Grey Matters

Newsletter of Givens Brain Tumor Center

Allina Health
NEUROSCIENCE
SPINE & PAIN INSTITUTE

Winter 2025

Welcome

Dr. Andrea Wasilewski
Medical Director

As we close out the year, I am excited to share key updates and developments from our Neuro-Oncology team. From new staff members to innovative treatments, patient stories, and new programs, there's much to celebrate as we continue to improve care for those affected by brain and spinal cord tumors. Our team continues to expand, and we are excited to introduce new team members. We are thrilled to have these talented individuals join us!

Lehn Grube, RN brings her oncology expertise to support patient care.

Katie Brusnahan, LSW has joined our team as our Social Worker.

And we wish the best to **Patti Burns, MWN, APRN, CHS, OCN,** who after many years of exceptional service, has retired. We thank her for her dedication to our patients and countless contributions to our team. **Becky Moore, LICSW,** has transitioned to a therapeutic role, continuing to help patients with the emotional aspects of cancer care.

Our patients continue to inspire us every day and their stories in this issue have all inspired me. Juan Sanchez embodies resilience as he continues to fight brain cancer with hope and strength. Ginger Peterson is a reminder of the power of support networks and the importance of staying engaged in life. Tyler Swenson demonstrated extraordinary courage as he faces a life changing diagnosis. We also highlight the vital role our caregivers place in supporting patients. Their compassion and dedication are central to the healing journey. In this issue you will also find information on home care and companion services, designated to provide additional support to families.

Over the past year we have introduced a variety of new treatments for our patients. Dr. Hrachova will review intrathecal chemotherapy for treating leptomeningeal disease. This innovative therapy delivers chemotherapy directly to the cerebrospinal fluid,

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Givens Brain Tumor Center

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Dr. Wasilewski

increasing drug effectiveness in targeting cancer cells in the brain and spinal cord. We will also highlight vorasidenib (Voranigo), a new oral therapy, which as been FDA-approved for IDH-mutant gliomas. This targeted drug inhibits the IDH mutation, offering a new option for patients with these specific genetic changes and is a significant step forward in personalized brain cancer care.

We are incredibly proud to launch the Hedberg Survivorship Program, designed to provide multidisciplinary support to patients at all points of their cancer journey. This comprehensive program addresses the physical, emotional, and psychological needs of survivors, helping them thrive in life during and after cancer. Our Neuro-Oncology Survivorship Program is the first of its kind in the Midwest and we look forward to continuing to expand, develop and serve even more patients!

You will also hear from Marie Meyer from our research team who will discuss how we select clinical trials for our patients. These trials offer cutting-edge treatment options, and our clinical team ensures that patients are matched with the most appropriate trails for their needs. Additionally, we are sharing valuable insights into the role of nutrition and mental well-being in the healing process.

Lastly, a heartfelt thank you to our supporters for their generosity. Fundraisers like Humor to fight the Tumor, WalkTalkConnect, and the American Brain Tumor Association 5K help fund crucial research and patient programs. We are also grateful to our donors, who help us continue our relentless work in advancing neuro-oncologic care.

As always, I'm deeply thankful to our patients, families, and community. Together, we're making progress in the fight against brain and spinal cord tumors. Wishing you a happy and successful new year!

The Whole Way to Better

WELCOME to New Staff

Lehn Grube, RN, BSN

I grew up in northwestern Wisconsin and graduated from Viterbo University with my Bachelor of Science in Nursing. I started my 16-year nursing career on the Neuroscience floor at the University of Minnesota Hospital, and I still work casual there to this day. I really enjoy the neuro population and have a passion for patient care. I made the transition to patient education about 6 years ago and loved providing one-on-one individualized education to patients and their families who are going home from the hospital with complex cares. I provided education on stroke, central lines, tube feeding, tracheostomy, anti-coagulation, drains, etc. I truly feel that knowledge and education can help empower patients and their families. Since June, I have had the pleasure of being a part of the Givens Brain Tumor Clinic. I have been able to work an alongside incredible team to provide compassionate care to patients facing complex challenges. This group is so dedicated to their patients and want to enhance their experience, which is evident in their daily work.

A little about my personal life. I am married to my husband, Kyle, and we have 2 kids, son (7 years) and daughter (3). We also have a dog, cat, and a gecko (I would have more pets if my husband would let me). I enjoy gardening (growing pumpkins are my favorite), taking care of my indoor plants (I have 30+😊), reading, puzzling, being outdoors; camping, taking walks, playing with the kiddos, and playing volleyball.

Thank you for letting me be a part of your care team.

Katie Brusnahan, LSW, BSW

Hello all! I am excited and eager to learn and grow as a social worker here at the Given's Brain Tumor Clinic! I was born and raised in Milwaukee, Wisconsin and loved growing up on Lake Michigan. I have a large, blended family, and I have a 7-year-old sister, Lulu whom I adore and talk to everyday. I moved to Minnesota over 7 years ago to attend the University of St. Thomas where I majored in Justice and Peace studies and Social Work. During my time at St. Thomas, I worked with the Dakota Mdewakaton Indigenous tribe and worked on getting them federally recognized as part of my internship with Social Work and Justice and Peace Studies. I love learning, being outside, camping, traveling and reading books. On my days off you can find me adventuring by the Mississippi River or snuggling up with my two cats and reading a good book. I look forward to working here at Abbott and learning more about Neurology.

More Updates

Happy Retirement! Patti Bruns, MSN, CNS, OCN

Patti’s nursing career has always revolved around cancer care. She reflected that at the beginning, she remembers the Zofran clinical trial and when it was finally approved but cost each patient $98.00 per pill because it was not yet covered by insurance. Patti then went on to graduate from Seattle Pacific University with a Master of Science in Nursing with a focus in leadership and education. It was at that point where she was introduced to the world of neuro-oncology and found her true passion. Patti worked at the University of Minnesota from 2003 to 2009 with Dr. Trusheim and then came to Abbott, which she said she was referred to at the time as ‘The Big House Where Medicine is Made’ in 2010. All in all, Patti has worked 21 years in neuro-oncology and more than 30 years in oncology! Patti was someone who cared deeply for the patients she served. She took the time to get to know her patients and could rattle off the most minute details about them or people in their care circle. She was a champion for having serious illness conversations and went on to teach many providers this skill. She was able to have the hard conversations that many of us fear having because she knew that it was the best thing for the patient, and she could effectively deliver devastating news with grace, directness, and compassion.

We wish her the very best as she now shifts her focus to herself and new opportunities.

Congratulations! Becky Moore, LICSW

Becky will continue to be with Allina Health, however, she is moving on from the Givens Brain Tumor Center and Memory Clinic to begin her transition to the Mental Health Service Line as a Licensed Therapist. Becky has been a social worker at Allina for 5 years, first working on the inpatient side, and then with us in the Neuroscience Clinic. In our Neuroscience Clinic, Becky served the critical role of connecting our patients to necessary resources, performing numerous psychosocial assessments, restarting and co-facilitating our brain tumor support group, and always had the courage to have those hard conversations with patients and caregivers about hospice care and memory care.

We will missing having Becky as a co-worker. She always showed up with a positive attitude, we could count on her to make us laugh, and she helped foster a culture where everyone feels a sense of belonging. Fortunately, she will not be going too far as she will remain connected to the Neuroscience, Spine, and Pain Institute by being the therapist dedicated to seeing our patients.

Our Warmest Thank you to walktalkconnect.org

Kathy Kuhl, co founder of walktalkconnect.org presented the Givens Brain Tumor Team with a check for $4,000. These were proceeds were raised from the September 22nd, 2024 walktalkconnect event in Excelsior, MN. The fundraiser included a live music, a raffle, silent auction, catered food, and a 3 mile walk along Lake Minnetonka! [Why Walk? – WalkTalkConnect]

Kathy Kuhl from walktalkconnect donating a check to our clinic!

We are grateful to Kathy and her husband, Tom for the passion they have for connecting patients and their loved ones living with brain and spinal cord tumors.

Each event they host raises funding for programs, such as our new Hedberg Survivorship Program, that advances the "livability" for patients dealing with the effects of neurological tumors.

We appreciate the close relationship we have with organizations like walktalkconnect.org!

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.

Deborah Jones- Care Guide, MA

Reflections

Editor's Column

Our clinic has been reflecting on our accomplishments in the year 2024. It has been a busy and exciting year with new staff, increased patient load, the excitement of having new treatments to offer patients, the reintroduction of our support group, and the start-up of our Hedberg Survivorship Program.

As I reflect on the year 2024, I continue to be amazed by you. You are an incredible force that keeps you living, and me, inspired. When you are diagnosed with a serious, possibly life ending illness, you may feel like you are hanging onto the edge of a cliff. Where will this take me? What will I become? Finding a new purpose, or reshaping our purpose, can be daunting or even forgotten. Mary Radomski, PhD., shares in her article "Purpose when life is hard" that research has proven the importance of purpose which helps us to be stronger, more motivated, and provides us direction. Take the time to read her article and become inspired. Doesn't this apply to all of us, no matter our diagnosis or prognosis?

Maureen Doran, RDN, LDN, from the Penny George Institute for Health and Healing, encourages us to eat the rainbow! In her article, "Food for health and healing", she promotes having a diet rich in color which will make our food more interesting, lower the risk of chronic (long lasting) disease, give us less pain and inflammation in our bodies, aid in better digestion, and improved mood. When all your cells get the nutrients they need, your entire system is more in balance. Colorful whole plant foods give us super sources of proteins, carbohydrates, fiber, fats, vitamins and minerals.

Cindy Hokanson provided this beautiful photo of an old railroad bridge, and its reflecting pool, on a road to Hinckley, Minnesota.

Patient Stories

“Let Me Explain”

Juan Sanchez

I wish I could give you all the platitudes in the world about how strong us patients are, but that would be a lie. Or at least a stretch of the truth. My strength is, after all, the veil I'm hiding behind. There's no point pretending- I am absolutely terrified. From the moment I got that phone call that completely pulled the rug from under my feet, to now, five months later as of the time of writing this, this has always been in the back of my mind. Plus, it's literally on the back of my brain, ain't that funny?

Well, okay… My name is Juan. It's a Hispanic name because I was born and raised in Mexico, a Mexican citizen, and came to the US for school in 2011. One thing led to another, and I ended up living here as a naturalized citizen, married to my wife, Nicole. We went through a lot of **** in the immigration journey, so we thought we were done with difficulties, but life isn't quite that simple.

In the grand scheme of things, five months post-diagnosis is still fairly recent. I have not been part of this club-that-no one-wants-to-be-in for that long. I have always liked learning new things, though, and I for sure have learned a lot of stuff in the past few months after discovering that this entire world even existed.

I have had to adapt my life to this new reality quite a bit, and truthfully, I haven't always been the most composed about it. Actually… I haven't been composed at all. I had just been laid off one week before diagnosis and was in the middle of a job hunt when this began. This is the part that's tricky… It's a very common thing among patients to want to get back to “normal”, but what that looks like is not clear. Very few are able to return to how things were. For the rest of us, since returning is not an option, I'd say let's move forward instead! But that's a platitude, and I've made clear how I feel about those.

I made sure everyone in my life was aware of my tumor fight. After personally reaching out to a few people to notify them in person(ish), I made a public post about it on Facebook and let it spread on its own. I provided updates on the situation whenever I had them through posts on my wall and got a lot of positive reactions, online and from people I regularly see in real life. One thing that surprised me was the number of people who told me they enjoyed reading my posts because they were so well-explained. I tested the waters by writing a post about how radiation therapy works, explaining the process. It was very successful- a lot of people in real life told me and my wife that it was very well-written and explained for the layman.

I am a trainer by trade, so this is a skill for me: explaining complicated concepts to people in ways they can understand them. Seeing success, I created a new page called Let Me Explain on Facebook, where I regularly post updates on my experience or Explanation of the science behind what I'm undergoing. I hope you enjoy reading it if you decide to check it out. And if not, I hope you enjoyed reaching this bio!

“Brain tumors don’t stand a chance against Big Tex”

Tyler Swenson

In preparation of my second son Graham being born in June 2022, my wife, Anna, and I were getting his room ready which included painting the ceiling. A week later I started having issues with double vision that would come and go and I chalked it up to getting paint in my eyes and assumed it would fix itself. It eventually wouldn’t go away and got worse. After seeing an Ophthalmologist I was immediately sent to the ER for an MRI which revealed a brain tumor on my pineal gland. I was put in an ambulance and sent down to Mayo for surgery. The EMT’s wouldn’t turn on the lights for me, unfortunately! The next day, October 25th, 2022, I had surgery to biopsy the tumor which indicated it was germinoma. I was beyond relieved to hear that germinoma is very treatable with chemotherapy and radiation and does not like to spread. After five months of treatment, MRI scans all came back positive and I was cancer free.

Fast forward to April 2024 and I started having pain in my chest and back. It would come and go and eventually wouldn’t go away and got more painful. Over the course of a weekend, I went from having some tingling in my legs to not being able to walk without assistance. The germinoma ended up traveling down my spinal cord and found a new home in my thoracic spine. On May 1st,2024 I had surgery to remove most of the tumor, but a little stayed behind in my spinal cord. Good news again, germinoma is very treatable. After 5 weeks of radiation, MRI scans indicate the treatment was successful.

The nerve damage from the tumor still affects the strength and coordination in my legs, but with physical therapy I’ve made huge strides. I’m now able to walk without assistance, ride a bike, golf, and even jog. Thanks to Dan and Beth at Courage Kenny Golden Valley for supporting and pushing me when I needed it.

It’s been a journey, but I always knew this isn’t how things were supposed to end for me. By boys, Graham who is 2, and Bennett who is 5, have been my inspiration every day to get up and keep going. I dreaded going to PT, but I knew it was what I needed to get better, so I can chase after those two balls of energy like they need me to.

I am so thankful for the care I received from Dr. Wasilewski and the team at Givens. They’ve taken their time with me, listened intently, treated me like a person and really care about what’s going on in my life. They have made this experience bearable which is so appreciated.

I wouldn’t have been able to do this without the unwavering support of my wife and our tight network of friends and family in the area. When I started radiation treatment for the brain tumor it was scheduled every day Monday-Friday for 5 weeks. I couldn’t drive due to the double vision I was still experiencing, and Anna had to work so she couldn’t take me every day. She put together a Google spreadsheet and sent it out to the friend group to sign up for days to take me to Abbott for treatment. All 5 weeks were filled up that same day.

I’m incredibly grateful for my favorable prognosis, medical team and care, and support system through all of this. I’m looking forward to living the rest of my life to its fullest and never taking a day for granted.

“Anna had a banner made for me that says “Brain tumors don’t’ stand a chance against Big Tex” We lived in Texas for 5 years after college so our friends all call me Big Tex now

Ginger Peterson

“...connecting with other brain tumor patients made the journey possible”

On the Greek Island of Chios with my friend Lynn, wearing my decorative eye patch.

When I was asked if I would tell my story, I was wondering how far back I should go, and would the length of ‘War and Peace’ be appropriate? I had lived 55 years before I was diagnosed with a right sphenoid meningioma in 2002. The math was simple 55+22= 77. I grew up in South Minneapolis where I went to school and graduated from the University of Minnesota.

I spent my working years in Incentive Travel, living in England, and teaching. I taught High School social studies, was a media specialist, Athletic Director, and coached high school tennis, basketball, downhill skiing and softball.

I learned about my brain tumor when I visited one of my best buddies, for lunch, who worked in neuroscience at Abbott. I mentioned I was having ringing in my ears and wondered if she could hear it. She didn’t, she knew one of the audiologists, so off we went to check it out. No hearing loss, but I should see her ENT friend. Northing wrong there either. However, as we were walking out of his office, the audiologist said to me “If you were my sister, I would tell you to get an MRI.”

Ten days after the MRI, I got a phone call, just as I was leaving for work, informing me that I had a brain tumor. When my hands quit shaking, I called my friend at Abbott Neuroscience and said, “HELP!” She told me to make an appointment with one of the neurosurgeons at Neurosurgical Associates. Five days later, on June 11th, 2002, I was having my head cut open and my forehead removed along with the tumor. They did put my forehead back along with two pinwheels and a titanium plate. As I was just about conscious in the ICU, I heard the nurse say, “Ginger, you’ve died and gone to hell.” Well, the nurse was a good friend of mine! After three days in the hospital, I was sure they were never going to send me home because I couldn’t keep any food down. Finally, another friend (I’m popular) brought me White Castle and I was finally sent home.

When I went back to Neurosurgical Associates to have my staples removed, -I can still hear them being dropped in the stainless-steel pan- I asked why my right eye couldn’t open. It seems that the tumor was on my optic nerve and two of the nerves had been cut. My eye did eventually open part way, but I had permanent diplopia. That’s the Greek word for double vision. When I asked about going back to work, they said, “You’ve just had major brain surgery.” It never happened and my teaching and coaching career was over. My new wardrobe accessory became an eye patch.

Fast forward a few years and the next unwanted phone call was “you’ve got ovarian cancer.” This time I had a robot operating on me and I had chemo and radiation. This time with my hair gone I looked like Elmer Fudd. Intellectually I was OK after having gone through the emotional aftermath of having a brain tumor.

Reflecting back, I was connecting with other brain tumor patients that made the journey possible. I will never forget them. You can read more about this and my story on page 23.

Neuro-oncology News

Dr. Maya Hrachova

What is Leptomeningeal Metastases Treatment

Leptomeningeal metastases (LM) occur when cancer spreads to the thin layers of tissue surrounding the brain and spinal cord, known as the meninges. LM is also called:

- Leptomeningeal disease
- Leptomeningeal carcinomatosis
- Neoplastic meningitis
- Meningeal carcinomatosis

Cancer cells can reach the meninges through the bloodstream from a primary tumor or a metastatic lesion in the brain. While LM is relatively rare, it happens in 5-10% of patients, especially in those with cancers like breast cancer, lung cancer, or melanoma.

Signs and Symptoms

LM can cause many symptoms, which may sometimes be mistaken for side effects of cancer treatments like chemotherapy or radiation. Common symptoms include:

- Headaches
- Vision changes
- Weakness
- Confusion imbalance or dizziness
- Hearing changes
- Lower back pain
- Seizures, nausea, and vomiting

Treatment Goals

Treatment for LM focuses on improving symptoms, quality of life, and prolonging survival. Options vary depending on factors such as overall health, the extent of disease in the brain and spinal cord, and the type of cancer.

Studies show that combining systemic therapy (like chemotherapy that works throughout the body) with intrathecal therapy (where medication is delivered directly into the fluid around the brain and spinal cord) can lead to better outcomes.

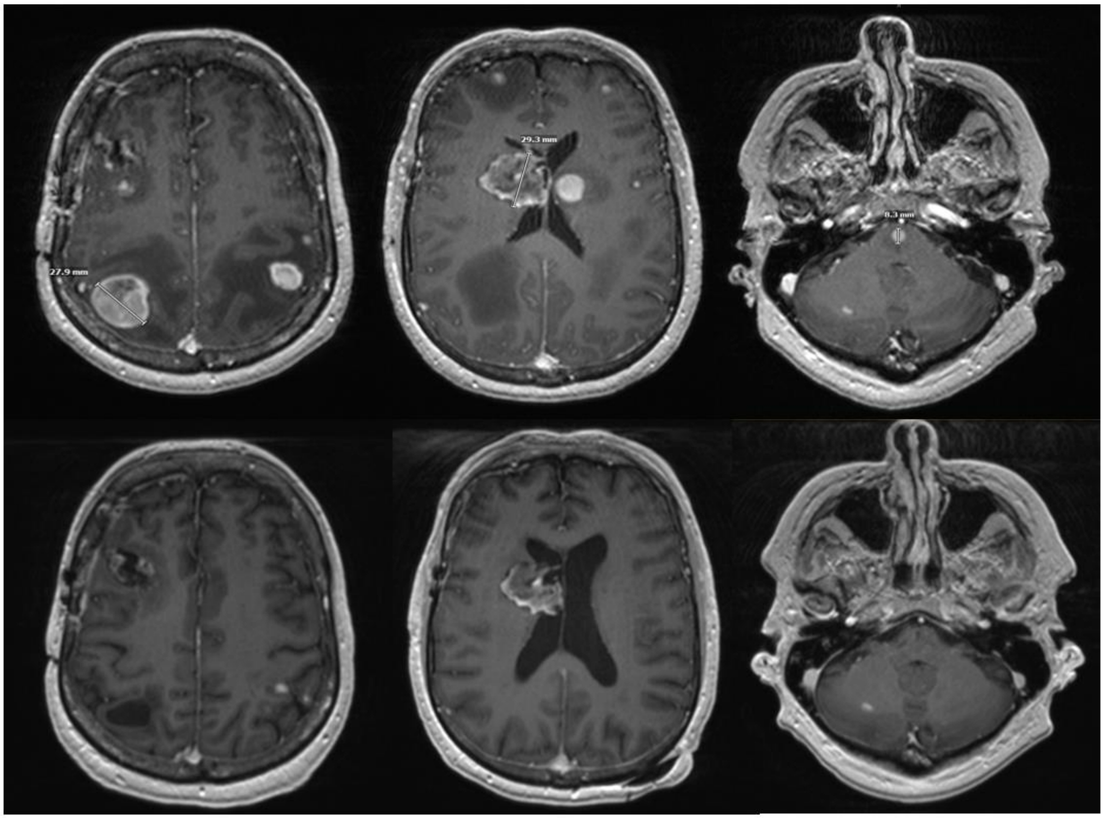
Continued on next page

Advanced Treatment at Givens Brain Tumor Center

At the Givens Brain Tumor Center, we're excited to offer advanced treatments for patients with leptomeningeal disease, including

- Conventional intrathecal chemotherapy
- Advanced intrathecal therapy including immunotherapy and targeted therapy.

Access to advanced chemotherapy options could result in significant improvement. For example, a patient with metastatic melanoma was treated with intrathecal immunotherapy (nivolumab) and systemic therapy (dabrafenib/trametinib). Six weeks later, imaging showed significant improvement in both brain and leptomeningeal disease.



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10.14.2024

Moving Forward Together

We are committed to providing cutting-edge care to improve outcomes for patients with LM. If you'd like to learn more about these treatments or explore your options, please contact our team at the Givens Brain Tumor Center.

Neuro-oncology News

Dr. Andrea Wasilewski, Medical Director

Vorasidenib

Patients with IDH-mutant, low grade astrocytoma and oligodendroglioma have historically had limited treatment options and limited access to clinical trials. These patients tend to be younger in age (20-40s) with slower growing tumors that require interventions during the prime years of their lives. Typically, these tumors are treated with surgery, radiation and/or chemotherapy which carry risks to cognition, memory, fertility and the ability to continue working.

Over the past decade extensive research has discovered that a mutation in a gene called IDH which is present in these tumors, is a key driver of tumor growth. Drugs have been developed and tested that target this tumor mutation and have been shown to slow tumor growth and in some cases even reduce tumor size.

In August 2024, the FDA approved vorasidenib (Voranigo), a once daily oral medication that penetrates the brain and targets the IDH-1 and IDH-2 gene mutations in grade 2 astrocytoma or oligodendroglioma. Vorasidenib is approved for patients who have had at least 1 prior surgery. The treatment is approved for patients aged 12 or older. In a large, randomized study that was published in the New England Journal of Medicine, vorasidenib slowed tumor growth and delayed the time for next treatment (such as surgery, radiation, chemotherapy).

Because vorasidenib is a targeted therapy, it acts only on cells with an IDH-mutation and specifically targets tumor cells. This also means that side effects from treatment are generally mild, and the medication is well tolerated because no other cells in the body carry this mutation.

I am very excited to bring this new treatment to our patients at the Givens Brain Tumor Center and add another tool to our neuro-oncology toolbox! With the addition of vorasidenib patients have more treatment options that can help them live better and longer.

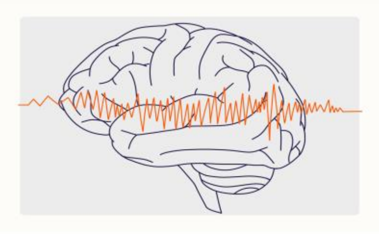
Introducing the Hedberg Survivorship Program

In July, 2024, the Givens Brain and Spinal Cord Tumor Center was gifted with funds from the Jeremy Hedberg family which has allowed us to begin the Hedberg Survivorship Program!! We are very proud to be able to offer this unique program for our patients and their loved ones. There are only a few other neuro-oncology clinics offering this type of program in the Midwest. Since July 2024, we have had monthly survivorship clinic days which have been a great success. Below is more detailed information, how to contact us to learn more, and a few comments from those who have participated in this new program!

- Dr. Andrea Wasilewski

> **"I found the experience very valuable; I felt I had a plan to move forward with as I continue to struggle in certain areas since my diagnosis and treatment 9 years ago. I highly recommend the program!!" ~Kathy K.**

> **"There are several providers who meet individually with us on that day, they talk with each other and come up with a plan." ~ Tyler and Anna S.**



> **"It was useful. The conference gave me a lot of information. It met my needs." ~ Juan C.**

A survivor is anyone living with a brain or spinal cord tumor, during, or after active treatment. Survivorship begins at the point of diagnosis and continues until end of life. A team of interdisciplinary providers, focused on the health, quality of life, and well-being of persons living with brain or spinal cord tumors; meet, for about three hours, with you and your caregiver, at the Givens Brain Tumor Center. Interdisciplinary providers include neuro-oncology, psychology, physical medicine and rehabilitation, nutrition, integrative medicine, and social work. A detailed plan is given to you after the visit ends, that contains a summary of your treatment plan and recommendations for follow-up care.

We would love to answer your questions. Please contact the Givens Brain and Spinal Cord Tumor Center at 612-863-3732 for more information.

Neuro-Oncology Research

Marie Meyer, MA, CCC-SLP
Manager Clinical Research, Allina Health

How are clinical trials conducted? How do we select clinical trials to bring to our clinic?

Allina health is dedicated to staying on the cutting edge of cancer research. Promising new treatments and therapies are studied in clinical trials; this is how medical innovations are evaluated for safety and effectiveness before widespread use. Patients have asked how we review and select clinical trials to bring to our center.

Clinical trials are conducted in a series of phases. Each phase has a different purpose and helps researchers answer different questions.

- **Phase I trials** study a potential treatment in a small group of people. This is the first time the treatment is tested in people. The purpose is to study the treatment's safety, determine a safe dosage, and identify serious side effects.
- **Phase II trials** study the new treatment in more people (100-300) with a specific condition to determine its effectiveness and continue to monitor its safety.
- **Phase III trials** give the new drug or treatment to large groups of people (1,000-3,000) to confirm the effectiveness, monitor side effects, compare it with standard or similar treatments, and collect information that will allow the new drug or treatment to be used safely. Once completed, the treatment may be approved by regulatory agencies (the FDA in the United States)
- **Phase IV trials** occur after a drug is approved by regulatory agencies and made available to the public. Researchers track its safety in the general population, seeking more information about a drug or treatment's benefits, and optimal use.

Aligning with Givens Brain Tumor Center's mission to provide world-class coordinated, whole person care for patients with brain cancer, our research program is focused on phase II and III clinical trails. Our Medical Director evaluates promising clinical trials and closely reviews the protocol, the detailed plan of the trial, to ensure it offers potential benefit to our patients and has sound scientific background in preliminary study.

After selecting a clinical trial, our neuro-oncologists present the protocol for review by the Allina Health Neuroscience, Spine & Pain Institutes Scientific Protocol Review and Management Committee (SPRMC). The members of this committee are specialized neurologists and neurosurgeons experienced in conducting clinical trials. The purpose of the SPRMC is to ensure that all clinical trials have scientific merit, meet with scientific priorities of our center, have protocols that are logistically feasible, meet the needs of or patient population, and demonstrate reasonable progress once opened for enrollment.

Finally, before bringing the investigational treatment to our patients, the clinical trial is reviewed and approved by our Institutional Review Board (IRB). IRBs ensure that appropriate steps are taken to protect the rights and welfare of humans participating in research. This process creates a safe, responsible and successful research program at our center.

Purpose When Life is Hard

Mary Vining Radomski, PhD, OTR/L
Senior Scientific Adviser
Courage Kenny Research

At some point in life, most people hit a speedbump or face an unexpected detour that forces them to grapple with the Big Questions: *Who am I now? How do I live a life that matters in the circumstances I find myself?* A new diagnosis or a new care partner role are among the many circumstances that upend our business-as-usual lives. I appreciate the importance of these questions because I study purpose in life renewal (the Compass Course) at Allina Health and blog about the topic on a website I created.

Purpose in life refers to having goals that motivate a person's daily pursuits, decisions, and resource use. It also provides a sense of meaning and direction. Beyond the vibrancy that this infuses into our daily lives, having a purpose is important to our health.

Results from studies of adulthood demonstrate that having a sense of purpose is associated with longevity, maintaining cognition and functioning, resilience, hope, and life satisfaction, as we age.

People experience their lives as purpose-full when 1) they figure out what makes them tick (that is, their inner compass – values, strengths, and sources of meaning), and 2) use that self-knowledge to make choices in everyday life that align with their larger life aims. Doing this might sound easy but it's not. Sometimes these efforts feel like too much- especially when a person is in the midst of significant health or life transitions.

Dr. Viktor Fankl proposed that even in these difficult circumstances, it is possible to live with purpose and meaning. He was a neurologist and Holocaust survivor who wrote an important book on his concentration camp experiences entitled, *Man's Search for Meaning*. In it, he suggested that people find meaning and purpose in 3 human endeavors: what they do or accomplish; the experiences they savor; and the attitudes they choose to embody. I love Dr. Frankl's contention that living with purpose involves more than what we do; purpose can also be lived out as we choose to savor beauty, nature and love and choose the attitudes that guide our countenance and behavior. Here's how he described these fundamental choices:

> *"We who lived in concentration camps can remember who walked through the huts comforting others, giving away their last piece of bread. They may have been few in number but they offer sufficient proof that everything can be taken from a man but one thing: the last of the human freedoms- to choose one's attitude in any given set of circumstances, to choose one's own way."*

Many of our study participants with cancer, long haul COVID, and persistent symptoms from concussion demonstrate Dr. Frankl's point. Even though they continues to have symptoms and unclear future, research participants revitalized their sense of purpose by embracing the richness of their existing everyday experiences and by choosing their attitudes. For example, participants told us that they had reinvested in self-care; reframed bathing their children as moments of connection rather than chores to rush through; walked a little slower to pay attention to beauty all around them; cherished the interactions with others at a boring day; chose to say kind words to strangers even though the rest of their day was utterly unmanageable.

Continued on next page

These choices are available to all of us. If we want to live a purposeful life during times of challenge and uncertainty, we begin by reminding ourselves of what really matters to us, shifting our lens to notice and savor the rich experiences that are already present, and setting intentions to adopt attitudes that embody our deepest values. This is more than enough for now; we can save action plans around bigger life aims for another day.

Contact Mary or continue to explore options:
mary@choosingpurpose.com
https://www.choosingpurpose.com/
https://www.compasscourse.net

Food for Health and Healing

By Maureen Rose Doran, RDN, LDN

The way you feed yourself has a profound impact on how you heal, and how you feel.

The foods you eat provide your body with nutrients. Food can also help support healing by connecting with others, with the seasons and the earth, with your culture, your values, your spirituality, and with your own body's needs.

How it can help

The goal of optimal nutrition is to help you feel better, enjoy your food, support your energy, and focus so you can do all the things you love to do! A whole food, plant forward eating plan is associated with lower risk of chronic (long-lasting) disease, less pain and inflammation, better digestion, and improved mood. When all your cells get the nutrients they need, your entire system is more in balance.

What are whole and plant foods

Whole foods are foods that are lightly processed or unprocessed and contain most of their nutrients and fiber. Plant foods are vegetables, fruits, nuts, seeds, beans, lentils, olives, root vegetables, whole grains, and herbs and spices.

Highly processed foods often contain artificial colors, preservatives, white flours, and added sugars. They often have less fiber and nutrients. When you eat too many processed foods it can lead to more inflammation, and blood glucose swings. Eating excess processed foods may even lead to negative moods. When you eat more whole foods and plants you naturally reduce the amount of highly processed foods you eat.

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Eat mostly plants

Look for colorful fruits and vegetables. Here are some examples of foods that would be beneficial: avocados, beans and legumes, berries, corn, herbs, and spices, leafy greens, lentils, nuts, olives, root vegetables, seeds, whole grains, and healthy fats. Healthy fats include olives and olive oil, avocados or avocado oil, nuts, seeds, and fatty fish such as salmon, tuna, sardine, herring, halibut or walleye.

You can find plant foods in many places. At the grocery store in the fresh, frozen, or canned food sections, in your garden, at a farmers' market or food pantry, or from a meal kit service.

Olive Oil Vinaigrette

Extra virgin olive oil has many health benefits. Try using it in this easy, delicious homemade salad dressing.
¼ cup red or white wine | apple cider vinegar | lemon or orange juice
½ teaspoon salt
¼ teaspoon ground pepper or red pepper
¾ cup olive oil
Mix-ins:
1 tablespoon jam, honey or maple syrup
½ teaspoon dry mustard, chopped garlic or garlic power, dried herbs (basil, oregano, rosemary, tarragon, thyme) or 1 to 2 teaspoons minced fresh herbs
In a mason jar, combine all ingredients, cover, and shake well. Serve immediately or refrigerate up to 1 week.

TIP: Delicious as a salad dressing, a marinade for children, cooked white beans, chickpeas, or lentils. Drizzle it over roasted vegetables like potatoes, broccoli, cauliflower, or Brussel sprouts. Use it to sauce up cold or hot whole grain pasta, use as an ingredient in a dip, drizzle on top of your favorite vegetable soup- the possibilities are endless!

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 near or far, we are grateful for you. We appreciate your decision, commitment, courage, and ability to stay the course. We understand very well the importance and sacrifices of caregiving. We feature this column in the Grey Matters Newsletter to include your stories, ideas, or activities, and maybe a bit of humor; just for you! 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 you and your loved one.

Simonson Strong-No One Fights Alone

One thing we started in the summer of 2018, Kevin's sister designed t-shirts that said "Simonson Strong- No One Fights Alone". On MRI days, we asked people to think of us and wear their shirts in solidarity. People would post their pictures to share with all family and friends.

On June 30th, 2017, my journey as a caregiver was added to my role as Kevin's wife. I believe caregiving is an extension of what I had done all our married life. I also believe each caregiver carves their own path based on illness, circumstances, age and family. Everyone's journey is right for them.

Almost 36 years ago when we said for better or worse, in sickness or in health, you really never think you will have worse or sickness that will change your life forever.

I noticed a few differences in Kevin's routine and personality. He was so distracted and couldn't stay on task. Some friends also noticed that he seemed different. His supervisor called and said he had stumbled at work and couldn't do some of the routine tasks he had done for 30 years as a restaurant manager. We saw his doctor and had an MRI that reveals a rather large brain tumor requiring surgery.

His tumor was about the size of a tennis ball, and he was able to remove about 98% of it on July 3rd. The pathology report came back as Glioblastoma multiforme, grade 4 and the neuro-oncologist at the Givens Brain Tumor Center would oversee Kevin's treatment plan including radiation, temozolomide, Optune, and avastin.

At the beginning, Kevin could not be by himself because of the possibility of seizures. He had done stats for football on the sidelines for years and kept the book for wrestling. We had a platoon of friends, including young wrestlers, who would take turns staying with Kevin. They were honored to be on Kevin's Adult Day Care Team! And during games I would ask the guys working with him to watch and protect him from getting hit by any of the players. At the end of the season, the team presented him with a Tackle Cancer Football signed by the team members.

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Caregivers wear many hats, they are cheerleaders, schedulers, transportation, motivators, managers, and a liaison between medical personnel and your loved one. Caregivers may also have to take on tasks and roles their spouse once did.

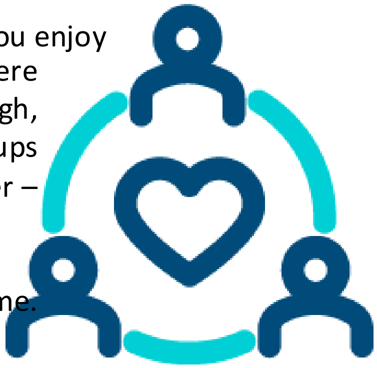
As a caregiver, I wanted to make life as normal as possible and to help Kevin take part in the activities he loved. We dealt with chemo fog-which for him was some short term memory issues, but the biggest one was fatigue. We worked around it the best we could, he rested and napped frequently, and especially enjoyed our dog by his side.

One day, in July 2017, as I walked past my refrigerator, I happened to see a county caregiver support group meeting course that met at our church, which I had never noticed on the church calendar, before. But that day, it jumped off the page and I made plans to attend. I immediately felt a part of the group.

Everyone was at a different point in the caregiver journey, different ages and medical conditions of their care receivers. Each caregiver and their tasks are as unique as the loved one they care for. One of my ah ha moments was that caregivers need support and care, to be their best for their loved one. I shared at one point how sometimes I felt frozen or stuck. I had things I needed to accomplish, but I just couldn't seem to get started. One piece of advice was to pick one task, and work at it for a set amount of time. I set a timer to complete many tasks or break up larger ones. Set goals, be specific and reasonable. Sometimes, I still have those feelings of being overwhelmed, and I just have to take a few minutes and remember- small steps.

We also learned how to enhance communication with your care receiver, family members and friends about what you might need and how to ask for help. Did you know caregivers sometimes feel guilty, grief, stress and isolation? I learned to identify these feelings and ways to work through them. Each person is so individual and has to find what works best for them. I never really thought about grief, but there is grief or loss of what has been. We were close to retirement age and the loss of plans of our retirement also caused grief.

Caregiving is emotional and will change over time, most often becoming more intense. If you have some things in your life that zaps your energy or don't have the priority they once had, let them go. I learned to take time for myself each day, doing something I **WANT**, even 10-15 minutes a day can be rejuvenating.



You cannot do it alone. I encourage you as caregivers to try and carry on activities you enjoy and stay connected to your family and friends. Facebook and Caring Bridge were wonderful ways to keep friends and family up to date on what we were going through, and also keep in touch with them. Search your church, community, support groups and even online. There are many ways to be a part of one's care and their caregiver – share a hug, a listening ear, phone call, prayer, a meal, time, love and support.

After almost 2-1/2 years since Kevin's diagnosis, we moved Kevin to the nursing home. I couldn't safely take care of him. He spent the last 2 weeks of his life there.
On November 5th, after an MRI, we were told there was more progression and nothing more could be done. I was with Kevin on November 10, when he peacefully entered eternity. His services were a testament to how loved and admired he was! The Givens Brain Tumor Center was our team when we were on this journey, and I appreciate all the support and coordination from them.

Have your Voice in Research:
An Anonymous survey for brain tumor patients and family members.

University of Pittsburgh

Have Your Voice in Research

Understanding Access to Healthcare Providers and Services in Persons with Brain Tumors

Requirements

- 18 years and older patients who have been diagnosed with a brain tumor
- Family of patients 18+ with a brain tumor

How to Participate

- Take a one time anonymous 15-20 minute online survey

Website

Persons with brain tumor:
https://pitt.co1.qualtrics.com/jfe/form/SV_7alBfvEbLVG5GNU
Family of persons:
https://pitt.co1.qualtrics.com/jfe/form/SV_5gq6ikwF47PRjwy

QR Code

Persons with brain tumor:

Family of persons with brain tumor:

We would like to invite you to participate in an international survey to provide data to help support people with a brain tumor. The Given's Brain Tumor Clinic has joined researchers from the United States and Europe in seeking to better understand which healthcare services accessed by patients and family members are useful and what makes these resources easier or harder to access. People with any type of primary brain tumor and their family members aged 18 or older are asked to complete a 20-minute online anonymous survey about their experiences. The survey link can be found here or in person at the Given's Brain Tumor Center. Thank you for supporting research! Please contact 612-863-3452 with any questions.

Home Care and Companion Services

Becky Moore, LICSW

Below you will find a short listing of private-pay Home Care and Companion Service agencies in the Twin Cities area. These agencies provide a variety of services including homemaking, companionship, and personal cares. The rate charged will depend on the level of service needed. Be sure to discuss your home health needs with the agency you are calling. Most agencies will require a 3-4 hour minimum per visit.

Lifespark: 952-345-8770 Reinventing Senior Care | Lifespark - Age Magnificently

Community Home Care is extra support you want- no matter where you live. It could be a caregiver who pops in now and again, or someone who lives with you full time. A key difference with LifeSpark is you always have an RN Case Manager providing professional oversight who can also help you manage medications or connect you to resources. The Community Home Care team manages your health needs, assists with daily activities, and keeps you living life on your terms.

Home Instead Senior Care: 952-641-7216 In-Home Senior Care | Home Instead | Edina, MN

Our senior care services help aging adults stay engaged in everyday life with tailer-made support to stay safe and well at home. It's our mission to provide an elder care plan personalized to your family's needs to bring you comfort, companionship and peace of mind. In home care, personal care assistance, such as toileting, bathing and grooming. Maintaining a safe environment, meals. Assist with ambulation and socialization, transport to medical appointments and other events. Light housework and other household tasks. Pet care. Can be 24 hour live in care.

Joyful Companions: 763-544-0401 In Home Senior Services Minneapolis, MN | Joyful Companions Home Care

We are a Christian based service providing compassionate home care for older adults. Our desire is to preserve the quality of life and independence for seniors and people with disability. We develop an affordable care plan together to assist our clients in remaining independent for as long as possible. Service with love, grace, and a high level of expertise gives our families the comfort and security that their loved ones are cared for. Help with meal preparation, light housekeeping, memory care, transportation, companionship.

Visiting Angels: 877-812-6435 Senior Care and Home Care Minnesota (visitingangels.com)

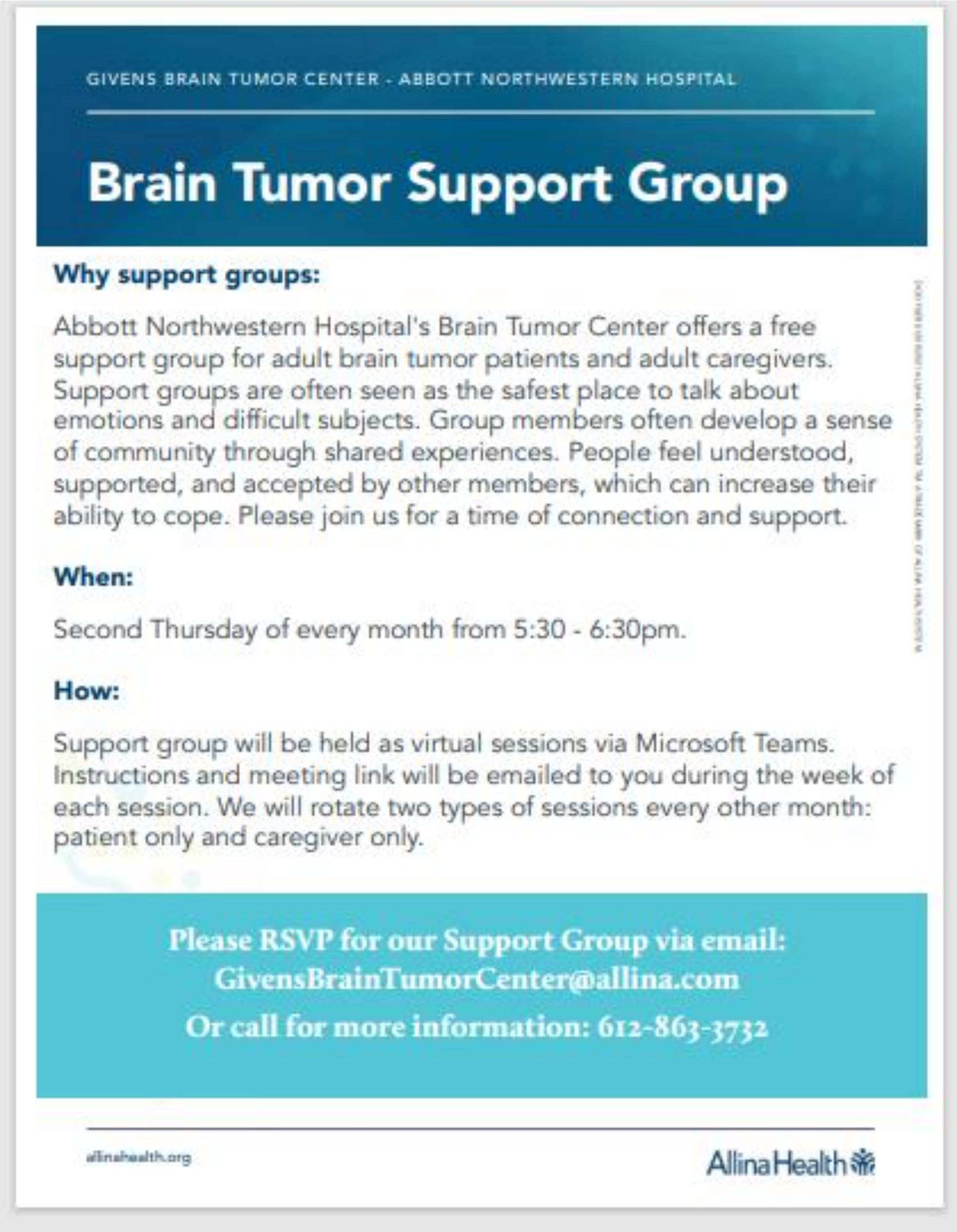
Private duty home care, providing senior care, in-home care, Dementia care, Alzheimer's care, elder care, personal care, respite care and companion care to seniors and adults throughout the state. Services are available in Eden Prairie, Cambridge, Burnsville, Minneapolis, Red Wing, Rochester, Shoreview, Owatonna, Oakdale, St. Cloud, Wayzata, St. Louis Park, and Mankato. Our mission is a simple one. TO allow seniors and disabled adults to remain independent in their own home with dignity.

Baywood Home Care: 763-546-8899 In Home Caregivers | Minneapolis & St Paul, MN (baywoodhomecare.com)

Baywood provides both 24-hour "live-in" care, as well as in home caregivers on any "hourly" schedule that is needed. Services scheduled by the hour can be for as little as three hours at a time, or as much as 24 hour awake care. Scheduling can be charged with 24 hour notice. Baywood can provide all the care that a client needs or can just fill in the gaps between family caregiving. Baywood provides in home caregivers in the greater Minneapolis/St.Paul metro area, much of south central and southwestern Minnesota, and in bordering areas of western Wisconsin (particularly St. Croix County)

Legacy Home Care: 763-593-9000 The Leading Twin Cities Home Care Company | Legacy Home Care

We offer a broad array of home care services rendered by experienced professionals with specialized skills: Live-In Care, 24 hour wake care, overnight care, hourly home health aid, in home nurse care, home therapy services, social work services, home safety supervision, companion services, and medication management. We are proud to serve clients residing in 21 MN counties. Our service area encompasses the greater Twin Cities metro area, St. Cloud and southern Minnesota. Our team of experienced liaisons are available 7 days a week to answer any of your home care questions, free of charge.



GIVENS BRAIN TUMOR CENTER - ABBOTT NORTHWESTERN HOSPITAL

Brain Tumor Support Group

Why support groups:

Abbott Northwestern Hospital's Brain Tumor Center offers a free support group for adult brain tumor patients and adult caregivers. Support groups are often seen as the safest place to talk about emotions and difficult subjects. Group members often develop a sense of community through shared experiences. People feel understood, supported, and accepted by other members, which can increase their ability to cope. Please join us for a time of connection and support.

When:

Second Thursday of every month from 5:30 - 6:30pm.

How:

Support group will be held as virtual sessions via Microsoft Teams. Instructions and meeting link will be emailed to you during the week of each session. We will rotate two types of sessions every other month: patient only and caregiver only.

Please RSVP for our Support Group via email:
GivensBrainTumorCenter@allina.com
Or call for more information: 612-863-3732

allinahealth.org

AllinaHealth

My Personal Experience with the Givens Brain Tumor Support Group

By Ginger Peterson

When I was diagnosed with my brain tumor 22 years ago, and later ovarian cancer, I lived alone. I had friends and my mom who stayed with me for the summer, but lived in Arizona the rest of the year. What was I going to do? I was the last person in the world to think of going to a support group, but the social worker suggested I go. She assured me all I had to do was say my name and what kind of tumor I had. It changed my life. I was with my people. They too, had questions and anxiety about the future and what life was going to be like going forward. We, as patients, were all at different points in the journey. At that time, the brain tumor support group was for caregivers and patients and was in person. Both groups were facilitated by staff from the Givens Bran Tumor Center. We were like a family. Different ages, different tumors, different stages of treatment. Many experiences similar reactions of treatment. It was not all gloom and doom. Far from it. Humor had its place. It was hard not to think what I am complaining about when Ken had Glioblastoma. He looked right at me and said, “It’s not a competition.” Words I still remember.

I also was the de facto correspondent for the Givens Brain Tumor Support Group for many years emailing reminder notices and any info that the brain tumor clinic wanted sent out. I later went to Arizona to be with my 96 year old mom who was fine- just old or as the hat I bought her said- Older than Dirt. I always had the patient role but now I was on the other side- caregiving. Somedays, role reversal was fantastic- saying do this, do that, eat this, drink more, etc. My mom listened about as much as I did when I was growing up. Saddest day of my life when my mom passed.

Thank you, Ginger, for sharing your experience with us, and for being the “de facto correspondent” for the Givens Brain Tumor Center Support Group for all those years!

Raising Awareness About Brain and Spinal Cord Tumors

Below are organizations who work tirelessly to increase awareness about brain and spinal cord tumors, and funding to help cures, conduct research, help us live better lives, and keep us connected*! And many thanks to the patients and donors who have also donated funds to the Givens Brain Tumor Foundation*. We thank you!!!

Highlights from this year's fundraisers!

Humor to Fight the Tumor Gala- September 7, 2024. Humor to Fight the Tumor

Over 650 of the Twin Cities' most dedicated advocates in the fight against brain tumors came together for a truly and unforgettable evening. Their generous support will directly advance critical brain tumor research and provide essential resources for families navigating this challenging journey.

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walk·talk·connect
for brain & spinal cord tumors
#powerofpersonalconnection

WalkTalkConnect Event - September 22, 2024

Walk Talk Connect | For Brain & Spinal Cord Tumors – WalkTalkConnect

ABTA BT5K Breakthrough for Brain Tumors- October 5th, 2024

[Twin Cities BT5K - American Brain Tumor Association (abta.org)](https://abta.org)

BT 5K
AMERICAN BRAIN TUMOR ASSOCIATION
BREAKTHROUGH
FOR BRAIN TUMORS

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

Givens Brain Tumor Staff

Andrea Wasilewski, MD - Neuro-Oncologist, Medical Director
Maya Hrachova, MD – Neuro-Oncologist
Seth Hartman – Certified Nurse Practitioner, APRN, CNP
Tankia Barnes -Medical Assistant
Lani Hoese – Clinical Support Specialist
Brenda Wrenn – Clinical Support Specialist
Megan Elia- Nurse Navigator, RN, BSN
Lehn Grube- Nurse Navigator, RN, BSN
Karen Holmseth - Nurse Navigator, RN, BSN
Will Majerus – Nurse Navigator, RN BSN, CNRN
Deborah Jones – Care Guide, MA
Katie Brusnahan, Social Worker, LSW
Meghan Peters, OTR/L - Manager, Clinical Operations and Program Development

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.