier: NCT0442738)

In addition to our clinical trials, sponsored through the pharmaceutical industry, Neuro-Oncology Research also supports investigator initiated research protocols developed by our clinic providers. Patti Bruns APRN, CNS has initiated an evaluative study of Primary Central Nervous System Lymphoma (PCNSL or Primary CNS Lymphoma). PCNSL is a highly aggressive form of cancer in the brain, which originates from the immune cells called B-cells or lymphocytes. PCNSL can also spread to the eyes or spinal cord thus careful monitoring is required. This rare type of cancer is most commonly, but not exclusively, diagnosed in people who have impaired immune system responses and can be very difficult to manage.

Our current approach to treatment at Givens Brian Tumor Center involves an initial biopsy by a neurosurgeon to provide a definitive diagnosis of the primary CNS lymphoma. Once the diagnosis is established, there are numerous medications dispensed on a strict in-patient schedule. There is also stringent monitoring of patients labs throughout the hospital stay.

This study includes a retrospective comparison of the available treatment modalities used in patients from Givens Brain Tumor Center against established national data to help further guide treatment options.

The research team consists of experienced research nurses, coordinators, a project manager, and regulatory specialists who work with our Abbott Northwestern team of specialists and technicians to provide whole-person care.

Neuro-oncology Community

Meet our Neuro-oncology Research Nurses

Kelsey Jackson, RN, BSN

SENIOR NURSE RESEARCHER

Kelsey is a Twin Cities local and grew up in Oakdale, Minnesota with a passion for sports and health care. She earned a Bachelor of Science in Nursing in 2016 at Bethel University and was drawn immediately into Neuroscience at Mercy Hospital. After two years of working in the neuroscience, trauma, and stroke unit, she was introduced to the field of nursing research at Abbott Northwestern and never looked back. Some of the things Kelsey loves most about Neuroscience Research are the innovative new drug and device treatments in clinical trials, coordinating clinical and operational aspects of patient care, and being able to share in the treatment journey with trial participants. When not at the Givens Center, Kelsey enjoys softball, where she plays first base for women's and co-ed teams. She is on the field year-round, and when not competing locally, she can usually be found planning her travels for their next national tournament, where she plays up to 13 games in a weekend!

Katrina Stremski, RN, PHN, MN, MA

NURSE RESEARCHER

Katrina Stremski joined Neuroscience Research in May 2021, transferring from Allina Home Care and Abbott Northwestern Neuroscience. Some of the things she loves most about being a nurse researcher are connecting with trial participants and assisting them in navigating their complex treatment journey with the latest medical advancements. Although she knew she wanted to work in health care at a young age, she found many other interests along the journey to becoming a nurse. She completed a Bachelor of Science in Kinesiology while working as a physical therapy aide, a Master of Organizational Management working in business operations and held a position in academia as an academic advisor to military students and families. While assisting her students in planning for civilian life, she was inspired to follow her calling to nursing school. Despite having a brand new baby, her husband and high school sweetheart Tony was in full support of moving from southern California to Minnesota to attend the Master of Nursing program at the University of Minnesota. After graduation, they loved it so much that they decided to stay. Katrina, Tony, and their two children Aurion (6), and Liam (3) are an active family. Together they love the outdoors, spending time with friends and family, testing out new activities, watching Tony's hurling (an Irish team sport) and hockey matches, and Irish dancing. At home you will find them curled up together reading endless books or in the garden.

Kelly Featherstone-Sood, RN, BSN, PHN

NURSE RESEARCHER

Kelly Featherstone-Sood, RN joined the Allina Health Neuroscience Research Department as a research nurse in December 2021. She works alongside Kelsey Jackson, RN and Katrina Stremski, RN in supporting clinical research at the Givens Brain Tumor Center. Before joining the research team, Kelly worked in the neuro-trauma unit at Mercy Hospital for 2 years. This is where she found a passion for working with patients affected by neurological conditions. She also has experience working as a float pool nurse at Unity Hospital and as an inpatient child and adolescent mental health nurse.

"While moving away from bedside nursing has been a big change, I am excited by the opportunity to build relationships with patients while helping them understand the clinical trials available to them. It is also rewarding to know that the data we gather through these clinical trials can help contribute to improved patient outcomes."

Kelly grew up in Blaine, MN. She completed her Associates Degree in Nursing at Anoka-Ramsey Community College in Coon Rapids, MN. She then began her career working as mental health registered nurse while finishing her Bachelor's Degree in Nursing at Metropolitan State University in St. Paul.

Kelly and her husband Erick just got married in October 2021. Together they enjoy traveling, cooking, playing board games, and spoiling their cat Luna.

Insurance Changes

Please call us at the Givens Brain Tumor Clinic to let us know if your insurance has changed or will change in the future! Thank you! 612-863-3732

Commonly Asked Questions about Seizures and Brain Tumors

by Andrea Wasilewski, MD

Many patients with brain tumors will experience a seizure during their course. For some patients, a seizure may have been the initial symptom that led to the diagnosis of their brain tumor. Whether a patient with a brain tumor will experience a seizure depends on multiple factors including the type of tumor (pathology), tumor location, and history of tumor treatments.

Most patients who have had a seizure in the setting of a brain tumor will be started on antiepileptic medications to help prevent further seizures. There are many available antiepileptic medications and some patients may require more than one medication to control their seizures.

It can be scary to witness a seizure. Knowing what to expect and what to do in the event of a seizure can be very helpful for patients and their caregivers. Here we address some commonly asked questions about seizures.

What is a seizure?

A seizure is sudden, uncontrolled electric disturbance of the brain.

What things can trigger seizures?

Seizures are more likely to occur if you have missed doses of your seizure medications. Other factors that can increase the risk of a seizure occurring include having an infection and poor sleep. Alcohol and certain medications may also increase seizure risk, so talk to your doctor before starting new medications.

My loved one is having a seizure. What should I do?

1. Never lift up a person who has fallen to the ground until you are certain that their neck is not injured.
2. Carefully reposition them to a safe area where they cannot harm themselves.
3. Roll the person gently onto their side to prevent aspiration.
4. If the ground is hard, place a soft object under their head (e.g. towel).
5. Note the length of the seizure on your watch or clock.
6. If the seizure lasts longer than 5 minutes, call 911 for further medical attention.

What should I be looking for when someone is having a seizure?

Observe the person and tell your doctor what the seizure looked like. Pay specific attention to the appearance of the eyes, face, and movements of the arms and legs.

The seizure stopped on its own. What should I do now?

Observe the person to ensure stable breathing and that they are waking up appropriately. Call your doctor immediately to let them know. They will be better able to assist you and can help determine if further medical attention is needed.

I had a seizure which stopped on its own but I sustained an injury. What should I do?

If you believe that you are injured as a result of your seizure you should seek medical attention. Call your doctor or 911 if immediate attention is required.

Are there driving restrictions if I've had a seizure?

Anyone who has had a seizure resulting in loss of consciousness or loss of awareness is legally not allowed to drive for 3 months from the time of their last seizure. Patients must report a seizure to the Minnesota Department of Vehicle Services within 30 days of the episode.

More Facts About Seizures and Brain Tumors

By James White, MD, Minnesota Epilepsy Group

Patient Story

Anna is a 24 year-old woman who was out for a run. She was enjoying her exercise until suddenly she felt a rising nauseated sensation in her stomach. This was a feeling that she had felt before, and the feeling frightened her. She stopped running immediately, hoping the feeling would stop.

She first noted this nauseated feeling two weeks prior to her run and the sensation had occurred four times. Initially, the feeling was not concerning with the symptoms being mild and brief. However, as the events continued, they seemed to be more intense. She had one episode that was very concerning to her. The nauseated feeling that occurred was followed by confusion and difficulty speaking for about 30 seconds. So, when she felt the rising nauseated sensation while running, she knew she needed to stop and see what was going to happen. Anna felt the sensation rising, the nausea became more intense. She felt like she was going to vomit. She then lost consciousness, collapsed to the ground and had a full body convulsive seizure.

Anna was taken to the emergency department. After approximately a half hour she recovered fully. Because of the seizure, she underwent an MRI of the brain. Anna was found to have a left temporal lobe brain tumor.

Important Patient And Family Questions About Seizures And Brain Tumors

Anna’s story is not uncommon. Patients with brain tumors have an increased chance of having seizures and needing antiseizure medications. Patients with brain tumors (and their families of course!) often have many questions about seizures and antiseizure medications. The following addresses some of the most important questions about seizures for patients with brain tumors:

What is a seizure?

A seizure is due to abnormal electricity coming from the brain. The brain works by having a normal flow of electricity between the cells in the brain called neurons. When a person speaks or moves their arms and legs, this activity is produced by a normal flow of electricity from the brain. If the flow of electricity is too high (like a power-surge), the brain function can be taken over by the abnormal electrical activity producing seizure activity. Imagine abnormally high electrical activity in the area of the brain that controls arm movements. You can understand that the high electrical activity could produce jerking movements which is how a seizure can present.

How do brain tumors cause seizures?

Brain tumors can cause disruption to the normal flow of electricity in the brain. Imagine a brain tumor pressing on the brain’s neurons. This can cause alteration in the normal flow of electricity which can produce seizures. One possible reason for the abnormal electrical charge brain tumors can cause chemical changes in the brain making electrical activity in the brain more active which can lead to the risk of seizure activity.

How many patients with brain tumors will have seizures?

Approximately 20-60% of patients with brain tumors will have seizures. Seizures may be the first symptom of a brain tumor in 20-30% of cases.

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What types of brain tumors are most likely to cause seizures?

Slower growing tumors are more likely to cause seizures than faster growing/more malignant tumors. Larger tumors are also more likely to cause seizures (although this is not a consistent finding).

What are the best ways to treat seizures related to brain tumors?

Antiseizure medications: Antiseizure medications are commonly prescribed for patients with brain tumors. When choosing the best antiseizure medication option, your providers will consider the following:

- It is preferable to have an antiseizure medication that does not take too long to get to a therapeutic dose.
- Also, it is very important to consider medications that are well tolerated from a side effect standpoint. Patients with brain tumors need to have good energy/not sedated, and good coordination. Choosing the best antiseizure medication from a side effect standpoint is important for the patient's quality of life.
- Another critical issue is drug interactions. Patients with brain tumors are often on chemotherapy or other treatments for their brain tumors. Some antiseizure medications can have significant drug interactions that reduce the effectiveness of chemotherapy. This is unacceptable in most cases! Fortunately, there are multiple antiseizure medications that do not reduce the effectiveness of chemotherapy.
- Some antiseizure medications that are often used in brain tumor patients:
    - Levetiracetam (Keppra)
    - Lacosamide (Vimpat)
    - Valproic acid (Depakote)
    - Pregabalin (Lyrica)

Surgery

Patients with brain tumors may undergo surgery with the goal to remove as much of the tumor as possible without causing injury such as speech impairment, loss of ability to move the arms or legs, or visual loss. The more of the tumor that is removed, the better control of the seizure. For many patients, if the tumor can be thoroughly removed, the seizures can be completely controlled.

Conclusions

Patients with brain tumors may experience seizure activity. Fortunately, antiseizure medications and surgery are usually very effective at controlling a patient's seizures.

After a cancer diagnosis, what should I eat?

By Heidi Ganzer DCN, RDN, CSO, LD, Clinical Oncology Dietitian

For many, eating is taken for granted, almost an afterthought. However, after a cancer diagnosis, nutrition comes to the forefront. Side effects from treatment may make it challenging to eat. Additionally, all of the information available about diet and cancer can be overwhelming. It might be difficult to know what to believe. Different sources may provide information about diet. Perhaps the information is different from one source to another. This might contribute to fear about eating "the wrong things". One of the main questions people ask oncology dietitians is "what should/shouldn't I eat" after a cancer diagnosis and/or during treatment?

To help answer this question, it is best to look at reputable evidence based resources, such as the American Institute for Cancer Research (www.aicr.org) or the American Cancer Society (www.cancer.org). Both recommend a plant-based diet focused on whole grains, beans and legumes, fruits and vegetables. These foods provide healthy complex carbohydrates, provide antioxidants and phytochemicals* (naturally found in food, think about eating the colors of the rainbow) and is anti-inflammatory. The guidelines also recommend maintaining a healthy weight, being physical activity, limiting red meat (beef, pork, lamb) and processed meat (bacon, sausage, ham, hot dogs, etc.), limiting sugar-sweetened beverages and processed foods (these are empty calories and tend to promote weight gain), and limiting alcohol. Detailed information about the guidelines is available on the AICR website, under "Blueprint to Beat Cancer".

In 2022, the American Cancer Society published "American Cancer Society nutrition and physical activity guideline for cancer survivors". It is a detailed report that provides evidence based guidelines for cancer survivors in general, but also specific to different types of cancer (Rock, C et al, CA Cancer J Clin 2022; 1-33).

A resource that addresses some of the most common questions surrounding cancer and nutrition is the Academy of Nutrition and Dietetics Oncology Nutrition Dietetic Practice Group (ON DPG). The website is available at www.oncologynutrition.org. At the home page, select "Eat Right to Fight Cancer", then "Healthy Nutrition Now" and "Food".

If exploring cookbooks, consider the AICR's "The New American Plate" and Rebecca Katz's "The Cancer Fighting Kitchen". Both incorporate the cancer prevention/survivorship guidelines into their recipes and both include information about the health benefit of the food that is within the recipes.

One additional (free) resource is the National Cancer Institute's "Support for People with Cancer. Eating Hints: Before, during and after Cancer Treatment. This resource is downloadable at https://www.cancer.gov/publications/patient-education/eating-hints. The booklet provides eating strategies for some of the most common side effects someone might have if undergoing treatment (i.e. poor appetite, fatigue, constipation or diarrhea, taste changes, sore mouth, etc.)

When information about the diet seems overwhelming, remember that food is a friend, not an enemy. Diet and lifestyle are some of the few things in life that we can control. Using reputable, evidence based resources will provide accurate information that you can have confidence in!

*For more information on phytochemicals and antioxidants, view the AICR "The Cancer Fighters in Your Food" pamphlet! To purchase: **https://store.aicr.org/collections/popular/products/the-cancer-fighters-in-your-food**. For more information: **https://www.aicr.org/cancer-prevention/food-facts/**

Help, Hope and Healing for Patients Through CaringBridge

With so much information to share and process after the diagnosis of a brain or spinal cord tumor, many Givens Brain Tumor Center patients and families have found in the nonprofit CaringBridge a safe online place for help, hope and healing.

Marking its 25th anniversary this year, CaringBridge is used by people on health journeys in all 50 states and every country in the world. But like the Givens Brain Tumor Center, CaringBridge is Minnesota-based. Sona Mehring of Eagan, a software engineer, launched the first website on June 7, 1997, to support friends whose daughter, Brighid, was born prematurely. Over time, "Caring for Brighid" became "CaringBridge."

Although so much in the world has changed since 1997, the need to communicate during a health crisis and draw family and friends close remains essential. And while nothing is simple during treatment for brain and spinal cord tumors, CaringBridge has been a simple way for many families to keep everyone connected.

Michael Bischoff of Minneapolis, a Givens Brain Tumor Center patient, wrote on CaringBridge over the nearly five years that he lived with glioblastoma multiforme. In addition to keeping everyone updated, Michael used CaringBridge to reflect on healing, even in the absence of cure.

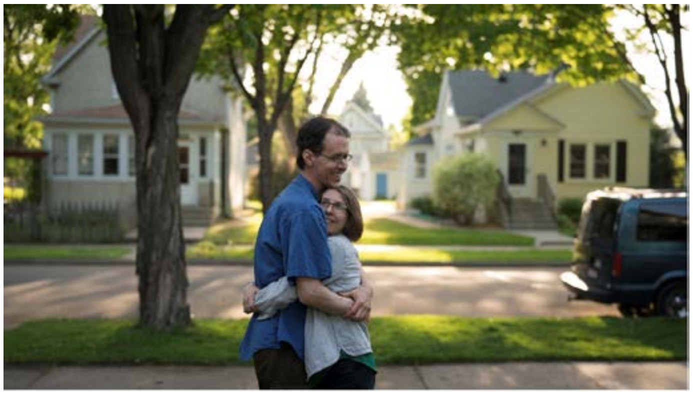
Michael pedaled everywhere on his bike, even to appointments at the Givens Brain Tumor Center. (Photo courtesy of CaringBridge).

He truly believed in the healing power of storytelling, and how it can give hope, and strength. "Even if I die tomorrow," Michael wrote, "I still want to celebrate miraculous healing today."

Hoping that his experience with brain cancer might help others, Michael worked closely with the CaringBridge team and National Geographic photographer David McLain beginning in 2017 to shape an ongoing project called How We Heal. His story is among a collection that has now grown to 50 explorations of the topic of healing.

Alongside Michael, Givens Brain Tumor Center director Dr. John Trusheim also participated in the How We Heal project. A recording of their 2018 heart-to-heart conversation on what it's like to have, and to treat brain cancer, has been viewed many thousands of times.

Michael has been gone since 2020, but his legacy is in believing that healing is always possible, and valuable, regardless of health outcome. His wish would be that you might believe this, too.

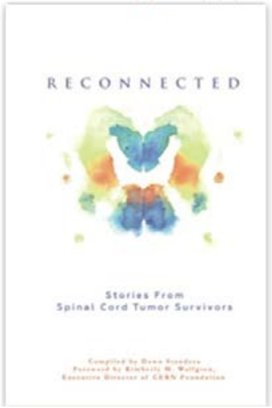


Michael Bischoff and his wife, Jenny Larson, outside their Minneapolis home. (Photo courtesy of CaringBridge)

Learn More Visit the How We Heal project at CaringBridge.org/healing. And watch the conversation between Dr. Trusheim and Michael Bischoff at https://www.caringbridge.org/resources/healing-story-session/

To Start A Caringbridge Site
Visit https://join.caringbridge.org/

Are you a Spinal Cord Tumor Survivor?



Or do you know someone who lives with or cares for someone living with a spinal cord tumor (SCT)? Then you already know that SCTs are rare, which makes connecting with others who are familiar with this condition a challenge. Reconnected: Stories from Spinal Cord Tumor Survivors, by Dawn Standera, is a compilation of stories of persons from all over the country and one outside the United States who are living with the effects of a spinal cord tumor. Dawn was herself diagnosed with a spinal cord tumor in 2017 and wrote the book, ReWired: A Story of Recovery from Spinal Cord Tumor Surgery, about the first year of her life after surgery.

Recently Dawn connected with the CERN Foundation (Ependymoma Cancer Research Network | CERN Foundation (cern-foundation.org), part of the National Brain Tumor Society, and a Givens Brain Tumor Center patient, Kathy Kuhl, co-creator of https://www.walktalkconnect.org, to gather stories for this book. The stories are detailed, personal, and shed light and reality on the complexity of a rare tumor in this sensitive and dangerous location in the body. The title, Reconnected, speaks to reconnecting the central nervous system and the body as people heal while also providing an idea of what life is really like after diagnosis and surgery. The stories each recognize the reality of the "moment" when lives are changed by this diagnosis. The book can be purchased at **www.amazon.com**.

Find support groups and resource information for patients and their loved ones on our website: **tinyurl.com/2pe8vcmj**

Or scan this QR code with your phone's camera to see the webpage.

Our Call to Action

It has been more than two years since the killing of George Floyd, which deeply impacted the Abbott Northwestern Hospital community and beyond. His death, and the after effects, happened during a time of uncertainty and isolation due to the COVID-19 pandemic.

Although the man who killed George Floyd has been held criminally responsible, we at Allina Health recognize that it takes continued commitment for meaningful change in our communities and within each other to happen over time. Allina Health is committed to continuing to advance our work with diversity, equity, inclusion and belonging and acknowledges that it continues to be an emotionally charged time in our communities and our nation.

We have made progress, and there is more work that needs to be done, to ensure we are delivering on our promise to provide an environment for ALL patients, employees and our communities that is physically and emotionally safe. Our goal is to weave the many faces of our communities into the fabric of Allina Health. As places of healing, we are focused on serving you, our patients, and your loved ones. Our diversity, equity, inclusion and belonging work is a high priority for Allina Health leadership to ensure we provide equitable health care, to help our employees' health and well-being, and to be a valued business partner and investor.

Givens Brain Tumor staff

John Trusheim, MD Neuro-Oncologist, Medical Director
Andrea Wasilewski, MD Neuro-Oncologist, Medical Director
Tankia Barnes Medical Assistant
Patti Bruns Clinical Nurse Specialist, MSN, APRN, CNS
Margaret Callan Social Worker, LSW, ACM
Megan Elia Nurse Navigator, RN, BSN
Lani Hoese Clinical Support Specialist
Karen Holmseth Nurse Navigator, RN, BSN
Deborah Jones Care Guide, MA
Emma Sacco Nurse Navigator, RN, BSN

PROTECT
ALL THE SKIN YOU'RE IN

U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention

Use a Layered Approach for **Sun Protection.**

Sunscreen works best when used with shade or clothes, and it must be re-applied every 2 hours and after swimming, sweating, or toweling off.

Use broad spectrum sunscreen with at least SPF 15 to protect exposed skin.

Wear a hat, sunglasses, and protective clothing to shield skin.

Seek shade, especially during midday hours.

CS277180

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