



# Grey Matters

Newsletter of Givens Brain Tumor Center

Summer 2024

## Welcome

### Dr. Andrea Wasilewski Medical Director



Welcome to the summer 2024 edition of our Grey Matters newsletter! As we enter warmer months, we here at the Givens Brain Tumor Center have a lot to be grateful for. Our team is growing, and we are looking forward to expanding the services and care we offer to all our patients. In this issue we share a wide range of topics including inspiring patient stories, clinical and research updates, disease state information and tactical tips for maintaining our well-being during the summer months.

I'm thrilled to announce the arrival of our new neuro-oncologist, Dr. Maya Hrachova! Dr. Hrachova joins us from her position as the Medical Director of Neuro-oncology at the Peggy and Charles Stephenson Cancer Center at the University of Oklahoma. She completed her Neuro-oncology fellowship at Mayo Clinic in Phoenix, Arizona and her Neurology residency training at University of California, Irvine. Dr. Hrachova is a force. Her clinical expertise, research background and kind bedside manner will be a wonderful addition to our team.

I am also very excited to introduce Seth Hartman, APRN, CNP, as a key member of our brain and spinal cord tumor team! Seth comes to us from within Allina with extensive patient care experience. His energy, compassion and knowledge will be a great asset to our team!

Will Majerus, BSN, RN, CNRN, also joined our team earlier this year with extensive nursing experience in neuroscience, most recently as part of Allina Health's stroke program. We thank him for his willingness to jump right in and get involved during a time when we were short staffed. Thank you, Will!

Please join me in providing Dr. Hrachova, Seth, and Will, with a warm welcome!

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## Givens Brain Tumor Center

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## Dr. Wasilewski

Our monthly support group continues with dedicated sessions for both patients and caregivers, allowing for unique peer connections in a facilitated format. We are grateful to Rebecca Moore and Deborah Jones who continue to support this program.

In this newsletter you will find stories from our inspiring patients and caregivers. The stories you will read will resonate with you and show the strength and compassion of these amazing individuals. You will find community resources for supportive care resources and information about upcoming fundraising events. Please take a moment to voice your experience with healthcare services by participating in the University of Pittsburgh voluntary, anonymous survey for persons with primary brain tumors. See page 11!

In our healthy lifestyles to promote good brain health section, our Research Nurse, Katrina Stremski, shares lifestyle tips for keeping healthy during the summer months. Summer is a great time to spend time outdoors with friends and family, engage in various physical activities and savor healthy and nutritious food! I hope that this information inspires you to incorporate more physical activity into your lives!

Neurorehabilitation is critical at many points during your cancer journey. Many of you have benefited from therapies such as speech, physical and occupational therapy. Our Cancer Rehabilitation program at Courage Kenny Rehabilitation Institute (CKRI) is a key partner in brain and spinal cord tumor care. Dr. Liat Goldman from CKRI shares valuable information about the role of rehabilitation medicine and the ways it helps patients.

Dr. Glen Varns, Medical Director, Hospice and Palliative Care; and Katy Hentges, NP-C, Clinical Director for Palliative Care; wrote an article about hospice and how it is beneficial for you and your loved ones as part of your treatment journey.

And we have a patient story describing Adam Bahr's experience of a stem cell transplant as a result of a CNS (Central Nervous System) Lymphoma diagnosis and recurrence. We included an article, also by Katrina Stremski, about this rare and aggressive cancer that affects the immune system in the brain or spinal cord.

As always, our team remains dedicated to providing the highest level of cutting edge, multidisciplinary neuro-oncologic care. I am eternally grateful to each of you and thank you for letting us be part of your journey.

Dr. Wasilewski

# The Whole Way to Better



## WELCOME to New Staff



### Dr. Maya Hrachova

Hello everyone!

It is my pleasure to join Dr Andrea Wasilewski and her team at the Givens Brain Tumor Center in May 2024. I am a board-certified neurologist and neuro-oncologist who specializes in the diagnosis and treatment of primary brain and spinal cord tumors, primary central nervous system lymphoma, brain metastases, neurofibromatosis and neurological complications of cancer including paraneoplastic syndromes. I completed my neurology training at the University of California Irvine followed by a Neuro-Oncology fellowship at Mayo Clinic in Phoenix, Arizona. Subsequently, I served as an Assistant Professor at

the University of Oklahoma in the Department of Neurosurgery where I solidified my practice philosophy where I place the utmost importance on establishing partnership with patients and their families.

In addition to clinical care, I am also actively involved in research, and interested in developing clinical trials for patients with brain metastases, leptomeningeal carcinomatosis, meningiomas and neurofibromatosis. I am excited to work closely with an outstanding multidisciplinary team at the Givens Brain Tumor Center and at Allina Health where we bring together expertise in neurosurgery, neuropathology, neurology, neuroradiology, hematology-oncology, and radiation-oncology in order to deliver exceptional medical care. And of course, it is my true honor to partner with you and your loved ones to provide the state-of-the-art neuro-oncological care, clinical trial opportunities, support and help to navigate your brain or spinal cord tumor journey. I look forward to meeting many of you soon!



### Seth Hartman, APRN, CNP

I am joining Givens Brain Tumor Center with a great deal of excitement in the anticipation of contributing to whole-person care. I grew up in Wisconsin but have been living in the Twin Cities Metro Area for several years now. Being a true Midwesterner, I knew early on that I would pursue a career which allowed me to connect with people as I enjoy socializing; both sharing stories about myself and hearing about others' stories as well. Healthcare has offered me the ability to connect with people that few other professions would. I graduated with a bachelor's degree in nursing from George Washington University. After just a couple short years of inpatient care, I desired to contribute more by pursuing a greater scope of practice. I returned to George Washington

University and successfully completed advanced practice training and Nurse Practitioner certification. Neuro-Oncology is a medical specialization that I am passionate about and offers the opportunity to use my experience and education to continue building relationships.

Outside of healthcare I am a husband and father of two toddlers. My family and I enjoy traveling, playing, watching sports, and whatever else may burn a toddler's energy.



## Will Majerus, BSN, RN, CNRN

It's been such a pleasure meeting many of you and your families in the first few months here at the Givens Brain Tumor Center. I look forward to getting to know you even more this summer. Neuroscience has been my passion since I graduated nursing school in 2016 from the University of Minnesota (Go Gophers!). The Givens Brain Tumor Center piqued my interest after observing many brain cancer survivors over the years as a nurse and their inspirational stories. The strength, love and gratitude I've absorbed from all of you, along with the Givens Team has been incredible. My goal is to cultivate a relationship with all of you here and support you and your families navigate the complex world of living with a brain tumor.

I'm originally from Roseville, Minnesota and live in the metro area. If you don't see me at clinic, you can definitely find me outside biking, running, hiking, camping or fishing. I love the outdoors, but nursing is my true passion! I continue to work at the University of Minnesota as a neuroscience nurse in the inpatient setting on the weekends and chair a non-profit for neuroscience nursing education. I'm the youngest of 5 siblings and a million nieces and nephews. Family time is crucial to my well-being as I'm sure is the case for many of you. The Givens Brain Tumor Center is a special community and I look forward to being a part of this family.

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# CONGRATULATIONS!

## **Rising Star:**

Our very own, Dr. Andrea Wasilewski, was recognized as a Rising Star in the April, 2024, issue of Mpls St. Paul magazine. “Deeply vested in understanding the complex needs of their patients, these doctors are in it for the long haul and love being part of the patient journey. They not only help people navigate a crisis or unexpected setback but also help them understand and manage the potential challenges ahead. These doctors are among the many standouts in our 2024 Rising Stars list of specialists who have been recognized for significant achievements in their first decade as professionals. These doctors are advancing treatments, improving care, and using their talents to help individuals get and stay healthy.” Each year, there is a rigorous process for selection as a rising star. You can read more about it here. [2024 Top Doctors: Rising Stars Edition - Mpls.St.Paul Magazine \(mpsmag.com\)](https://www.mpsmag.com/2024-Top-Doctors-Rising-Stars-Edition)

## **Allina Health Stroke Hero Award!**

Will Majerus, BSN, RN, CNRN, was one of the winners for the 2024 Allina Health Stroke Hero Award! This award is given throughout the year to those individuals who have demonstrated a commitment to stroke prevention and care makes a difference in the lives of patients every day. Congratulations, Will!

## **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



Ahh! It is summer in Minnesota. There is color blooming everywhere amongst the green foliage of the trees, bushes, and grass. The mosquitos are out and the bees and hummingbirds are filling their bellies with nectar. The mornings start early from the late night slumber, and evenings end late into darkness. The lakes are busy with little children wading at the edge, canoe paddlers moving quietly through the still waters, and big boats sailing down the river or on the lakes. There are fresh vegetables from the farmers' market or from our own gardens devoured at family reunions. Musicians are happily playing their guitar or violin at the local outdoor concert to happy and contented audiences. Thunderstorms appear with their billowing, threatening clouds releasing loud thunder, lightning, and a thousand raindrops that satiate our trees and fields of corn leaving puddles of still water on the sidewalks and roads.

We have a summer issue full of fresh new stories and articles and a couple recipes you might enjoy.

We hope you will take the time this summer to recharge. Turn to page 20 and read about the ways you can recharge your brain including getting outside and experiencing the colors around you and on your picnic plate! Share your unique story with others which can be healing and help them learn about you and your experience! Go play in the puddles! Go to an outdoor concert!

We are excited to welcome our newest neuro-oncologist, Dr. Maya Hrachova, who joined us in May! Seth Hartman also recently joined us a Nurse Practitioner along with Will Majerus as a Nurse Navigator. We look forward to continuing to grow our practice and serving more patients and their families.

I am very proud of our team who strives to provide the best care and support for you and your loved ones. We realize your journey with your brain or spinal cord tumor is unique and personal to you and it is our intention to ensure we serve you in that manner.

As soon as we publish a newsletter we start thinking about our next issue. We want to provide stories you can relate to along with articles to help inform you about brain and spinal cord tumors, treatments, the latest research, and more. We would love your suggestions, ideas, and your contributions, too! I can be reached at [deborah.jones@allina.com](mailto:deborah.jones@allina.com) or 612-424-1076. Or you can call the main phone number at 612-863-3732.

Happy Summer!





# Patient Stories

“ I thank God for my cancer. ”

## Denise Folkerts

*Family, Friends, and Faith in God*



I am so thankful for my family and friends, and I thank God for my cancer. I was diagnosed with Glioblastoma, five years ago, in May, 2019. My treatment has included two surgeries, chemoradiation, 12 cycles of temozolomide, lomustine through the AGILE clinic trial, and most recently Bevacizumab infusions. To be honest, I was never really devastated by this change in my life. I know that God works things out.

After a year of college in Nebraska on a voice scholarship, I joined The Reach Out Singers in 1984 and toured with them throughout the Midwest, Germany, Switzerland, and France. When it was over, I moved to Chicago with some of my touring friends and stayed there for 9 years. I was actively involved in my church there as part of the worship team and a soloist. I often sang at weddings and probably the last time, at my father’s second wedding in 2006.

Eventually, I moved back here to the Burnsville area where I had grown up. I worked for 25 years. as a buyer and inventory manager. The work was challenging and I did the best job I could at an organization that was very male dominated. I received many accolades during my years with my employer. I have been overweight much of my adult life which felt like an obstacle keeping me from other career opportunities. My diagnosis with glioblastoma ended my career.

Selling Longaberger baskets was an important part of my life for many years. My Longaberger business gave me the opportunity to collect many of their baskets which I have displayed in my condo. My sister, mom, and I went on a bus trip to Dresden, Ohio, to see the Longaberger headquarters. My mom came to all of my parties and bought my first basket.

My sister, Lisa, who has been an RN with the Allina Health system for more than 30 years, has been there with me the through this entire journey. She helped me find my neurosurgeon, takes me to appointments, and generally is always available. We have a tradition of going to Applebee’s after my appointments. Lisa and her husband, Jim, have a daughter Elisha who is in college in Tennessee. My brother, John, lives in Rochester with his wife Karla, and has four adult children and a few grandchildren. I have always been close to my nieces and nephews – Gretchen and Jesse, Teddy and Allie, Kathryn and Nick, Peter and fiancé Heidi, and Elisha – and have kept in touch with them wherever they are living. I hope to dance with Peter at his wedding in July.

My parents adopted me in 1961. Even though I grew up knowing I was adopted, I accepted it. Around the time of my brain cancer diagnosis, I found my biological sister, Julie and my Aunt Rita, but my biological mother had passed away earlier. The journey finding them has been very healing giving me more gratitude for the family who adopted and raised me.

I wouldn’t have survived as long as I have without my family, my friends, and my faith in God. They have been so supportive walking with me throughout this journey.



Me and my biological sister Julie.

My adopted family. My sister Lisa is on the far right standing next to me.





## “ Cancer does not define me. ”

### Heather Kuikka

*Maintaining my sense of humor has helped me*



My name is Heather, I was diagnosed with Glioblastoma on December 8, 2022, at the age of 48. I knew something was wrong starting in mid-October of 2022. My symptoms were getting worse every day to the point I couldn't even remember my phone number and I could no longer read or write. My husband and I didn't carpool very often, but that day we did. After he dropped me off at work, I started feeling more off than usual. I thought I was having an anxiety attack and I started texting John to come and get me and take me to the hospital. Fortunately, a few co-workers came in to work early and I was able to communicate with them that something was wrong. I was taken to the hospital that was less than a mile away. They did a CAT scan and noticed something wasn't right. I was then transported to Abbott for further testing. The MRI showed a tumor the size of a

lemon and surgery was scheduled. The following week I had a doctor's appointment to go over the findings of my tumor. I found out it was terminal cancer with hopefully two years to live. As of May 2024, I have survived this cancer for 17 months.

It was devastating news, there was so much I had planned for my future. I didn't know how the cancer was going to affect me, both mentally and physically. After the initial shock wore off, my husband and I started planning for the inevitable. We sold our house and moved into a large apartment knowing that eventually stairs might be too difficult for me. As time went on, my outlook on everything had changed. I've always been a strong and independent person that took on many challenges and conquered them. I became determined to live life as normal as possible, so much so that most people don't believe I have terminal cancer. I believe maintaining my sense of humor has not only helped me, but it's helped others when they don't know how to react to someone who has a terminal illness.

I decided that cancer wasn't going to deter me from living my life as normal as possible. I've worked at Three Rivers Park District for 18 years and I am still there working full-time. I also went back to working at Walmart on Saturdays because it keeps my body and mind active. I'm slowly increasing my exercise by walking my dogs a little further each week. I was so worried we wouldn't be able to go on vacations because I was "sick". Then I remembered who I am and what is important to me, travelling and enjoying life. We have gone on many trips and have a few more planned this year. The most important thing, I was able to travel to Georgia a couple weeks after my surgery for my daughter's wedding. Cancer does not define me.







## Adam Bahr

*I'm so thankful for all the people who love me regardless of how I feel*

“ I beat PCNSL twice! ”



My name is Adam Bahr, I'm 41 years old and in the span of 3 years I was able to beat Primary Central Nervous System Lymphoma (PCNSL) twice! It wasn't easy but I am blessed with an amazing wife, loving family and a great cheering squad and the absolute rockstars at Abbott Northwestern / Givens Brain Tumor Center. If even one piece of that equation was removed, I'm not sure I would have made it to where I am today.

It all started in January of 2020 with what I had assumed at the time was a recurrence of an episode of bipolar depression. After being diagnosed with Bipolar Disorder I in my early 20s, much of my adult life has been learning to live life to the fullest while maximizing stability and minimizing risk.

To that effect I take all my medications as prescribed, abstain from drugs

and alcohol, exercise regularly, and in general stay pretty attuned to my sense of self. When I started having extreme problems in social situations (barely able to put together a sentence), sleeping a ton, and underperforming at work, I thought that I had just forgotten how bad depression could be. In February we had a big family trip to Mexico planned; we were all hoping a change of scenery and some sunshine would help me get out of the “funk” I found myself in. A series of events while in Mexico (falling into my suitcase, bouncing like a pinball off various objects while walking down the street, barely making it through customs) led to the decision to call a provider of mine back at home. While talking to a nurse at the clinic, I was unable to state my name and birthday when asked – that's when I knew there was something deeply wrong with me. A little over 24 hours later I was in the ER in Mexico and ended up getting a CAT scan because that was all that was available at the location. It showed a large mass in my brain. At this point my language was so limited that when my girlfriend (now wife) and my dad broke the news to me, all I could do was laugh. My internal thoughts weren't nearly as impacted as my ability to express them was – I was terrified that I was going to be stuck, trapped in my own head, forever.

Not long after the CAT scan we were on a flight back to MN and the emergency room at Abbott Northwestern. Over the next week, a lot of diseases were ruled out, but after a brain biopsy I was given the news that nobody wants to hear... you have brain cancer. The next day Patti Bruns (Givens Brain Tumor Center Clinical Nurse Specialist) came to give us more information about (PCNSL); in the flood of information I was presented, one sentence stuck out more than any other, “it's really rare”. In my head rare equaled hard to treat...luckily, I was wrong about that! Patti explained that if I could survive the chemo I had good odds of melting the tumor (who is not so affectionately referred to as “Lumpy”). The frontline treatment for PCNSL consists of high dose Methotrexate which is delivered in one 4-hour infusion on the first day. The quantity needed to get through the blood brain barrier is large enough that, when combined with the color, it always felt like I was getting shot up with a two liter bottle of Mountain Dew. After the infusion, the waiting game began to see how long it would take for my body to clear the drug, which meant I could go home – the lucky number I was always hoping to hear was “under 0.1”. Because all this treatment was happening right as COVID was starting to run wild, I was only able to have visitors for the first two treatment cycles. I wasn't nearly as lonely as I thought I was going to be thanks to all the AMAZING nurses at Abbott on the oncology floor – I consider many of them friends at this point. The cycles of treatment continued for roughly 4 months, (every other week for 8 treatments) and by the end of it I heard the words that every cancer patient dreams of, “no evidence of active cancer”.

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I went on to live some of the best moments of my life, the highlight was marrying my amazing wife Jessica, up until December of 2022. During one of the quarterly routine MRIs I would be getting for the rest of my life, I got the news that Lumpy had returned. We couldn't believe it. I was feeling so good without any of the scary symptoms from 2020...knowing that Lumpy can be plotting his return even when I feel great is not a comforting fact and contributes to a good amount of "scan anxiety" that I still struggle with. Dr. Waslewski and the dream team at Givens went right to work getting my port installed within the next couple of days and before I knew it, I was back on the 3<sup>rd</sup> floor at Abbott Northwestern Hospital with my oncology nurses and my weekly dates with high dose Methotrexate. Because it had done such a good job at melting Lumpy the first time and we saw a solid decrease at the midpoint of treatment there was no reason to think it wouldn't be gone again. Unfortunately, Lumpy had learned more tricks while he was away and I needed to get a couple of doses of Cytarabine and Thiotepa in an attempt to get rid of the cancer before my autologous system-cell transplant planned for July 2023 at the Mayo Clinic in Rochester. The first round of that chemo put me in the hospital with a neutropenic fever and was the first time throughout this whole ordeal I was afraid I was going to die. The fever eventually broke, and I was cleared to get my pre-transplant testing done at Mayo. Part of this testing was another MRI which showed that some cancer remained after the initial dose of Cytarabine. I advocated for a second dose in an attempt to kill the rest of the cancer and Dr. W agreed so it was back to Minneapolis for my last round of chemo at Abbott.

We got the amazing news that the cancer was gone after the second round, and I was confident heading into transplant that any microscopic remnants of Lumpy would be eradicated with the extremely high doses of chemotherapy given prior to the stem cell transplant. One thing to mention is that steroids are generally given as a pre-med for many chemos to help mitigate the side effects. Unfortunately, steroids also have been proven to trigger manic or hypomanic episodes in me. The chemo prior to the stem cell transplant triggered the most intense manic episode of my life. I announced my intention to run for President (in my quickly deleted episode of my podcast, The Bahr Mitzvah Party), I thought I was Professor X from the X-Men and I wasn't sleeping at all. I am forever thankful to my dad, wife, brother and Aunt Kathy who were my caretakers at the transplant house and helped see me through that nightmare. From a cancer point of view, everything is great – every scan so far has been as clean as can be. Unfortunately, I am still deeply struggling with rebound depression from that manic episode in July. Fatigue and depression are common side effects post-transplant and I'm confident that my pre-existing condition is contributing to my situation. It could also be that having multiple tumors and all the chemo associated with the treatment over the course of 3 years had an adverse effect as well. Ultimately, the root cause of "why" doesn't do much good as treating mental health conditions involves trial and error. There isn't a "scan" I can do to measure how well my Bipolar Depression is responding to medication or therapy. I'm not one to give up and I encourage anyone who is struggling with a cancer diagnosis to be open and honest about your feelings and seek help. I have faith that I will feel like myself again one day and I'm so thankful for all the people who love me regardless of how I feel.





# More About PCNSL, Primary Central Nervous System Lymphoma

**Katrina Stremski, RN, OCN, PHN, MN, MA**  
**Research Nurse**



Primary Central Nervous System Lymphoma (PCNSL) is a rare and aggressive form of cancer of the immune system, affecting the brain and spinal cord. It originates within lymphocytes, a type of white blood cell, which help the body to fight infections. When normal cells begin to behave in an abnormal way, for example, multiplying out of control, they can overtake healthy cells and become cancerous. With PCNSL, this most commonly occurs in the B-cells, but can happen with T-cells as well. Even though the cell origin of the cancer is that of white blood cells, it is considered a primary brain tumor. The difficulty with all brain tumors is due to the difficulty in treating them due to the brain's protective mechanism called the blood brain barrier. The blood brain barrier is a tight layer of cells that which maintains the health of your brain. It prevents harmful substances from getting into the brain as well as holding good things in the brain to maintain the correct chemical balance.

Although we do not know the cause of PCNSL, there are associated risk factors for developing the disease including having an immune disorder or disease which already weakens the immune system, having had the Epstein-Barr virus, HIV/AIDS, history of an organ transplant, or being over the age of 60. Because the cause is not known, there are no recommendations of actions to be taken to avoid developing PCNSL.

As with all brain tumors, the region of the brain where the lesion or lesions are located can dictate the symptoms that one presents with. Neurological changes may occur rapidly over weeks to months and range from non-specific to focal. Some common first symptoms could be confusion, weakness, headaches, nausea or vomiting, memory loss, seizures, or difficulty speaking. Steroids may be used to treat some of the initial symptoms however they are not started until the diagnosis of PCNSL is made.

To make the diagnosis of CNS Lymphoma, different tests/procedures are completed including MRI, CT, and/or PET scan imaging, surgery to obtain tissue to provide a clear diagnosis, a lumbar puncture to test the spinal fluid for cancer cells, and blood tests to test various laboratory values. An eye exam by a neuro-ophthalmologist is also required because PCNSL can occur in the eyes as well. The staging of the cancer also takes place during diagnosis which allows doctors to classify the size, location, and spread of the cancer beyond where it started. It is rare for PCNSL to spread outside of the nervous system although it can happen.

Treatment for PCNSL will be determined with a patient's care team and usually consists of chemotherapy with high-dose methotrexate, oral temozolomide and a monoclonal antibody called rituximab. If a patient has an appropriate response, a stem cell transplant may be recommended. Other treatments include the use of targeted treatment drugs such as ibrutinib or radiation to the whole brain.

PCNSL can be difficult to treat, and it is important for treatment to begin as soon as possible after the diagnosis is made. Although the treatment is intense and time-consuming, survival is possible for some patients. The Given's Brain Tumor Clinic team is proud to serve our patients and their care partners during this difficult time of diagnosis and treatment. We are honored to be your partner in health and wellness.



# Courage Kenny Rehabilitation Institute (CKRI) Rehabilitation Specialists in Neuro-oncology

## Dr. Liat Goldman Physical Medicine and Rehabilitation Physician



Most patients have never seen a Physical Medicine and Rehabilitation specialist before they were diagnosed with a brain tumor or spinal cord tumor.

Here's an introduction:

Rehabilitation doctors work collaboratively to help someone improve function and mobility.

At Allina, the Cancer rehabilitation program works with patients who have benign tumors and cancerous ones. Sometimes we treat problems that are directly related to having a tumor in a specific part of the brain or spinal cord. Other times we help with people who have more general weakness or mobility concerns.

In addition to prescribing these different types of exercise-based therapy, rehabilitation physicians can assist with equipment like braces or walkers, medications to alleviate stiffness or pain, and do additional work up to identify a problem.

We specialize in treating the whole person to improve independence and quality of life. We can help people with a wide range of problems from muscle pain or difficulty using a keyboard to difficulty with getting dressed or walking.

We work with you to prioritize your biggest concerns and collaborate with PT, OT and SLP to help you get the best and most targeted treatment for your problems.

Here are some ways that we commonly help patients:

1. Nerve pain or discomfort: we will figure out the cause of the symptoms and provide medication and therapy to address the problem. We will also check balance and how well a person is walking as these things can be affected as well.
2. Muscle stiffness/pain or joint injuries: in addition to PT or OT, we often check Xrays or MRIs, prescribe medicines that reduce stiffness or pain, and do procedures like joint injections or muscle injections to help decrease pain and improve movement.
3. Difficulty with walking: we help identify the main cause of a problem. Sometimes this is helped with a brace to keep your foot from catching on the ground, or a brace to stabilize a joint. Some patients have weakness on one side and need equipment to be able to move more independently. We can also help with prescribing equipment for your home, starting home health treatment and transitioning to outpatient treatment.

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4. Difficulty with thinking or concentrating: We can help by identifying if the problem is with speaking and producing language or with concentrating and thinking. We often order additional assessments to test where you are having trouble with concentrating or organizing information and with figuring out how to accommodate for the problems you are having.
5. Difficulty swallowing: we work with speech and language pathologist (these people are swallowing specialists) to improve your ability to eat and swallow different textures and consistencies of food. We also often work with a registered dietician to help make sure you are getting the right nutrition to get stronger as quickly as possible.
6. Swelling: we treat different types of swelling. Sometimes we do additional testing to determine what is causing the swelling and we also prescribe equipment like compression stockings that can help decrease swelling long term.
7. Fatigue: we work with strategies to improve mobility, address sleep, pain or mood, and improve nutrition in order to address lack of energy and improve speed of recovery from surgery or other treatment.

If you feel you would benefit from seeing a cancer rehabilitation provider, you can ask a member of your Neuro-oncology team to send a referral. From there, you'll be scheduled for a comprehensive evaluation. Prior to the appointment, our Cancer Rehabilitation Nurse Navigator will contact you or your family members to get information on your reasons for the visit and your concerns.

The cancer rehabilitation program has comprehensive services in multiple locations in the Twin Cities area. Our 2 main physicians are Dr. Liat Goldman (Medical director) and Dr. Sara Lay. Our Nurse Practitioner is Erin Swift. Our Nurse Navigator is Connie Brenna. We're committed to partnering with the Givens Brain and Spinal Cord Tumor Center and work with a large team to provide services within the Twin Cities and greater metropolitan area.

For more information or to make an appointment contact the scheduling line at **612-863-2123**.





# How Does Hospice Fit into My Care as a Patient?



**Dr. Glen Varns**  
Medical Director, Hospice  
and Palliative Care



**Katy Hentges, NP-C**  
Clinical Director for Palliative Care  
and System End of Life Care

For individuals with brain tumors, it can be particularly difficult to think about hospice as an option in treatment. Brain tumors have been difficult to treat for such a long time, and now that we have more sophisticated treatment, it is possible for individuals to live well for many years. Understandably, the focus of patients and their caregivers is often on treatment, managing side effects and trying to live each day as well as possible.

What we'd like to do is offer several thoughts about when and how hospice can fit into the care of a person with a brain tumor, in the form of some questions and brief answers.

*Q: What is hospice?*

A: This is an important question, and not simple to answer! At its heart, hospice is a philosophy of care that prioritizes the physical and psychological comfort of an individual with a terminal prognosis. It helps the patient and their caregivers cope during the dying process. Hospice care is delivered wherever a person lives by a team of caregivers representing nursing, medicine, spiritual care and social work, among other disciplines. The team makes intermittent visits to the patient's home; they are not usually present 24 hours a day.

*Q: How is hospice different from palliative care?*

A: At their cores, hospice and palliative care are very similar things—they both seek to reduce suffering in people with serious illnesses. The main difference is that palliative care can be given alongside attempts at curative care (such as chemotherapy) whereas hospice is typically reserved for persons who either don't have or don't desire to receive curative care. The other main difference is that hospice access is typically limited to individuals with a terminal prognosis.

*Continued on next page*



*Q: What do you mean by a terminal prognosis?*

A: A terminal prognosis means that in the normal progress of illness, the individual will likely live less than six months. Medical providers use a variety of data to inform their ideas about prognosis, including scans and response to treatment, but we also use how a patient is functioning day-to-day to tell us what the future will look like. It is common for patients with brain tumors to be referred to hospice when they have developed much more difficulty with mobility or swallowing, or when they are having more difficulty with seizures or control of agitation. It is also common for patients to consider hospice when the side effects of treatment are greater than the benefit of additional treatment.

*Q: What does hospice do about the symptoms? Will I have to take morphine?*

A: Medically, one of the main things hospice does is to figure out what is bothersome to the patient and use simple regimens of medications to treat those symptoms. If pain is a significant problem, we do sometimes use opioid medicines like morphine, but not always. The priorities of the individual and their caregiver always lead the way.

One thing that often surprises people about hospice is that we will continue many of the medications that have been helpful for preventing seizures and reducing tumor growth that leads to distressing symptoms. These include most seizure medications and steroids, although we often have to alter the regimen when individuals develop more difficulty swallowing, as many of these medications come in pill forms that can't be crushed.

*Q: How does hospice help caregivers?*

A: Perhaps one of the greatest benefits of hospice care is that it provides a set of resources that help caregivers gain the skills they need to care for someone at home. Hospice nurses and aides help caregivers learn to do physical cares safely, and help them spot changing symptoms and make a plan so that the caregiver knows what to do as things change. Social workers and spiritual care providers can help everyone involved process the many things they may be feeling. Grief counseling is available while the individual is in hospice and for 13 months after they have died.

Another way that hospice helps caregivers is by helping spot when care is no longer feasible in a home setting. When that happens, we work with caregivers to identify available alternatives including residential hospice homes.

*Q: What advice would you give someone who is thinking about hospice, but not decided yet?*

A: Our advice would be to have honest conversations with your caregivers and your medical providers about what makes for good quality of life, and to keep those conversations going as you go through treatment. This will help your caregivers and your providers understand your values and priorities as the illness changes.



# Home Hospice Care Overview

## Becky Moore, LICSW



### Purpose of Hospice

The last stages of a terminal illness can be very difficult for patients, their families, and their caregivers. Hospice is a special type of care that seeks to make the time easier. Hospice treats the physical, emotional, and spiritual needs of the patient, and focuses on comfort and having the highest quality of life possible. This is known as comfort care. Every hospice patient and family is assigned to a hospice team who will work with them and the patient's caregiver to create a plan of care according to the patient's needs.

### Home Hospice Team

The hospice team provides comfort care in your home when possible. Your team may include: nurses, social worker, home health aide, chaplain, primary care provider, nurse practitioner (NP), pharmacist, volunteers (and a volunteer coordinator). Grief counselors, therapists and dietitians may also be a part of this team if needed.

Nurses are available by phone 24 hours a day, 7 days a week and make home visits as needed. The nurses check your health status, help with medical needs, treat and monitor your physical symptoms, and help your caregiver properly care for you.

### Home Hospice Services

Care Coordination It can be difficult to know what type of care is needed at each stage of illness. Care coordinators are available to help determine what type of care is needed and connect you with the resources to get that care.

Personal Care can include bathing, shaving, dressing changes, linen changes and household services to keep a safe and clean living space. Hospice home health are trained and certified to help with personal care for the patient in his or her home.

Symptom Management is also called comfort care. It treats the physical, emotional and spiritual needs of the patient while focusing on comfort and having the highest quality of life possible. The nurse case manager provides pain and symptom management. He or she is a registered nurse (RN) and may also be a certified hospice and palliative care specialist.

*Continued on next page*





Companionship and Support is available through trained hospice volunteers. A volunteer coordinator on the hospice team will call the patient or the family to talk about how a volunteer might help. Volunteers can help by visiting patients for socialization, providing respite to give a caregiver a break from caregiving responsibilities, doing light housework or preparing meals.

Spiritual Care is a broad service available to the patient throughout his or her stay. It is tailored to the patient's personal and spiritual points of view, regardless of his or her faith, religion, or cultural background. The chaplain can provide spiritual and emotional support by listening to the patient's life stories and experiences and talking about any spiritual concerns the patient may have. The chaplain also provides guidance and explores the role of spirituality in illness, suffering and healing. Together, the chaplain and the patient's spiritual leader make sure the patient is getting the highest quality of spiritual care.

Grief Counseling is available for 13 months after the patient's death. Family members will receive information about grief counselors at Allina Health Hospice by mail after the death of their loved one. Some of the resources available include booklets and bibliographies, [referral lists for local support groups](#), phone counselors, volunteer grief support visitors and grief counselors.

Community Resources can be recommended through your social worker. Resources and services may include patient counseling, family or caregiver counseling, financial and legal information (such as power of attorney, Family and Medical Leave Act, money management or social security application), discharge planning, children's support and patient and family advocacy.

Other Therapies such as physical, music and massage therapy are available on a limited basis. These therapies are used to treat the patient's symptoms and make the patient more comfortable. Your case manager will be able to determine availability of these therapies based on the patient's plan of care.

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

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



# 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.

## When:

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

## How:

Support groups 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](mailto:GivensBrainTumorCenter@allina.com)**  
**Or call for more information: 612-863-3732**





# Neuro-oncology Research



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



Research plays a crucial role in treatment for brain tumors, by driving advancements in understanding the disease, developing innovative therapies, and improving patient outcomes. Clinical trials allow researchers to evaluate the safety and efficacy of new treatments, and participating in clinical trials allows patients access to cutting-edge drug & device therapies that may not be available through standard treatment options. As more patients with brain metastases are receiving care at Givens Brain Tumor Center, the Neuro-oncology Research team works to add to our clinical trial menu to serve this patient population. In collaboration with neurosurgery, medical oncology, and radiation oncology providers at Allina Health, we recently opened the ROADS study: Post-Surgical Stereotactic Radiotherapy (SRT) Versus GammaTile-Radiation One and Done (ClinicalTrials.gov identifier: NCT04365374).

ROADS compares 2 FDA-cleared radiation treatments: GammaTile® Surgically Targeted Radiation Therapy (STaRT) and stereotactic radiotherapy (SRT) for patients with metastatic brain tumors, also called secondary brain tumors. This trial compares a variety of outcomes important to people with brain tumors, including functional status, quality of life, neurocognitive status and safety.

We are continually evaluating new clinical trials and diagnostic tools to advance the care our patients receive; our dedicated team of research nurses and study coordinators look forward to partnering with you in your care.

## Research Opportunity!

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 and 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.

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://johncolquhanna.com/jc/forms/SV\\_TotBt\\_VXBLVGS5NU](https://johncolquhanna.com/jc/forms/SV_TotBt_VXBLVGS5NU)

Family of persons:  
[https://johncolquhanna.com/jc/forms/SV\\_Sga\\_Skaf4799xy](https://johncolquhanna.com/jc/forms/SV_Sga_Skaf4799xy)

**QR Code**

Persons with brain tumor:

Family of persons with brain tumor:



# Healthy Lifestyles to Promote Good Brain Health

Here we focus on healthy lifestyles to help promote good brain health, which is important for all of us.

## Brain Summer Refresh

Katrina Stremski, RN, OCN, PHN, MN, MA

The seasons are changing and so is your brain! With summer right around the corner, we are transitioning from our winter slowdown into our summer refresh. These longer, warmer days promote a bloom in brain activity, cognition, and mood, and increases the size of the brain! Now is the best time to prioritize diving into mental health and overall wellness. Pour yourself a large glass of water, open those windows, and get out your hats, and sunscreen; because we have some ways to help you kick-start your summer. Reframe this as your summer of wellness.



**Get outdoors and take a deep breath!** Physical activity decreases stress, improves memory, supports the immune system, sharpens thinking, and boosts energy. Take a walk along the water, find a new favorite bench, try out forest bathing, enjoy some local music, or have a picnic.

**Eat in color!** Let your plates reflect the beauty of the season by trying new fruits and vegetables. Visit a farmer's market and see how many colors you can include on your plate. Not only will it look beautiful, but those exciting colors are nutrient-dense foods that will make you smile as they boost cognitive function and focus.

**Take a pause.** Go ahead and squeeze the most out of these summer months, but remember it is important to give yourself time to rest too. Take a break between the activity and heat. Sit outside with a book and breathe deeply or perhaps take a 10-30 minute power nap. Pausing invites a feeling of refreshment and adds peace to our days.

**Spend time with friends and family.** Create special memories with your loved ones, try a new activity together, or play a game. Social connection boosts mental health and increases quality of life as well as stimulates attention, and memory, and strengthens neural networks. *Continued on next page*





# Healthy Lifestyles to Promote Good Brain Health

**Keep your routine.** Our brains need sleep to function their best, so keep your schedule consistent to ensure you are getting at least 7 hours to recuperate overnight. For your best sleep, stick to your sleep schedule 7 days per week, keep your bedroom comfortable, exercise during the day (preferably outside), avoid caffeine, alcohol, and large meals before bedtime, limit napping, and disconnect electric devices an hour before bed.

**Reflect and share your story.** Laugh and connect with old and new friends. Each of us is on a unique journey, and when you open and share your story, you not only form closer bonds but also experience gratitude and empower others.

You don't have to stray far from home to enjoy your summer, start boosting up your Minnesota bucket list with the best that our state has to offer. Wherever your season takes you, please remember to stay sun-safe, cover up, reapply sunscreen frequently, and hydrate well.

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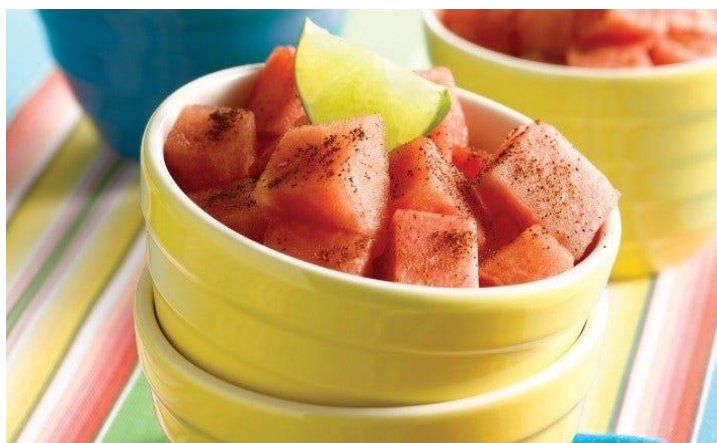
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This is a great recipe for parties and family gatherings during the summer. Other seasonal fruits can be used in place of watermelon, such as peaches, other melons, papaya, or any combination of berries. For younger children, you can omit the chili powder or use less.

**Prep Time:** 5 minutes  
**Total Time:** 5 minutes  
**4 Servings**

**Watermelon, cubed, 4 cups, chilled**  
**Chili powder, 1 teaspoon**  
**Salt, to taste**  
**Limes, 3, divided**



Place the chilled watermelon into individual glasses or glass bowls.

Mix the chili powder and a pinch of salt together. It is best to put the mixture in a salt shaker to better control the amount of spice being sprinkled onto the watermelon.

Juice two limes. Sprinkle the watermelon with lime juice and the chili powder mixture, according to your preference.

Cut the remaining lime into wedges and serve with the watermelon.

**Excerpted from:** Maya's Secrets, Copyright ©2013 American Cancer Society.



# Healthy Lifestyles to Promote Good Brain Health



## Ingredients

- 2 (15-ounce) cans black beans, rinsed and drained
- 1 cup fresh, frozen, or canned no-salt-added corn, drained
- 1 tomato, chopped
- 1 red, yellow, or green bell pepper, seeded and chopped
- ½ small red onion, chopped
- 1 jalapeño, seeded and finely chopped
- 2 tablespoons fresh lime juice
- 1 tablespoon olive oil
- 1 teaspoon ground cumin
- Salt and freshly ground black pepper
- ¼ cup chopped fresh cilantro

## Directions

In a bowl, combine black beans, corn, tomato, bell pepper, onion, and jalapeño. In a bowl, combine lime juice, oil, and cumin and drizzle over bean mixture. Season with salt and pepper and sprinkle with cilantro.

## Excerpted from:

*The Great American Eat Right Cookbook*  
Copyright ©2007 American Cancer Society.

## Insurance Changes –

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



## Caregiver Insights



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

### Jennifer Arbuckle



After my brain surgery I struggled to find purpose. The loss of the use of my left arm had this lifelong musician aimless. Years later, I gripped the hand of my partner and seven-year caregiver as she lay in ICU following a debilitating stroke. With teary eyes and an aching heart, it all became very clear to me. I had my purpose. For the first time in nearly a decade, she needed me.

Now, don't think there were any miracles and I was suddenly able to be her caregiver in the traditional sense of the word. A strong wind is enough to put me on the floor and most day to day tasks are

beyond me, but I had so much more to offer in a completely different way.

As Connie began her rehab for a heavily effected left side, my empathy was in overdrive. I wanted to help at every turn. PT and OT worked her hard and found that she was quite the spitfire, determined and hardheaded. Once she grew accustomed to the therapy, I began walking with her therapist and her at every opportunity. On Connie's off days, we could be seen in the halls of Courage Kenny at both Abbott and Golden Valley exercising on our own. That set a precedent.

When Connie finally came home, after 2 months of hospitalization, I was nervous and excited and ready to have her home. Very soon after, we began walking the halls of the apartment building. Then I began the passing on of experience. For example, when entering an elevator, place your effected foot directly on the door track on the floor. Your foot won't catch if you're standing on the track. The same applies to flooring changes, cracks in the sidewalk, etc. I've been tickled since to see her do it! We have continued our walks and are expanding the distance whenever she has no therapy on the calendar.

*Continued on next page*



We work together on standing exercises at the counter in the kitchen. We work her arm using both no resistance and resistance. I have encouraged her love of card games and she's working on her concentration with video poker and short stints on social media along with becoming hands-on involved with paying bills again. But, with all I have to offer, the tricks and tidbits, there is nothing as important as tips on getting dressed with only one arm!

Ladies, I'm skipping right over the entire bra issue, that would be another article entirely! The key to dressing is simple. (Yeah, right.) Make damn sure your clothes are right side out! I can't tell you how many times I've had the wrong arm in the wrong hole. At that point, I offer the very best tip I can. Laugh. While that may be nearly impossible to do sometimes, don't let clothing get the best of you! A therapist once cited to me how long it took to get dressed as a child. Keep that in mind and try again.

As I said, I cannot be a typical caregiver, I can't fold clothes or mop the floor, but having been through such a similar experience, I offer the knowledge I have often learned the hard way. I've been oddly blessed to have the opportunity to live what I have learned and pass it on to the very person who got me through the hardest time of my life. I am proud to be a most non-traditional caregiver/getter...Let someone else do the laundry.

*\*Jenn was diagnosed with an oligodendroglioma brain tumor in February, 2017. She has since lived with left sided hemiparesis. Hemiparesis is weakness or the inability to move on one side of the body making it hard to perform everyday activities like eating or dressing. One-sided weakness in your arms, hands, face, chest, legs or feet can cause loss of balance. Photo of Jenn and Connie at Disney World prior to any brain tumors or strokes.*

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

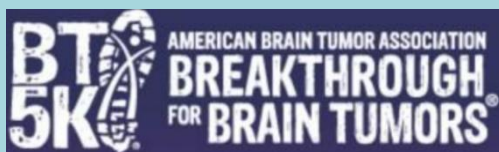
## Save the Dates!



**Humor to Fight the Tumor –  
September 7, 2024**



**WalkTalkConnect –  
September 22, 2024**



**ABTA BT5K Breakthrough for  
Brain Tumors – October 5, 2024**





## Givens Brain Tumor Staff

Andrea Wasilewski, MD - Neuro-Oncologist, Medical Director

Maya Hrachova, MD – Neuro-Oncologist

Tankia Barnes -Medical Assistant

Patti Bruns – Clinical Nurse Specialist, MSN, APRN, CNS, OCN

Seth Hartman – Certified Nurse Practitioner, APRN, CNP

Karen Holmseth - Nurse Navigator, RN, BSN

Megan Elia – Nurse Navigator, RN, BSN

Lani Hoese – Clinical Support Specialist

Deborah Jones – Care Guide, MA

Will Majerus – Nurse Navigator, RN BSN, CNRN

Becky Moore – Social Worker, LICSW

Brenda Wrenn – Clinical Support Specialist

Meghan Peters, OTR/L - Manager, Clinical Operations and Program Development Allina Health Neuroscience, Spine, and Pain Institute

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

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





# Allina Health Call to Action



## Allina Health Neuroscience, Spine, and Pain Institute

**Meghan Peters**  
Manager, Neuroscience  
Programs and Operations



In April of 2023, Allina Health announced the creation of our Neuroscience, Spine, and Pain Institute. The goal of this Institute is to deliver comprehensive, inclusive, and seamless neurologic and neurosurgical care across our geographic region and to create focused sub-specialty programs at our metro hospitals. I am excited to share that we are well on our way!

Since the announcement, our Neuroscience Clinic at Abbott Northwestern Hospital has created an Epilepsy Clinic and Headache and Migraine Clinic. In September we will also launch a Movement Disorder Clinic.

Recruitment efforts are underway for the following physicians:

- 4 general neurologists
- Dementia neurologist
- Neuromuscular neurologist
- MS-neuroimmunology neurologist
- Headache/Migraine neurologist

What does this mean for the Givens Brain Tumor Center? Access to sub-specialty and general neurology within our very own clinic! It is an immense privilege to lead the creation of these programs and improve the access to our current patients and community for all neurological needs. I look forward to providing more updates as we continue to successfully unify and grow the Neuroscience, Spine, and Pain Institute.

AllinaHealth 

**all  
together  
better.**