

Grey Matters Newsletter of Givens Brain Tumor Center

Allina Health % NEUROSCIENCE SPINE & PAIN INSTITUTE

Summer 2025

Welcome

Dr. Andrea Wasilewski Medical Director

Continuing to Lead with Heart, Science and Vision



As we turn the page on another season of progress, I'm filled with pride at the incredible momentum within our neuro-oncology program. Our team continues to lead with both compassion and excellence. This spring has brought well-deserved recognition to several of our clinicians. Dr. Hrachova and I had the opportunity to share our expertise on

podcasts, news stations, and national conferences, helping our broader community understand the complexities of brain tumors. And yes- we're celebrating another *Mpls. St. Paul Magazine* "Rising Star" honor. These moments in the spotlight are a reflection of the tireless, behind-the-scenes dedication I see every day.

I'm honored to re-introduce the Givens Family, whose generous contributions support our program and remind us that our mission is about more than medicine. It's about people. And this theme continues in our inspiring patient stories this month. Joel Shanight's resilience, Jim Covington's courage, and Rebecca Devine's grace throughout treatment offer powerful reminders of why we do what we do.

In this issue, we're also shining light on the role of genetic counseling in neuro-oncology- a field rapidly transforming how we personalize treatment and exploring vital topics like sexual health and fertility during cancer care. Our "Healthy Lifestyles" section features a much-requested discussion on fatigue in brain tumor patients, along with a refreshing, easy-to-make recipe. For caregivers, we've included practical self care strategies, because caregiver well-being is just as essential as the patient's they support.

Continued on next page

In this issue

- Medical Director's Column
- Staff Updates- Doctors in the News!
- The Givens Family
- Editor's Column
- Patient Stories
- Neuro-oncology News
- Healthy Lifestyles
- Caregiver Insights
- Donations and Fundraising
- Allina Health Neuroscience (AHNSPI) Update
- ANV Revitalization/Construction Update

Givens Brain Tumor Center

The Allina Health Neuroscience, Spine, and Pain Institute

913 E 26th St. Minneapolis MN 55407 Mail Route 39304

Phone: 612-863-3732 Fax: 612-863-2837

www.allinahealth.org/givens

Allina Health 🔆

all together better.



Dr. Wasilewski

We're deeply grateful for the ongoing generosity of our community. Save the dates for upcoming fundraisers and awareness events supporting patients with brain and spinal cord tumors- your contributions make real, tangible differences. And exciting change are underway: the next phase of development for both the Givens Brain Tumor Center and the Allina Health Neuroscience Spine and Pain Institute will expand access to care and research in bold, meaningful ways.

Finally, we're excited to share an update on the Abbott Northwestern revitalization and construction efforts, signaling not only a physical transformation but also a renewed commitment to innovation, healing, and hope. I continue to be incredibly grateful to our wonderful team and to each and every one of you as we move forward together.

Staff Updates Doctors In The News!!

Dr. Andrea Wasilewski, Medical Director, Givens Brain Tumor Center, was nominated for the second year in a row, by *the Mpls. St. Paul* Magazines Top Doctors: Rising Stars List! 2025 Top Doctors: Rising Stars Edition- Mpls. St. Paul Magazine

To appear on this list, physicians are nominated by their peers, then grouped into 46 specialties, and evaluated on a myriad of factors such as peer recognition, professional achievement, and disciplinary history. Those with the highest scores in each specialty are then chosen using a patented multiphase selection process combining peer nominations and independent research evaluations with independent research.

Listen to the podcast interviewing between Dr. Wasilewski and Rebecca Divine on Rebecca's podcast, Brainy Blonde: 7 Year Anniversary Edition for all my Brainy friends: A Deep Dive into all your Pressing Questions about Glioblastoma with the Brilliant Neuro-Oncologist Dr, Andrea Wasilewski

The Whole Way to Better



Dr. Maya Hrachova, Medical Director, Brain and Spinal Metastases Program, Givens Brain Tumor Center

Dr. Hrachova presented at the 2025 AAN (American Academy of Neurologists) Annual Meeting in April this year in San Diego regarding neurological consultations in cancer patients. This meeting attracts thousands of neurologists and neuroscientists from the United States and abroad.

Watch Dr. Hrachova's interview with Kare 11 on May 27th, 2025 to raise awareness about the symptoms of a brain tumor. What are the symptoms of a brain tumor? I Kare11/com.

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© 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 Springing into Summer

Editor's Column



As we spring into summer, we will begin changing the configuration of our staff and patient areas to accommodate our growing patient census. Our goal is to make this transition as seamless as possible to you, our patients, and your loved ones. We are excited about new carpet, freshly painted walls, and updated equipment in our patient rooms to make your experience more pleasant! The plan is to complete this by year-end.

As you thumb through this newsletter you find many new interesting topics. We offer our usual inspiring patient stories along with information about genetics counseling, sexual health before, during and after cancer treatment, and an article about brain tumors and fatigue.

We also share helpful strategies for our supportive, overworked caregivers. We hope our caregivers find this informative and that you take away at least one helpful idea.

It is officially Summer! Enjoy the warm sunshine, the longer days, and make new memories with family and friends!





The Whole Way to Better



Patient Stories

Fighting the beast... by counting our blessings

Jim Covington

Written by Marianne Covington



Jim Covington was born on September 11th, 1950, in Long Beach, California. Due to his father's career as a Petroleum Engineer, the family moved around the western US for most of Jim and his brother John's early years. With the boys approaching middle school and preparations for high school, their parents decided to permanently settle in Fullerton, California. They attend Sunny Hills High School. Jim went onto Fullerton Junior College (where he was class vice-president), and Cal State Long Beach, while John went to the Air Force Academy in Colorado Springs.

Jim worked his way through college at Disneyland. He still has many friends and memories from those days at the park, including canoe races around Tom Sawyer's island, midnight parties at Marries Pizza Parlor, and tuna boat burgers when there was not enough grocery money.

Jim always had very interesting friends and roommates. The most memorable one was Mark. It was at Mark's wedding to Judy where Jim, the best man, met his future bride, Marianne. This only happened because Marianne's mother, who was the bride's mother's very best friend, was in bed with influenza. Marianne was urgently called home from college finals week at USC to attend the wedding because "your father will never remember all the details that I want to know". The rest became history when Jim and Marianne married 18 months later, with Mark and Judy in the wedding party.

Jim had majored in Manpower Management at Cal State Long Beach. He strengthened his career with the wise choice of joining Marianne's family of USC Trojan Alums, as a third generation Trojan to pursue an MBA. They spent the next 30 years raising two daughters- Melissa and Veronica. It was a great time to live in Southern California with a large extended family all around and all the usual activities of school, sports, church and all the extra-curriculars to keep us busy. The girls are now married, and both are navigating four children through 21st century life.

In 2008 when the US economy tanked due to banks writing too many subprime mortgages, Jim's mid-level management position was eliminated during a major downsizing. After six months of job searching, he found a response from Weill Cornell Medical School in his spam email folder, which he typically never looked at. Cornell had been one of the five major US universities invited to Doha, Qatar by the emir to help develop this small Middle Eastern country which had been mostly nomads and Bedouins as recent as 30 years ago. This was not as scary as one might think. The Economist Magazine had done an extensive survey of all 17 Middle Eastern countries with the purpose of ranking them in order of "likelihood to have a civil uprising". Qatar came out at the bottom of the list! Today Qatar is known for hosting/facilitating most of the peace talks in the Middle East. We were very happy and safe and took advantage of traveling around that part of the world. We also made some of our best friends we still have today, from all over the world, who had met up in Doha.

We came back home at the end of Jim's contract in 2011. He continued to work in Buffalo, NY, Minneapolis, MN, Shreveport, LA, and Austin, Tx up until his retirement in 2023. On Saturday of his last week of employment he suffered a seizure, and the glioblastoma was found. He has been "fighting the beast" for over 2 years under the guidance of Dr. Wasilewski and her team here at Givens Brain Tumor Center. He had requisite survey, radiation, and chemo. He has been using Optune by Novocure since August 2023. He tolerates it well and is always happy to explain it to anyone who asks what is on his head. We maintain a positive attitude by counting our blessings and looking forward to the future.



Cancer Saved My Life!





Rebecca Devine

Hi, I'm Rebecca, a mom of four, entrepreneur, business owner, podcaster and 7year survivor of Glioblastoma. And I believe something kind of crazy: cancer saved my life. There is a four-letter word people like to use when talking about cancer. Mhm, that's the one. But the one I prefer is HOPE. You see, after the initial shock of being diagnosed with Glioblastoma there has been nothing but good newsokay, that's not true. At first the bad news piled on (IDH Wild, unmethylated). But the bad news led to digging deeper. Then to some really, really good news. Some might even say miraculously good.

My story starts in 2001 when my mom received a GBM diagnosis fifteen years before me. And even though they say it was not genetic; I was so anxious and became obsessed with health and fitness just in case. So, when I found out myself in the hospital, confused to hear I was in a car accident driving home from yoga and lucky to be alive, only to be told I had Glioblastoma, well you would expect

I would be devastated. I would have expected I would have felt devasted. Abandoned. Cheated. Why me? It's too cruel. It's too much. It's not fair. I was doing ALL the right things. But I didn't respond in that way at all. It was weird. I was calm and almost relieved. It was like this was the moment I'd really been preparing for all my adult life. I felt armed and ready. I wasn't doing all that to avoid getting sick; I was preparing myself for battle. Why not me?

I vested 5 neuro-oncologists within two weeks of receiving brain surgery! I was lucky enough to find a doctor who would collaborate, Dr. Trusheim. I had just found out about a new treatment: a vaccine using my own tumor tissue to create T cells to fight the cancer. I met Dr. Saskia Biskup in 2018 and in my gut, I just knew Saskia was onto something and I was willing to risk my life on that. And Dr. Trusheim was willing to support my decision. So, I chose treatment at CeGaT. It meant 11 trips to Germany over two years. And a huge up-front expense. And 2 years has turned into 7 and counting.

But it was worth it. Hope is now reality. I don't know what the future holds. I know I did my part. I had the surgery. I fought back to regain my strength with daily yoga, even during concurrent radiation/chemotherapy/ketogenic diet/intermittent fasting. I diligently maintained a strict, clean ketogenic diet to avoid fueling the cancer with sugar. I sought out all the medical help I could find. I read the books and prayed. And I have kept a positive attitude. And now I have the wonderful support of Dr. Andrea Wasilewski who is always willing to consider new ideas and supports lifestyle as an important component to fighting this cancer. She makes me feel empowered.

I recognize that I have not done this alone. There have been miracles all along my path. From the snowbank that cushioned my car, to the firefighters who came to the scene of the terrifying crash that started this whole thing, to the spectacular brain surgeon who removed all my tumor without in anyway impacting my brain function upon recovery, to my family and steadfast friends who've cared for me in every way through this. And the happiest miracle could be the friendship that developed into undeniable, soul-connecting love. While doing all of this I married my soulmate in November 2019. Second chances. In gratitude and to pay it forward, I have started a podcast to provide hope and connect other GBM warriors and their families to resources.

> **Brainy Blonde Podcast** Cancer Saved My Life

http://www.rebeccadevine.com

@thatbrainyblonde



Joel Shanight

66 I got a good deal on life today! **99**



I am a 45-year-old disabled army veteran, who served in the Army National Guard. I grew up in Edina, Minnesota in a hardworking, dedicated, and respectable family, spending many weekends in Rush City, MN. I have had and lived through many experiences in my lifetime. There was always something a little off with my life, but I just kept trying at sports and school. I have learned to practice failing forward in life. Learning from mistakes, I now try to focus on questions rather than answers or solutions.

I was an Army Biathlon Medal winner, which is one of the toughest sports ever, an AmeriCorps Crew Leader, and part of the Conservation Corps in 2008. I earned a BA in Finance at Fort Lewis College in Durango, CO in 2002, and later pursued my Masters of Public Administration, from American Public University, in 2013. I was involved in mountain climbing, climbing Mount Ranier and, in 1999, climbed the Annapurna Trek in Nepal to 17,000 feet.

People remind me that I do things in a big way and do what it takes at that moment. Survival traits?

My fellow soldiers called me "Superman" because of my constant showing up in life. My work in the Army was so challenging you could call it one of the hardest things in the world to do at the time. I served our country repeatedly until I was medically unable to continue. Many of the orders I was put on were the ones nobody else could accomplish, a lot of behind-the-scenes work. I have had other jobs including managing a climbing wall, working in crisis management, accounting, and as a Janitor at Target Center. Now my work is my health, my parents, and our dog KONA. These days, I frequent Vail Place Minneapolis, which is a non-profit organization that provides community-based recovery services for adults with serious mental illnesses.

Humility is a big part of my personality. I do not leave people behind. I am an American who has survived many, very stressful environments before I knew that I was diagnosed with Oligodendroglioma brain cancer in November 2023. PTSD from previous events has transformed my world into being authentic and forgiving the world. In my life, there have been a lot of nightmare situations which have made me more empathetic to society. The unknowns in life are what can be dangerous in life, but over a long enough timeline everyone has unknowns. I do have good intentions and am working on that.

I am getting back into golf for the benefits of motion and being outside. The motion of gold stretches my muscles out, and I plan to play a lot moving forward. When I am hiking, skiing, and physically fit, it makes life with my brain tumor more tolerable. I have been visiting my friend, Ali in Steamboat Springs, Colorado for hiking, soaking in the hot springs, and skiing. The old town hot springs there are very much a pain reliever.



A lesson I have learned is to get back in touch with old friends, if the need is there for support. My Veteran friends are very loyal and have been so strong in my journey. Forgiveness, Reconnection, and Love are probably the best cures for illness and pain. I choose to be confident and resilient in my life!



Neuro-Oncology News







Andrea Edwards, MS, CGC

Certified Genetic Counselors • Allina Health Cancer Institute

The Role of Genetic Counseling in Neuro-Oncology

Most cancers and tumors are sporadic, meaning there are no hereditary (genetic) cause. However, a small percentage of brain tumors are hereditary, meaning an individual was born with a genetic change or mutation that contributed to their diagnosis (also known as a hereditary cancer syndrome).

Certain individuals with tumors of the central nervous system may benefit from a genetic counseling appointment to determine if they have a hereditary cancer syndrome. At Allina Health, we provide genetic counseling through in person or virtual visits. A genetic counselor may look at an individual's cancer type, results of testing on their tumor, age of diagnosis, additional personal history, and/or their family history. If the genetic counselor determines that there is

concern for a hereditary cause of an individual's tumor based on this assessment, genetic testing (also called germline testing) may be recommended.

One of the many hereditary cancer syndromes that can increase the risk of brain tumors is called the Lynch syndrome. In addition to brain tumors, Lynch syndrome also increases the risk for several other cancers, such as colorectal and uterine cancers. A rarer hereditary cause of central nervous system tumors is called Li Fraumeni syndrome. Individuals with Li Fraumeni syndrome are also at an increased risk for other cancers, such as breast cancer, sarcomas, and blood cancers.

Some features that might suggest a hereditary cause of brain cancer tumors include young diagnosis (e.g brain cancer diagnosed before age 50), certain rare cancer tumors (e.g hemangioblastoma), multiple family members with the same or possibly related cancer types (e.g. glioblastoma and a family history of 2 relatives with glioblastoma, colorectal, uterine, or other related cancers), or multiple separate cancers in one individuals (e.g. personal history of astrocytoma and melanoma.

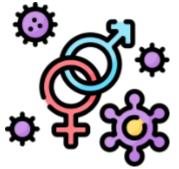
Many individuals with brain cancer or tumors have their tumor tested for somatic genetic mutations (gene change acquired during an individual's life). These results can help their care team with the diagnosis and treatment of their tumor. This testing is different from germline testing because it does not look at the genetics an individual is born with or the genetics that an individual passes on to their relatives. Additionally, while tumor testing is usually done on a sample of the tumor, germline genetic testing is usually done on blood or saliva.

Genetic counselors can be a valuable part of an individual's care team. Our goal is to give information to individuals and their relatives about cancer risks and potential screening/prevention methods. Individuals interest in a genetic counseling appointment can talk to their oncologist/primary care provider or visit our website to learn more (account.allinahealth.org/services/683).



Sexual Health, Contraception, Fertility, and <u>Pregnancy During Cancer Treatment</u>

If you have any concerns or questions about any of these topics, we encourage you to bring it up during your visit with our providers. All questions are important and okay to ask!! We are able to refer you to other providers and resources.



Women, Brain and Spinal Cord Tumors and Fertility

For women who are in their reproductive childbearing years and develop a brain or spinal cord tumor, the recommended treatment may include surgery, radiation, chemotherapy, or some combination. These treatments can impact a woman's fertility and pregnancy. Additionally, sexual partners of persons diagnosed with a brain or spinal cord tumor who are undergoing treatment must be aware of proper contraception during sexual intercourse. It is important to have discussions with your provider about sexual intercourse and fertility **before** the initiation of these therapies.

Radiation and Fertility

The type of radiation used for treatment of these tumors is focused on the tumor and a small margin surrounding the tumor. There is little risk to a woman's ovaries or her eggs from the radiation. However, the radiation can affect the pituitary gland, a small structure housed deep in the brain that controls the secretion of hormones necessary to become pregnant and to sustain pregnancy. This is most often seen in patients who have radiation directed at the pituitary gland itself, as some tumors grow there, but pituitary dysfunction can happen also if the radiated tumor is somewhere near the pituitary.

Chemotherapy, Targeted Therapies, and Fertility

Some, but not all, chemotherapies can affect a woman's fertility. Chemotherapy can stop the ovaries from working temporarily and sometimes, permanently. Women's periods may stop. Permanent infertility is more likely in older women, especially those approaching menopause naturally, and when high doses of chemotherapy are given. In these cases, a woman would start to experience signs of menopause. In cases of temporary infertility, a woman may stop having her period but could still be producing eggs. In these cases, I can take up to 6 months or longer after the completion of chemotherapy for periods to become regular again. For this reason, it is important that any woman of child-bearing age use reliable contraception. There is a good chance that a baby conceived while a woman is on chemotherapy would have significant developmental deformities. In addition, when a female is born, she is born with all the eggs she will ever have. The chemotherapy may have effects on the eggs, making them less likely to produce a viable fetus.

Targeted therapies such as vorasidenib, and IDH inhibitor, blocks certain abnormal proteins in certain brain tumors. This drug may affect a woman's ability to get pregnant and can potentially cause harm to an unborn child. Birth control along with other birth control such as condoms are advised for the patient or sex partner during treatment for several months after stopping treatment.

Contraception

Women and men should take pregnancy measures during treatment since exposure to bodily fluids can be toxic. Pregnancy preventive measures such as using condoms should be followed.





Pregnancy at the Time of Diagnosis

Women who are diagnosed with a brain tumor or spinal cord tumor when already pregnant face unique decisions. Depending on the aggressiveness of the tumor, the extent of the tumor, and the treatments being recommended, it may or may not be safe for the mother to carry the baby all the way to full term. In early pregnancy, a termination may be recommended but delivery may still be possible in a later pregnancy. There are many variables that go into a decision like this. Patients should have candid conversations with both the oncology and obstetrics team about what the best options for mother and baby are.

Fertility Preservation

The decision on whether to take steps to preserve fertility is a personal one based on personal wishes and realistic expectations about prognosis. If you do decide to pursue preservation, there are several ways to do so, including freezing of embryos and freezing of eggs. A fertility specialist can help guide you on the choices.

Getting Pregnant after Treatment

Most oncologists will recommend you wait at least a year after completion of therapy to start trying to get pregnant. This is not because the pregnancy can affect the cancer, but because recurrences of cancer are more likely to occur in the first year or so. If the cancer came back, more treatment would be required, and difficult decisions would need to be made regarding the baby.

Women's Sexual Health After Treatment

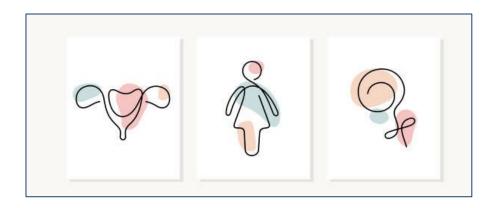
Sexual health is the physical, psychological, emotional, and social aspects of sex; how you see yourself, how your partner sees you, starting and maintaining sexual relationships, and the importance of sex to your quality of life are all part of your sexual health. Some women may experience vaginal dryness. Pain during sex can be challenging and may be addressed via vaginal moisturizers, pelvic floor physical therapy, or consulting with a sexual health therapist. Achieving orgasm is another complex aspect, and may entail speaking with a mental health consultant, finding ways for women to refocus their bodies during intimacy, looking at physical causes such as prescribed medications, and analyzing lab work.

Men's Sexual Health

Although a man's sexual function may have been healthy prior to their cancer diagnosis, psychological sexual dysfunction can occur due to being diagnosed with cancer and undergoing treatment. Your medical team can work with you and refer you to a provider who can help patients figure out how to get the same satisfaction as before. Often there is unwillingness to seek help and after seeking help, patients wish they had sought this out sooner.

For erectile dysfunction, there are several medications along with various devices, prostheses, injections, and other possible options in research and development. Your doctor can help you determine when it is safe to resume sexual activity after surgery or treatment. Other things to consider are that chemotherapy can be caustic to sperm, and it is advisable to use condoms during that time. Chemotherapy treatments and targeted therapies can be systemic and cause genetic changes to and affect production of the sperm. It is generally advisable to wait six to nine months after stopping treatment for fertility purposes. Your physician may also advise a patient to freeze a sample of their semen prior to treatment.





References and Referrals

The following were consulted for article content and may also be helpful to readers who are interested in learning more about these important topics. Bethany Kenny, Women's Health Nurse Practitioner-Oncology, Allina Health Cancer Institute also provided information and content.

Brain Tumors and Family Life

•URMC Brain Tumor and Spinal Tumor Program, Neurology-WomenBrainTumor-Brochure-FINAL.pdf

Reproductive endocrinology (i.e. fertility preservation) Specialists

- •Center for Reproductive Medicine (CRM), <u>Center for Reproductive Medicine | Fertility Specialists, Minneapolis-St. Paul</u>
- •CCRM, CCRM Fertility Clinic and IVF Clinic | Colorado Center for Reproductive Medicine
- •RMIA <u>Turning Patients Into Parents Since 1999 Reproductive Medicine & Infertility Associates</u>

Allina Health Cancer Institute (AHCI) Videos

- AHCI Five FAQ's about Women's Sexual Health;
- AHCI Five FAQ's about Men's Sexual Health.

Sexuality / Sexual Health

- •Managing Sexual Side Effects as a Woman with Cancer | American Cancer Society
- •https://www.mskcc.org/pdf/cancer-care/patient-education/medications/adult/vorasidenib
- •ISSWSH International Society for the Study of Women's Health ISSWSH Home
- •National Brain Tumor Society Navigating Fertility Preservation: A Guide for Patients with Brain Tumors
- National Cancer Institute [https://www.cancer.gov/about-cancer/treatment/side-effects/sexuality-women]
- •OncoLink [https://www.oncolink.org/support/sexuality-fertility/sexuality/women-sexual-health-and-cancer]
- •PRISM Program in Integrative Sexual Medicine (PRISM) for Women & Girls with Cancer UChicago Medicine
- •Prosayla | Sex After Cancer
- •https://www.roon.com/gbm/question/i-have-gbm.-will-i-be-able-to-have-children--
- EF6foCAfYkXaTosQzzfYX5?&sourceScreen=Referral&sourceScreenSection=Share&isQuestionUngated=true
- •https://www.roon.com/gbm/question/can-i-have-sex-with-my-partner-who-has-gbm--

PwuhF8tQieikgm7zCBbE4L?&sourceScreen=Referral&sourceScreenSection=Share&isQuestionUngated=true



Healthy Lifestyle to Promote Good Brain Health

Fatigue and Brain Tumors- Part I

(Watch for Part II in our Winter, 2026 issue – What Can Patients Do to Manage Physical Fatigue?)

Fatigue is one of the most common and debilitating challenges faced by people with brain tumors. Unlike ordinary tiredness, this type of fatigue can be relentless and impact every aspect of daily life. Understanding fatigue and learning how to manage it is key to improving quality of life for patients and caregivers.

What is Fatigue?

Fatigue is a persistent sense of exhaustion that doesn't go away with rest. It is a more intense lack of energy than typical tiredness and can significantly affect one's ability to perform daily tasks.

Patients may experience physical fatigue, cognitive fatigue, or both, due in part to the tumor's location and/or side effects from treatment or medication.



An article in *CNS Oncology* reports, "As in many other solid tumors, fatigue is frequently reported as the most common and distressing symptom in brain tumor patients throughout the disease trajectory, particularly patients facing high-grade gliomas." The same article also shared, "among patients with low-grade glioma, 39% reported fatigue up to eight years after completion of therapy."

Physical fatigue affects the body, making one feel heavy, weak, or unable to perform physical tasks. **Cognitive fatigue** affects the mind, causing difficulty with concentration, memory, or mental sharpness.

"Fatigue has been the hardest out of all of the symptoms because I feel that fatigue takes away from the quality of life," said Tresa Roebuck Spencer*, a former clinical neuropsychologist with recurrent glioblastoma (GBM). "It makes it where I feel hesitant to go out because I never know when that fatigue is going to become too much. I find fatigue very limiting."

What Does Physical Fatigue Feel Like?

While the experience of fatigue can vary, many people living with brain tumors describe it as a unique sensation that can be a significant impact. Tresa said, "Sometimes it just feels like you would expect. I just feel tired and need to rest. Sometimes, when it is really bad, it's just an overall weakness. Sometimes it feels like I have a really heavy coat on, and it's hard to just move through space and do normal activities."

Eric Galvaz, a former physical therapist living with meningioma, said, "Brain tumor fatigue just feels like things are heavy. It's like you are moving in slow motion through a fog."

Continued on next page



Healthy Lifestyle to Promote Good Brain Health (Continued)

How is "Regular" Fatigue Different From Brain Tumor Fatigue?

For many patients, the distinction lies in how unrelenting brain tumor fatigue can be, defying the usual remedies like rest or sleep. Tresa said, "My husband will say, 'If you're tired, why don't you take a nap?' And I'll say, 'Well, this isn't the kind if fatigue that I can take a nap and feel better.' It's almost like there's a weight on me, and I need to just rest. But taking a nap doesn't help it. It continues until it runs its course."

Adding to this prespective, Carly N., who has glioblastoma, explains how brain tumor fatigue differs in its different persistence and resistance to typical recovery methods. "The difference is that if you're really tired or exhausted, you can sleep it off, have a drink, or do your favorite activity and feel better the next day," Carly shared. "But when you have a brain tumor, no matter how much sleep you get, you can't shake the fatigue off easily."



How Does Physical Fatigue Impact the Patient?

Physical fatigue can profoundly impact daily life, restricting mobility, self-care, independence, and the ability to work. Many patients experience a sharp contrast between their current stamina and what they could achieve before their diagnosis.

"During chemo and radiation treatments and upon returning to work, I physically felt exhausted," Carly said. "My stamina dropped. I used to be able to work 11–12-hour days no problem, and now I've cut my hours in half." The emotional toll of fatigue often extends beyond the physical. Feelings of isolation and being misunderstood by others can compound the challenge. Many patients find it difficult to communicate the magnitude of their fatigue, leading to frustration when others don't grasp the full impact of their condition.

Excerpt from "7 Tips to Manage Physical Fatigue as a Person Living With a Brain Tumor" National Brain Tumor Society, Educational Resources, January 30, 2025.

7 Tips to Manage Physical Fatigue as a Person Living With a Brain Tumor

Simple Healthy Slaw

From Cookie and Kate

Find it online: https://cookieandkate.com/simple-healthy-coleslaw-recipe/1

This healthy slaw recipe tastes amazing! It's made with a simple lemon dressing and features toasted sunflower and pumpkin seeds. Gluten free and vegan. A perfect potluck dish. Best served the same day, but keeps several days, covered, in the refrigerator.







Prep Time: 15 minutes Cook Time: 5 minutes Total Time: 20 minutes Yield: 4 to 6 side servings

Ingredients

For the Coleslaw:

- 2 cups finely sliced purple cabbage (one small cabbage will be more than plenty)
- 2 cups finely sliced green cabbage (one small cabbage will be more than plenty)
- 2 cups shredded carrots (I used store-bought shredded organic carrots, but you could also grate them on a box grater, in a food processor, or julienne the carrots with a sharp knife)
- ¼ cup chopped fresh parsley
- Up to ¾ cup mixed seeds (I mostly use pepitas- AKA green pumpkin seeds- and sunflower seeds, with some sesame seeds and poppy seeds)

For the Lemon Dressing:

- ¼ cup olive oil
- 2 to 3 tablespoons of lemon juice, to taste
- 1 clove garlic, pressed or minced
- ½ teaspoon ground cumin
- ½ teaspoon salt

Continued on next page



Simple Healthy Slaw (Continued)

Instructions

- 1. In a medium serving bowl, combine the prepared purple and green cabbage, carrots and parsley. Set aside.
- 2. Measure out your seeds into a small skillet. Toast over medium heat, stirring frequently, until the seeds are fragrant and the pepitas are starting to make little popping noises. Pour the toasted seeds into the mixing bowl and toss to combine.
- 3. To make the dressing, in a small bowl, combine the olive oil with 2 tablespoons of lemon juice.
- 4. Add the garlic, cumin, and salt and whisk until thoroughly blended.
- 5. Drizzle the dressing over the slaw and toss until all of the ingredients are slightly coated in dressing. Taste and add an additional tablespoon of lemon juice if the slaw needs a little more zip.
- 6. Service immediately or cover and refrigerate to marinate for up to several hours.



^{*}Recipe adapted from The Adventurous Vegetarian Cookbook by Jane Hughes



Caregiver Insights

Self-Care Strategies for Caregivers- "There is no right way!"

You as a caregiver are an integral and valued part of the care team here at the Givens Brain and Spinal Cord Tumor Center. We welcome and encourage you to share your concerns and questions with us. We value and respect your time and appreciate your dedication and assistance. We thank **YOU** deeply.

As a caregiver of a person who has been diagnosed with a brain or spinal cord tumor, you may find that your loved one needs more support due to their neurological or physical side effects and symptoms. You are now in a situation requiring you to take on many new roles you haven't experienced before or those with which you have had no previous responsibility. Additionally, your loved one, along with yourself and other family members, are learning to accept the emotional and psychological effects from the diagnosis, treatment, and prognosis. The role of caregivers can be vast and change from day to day.

New responsibilities and additional roles may include managing your loved one's medications, communicating with doctors, nurses, and social workers; scheduling and attending appointments; providing transportation; following up with physical and occupational therapy appointments; handling medical benefits questions and claims; and providing assistance with changing dressings or helping your loved one with supportive or treatment devices. You may also be tending to legal and financial matters. However, as you settle in with your medical team and gain some understanding of their diagnosis and prognosis, believe it or not, you may find yourself in a daily rhythm of care.

Caregivers can struggle with conflicting emotions such as feeling hopeful, positive and strong while also feeling fearful, resentful, guilty, and possibly depressed. This is why it is important to prioritize your wellbeing. Below are some strategies you may find helpful.

- Focus on positive moments of joy, happiness, love, and compassion even when things are going badly or stressful. Sometimes it helps take note of those moments each day, too.
- Prioritize tasks into levels of urgency and importance. Those that were once very important may now be less important while new ones, such as managing seizures, become an urgent priority.
- Take time to consider what matters most to you. What mattered most prior to your loved one's diagnosis may change. When ready, let go of those things that no longer matter and are no longer realistic. Although this letting go may be a source of grief, anger or sadness, this can help refocus your purpose and help you find fulfillment in new ways.
- Find support for you and your loved one. There are online and in person support groups, and spiritual community resources who may provide support for cancer patients. Communicate and gather with family and friends you find supportive, and find other community resources for transportations, meals, home repairs, and care companions. We provide similar resources on our website Givens Brain Tumor Center | Abbott Northwestern Hospital.
- Find humor, a light heart, and laughter! Research has found these are great stress relievers and can help us move from crisis mode to recovery. If not today, perhaps tomorrow.
- Take time to pause and reflect on the ways you have frown, the skills you've learned, the wisdom you've gained, the intimacy that has grown between you, your loved one, and potentially your family, from sharing openly between each other. Recall these moments when you feel discouraged or depleted.
- Above all, remember to treat yourself with kindness and compassion.

References and Resources

Caregiver-Handbook 2019-1.pdf (ABTA)

Caregiver Handbook: Managing Brain Tumor Side Effects & Symptoms

Caregiving 101: On Being a Caregiver

ucsf caregiver handbook (1).pdf

Brain Tumor Support Group

Why Support Groups

Abbott Northwestern Hospital's Givens 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.

How and When:

Support group will be offered monthly as a **hybrid meeting**. You can join us **either in person or virtually**. Both versions will be accommodated during each session. Patients and caregivers are both invited.

In Person Sessions: Room PB6670 in the Piper Building. We will provide validated parking for those who attend in person.

Virtual online: A Microsoft Teams invitation will be provided if you wish to attend online.

Registration:

To sign up for our Support Group, email us at GivensBrainTumorCenter@allina.com, or call for more information: 612-863-3732.

We will provide monthly email updates with meeting details.

2025 Meeting Time and Dates

Sessions will be held on Thursdays once each month

Time: 11:00 am – 12:00 pm

We will meet the following Thursdays through the end of the year:

July 24th August 21st September 18th October 16th November 20th



Raising Awareness About Brain and Spinal Cord Tumors Save the Dates!

We are very lucky in our community to have many benefactors who make it their life mission to help increase awareness about brain and spinal cord tumors, and raise funding to help find cures, conduct research, help us live better lives, and keep us connected.



Humor to Fight the Tumor Gala- September 6th, 2025

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.

Humor to Fight the Tumor



Check the website for upcoming events!!





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



Twin Cities BT5K

Saturday October 4th 2025 • 9:00 am

Como Regional Park, 1199 Midway Parkway Saint Paul, MN

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

Twin Cities BT5K - American Brain Tumor Association (abta.org)



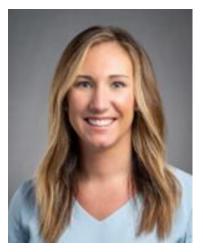




Visit us online for more patient stories and to see previous issues of our newsletter.

It's growing season all year round within the Neuroscience, Spine and Pain Institute!

Meghan Peters Manager, Neuroscience Programs and Operations



We are continuing to add care team members to currently established programs as well as building out new sub-specialty neurology programs through continued success with physician recruitment. Our end goal is to build regionally and nationally recognized programs while delivering comprehensive, inclusive, and seamless neurological and neurosurgical care across our geographic region. I am excited to share that we are well on our way!

All of this growth means we need more space! Earlier this year, we received funding approval to build a second outpatient Neuroscience Clinic on the 6th floor of the Piper Building, which will house our new specialty neurology and general

neurology programs. In addition, the 3rd floor Neuroscience Clinic will also be undergoing construction to add 2 new exam rooms and care team touchdown space. The entire clinic will be getting a much-needed refresh as well! The Givens Brain and Spinal Cord Tumor Center will remain in the 3rd floor clinic. The 3rd floor construction will start at the end of June with the project being completed towards the very end of the year. Although this will inevitably cause a bit of disruption, we will do our best to limit it as much as possible. Thank you for your understanding during this time!

Here are a few key recruitment and program highlights:

- Metropolitan Neurosurgery and Neurosurgical Associates joined forces to create Allina Health Neurosurgery, making us one of the largest neurosurgical groups in the region.
- Dr. Allyson Connor, a movement disorder neurologist joined our team September 2024.
- Dr. Armin Jewell, epileptologist joined our team June of 2025.
- Dr. Kelsey Jensen, a movement disorder neurologist who will also do general neurology joins our team July 2025
- Dr. Alejandra Duque, a multiple sclerosis/neuroimmunologist joins our team August 2025.
- Dr. David Kopel, a headache and migraine neurologist joins our team September 2025.

R. M. Schulze Surgical & Critical Care Center



When the 10-story building is complete in the fall of 2026, patients will receive care in the Richard M. Schulze Surgical and Critical Care Center, the name of our newest campus facility.

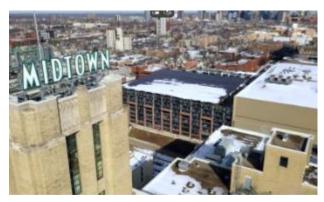
The name recognizes and honors the philanthropic support of Richard M. Schulze and the Richard M. Schulze Family Foundation. At the groundbreaking ceremony for the new building, Richard Schulze, the founder of Best Buy, shared what the donation meant to him. "We are honored to be part of a project that will ensure the world-class care Abbott Northwestern Hospital is known

for continues for generations to come. One of the focus areas of the foundation is Health & Medicine because investing in exceptional care teams and first-in-class technology benefits all of us." The Richard M. Schulze Family Foundation donated \$25 million for the center, Allina Health's largest donation to-date.

Solar Garden Benefits Our Neighbors and the Environment

The Abbott Northwestern Hospital Purple Parking Ramp is being topped off with a massive community solar garden that will soon help people in the Phillips neighborhood bring down their energy costs.

"This was an intentional decision by Allina Health to provide this for our neighbors," said Alison Pence, Allina Health director of community engagement. "This truly is their resource." The solar garden space is the roof of the new Abbott Northwestern Hospital Purple Ramp where a 2000-panel solar array is expected to generate 1.3 million kilowatt hours of electricity a year, much of which will be donated to the community in the form of credits



on energy bills. "We expect the panels will create enough energy to power about 150 homes in Abbott Northwestern's south Minneapolis neighborhood," Pence said.

Allina Health has partnered with <u>Cooperative Energy Futures</u> on the project. The group is currently building a co-op for the solar garden and will eventually work <u>Allina Health</u> with Xcel Energy to get credits to members.

all together better.



Givens Brain Tumor Staff

Andrea Wasilewski, MD - Neuro-Oncologist, Medical Director
Maya Hrachova, DO – Neuro-Oncologist, Medical Director
Tankia Barnes - Medical Assistant
Lani Hoese – 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
Katie Brusnahan, Social Worker, LSW
Deborah Jones – Care Guide, MA
Kelly Mehlhorn- Clinical Services Supervisor, RN, BSN, CNRN
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
Scan this QR code with your phone's camera to access the website.