



Grey Matters

Newsletter of Givens Brain Tumor Center

Allina Health 
NEUROSCIENCE
SPINE & PAIN INSTITUTE

Winter 2024

Welcome

Dr. Andrea Wasilewski Medical Director



Welcome to the winter edition of our Grey Matters newsletter! As we enter 2024, I encourage you all to take stock of the year past and to look forward with positivity and anticipation for the year to come. In this issue we share a wide range of topics including Inspiring patient stories, clinical updates, and many practical tips for improving our well-being during and after cancer treatment.

I'm thrilled to announce that the Givens Brain Tumor Center support group has resumed with monthly meetings. With specialized sessions for both patients and caregivers, the support group allows for unique peer connections in a facilitated format. A heartfelt thank you to Becky Moore and Deborah Jones who have been instrumental in the organization and ongoing success of this important resource.

In this newsletter we proudly feature stories from our incredible patients and caregivers. The stories you will read highlight the resilience, compassion, and bravery of these individuals. I hope that by sharing their stories, they help you feel less alone and inspire you along your journey. You will also find resources for community support with a focus on resources for adolescents and young adults. We also include updates on our clinical trials and research studies from Marie Meyer, Manager, Clinical Research.

In our Healthy Lifestyles section, we are focusing on the benefits of physical activity and exercise for brain health. Exercise is one of the best treatments that exists for keeping both our physical body and brain healthy. This is even more important when we are undergoing cancer treatment. I hope that this information, in conjunction with the energy of the new year, inspires you to incorporate more physical activity into your lives!

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Givens Brain Tumor Center

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together
better.**



Dr. Wasilewski

Neuroimaging, particularly MRI, is critical for evaluating tumors and their response to treatment. Many of you have had innumerable MRI scans and our imaging center is a key partner in brain and spinal cord tumor care. Holly Mazis, Manager, from the Abbott Northwestern MRI team shares important information about the nuts and bolts of imaging and how her team works to make MRI as comfortable and seamless of an experience as possible. I am also excited to share information regarding Optune Gio, an FDA-approved device, used for the treatment of glioblastoma. You may have noticed this device in Lani's office or on other patients in the clinic.

2023 was a busy year for philanthropy. The Givens Brain Tumor Center team participated in multiple fundraising events supporting our clinical efforts as well as brain and spinal cord tumor care and research in the Twin Cities. I am pleased to share highlights from Humor to Fight the Tumor, Walk.Talk.Connect and the American Brain Tumor Association Twin Cities 5k. Each of these events was a huge success and I am incredibly proud of the effort and impact our patients have had on these events.

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

With immense gratitude,
Dr. Wasilewski

The Givens Family



Mike Givens, 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



Happy New Year and welcome to the 8th edition of the Grey Matters Newsletter!

In this issue, one of our patient stories is from Ashley, who was in her 20's when she was first diagnosed with anaplastic astrocytoma, grade 3, brain cancer. It was a lonely time for her. In her story, she explains how she found resources for adolescents and young adults (AYA) which have helped her to continue to live an active and adventurous life, and more importantly, find companionship with others her age also diagnosed with cancer. She has been an invaluable resource for us providing cancer related resources for young adults which are included in this newsletter.

Another patient, George, provided his story and profound appreciation for the treatment modality he is using to treat his glioblastoma brain cancer: the Optune Gio. George, and his wife Cindy, are always very willing to share his appreciation for this device. He has found ways to befriend it rather than be discouraged or encumbered by it. You may have seen George, or someone else, wearing this device in our clinic and wondered about it. Look to George to learn about his experience with glioblastoma and also find an accompanying article which describes the purpose and function of the Optune Gio.

In our Caregiver Insights column, Tracy Boyle shares her very personal experience being both a caregiver and a mother to her daughter Molly. Caregiving is selfless and rewarding, but it is easy to lose your identity. Tracy's very moving article tells us how she has been able to continue to grow and learn as a person.

It takes a community here at our clinic and at Allina Health to provide you the care, support, and the resources you need to live the best life you can. Thank you for trusting your care with us.

Stay safe and stay strong! Please contact us if you have suggestions or ideas we can cover in future newsletters.

Deborah Jones

deborah.jones@usfamily.net

651-424-1076

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



Patient Stories

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There ARE others who
‘just get it’.

“

Ashley Kwiatkowski



Hi! My name is Ashley, and I am a 7 year cancer survivor. I enjoy being outdoors, fitness and going to breweries with friends and family. I grew up and currently reside in White Bear Lake. I was diagnosed with anaplastic astrocytoma grade 3 brain cancer in 2016 at the age of 24. While my friends were getting married and starting their families, I was suddenly faced with the fear of a cancer diagnosis and wondering if I was going to live long enough to experience those things as well.

In the summer of 2016, I had a grand mal seizure which ultimately brought me to the ER where the brain tumor was discovered. About 4 weeks later I had surgery at the Mayo Clinic in Rochester where they removed about 80% of the tumor. Radiation and Temodar chemotherapy followed. My tumor was stable until the summer of 2022 when it grew to the point of concern. I returned to the Mayo Clinic to have another resection done where they removed about 90% of the tumor. This was followed by radiation and Temodar chemo treatment, once again. I having been wearing the Optune device since 2016. Right before surgery in 2022, I lost my Neuro-Oncologist at Regions Hospital. Good timing, right? Thankfully, Dr. Wasilewski and the team at Givens Brain Tumor Center were recommended to me and I couldn't be happier with the care I have received!

Because I was diagnosed in my 20's, I felt very alone. I did not know anyone around my age that had any type of cancer. That made it hard to connect with anyone that knew what I was going through... someone that 'just gets it'. I have the most amazing family and friends who kept me going and continue to support me every step of the way. They definitely drive me to outlive this cancer. It brings me to tears thinking of how fortunate I am to have this support.

One night while watching a "Stand Up To Cancer" special on tv, I learned that there are multiple non-profit organizations for AYA (Adolescence and Young Adult) cancer patients. These organizations have the resources that I was looking for as a young adult with cancer. I have been able to take adventures, travel to some amazing places and make many new friends who 'just get it'. I am going to make it my mission to get these resources out to cancer centers so other young adult cancer patients don't have to feel that they are alone. There ARE others who 'just get it'.
(See p. 13-14 for a list of AYA organizations.)



Dr. Wasilewski and Ashley finishing the BT5K Breakthrough fundraiser at Como Park in St. Paul, October 7, 2023



“ Even though you get diagnosed with a brain tumor you have to keep going. You never know what might be around the corner to help you. Today we are enjoying our lives as long as we are here.



George Hokanson



George and Cindy at the Briksdalsbreen (Arm of Jostedalsglacier) in Norway. 2017.

George Hokanson was diagnosed with a brain tumor in June 2022. He had a fall at home on June 1 and ruptured the left quadricep tendon in his leg. At the ER, it was decided to do some brain imaging and George learned that day he had a right frontotemporal mass in his brain and had a brain biopsy on June 6. The tissue sample showed an astrocytoma, CNS WHO grade 4, or glioblastoma. He was treated with chemo radiation and after his 8th round of temozolomide chemotherapy, he experienced some progression. He has since continued with bi-weekly Avastin infusions. Additionally, he has faithfully worn the Optune Gio device since October 4, 2022.

George worked as an accountant for 28-1/2 years and retired 23 years ago. He loves being retired. He and his wife, Cindy travel

far and wide, he works in his workshop, and enjoys yardwork. Their travels have been extensive including New Zealand, Fiji, Australia, Cuba, trips to Europe, the NW passage of Alaska, Hawaii and the Panama Canal. Another favorite activity is to watch the snow fall in their backyard with the fireplace going and drinking coffee.

George and Cindy have 7 grandchildren. Two of their grandchildren, Will and Benjamin, are the sons of their son Rick and his wife Maria. Rick died about 10 years ago of glioblastoma at age 38. His children were 4 and 8 years old at the time of Rick's passing. Their son Ron, and his wife, Lori, live in California, have 5 children, and recently drove to Minnesota this summer to spend two weeks with George and Cindy.

George is grateful for the treatments available to him now that weren't available to his son 10 years ago. One of the treatments, the Optune Gio device, is a portable device that delivers electrical fields to disrupt biological processes in dividing cancer cells. Cindy applies transducer arrays every few days to George's shaved scalp which is attached to an electrical field generator which he carries in a frontpack. This device should be worn at least 18 hours each day. (See our article about the Optune Gio in the Neuro-oncology community section of this issue, p. 9.)



George wearing his Optune Gio Device stored in his front pack. wife Cindy, and grandson Will, at the walk.talk.connect walk August

George was troubled by the inconvenience of the Optune Gio device backpack for a number of reasons. One day he and his very cheerful wife, Cindy, went shopping at sporting goods stores to find another way to carry it. He knew he wanted something that could be worn in front and could be secured about his chest so that it wouldn't flop around. Alas, a very patient and intuitive salesclerk came up with a solution, a binocular front pack he has been able to adapt and wear much more comfortably. George has made various accommodations including replacing some of the fabric with mesh on the binocular front pack and placing a small battery powered fan on top of the electrical field generator inside the front pack to keep the battery cool. He finds wearing the device to be much more comfortable. Such resilience and innovation!

And....George and Cindy have started a practice of marking "Q" days on their calendar. "Q" meaning a quality-of-life day. This is another example of how George and Cindy find ways to live each day to its fullest.



“

It's the tu-mah!

”

John McAlpin

My wife, Shelly, and I have always tried to maintain our sense of humor during our life together. When the physician first said, “We think you have a brain tumor”, we both looked at each other and said, “it’s the tu-mah.” Then I was told I had 6 months to live.....12 years ago.

Many of my friends both old and new also have a sense of humor. We meet or talk on the phone and laugh our butts off! Laughing makes things feel better. Life is too short to take too seriously!

A little more about me. Shelly and I celebrated our 40th anniversary in 2023. We have 4 sons: Our oldest, Tony lives in New York, the other 3 are nearby. Andy has two children, Adeline and Dashiell; Jack is our other middle son; and our youngest, Chris, has a daughter Evie. My 36-1/2-year career was at the same organization in various positions in telecommunications finally retiring as a Central Office Telecommunications Engineer.



Jon and Shelly – Oklahoma on Broadway



My final run at Purgatory Ski Resort

I taught alpine downhill skiing for 25 years for Tonka Woods Ski School to young people ages 6-14 years and coached the Orono high school alpine downhill skiing team for 15 years. I also co-coached my sons’ soccer and baseball teams. I am passionate about sports. Golf is another passion and I worked hard at being a good golfer. Having been such a sports fanatic, I am now happy to be able to watch different types of sports on TV. I love watching the Tour de France every July, FIS alpine skiing, GP 50 sailing, Formula 1, and The History Channel.

For a period of time during 2010, my right arm would get weak and fail for no known reason. Then on December 26, 2011, I had a full body seizure in our basement when I was home alone. After recovering enough to call 911, we learned later that evening I had a mass in my brain.

I had a biopsy on January 12, 2012 in the left frontal area of my brain. Pathology showed I had two types of cancer cells or a mixed oligoastrocytoma, grade 2/3. It was inoperable due to the location in my brain. I had 12 months of temozolomide chemotherapy. In June 2013, I continued to have ongoing seizures involving my right side and had radiation therapy which improved my seizures. By the fifth year after my diagnosis, I was able to take one more final run on my skis at Purgatory Ski Resort in Durango, Colorado. In December 2021, I had some recurrence resulting in more radiation therapy in January 2022. Today I continue to have focal seizures in my right arm and more recently my right foot has become weaker. The seizures I experience feel electrical, like a buzzing in my body. This sensation can stay with me for a while after a seizure has stopped.



Maintaining my strength and balance is a constant goal.

Working out too hard, I can get push back from my tumor.

I walk with my friends or Shelly and am at my best on flat areas. Shelly and I often spend a good portion of the winter in Arizona at our patio home. We enjoy escaping the winter snow and cold of Minnesota and enjoy seeing many friends and family in Arizona.

We have appreciated the support and care from the Givens Brain Tumor Clinic providers and staff over the years. The Givens Brain Tumor Support Group has also provided us wonderful support and relationships since the beginning, and we are very excited it has resumed since the COVID hiatus! I will continue to have MRI’s every 3-6 months to monitor any changes and continue to live my best life.

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

Or call for more information: 612-863-3732





Neuro-oncology Community



MRI Center - Abbott Northwestern Hospital

Holly Mazis

Radiology Manager



Hello! I have had the pleasure and the honor of working with so many patients over my lengthy career here at Abbott Northwestern Hospital. I am an MRI technologist by training and have taken care of Given's Brain and Spinal Cord Tumor patients for all my 33+ years. A few years ago, I transitioned to managerial duties but continue to have hands on time with so many patients that need assistance with starting their IV's. This is truly one of my favorite things to do because I love the challenge of those tricky veins, and it gives me face time with the wonderful patients and family members I have come to know throughout the years.

Many of our MRI technologists have been here for 10 or more years and have come to know many of you; your story, your family, your favorite radio station, whether you like warm blankets or if you prefer the cool air during your time in the MRI scanner.

Our MRI Technologist complete an accredited radiography program for 24 months and spend about 7-9 months of on-the-job training in our MRI department after they graduate as an Xray technologist. Quite a bit of physics is involved when scanning a body part, every single sequence acquires anywhere from 15 slices to 500 slices, or images, in a 5-8 minute period.

We are the eyes and ears for the Radiologists who interpret the images and dictate the report for the referring provider. Radiologists and providers rely on us to acquire the correct images before the patient leaves the MRI Center.

As I read through previous Grey Matters newsletters, I found this excerpt about how Allina Health defines family which I included here.



The MRI Center Team from left to right:
Jordan, Kris, Liban, Edyta, Esther, Kris, Edyta,
Stacy and Jessica, Holly



Jordan, Kaja and Holly

"How we define family: We adopt the following definition of "family" within our visitor guidelines: "Family" means any person who plays a significant role in your life. This may include a person not legally related to you."

We are honored to be a part of your "family" and your journey when you are here at the MRI Center. We hope we have helped to make your journey easier and make you smile as we take care of you each time you are here. Although many patients we care for each day are claustrophobic, I am confident you are in good hands and our team will take good care of you. Thank you all for being part of my life's journey as well!



Neuro-oncology Community



Optune Gio in Glioblastoma



Glioblastoma (GBM), although it is rare, is the most aggressive and common type of malignant primary brain cancer in adults. There are limited treatment options approved by the FDA for patients diagnosed with GBM. Treatment encompasses a combination of surgery, radiation, chemotherapy or Optune Gio used together with temozolomide (temodar).

Givens Brain Tumor patients, 22 years of age or older, diagnosed with glioblastoma may be prescribed by our healthcare providers to wear the portable FDA-approved Optune Gio medical device that delivers Tumor Treating Fields or TTFields. TTFields are electric fields that disrupt cancer cell division by interfering with the electrical charges of rapidly dividing GBM cells; this interference helps to slow down and stop cancer cells from dividing and may even lead to cell death.

The Optune Gio device is not a helmet, rather it uses adhesive patches called transducer arrays applied to a clean, shaved scalp with help from a caregiver. Tumor Treating Fields therapy is delivered through the transducer arrays which are connected to the lightweight field generator (the actual Optune Gio device). The Optune Gio device is powered by a portable battery or by a regular power supply. Bags are included to carry the battery and the field generator device in the home and outside the home. Loose knit wigs, hats and head coverings can be worn over the arrays. Patients get the greatest benefit from wearing Optune Gio at least 18 hours each day.

Optune Gio has proven to extend survival and maintain quality of life for newly diagnosed patients with GBM. A large clinical trial where patients had surgery, radiation with chemotherapy, temozolomide chemotherapy and Optune Gio added 5-6 months. It can also be used for patients with recurrent GBM.

The most common side effects when using the Optune Gio are scalp irritation and headache. If you are interested in learning more about this treatment therapy, contact the Givens Brain Tumor Center. You may access the Optune Gio website at [Optune Gio™ | FDA-approved glioblastoma \(GBM\) treatment](#) for more information.

Note: The Optune Gio trademark was used with permission from Novocure GmbH.



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.

Exercise and Brain Health

Staying active can help us feel better, reduce fatigue, build strength, help our memory, but can also help us cope better with treatments and its subsequent side effects. We do not have to adopt a strenuous workout routine to do this.

Many studies for cancer patients, overall, show that exercise and physical activity is essential for our health and wellbeing. Preliminary studies, specifically about physical activity and brain tumors, suggest that the benefits of activity may be key in controlling neurological disease, brain plasticity, cognitive health, tumor progression, and longevity. More research and data about this needs to be conducted for this population.

Physical activity for those living with brain and spinal cord tumors can also help to:

- Increase energy
- Improve overall feeling of wellbeing
- Minimize fatigue and enhance sleep quality
- Add muscle strength and improve bone density
- Expand range of motion
- Preserve brain volume, improve vascularization, and blood flow
- Increase hormone levels beneficial to the

Bottom line: No matter our age or fitness level, any amount of physical activity can help.

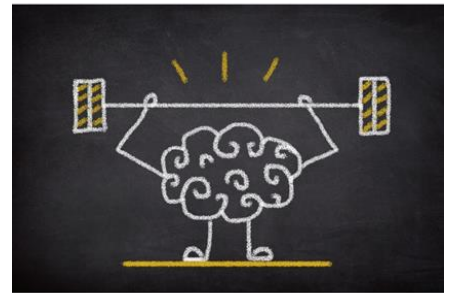




Healthy Lifestyles to Promote Good Brain Health

Try gentle, low-impact activities and exercises that keep you moving.

- Go for brisk walks.
- Ride a bike.
- Turn up the music at home and dance. Twist and turn.
- Do squats or march in place.
- Work around the house.
- Park at the back of the lot and walk to the store.
- Attend a yoga class.
- Garden. Rake leaves.
- Climb stairs instead of the elevator.
- Swim.
- Walk the dog.



Look for new ways to build physical activity into your daily routine. Go at your own pace. Even five minutes of gentle exercise has benefits.

Please consult The Givens Brain Tumor Team for any questions about your brain and spinal cord health and activity. We are here for you!!



Sources:

Living with a Brain Tumor - American Brain Tumor Association (abta.org)

The Benefits of Exercise for Glioblastoma Patients | Sandra Bornstein

Physical activity and exercise in adults diagnosed with primary brain cancer: a systematic review - PMC (nih.gov)

Exercise improves health-related quality of life sleep and fatigue domains in adult high- and low-grade glioma patients - PubMed (nih.gov)

Frontiers | The Potential Role of Exercise in Neuro-Oncology (frontiersin.org)

Exercise Guidelines for Cancer Survivors: Consensus Statemen... : Medicine & Science in Sports & Exercise (lww.com)



Neuro-oncology Research



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



Research is an integral part of the whole person care provided at the Givens Brain Tumor Center. Our dedicated clinical research team supports people living with cancer and their care circle through skilled education, ongoing assessment, early symptom identification, coordination of care, advocacy, and scientific innovation. We are proud to provide opportunities for our patients to access emerging treatments and take an active role in advancing the field of neuro-oncology.

Our clinical research team continues to offer cutting edge drug and device treatment trials for people with brain tumors. One such trial is Glioblastoma (GBM) adaptive, global, innovative learning environment (GBM AGILE), enrolling patients with both newly diagnosed and recurrent GBM (ClinicalTrials.gov identifier: NCT03970447). GBM-AGILE uses a flexible trial approach that allows multiple drugs and drug combinations from different pharmaceutical companies to be evaluated simultaneously, to more efficiently evaluate therapies. If one treatment arm outperforms another, a higher proportion of new enrollees will be assigned to that treatment arm, a technique called adaptive randomization. Through this trial, five treatment arms have been evaluated at the Givens Brain Tumor Center, and we look forward to opening new arms in 2024.

We are working to expand our offering of radiation clinical trials for brain tumors. One trial recently opened by our neuroscience research team is 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.

Our dedicated team of research nurses and study coordinators are here to partner with you in your care and to help you access the latest treatment options available.



Adolescent and Young Adult (AYA) Cancer Patient & Caregiver Programming

Provided by
Ashley Kwiatkowski

First Descents

First Descents is a recognized leader in outdoor experiential programming. Through outdoor adventures, skills development, and local adventure communities FD improves the long-term survivorship of young adults impacted by cancer and other serious health conditions. Our participants experience free outdoor adventure programs that empower them to climb, paddle, and surf beyond their diagnosis, reclaim their lives, and connect with others doing the same. Our programs are open to any young adult diagnosed with cancer or MS between the age of (15-39), and currently between the age of (18-45). Outdoor Adventure for Young Adults Living with Cancer and MS. firstdescents.org

Epic Experience – Cancer Camp for Adults

Cancer Survivorship is more than follow-up appointments, blood tests, and scans; it's about living life to the fullest beyond cancer. Epic Experience empowers adult cancer survivors to do just that through a combination of adventure, community, and virtual programming. Epic Experience's pinnacle program is a free weeklong adventure camp in the Colorado Rockies. Throughout the week, as participants challenge themselves physically, find community with other survivors, and talk through fears and worries, they gain hope and return home with tools and support to help them live and thrive beyond cancer. epicexperience.org

Send it Foundation

Send It is an expression that inspires positivity, enthusiasm, pushing boundaries and living life to the fullest. Born from the adventure sports community, Send It is what we say to encourage each other to go big and give it your all. Whether it's dropping into a couloir on skis, paddling out to the lineup, or reaching for the next hold on the rock wall — go for it. Send It Foundation provides free outdoor adventures for young adult cancer survivors. senditfoundation.org

Project Koru

Project Koru enriches lives through community and the outdoors as a way to move forward beyond cancer. Our goal is to help survivors reclaim and rediscover the best version of their life and themselves. Project Koru strives to be equitable and inclusive to all AYA cancer survivors. projectkoru.org

Continued on next page

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

Insurance Changes



Adolescent and Young Adult (AYA) Cancer Patient & Caregiver Programming

Provided by
Ashley Kwiatkowski

True North Treks

TRUE NORTH TREKS is a 501(c)3 nonprofit organization whose mission is to empower young adults and caregivers affected by cancer to "find direction through connection." One of the primary ways we do this is by taking groups on free backpacking and canoeing treks in beautiful and remote wilderness destinations where they can engage in three crucial connections that are missing from conventional cancer care: 1) connection with nature after going through something as unnatural as cancer treatment, 2) connection with peers who get it and have walked a similar path, and 3) connection with oneself through mindful awareness practices, such as meditation and yoga. truenorthtreks.org

Stupid Cancer

Stupid Cancer helps to empower everyone affected by adolescent and young adult (AYA) cancer by ending isolation and building community. In the years since its founding, through its innovative, award-winning, and evidence-based programs and services, Stupid Cancer has become the leader in the adolescent and young adult cancer space. The landscape for AYA cancer has changed dramatically over the last decade, in large part due to the work of Stupid Cancer. Although there are more resources for AYAs than ever before, the isolation of AYA cancer patients persists. stupidcancer.org

Elephants and Tea

Our mission is to help adolescent and young adult (AYA) patients, survivors, and caregivers know they are not alone in their experience with cancer. The Elephant in the room is cancer. Tea is the relief conversation provides. We are the only magazine written for and by the AYA cancer community telling their story in their own words. elephantsandtea.com



Slipping and falling on ice can cause serious injuries that plague us for months.

Winter Safety

Walking like a penguin can reduce your chances of slipping and falling. Here's how:

- Point your feet out.
- Keep your head up.
- Slowly take short steps or shuffle.
- Extend your arms out to your sides for balance and walk flatfooted.
- If you're going to fall, try to avoid landing on your knees, wrists, or spine; relax your muscles and fall on your side



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.

Here is the experience of a mother who is also a caregiver for her beautiful daughter.

Tracy Boyle



I never wanted to be a caregiver. I only wanted to be a mom.

Molly was 16 (17 years ago) when diagnosed with a brain tumor. The surgery left her partially paralyzed and unable to speak. Two and ½ years of intensive therapy brought her back to about 80%. Those were the days when we were still in the upswing of recovery and improvement – sometimes a little, sometimes a lot. Caregiving was difficult and time consuming, but we saw tangible results. Our family slipped into what most of us call our “new normal”.

When Molly’s cancer returned, with more surgery, chemo and radiation, there were setbacks, but she still recovered quite a bit of her independence and mobility. But in 2016, she fell down the stairs, reinjuring her already traumatized brain and putting her in a wheelchair. Caregiving got a lot more challenging. This is the point when we had to start considering remodeling our home or moving; thinking about getting additional help; thinking about the future when we, her parents, wouldn’t be here to be able to care for Molly’s suddenly increasing needs. It felt like our “new normal” was gone and the “newer normal” might be insurmountable and forever. Not only was Molly’s condition more difficult, but our role as caregivers was as well.

As I look back, I believe that was the time when I struggled the most mentally and emotionally. Thankfully, things have improved. Molly has moved into a group home, which gives us more physical support and more time for ourselves. Molly’s health continues to be a challenge. The physical demands are still there. The mental and emotional struggles are there as well. I have felt guilty; I have mourned; I have played the martyr. I felt and still feel (rightly or wrongly) that I am responsible for giving Molly the best possible life she can have. That’s a pretty tall order. Some days I feel I am accomplishing it and some days not.

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Caregiver Insights

If I could offer advice to anyone else, it would be to not lose yourself in caregiving. A few years ago, I started signing up for community ed classes – the chance to spend time to learn and grow that is just for me. My husband and I have been able to travel a bit with strong support from our other daughter and the staff at Molly's group home. It takes lots of preplanning and trust, but it's worth the effort.

Next, I can't emphasize how crucial I believe it is to stay healthy myself. I joined the Y many years ago. I go several times a week. I specifically go to work out classes because I need to feel part of a group. When I miss a class, my classmates wonder where I am. When my family has gone through past struggles, my Y buddies have offered words of support. As tired as I often am and as much precious time it takes, I NEVER intend to give up my workouts. Plus, they keep me physically strong so I can support Molly.

Lastly, and it has taken me years to be able to work up the courage to do this, I have started talking to a counselor. This is new for me, and I don't know where it's going, but I believe it can only help. My goal is to learn how to manage all my roles and responsibilities in an emotionally healthy way. I will still be a caregiver, but it won't define me. And most importantly when Molly sees me, she sees her mom, not her caregiver.



Painting by Molly Boyle



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



Raising Awareness About Brain and Spinal Cord Tumors

Below are organizations who work tirelessly to increase awareness about brain and spinal cord tumors and funding to help find cures, conduct research, help us live better lives, and keep us connected! Some have been started by our very own patients and families. Now that's saying something. We are so grateful. Thank you!



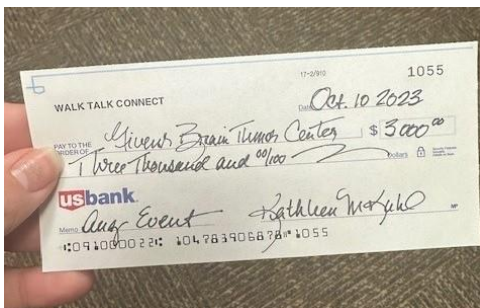
August 20, 2023 we celebrated our connections to one another! Walk.talk.connect raises awareness of these rare neurological tumors while raising funds for The Givens Brain and Spinal Cord Tumor Center. Research impacts diagnosis, treatment, and patient therapies ~ all for better outcomes for patients and families affected by these tumors.



Kathy Kuhl and husband Tom, co-founders of walk.talk.connect



Walkers at the August event



Kathy Kuhl presenting our team with a check from the August event!





Raising Awareness About Brain and Spinal Cord Tumors

On Saturday, September 9th, 2023, Humor to Fight the Tumor Foundation held its 20th annual gala. Their 750 gala attendees and donors have helped Humor to Fight the Tumor Foundation to raise over **\$675,000** to fund research and patient services in the battle against brain tumors. Parts of the evening included live and silent auctions, and comedy by Tommy Ryman, as well as a video showing stories of hope and determination provided by our two honorees, Jeremy Hedberg and Layla Julien.



Placing a bid at the live auction



Our team at the event!





Raising Awareness About Brain and Spinal Cord Tumors



2023 Fall BT5K October 7, 2023 Como Regional Park St. Paul



Dr. Wasilewski and husband Ian at the finish line!



Our team along with Patti Bruns' cheerleading family!



ABTA (The American Brain Tumor Association) hosts 5K run/walks around the country annually to raise funds for critical research grants, with more than \$681,000 going to Minnesota-based research scientists. Your support allows them to create and provide patient and caregiver-focused programs throughout the year. They continue to explore new programs and relationships right here in our backyard.



Givens Brain Tumor Staff

Andrea Wasilewski, MD - Neuro-Oncologist, Medical Director

Tankia Barnes -Medical Assistant

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

Megan Elia – Nurse Navigator, RN, BSN

Lani Hoese – Clinical Support Specialist

Karen Holmseth - Nurse Navigator, RN, BSN

Deborah Jones – Care Guide, MA

Becky Moore – Social Worker, LICSW

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

Emma Sacco - Nurse Navigator, RN, BSN

Brenda Wrenn – Clinical Support Specialist

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

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





Allina Health Abbott Northwestern Hospital

September 14, 2023. Groundbreaking for the future of Abbott Northwestern Hospital took place as well as the celebration of the \$25 million donation from the Richard M. Schulze Family Foundation. Minneapolis Mayor Jacob Frey declared this auspicious date as Abbott Northwestern Hospital Day!

The 575,000-square-foot surgical and critical care building is the largest facilities project in Allina Health's history. It will contain 30 future-flexible operating rooms that support the rapid evolution of medical technology and surgical technique, as well as four floors of technology-enabled single-occupant patient rooms with enhanced features for accessibility and comfort. As Allina Health's first LEED-certified building, the surgical and critical care building will meet globally recognized standards for environmental sustainability.

The surgical and critical care building is scheduled to open in 2026.

