

# Grey Matters

Newsletter of Givens Brain Tumor Center

SUMMER 2023

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## Givens Brain Tumor Center

Allina Health Neuroscience,  
Spine and Pain Institute

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## Dr. Andrea Wasilewski Medical Director



Welcome to the summer edition of our Grey Matters newsletter! In this issue, we have an exciting lineup of topics to share with you, ranging from remarkable patient stories to groundbreaking research and initiatives. Let's dive in!

Firstly, we are thrilled to announce that Dr. Singh has been appointed as the Director of the Allina Health Neuroscience, Spine and Pain

Institute. With his extensive experience, he is set to lead our institute to new heights of excellence. His patient-centered approach and commitment to advancing medical knowledge will undoubtedly benefit our patients and our team.

In this newsletter, we are proud to feature interesting and brave stories from our patients. These individuals have overcome tremendous challenges along their brain tumor journeys. Their resilience and determination serve as a reminder of the human spirit's remarkable strength, and we hope their stories will inspire and energize you.

We are also excited to provide updates on our glioblastoma clinical trials. We are thrilled to announce the reopening and expansion of GBM AGILE, a groundbreaking international clinical trial for glioblastoma patients.

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This adaptive platform trial aims to accelerate the discovery of effective treatments for this aggressive form of brain cancer. This issue also shines a light on occupational therapy and its crucial role in rehabilitation.

We are excited to introduce our new section on lifestyle medicine, with a focus on understanding and optimizing sleep. Sleep is a fundamental aspect of overall well-being, and its impact on our health cannot be overstated. In this section, we delve into the importance of healthy sleep habits, explore common sleep disorders, and provide tips for achieving restful and restorative sleep.

As we bask in the summer sun (finally!), it is essential to prioritize our safety. In this issue, we provide you with valuable tips for enjoying outdoor activities while protecting yourself from the potential risks associated with excessive sun exposure. From sunblock recommendations to hydration strategies, we want to ensure that your summer adventures are safe, enjoyable, and memorable.

Lastly, we are thrilled to share the exciting news of the revitalization and renovation of the Abbott Northwestern Hospital campus. This ambitious project aims to enhance our facilities, expand our services, and provide an even better healthcare experience for our patients. We look forward to sharing updates on this revitalization journey in future newsletters.

We hope you find the content informative, inspiring, and engaging. Stay tuned for more exciting updates, groundbreaking research, and compelling stories as we continue our mission to provide the highest level of care for all of you!

Dr. Wasilewski



### **The Givens Family**

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 with involvement with the Allina Health Foundation.

# Editor's Column

## Editor's Column

### Deborah Jones, Care Guide



After a long, cold and very snowy winter, summer came in a hurry this year! The mosquitos came in droves and, in spite of those pesky critters and the early heat, we have been enjoying the shady trees and shrubs; the beautiful pink, purple, blue,

and yellow scented flowers; the activities, vacations and celebrations that summer brings; and anticipating delicious vegetables from our gardens and farmers' markets.

In addition to our stories and articles mentioned by Dr. Wasilewski, we have a new section called Caregiver Insights. Today we provide two different perspectives from caregivers caring for a spouse diagnosed with different types of brain tumors.

An article from Dr. Wasilewski shares the Givens Brain Tumor approach to team-based care. We are dedicated to communicating and collaborating together to ensure you are getting the comprehensive, whole person care you expect.

Our team has several touch points throughout the day including a daily and weekly huddle to review patient care, concerns, and treatment. There is also a multi-disciplinary touchpoint with our neuro-oncology partners every two weeks during our tumor conferences. Read her article to learn more.

The Abbott Northwestern Hospital campus has been active in the Minneapolis Phillips neighborhood community for more than 140 years! We are currently in the midst of our Revitalization project to transform our campus facilities to provide even more exceptional care for another 50 years! The Call to Action section of the newsletter tells more and explains "what is all the construction about?".

Enjoy your summer days and remember to stay hydrated and wear sunscreen!

We love hearing from you! Be Well! Stay Strong!

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## Stop guessing, start finding your way in our metro hospitals with our free Allina Health mobile app



Download the Allina Health app today from the [Apple App Store](#) for Apple devices or [Google Play](#) for Android devices and start using it to navigate to and while on our three metro hospital campuses.

# Welcome Dr. Singh

## Announcing Dr. Singh and the Neuroscience, Spine and Pain Institute



Sanjay Pratap Singh, MD, FAAN, FANA has joined the organization as President of the Allina Health Neuroscience, Spine and Pain Institute. Dr. Singh joins Allina Health from Creighton University School of Medicine, where he served as professor and chairman since 2010. He also served as Director of the Neurological Institute at CHI Health; Executive Medical Director of the Neuroscience Service Line at CHI Health; Director, CHI Health – Creighton University Epilepsy Center; and a member of the board of directors for the CHI Health Clinic.

Dr. Singh received his medical degree from MLN Medical College in Allahabad, U.P. India and completed residencies in Neurology at George Washington University in Washington, D.C. and Epilepsy & Clinical Neurophysiology at Yale University School of Medicine in New Haven, Conn.

### **What is the Allina Health Neuroscience, Spine and Pain Institute?**

Allina Health recently announced the creation of our Neuroscience, Spine and Pain Institute to provide fully integrated Whole Person Care across its care continuum. The investment in this new Institute further aligns, coordinates and builds upon the talent and resources of Allina Health's complement of providers and outstanding clinical programs, such as the Givens Brain Tumor Center, that enhances our ability to serve our patients' needs across the region.

We're fortunate to have some of the most talented clinicians, staff and programs providing care for our patients and communities in the region. Through the Institute we will deliver seamless neurologic/neurosurgical care across our geographic regions while creating focused sub-specialty programs at our metro hospitals with the most high-tech and specialized care based out of Abbott Northwestern Hospital. This will solidify our position as the provider of choice for neurosciences, spine and pain services in the Twin Cities and Upper Midwest.

Whether coming to us for emergent stroke care, complex brain or spinal cord tumor treatments, or comprehensive spine services, patients will receive care that is consistent with our Population Health commitment by providing the right evidence-based care at the right place at the right time.

### **How will this affect me as a patient of the Givens Brain Tumor Center?**

You will continue to receive the same excellent care you currently receive at the Givens Brain Tumor Center. In addition to our current resources, the Neuroscience, Spine and Pain Institute will be committed to discovering new knowledge in neuroscience, new treatments of neurological disorders and adopting new models of neurological care that expands across the care continuum. Our clinical programs will not just use the latest technologies and newer treatments, but we will create new treatments and new knowledge.

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# Staff Highlights

This new institute model will span the whole of the Allina Health system and provide the entire spectrum of neurological care. We will have the capability of using the entire spectrum of technologies and new knowledge for the care of our patients. This will span from new knowledge to preventing neurological disorders and promoting good neurological health, to providing the most advanced neurotherapeutics, to neurorestoration, to home care.

Our patients will have access to the most advanced neuroimaging technologies in the world. They will have access to an intraoperative MRI and the ROSA robot for advanced brain surgeries as well as the most advanced neurophysiological technologies including magnetoencephalography. Allina Health has some of the most advanced neurointerventional cath labs that include the use of artificial intelligence to aid in diagnosis of neurological disorders.

What will not change, is our exceptional multidisciplinary team's steadfast dedication to providing Whole Person Care to each of you, our patients, one person at a time.

## Emma Sacco, RN, BSN – Nurse Navigator



It has been my honor to know and be involved with the care of so many of you during my time with Givens since 2016.

As part of my Bachelor of Science in Nursing program, I spent a semester abroad in South Africa gaining experience with public health, psychology, and learning about the universal healthcare system. The bulk of my nursing background is rooted in oncology working inpatient at Mayo Clinic to begin my professional career.

Neuro-oncology has been my specialty since joining Abbott NW in 2009 with the oncology research team. Since that time I have also gained experience with Courage Kenny's Cancer Rehab program. Both specialties have been invaluable to bring to my role here within Givens.

Outside of work, I love spending time with my family going for walks, relaxing at the cabin, enjoying concerts, and baking (and eating!) treats.

I enjoy getting to know patients and their care circle, understanding their lives outside of our clinic visit, and encouraging them to live life to the highest degree.

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### Insurance Changes

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



# Team-Based Care

## Team-Based Care at the Givens Brain Tumor Center

### Andrea Wasilewski, MD

The Givens Brain Tumor Center has always strived to provide a coordinated, whole person care approach to our patients and their loved ones. Within this approach, team-based care is at the center of our treatment philosophy. Every member of our team plays a key role in providing the highest level of care for our patients.

Every week, our entire team (myself, advanced practice clinicians, nurse navigators, social worker, medical assistant, clinical support specialist, care guide, and research nurses) holds a weekly conference to review all scheduled patients for the week ahead. At the end of each clinic day, I meet with our advanced practice providers (Patti and Michelle) and nurse navigators (Emma, Karen and Megan) to review all patients seen that day and to determine the next steps in their treatment and care plans.

Michelle and Patti, our advanced practice providers, are closely involved in the management of every patient at the Givens Brain Tumor Center. Moving forward, we will continue to expand our team-based approach to care with rotating visits between myself and our advanced practice providers. This allows for all three of us to be involved in patient care, providing more comprehensive and seamless support, and allowing for additional perspectives for every patient.

When you see Patti or Michelle, you can be assured that I have been updated on your clinical status and have personally reviewed your imaging. Likewise, when you see me, they

are completely up to date on your condition and treatment plan.

Additionally, the entire neuro-oncology community, including Radiology, Neurosurgery, Radiation Oncology, and Pathology meet regularly to discuss patients in a multidisciplinary manner during our tumor conferences. This allows for input from multiple specialties to review and create personalized treatment plans for our patients.

At the Givens Brain Tumor Center, we are a dedicated, compassionate, and collaborative team who believe you deserve excellent, comprehensive care that meets your unique needs. We are proud to be able to provide this level of care to you, our patient, and your loved ones.



*Ram Person, by Molly Boyle*

# Patient Stories

## Wayne Quehl

**“Replace fear with trust and doubt with confidence.”**

*As told by Barb Quehl*



My 71-year-old husband, Wayne, was diagnosed with Glioblastoma in December of 2021 after having a seizure while driving. He drove the car into the edge of the garage and was

dumbfounded that he couldn't see it. After this incident, we learned that the peripheral vision on his left side was gone due to the location of the tumors on his right parietal side.

Subsequent biopsy confirmed our worst fears. We elected not to do resection surgery based upon the surgeon's advice to "just enjoy the time you have left." We sensed that in the long run, it would not add quality time to his life. After six weeks of radiation and temozolomide the tumor quickly grew, so, he started infusions of Avastin twice monthly, chemo 5 days a month, and started wearing the Optune device: arrays of electrical probes on his shaved head that, along with a hefty battery pack, always keeps him company. I think of this device as the "iron lung" stage of brain cancer treatment. Changing the arrays twice weekly, smelling the fumes that emanate from the four arrays, and hearing the beeps that tell you to fix something,

can be overwhelming at times. I have hope that somebody, somewhere in the world can come up with something a little less intrusive! But all in all, maybe these life altering additions have delayed the tumors' ability to devour even more of our normal life.

Right now, fatigue is constantly present, along with, of course, the cognitive challenges, social withdrawal, and the constant fear of seizures that occur about once a month, despite anti-epileptic medicines consumed multiple times a day. The seizures are usually hour-long events, with extreme cognitive dysfunction, "flashing lights", and loss of left side motor control. I give him emergency Ativan: the drug a hospital would give him anyway, and it gradually gets better, but we never know how much of "him" will return.

On a positive note, our medical care has been good, our insurance is adequate, there are knowledgeable staff at the brain cancer clinic in Minneapolis that will quickly return calls and take time to talk me away from the cliff. We are grateful for these things. Sympathetic neighbors who clear my snow clogged driveway, prayerful church friends, and present adult children complete the support picture.

But, no matter how helpful people wish to be, there is nothing that I have experienced that can compete with the fears of a brain tumor. So, we live day to day, trying to replace fear with trust and doubt with confidence. My love of 48 years is a trooper!

# Patient Stories

## Kelly Carley

### Family, kindness, and compassion



I've lived several places in my life, from Hell, Michigan to Madrid, Spain, but eventually settled in Minnesota. I returned to school later in life to become a medical technologist.

I started my career at HCMC where I met my husband TJ. Four years ago we moved with our dogs, Jazzy and Jojo, to 2.5 acres in Isanti.

Three years ago, I started experiencing daily bouts of painful nausea and vomiting. I had every GI test under the sun, nobody could figure out why this was happening. According to the GI folks, I was healthy as a horse. Then, suddenly one day, I couldn't read the words on my phone. Concerned about a stroke, my doctor ordered an MRI - the tumor was found.

A craniotomy followed with the only diagnosis I didn't want - stage 4 glioblastoma. Devastated, but determined to fight it, I joined every study I could. I'm a scientist by trade, so I value research and understand the importance of clinical trials.

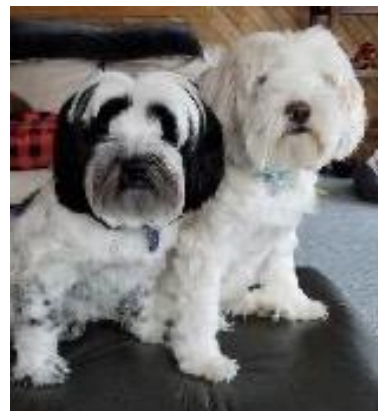
I have also made the decision to donate my body to the University of Minnesota. I had the privilege of observing an autopsy as a student

and was touched by the care provided to each donated body.

While I know I won't beat this disease, I do know that somebody eventually will. So, anything I can do to assist in the advancement of glioblastoma research I'm willing to do.

My days now are spent at home with my dogs, they love having their Mom home all the time. When the weather finally warms up, you'll find me barefoot in my yard, pulling weeds, watching birds and playing with the dogs.

The hardest part for me is realizing that I can't control this disease, I don't get to decide. This diagnosis has taught me that things, are just that. What matters most to me now: family, kindness, and compassion.



The people at Given's Brain Tumor Center have illustrated that kindness and compassion from the first day I arrived. They treat me like I'm their only patient and it means the world to me.

This diagnosis hits you like a truck, but these folks navigate the difficulties with such grace and professionalism, it makes it just a little easier.



# Patient Stories

## Karen Weber

**Accept help. Try not to worry.**



My name is Karen and I've lived in the St. Michael Albertville area for 35 years. When diagnosed with cancer, I was 59 years old and working full time as an Office

Manager. I'm married to Ivan, my hubby of 20 years. I have a son, daughter, son-in-law, and two smart and handsome grandsons.

The first sign of a medical issue was when I passed out at work on April 4, 2022. A brain scan showed some areas of concern, but it was too early to determine if it was serious. I was told to follow up in a month. April was pretty fuzzy for me. I couldn't drive and was too tired to work every day. Not a stellar employee!

In May, I had an MRI, which showed aggressive growth from April and a biopsy was performed, resulting in the diagnosis of Primary CNS Lymphoma, a form of brain cancer. I received a call from the neurologist on a Friday, and he already had an appointment set up with Dr. Wasilewski on the following Tuesday. Dr. Wasilewski calmly explained the treatment plan to me and my husband. I asked Dr. W if it was curable. She said yes, and I said, "then let's get started". I was admitted to Abbott and started treatment – 8 cycles of methotrexate, spread over 4 months. After several cycles, I had an MR. The lymphoma had shrunk considerably in a 2- month time span! It was fun to show family and friends the side-by-side images. Although the cancer wasn't completely gone, my cognitive and reasoning skills had drastically improved.

My husband arranged to have friends drive me to and from Abbott, which was great for catching up. It allowed my kids to take less time off work. A friend managed a Meal Train for us, which was a big help, both emotionally and financially.

My body tolerated the chemo well, and the lymphoma continued to shrink. My last chemo was in November 2022 with a follow-up MRI in January. What a happy day when we learned there was NO SIGN of cancer! A victory for the whole team!

As advice to others who are dealing with their own illness: accept help with meals, rides, gas cards, or whatever makes your journey easier. People find joy in helping! Now I'm determined to pay it forward. Try not to worry. Pray and be a good patient. Treatment can be expensive, inconvenient, and sometimes miserable, but hope and pray it is temporary.

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[Visit us online](#) for more patient stories and to see previous issues of our newsletter.

# Neuro-oncology Community

## Courage Kenny Cancer Rehabilitation Program and Brain Injury Clinic

**Mattie Anheluk, OTR/L**

**Joette Zola, OTR/L**



*Mattie Anheluk, OTR/L*

Occupational Therapy is one of the outpatient rehabilitation services available within the Courage Kenny Cancer Rehabilitation Program. Occupational therapists work as part of a team of rehabilitation providers including physical therapists, speech therapists, neuropsychologists, psychologists, Physical Medicine and Rehabilitation (PMR) doctors and nurse care navigators (See [Summer 2021](#) issue).

The role of the Occupational Therapist is often unclear to patients. Occupations are defined as “the everyday activities that people do as individuals, in families and within communities to occupy time and bring meaning and purpose to life.”

Acute medical diagnosis and challenges prompt a transition that impacts these life occupations. Having access to an Occupational Therapist can help you navigate these challenges with educational concepts to help individuals understand the barriers and guided reflection to explore and learn to use strategies to support the quality and consistency of life roles. Referrals focusing on cognitive rehabilitation are commonly made following neuropsychological consultation in which a person learns their unique strengths and areas of thinking that have been impacted. (See [Winter 2023](#) issue).



*Joette Zola, OTR/L*

Occupational therapy starts with an evaluation that includes a review of an individual’s prior levels of function, the strengths they bring to this experience as well as the challenges and / or changes they are navigating. The individual and therapist will explore how strengths can be leveraged to minimize the barriers that are impacting the life roles that are unique to their sense of purpose. Common factors such as fatigue, stress, physical changes or symptoms, distractions and multitask demands of tasks can impact a person’s confidence and abilities in daily life. Occupational Therapists can help individuals manage energy more consistently and intentionally, support their attention and memory and break overwhelming projects down into more achievable steps.

Referrals to Occupational Therapy can occur at different points in individual’s treatment including during the acute phase of interventions to years later. Timing is key; the Occupational Therapist often works in episodes of care that match the individual’s energy, needs and other priorities. It is important to understand and support individuals as they learn new strategies and develop new habits. Individuals often learn new skills; are discharged and return if they are facing new challenges or need support to get back on track. It is a privilege to support each unique person’s current goals in daily life through cognitive rehabilitation and life management strategies. If you are interested in an occupational therapy referral, please consider discussing this with your oncologist or PMR provider.

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# Neuro-oncology Community

In each phase of patient care, neuroradiology is the common entity. We highly value our role as consultants to our clinical and surgical colleagues and remain avid learners as the field of neuro-oncology continues to increase in complexity. This complexity necessitates a continued multidisciplinary approach using the collaborative efforts of highly trained specialists. This is where you will find neuroradiology at its best.

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## Neuro-oncology Research

**Marie Meyer, MA, CCC-SLP**  
**Manager, Neurosciences Research**



Our Neurosciences Research team collaborates with the Givens Brain Tumor Center and specialists across the Allina Health Neuroscience, Spine and Pain Institute to offer cutting-edge research and innovative clinical trials as a part of whole-person care that addresses the unique needs of each patient.

This spring, we were glad to expand enrollment in the GBM AGILE trial with the addition of several new treatment arms for patients with newly diagnosed and recurrent glioblastoma (GBM). GBM AGILE, an adaptive platform clinical trial, uses a model that allows for simultaneous evaluation of multiple investigational treatments. The intent is to lower the cost, time, and number of patients required to evaluate new potentially effective therapies for GBM faster and more

efficiently than ever before by enrolling more patients into treatments over control groups. (ClinicalTrials.gov Identifier: NCT03970447).

We continue to offer the TRIDENT EF-32 study for patients newly diagnosed with glioblastoma. This clinical trial is evaluating the safety and efficacy of Tumor Treating Fields (TTFields) delivered by the Optune® device paired with radiation therapy and temozolomide as compared to traditional chemotherapy and radiation followed by the Optune® device. Tumor Treating Fields (TTFields) are low-intensity wave-like electric fields, which interfere with the division of cancer cells. (ClinicalTrials.gov Identifier: NCT04471844).

This year, we look forward to expanding our clinical trial offerings to more patients with trials addressing additional types of brain tumors. Our dedicated team of research nurses and study coordinators are here to partner with you in your care and to help you access the latest treatment options available.

# Healthy Lifestyles to Promote Brain Health

In this and subsequent *Grey Matters* issues we will focus on healthy lifestyles to help promote good brain health, which is important for everyone.

## Sleep and Brain Health

Does this sound familiar? I didn't sleep well last night. I tossed and turned all night. I couldn't fall asleep. Once I fell asleep, I woke early and never went back to sleep.

Sleep is important for all body systems from the brain to our hearts and lungs to our emotions, our immune function and our ability to stave off illness and disease. Scientists believe that when we are sleeping our brain has time to clear harmful toxins and consolidate memories. When we have poor sleep hygiene, this can affect our blood pressure, our mood, diabetes, cardiovascular disease, and weight management.

What we know about the science of the brain and sleep is fascinating. Even when we are sleeping, our brain and body are very active. Certain areas of the brain are involved with interpreting light in our environment as it relates to our circadian rhythm and with managing hormones (melatonin) and chemicals (cortisol and serotonin) which control our sleep/wake cycles. Other areas send images, sounds and other sensations that fill our dreams. The stages of sleep, REM and non-REM sleep, and our biological clock work together to regulate our wakefulness and sleep.

How much sleep should I get? This varies greatly from one individual to another. Babies need the most sleep and school age children and teens need more sleep than adults. Most adults need 7-9 hours of sleep but as adults age their sleep tends to be shorter and lighter with multiple awakenings. Medications can also affect sleep.

Scientists are also learning that genes, or inherited sleep patterns, may have a role in how we sleep.

If you snore loudly or feel tired after a full night's sleep you may have a sleep disorder such as sleep apnea. Consult with your health care team who can help you determine next steps.

Review the Tips for Getting a Good Nights Sleep column for tips on improving your sleep.



Sunset, by Molly Boyle

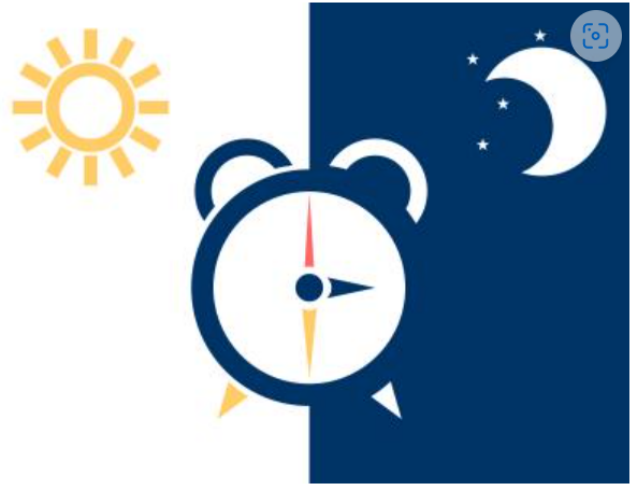


# Healthy Lifestyles to Promote Brain Health

## Tips for Getting a Good Night's Sleep

Getting enough sleep is good for your health. Here are a few tips to improve your sleep:

- Set a schedule – go to bed and wake up at the same time each day.
- Exercise 20 to 30 minutes a day but no later than a few hours before going to bed.
- Avoid caffeine and nicotine late in the day and alcoholic drinks before bed.
- Relax before bed – try a warm bath, reading, or another relaxing routine.
- Create a room for sleep – avoid bright lights and loud sounds, keep the room at a comfortable temperature, and don't watch TV or have a computer in your bedroom.
- Don't lie in bed awake. If you can't get to sleep, do something else, like reading or listening to music, until you feel tired.
- See a doctor if you have a problem sleeping or if you feel unusually tired during the day. Most sleep disorders can be treated effectively.



Source: [Brain Basics: Understanding Sleep | National Institute of Neurological Disorders and Stroke \(nih.gov\)](#).



*Como Path, by Molly Boyle*



*Boats at Harriet, by Molly Boyle*



# Caregiver Insights

The role of the caregiver is a vital, integral part of caring for our patients. Whether you are a wife or husband, friend or neighbor, son or daughter, cousin or grandchild, live far or near, we are grateful for you. We appreciate your dedication, commitment, courage, and ability to stay the course. We understand very well the importance and sacrifices of caregiving. On occasion we will run this column in the *Grey Matters* Newsletter that might include stories, ideas, or activities, and maybe a bit of humor; just for you, the caregiver! We hope this will encourage you to pause, take time to care for yourself, so you can continue to enjoy the experience of caring for your loved one.

Following are the stories of two caregivers who agreed to share their experience.

## Wayne and Barbara Quehl



In December of 2021, my 71-year-old husband, Wayne, was diagnosed with glioblastoma after driving the car into the edge of the garage while suffering a seizure. Since then, we have had a biopsy, radiation, many months of chemo, Avastin infusions and anti-epileptic drugs: the situation is currently “stable”, with extreme fatigue and cognitive challenges as an ongoing by product. As I think about my role as caregiver, time has certainly taken on new meaning! Here are my “ABC’s” about this journey:

**Blessings.** So many: encouraging family, attentive friends, kind neighbors, and thoughtful prayer chains, the list goes on. In our darkest moments, we try to focus on these blessings.

**Courage** What can we really change? When it all seems too much, I think: What resources are needed? Is it medical? A good friend? Spiritual counsel? The advice to myself: Be courageous and have the hard discussions with significant others. Painful, but it builds confidence. I am fortunate as my husband allows and understands these conversations.

**Grief** Sometimes I am grateful for grief. It makes me feel like I am *doing* something, but staying there too long isn’t a helpful habit. I give myself permission once in a while to just skip it, and, when possible, courageously peek into the future.

**Hope** I hope the treatments will continue their success in keeping the cancer as subdued as possible. I’m trying to foster trust in the many support resources: and also, confidence in myself to be able to continue this work.

**Knowledge** I have found that learning as much as possible can reduce stress but it can also be a nuisance. Google isn’t always a friend. I often ask: “why?” ... without clear answers: It’s a work in progress.

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# Caregiver Insights

**Strength** This super power needs to be renewed each day. To cope with these challenges, I walk and pray, learn and listen (also, whine once in a while), and have struggled to forgive myself for minor decisions that could have been better, but overall, surprising myself with newfound abilities.

**Trust** This is the continuous goal: overcoming fear with trust in the quality of the care being provided by everyone, trust in the future as it unfolds and in God's continued care.

**Uncertainty** I struggle with this one! I want to know what rougher patches are ahead. But as I ponder "what is the worst that can happen and how would I deal with it?", the fears become more manageable.

If you are new to this challenge or have been stumbling alone like me or even possibly succeeding beyond my imagination, I salute you! Together we are doing the collective hard work of caring, loving and letting go.

## Patricia and Tim Bride



My wife Patty had surgery to remove an anaplastic astrocytoma grade 3 in the pineal region of her brain in February 2014. There were complications following the surgery and she suffered brain damage resulting in multiple disabilities. Patty spent the next six months in hospitals and was allowed to return home in September 2014. We were trained on how to care for a disabled person by the Courage Kenny Center in Minneapolis. I have now been a caregiver for nine years.

The first few years were the most difficult as I had what I refer to as the trifecta - A full time job that included a daily 2-hour commute, two teenagers at home who were active in many pursuits and I was now a full time caregiver. I not only had two full-time jobs, but I had to do everything – Meals, shopping, getting the kids to and from activities and appointments, obtaining Patty's many prescriptions, getting her to multiple appointments, coordinating care providers to take care of her so I could work, navigating the health care system and a host of other duties. It was overwhelming.

As time went on things improved as we got more comprehensive home care from a hired caregiver and support from Patty's sister. The kids went off to college and I eventually retired meaning I was down to one full time job. My job as a caregiver requires that I be on duty 70 hours a week and although I don't have to work all 70 hours, I am needed intermittently meaning pretty much everything I do gets interrupted.

Patty has enough function in her body to do 20% of what is needed to live, the other 80% has to come from me.

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# Caregiver Insights

That includes getting her up in the morning, dressing, making breakfast, lunch, dinner, doing dishes, getting her through a daily one-hour workout, getting her to the bathroom 6-7 times a day, getting her down for naps, bathing, getting her to bed and various other duties. We own a home that requires considerable yard work through the spring, summer and fall. All of this has to be done while juggling her needs. Handling a disabled adult is a physical job and I have to keep myself in shape in order to handle her body and not become injured. My day doesn't end until she is in bed and this is a lifetime commitment.

We are mostly home-bound, I am able to get out 6 hours a week to get groceries and run errands with the help of our care provider Jane. I am able to get away to go see my dad, grandkids and other family members 2-3 times annually when Patty's sister comes and stays at the house and cares for Patty. To many, hearing about the life of a caregiver and the challenges detailed above would sound like a life of hardship with not much to look forward to each day. But it doesn't have to be that way.

I have many hobbies and interests that I am able to do from home. I am able to pursue my passions in life and I have a considerable amount of freedom to do so. Being retired from my career allows time for this and we feel fortunate that we have this luxury when many caregivers have to work to make a living. We have chosen to be positive, loving and to enjoy our situation. And I would highly recommend this to anyone in the position of a caregiver. Don't make a challenging situation worse by being irritable and negative. Make the most of your situation by creating a positive and fun existence for you and your loved one.



We featured some of Molly Boyle's photos in our Summer 2020 *Grey Matters* Newsletter – and we're excited to feature even more in this issue! Molly provides this brief bio about herself.

My name is Molly Boyle and I have been a patient first of Dr Trusheim's and now Dr Wasilewski's since my brain tumor surgery in 2006. My tumors and treatment have caused me to make many changes in my life but photography is one thing I have been able to keep. I have limited use of my right hand, so I use my iPhone now rather than a camera and sometimes I need someone else to push the shutter, but I still enjoy taking and editing pictures. Because I also have problems with my short-term memory, taking pictures also helps me remember some of the places I go and things I do.

# Summer Safety

## Wear Sunscreen & Insect Repellent

Use shade, wide-brimmed hats, clothing that covers, and broad-spectrum sunscreen with at least SPF 15 for sun protection.

Use insect repellent and wear long-sleeved shirts and long pants to prevent mosquito bites and ticks.



### TIPS

Apply sunscreen before insect repellent. After you come indoors, check your clothing, body, and pets for ticks. Reapply sunscreen after 2 hours and after swimming, sweating, or toweling off.

## Keep Cool in Extreme Heat

Extreme heat can be dangerous for everyone, but it may be especially dangerous for people with chronic medical conditions.



Stay cool.



Stay hydrated.



Stay informed.

## Givens Brain Tumor Staff

Andrea Wasilewski, MD - Neuro-Oncologist, Medical Director  
Tankia Barnes - Medical Assistant  
Patti Bruns – Clinical Nurse Specialist, MSN, APRN, CNS, OCN  
Megan Elia – Nurse Navigator, RN, BSN  
Lani Hoese – Clinical Support Specialist  
Karen Holmseth - Nurse Navigator, RN, BSN  
Deborah Jones – Care Guide, MA  
Becky Moore – Social Worker, LGSW  
Michelle Picconi – Nurse Practitioner, MSN-FNP, APRN, CNP  
Emma Sacco - Nurse Navigator, RN, BSN  
Brenda Wrenn – Clinical Support Specialist  
Meghan Peters, OTR/L - Manager, Clinical Operations and Program Development Allina Health Neuroscience, Spine, and Pain Institute

Find support groups and resource information for patients and their loved ones on our website: [tinyurl.com/2pe8vcmj](https://tinyurl.com/2pe8vcmj)

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





# Allina Health Call to Action

## Allina Health Abbott Northwestern Hospital

### ***Committed to improving our home in the Phillips neighborhood for the long run***

What is all the construction about on the Abbott Northwestern Hospital Campus?

Allina Health's multi-year infrastructure project at the Abbott Northwestern Hospital campus is underway. This work will help us transform our patient facilities and prepare us to provide care for the next 50 years in a neighborhood we've called home for more than 140 years.



In April 2021, we began building a new Central Utility Plant and a new parking facility called the Purple Ramp. The central utility plant replaces old, outdated equipment and technology to generate steam to heat and cool our buildings, sterilize 5 million surgical instruments per year and heat the Children's Hospital – Minneapolis Campus. We also need reliable power to provide 24/7 emergency, surgical and other medical services. Hospitals also need to be self-sustaining for up to four days in the event of a power outage.

About the same time, the Purple Parking Ramp (at 28th and Chicago) was built for parking for patients and employees. The designs enhance the safety and usability of Chicago Avenue and the sidewalk along the Greenway. It also reduces neighborhood congestion by getting more vehicles off the neighboring streets. This facility also provides electric vehicle charging stations and support for employees for multiple modes of commuting, like biking, ride sharing, and access to public transportation. Multiple trees and plants will be planted along the street and alongside the Greenway. A community solar garden will be installed on the roof in the fall 2023.

With completion of the central utility plant and the purple ramp, a Surgical and Critical Care Pavilion is now being constructed in the middle of the Abbott Northwestern Hospital Campus.

*continued on next page*

# Allina Health Call to Action

This will replace the hospital's existing operating rooms and old, inefficient buildings with a highly efficient building containing new operating rooms and spaces to treat patients requiring critical care. We have relied on operating rooms that were built during the mid-1900s when little technology was used and currently limits the types of procedures we can perform at ANW. Critical care spaces will also be built to support increased need, future technologies, and to support services for this high level of care.



*Concept drawing of a new Surgical and Critical Care Pavilion at 10th Avenue and Andersen Lane*

For more information, go to [Improvements and Updates for Abbott Northwestern Hospital](https://allinahealth.org/improvements-and-updates-for-abbott-northwestern-hospital) (allinahealth.org).



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