

Grey Matters

Newsletter of Givens Brain Tumor Center

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Dr. John Trusheim
MEDICAL DIRECTOR

Happy New Year 2022!

I hope your holidays were happy and full of joy in spite of the COVID-19 pandemic. As many of you know, our healthcare systems have been seriously challenged for many months and, although our providers do this work for the love of helping and serving patients, they are tired and weary particularly in our primary care and emergency care settings. I urge you, if you have not been vaccinated, please get your COVID and flu vaccinations now. We want you and your loved ones and our healthcare workers to be safe and healthy!

Our Winter 2022 issue is once again full of information, stories, and resources. Our focus is the importance of a multi-disciplinary approach in the treatment of brain and spinal cord tumors. Each issue we like to provide information about the people and multiple disciplines who collaborate together to provide you cutting edge, whole person care.

We have articles from three of our neurosurgeons! Drs. Kapurch and Nelson discuss the importance of partnering together with many players and disciplines for the overall wellbeing of our patients. This happens right from the beginning of diagnosis, into the operating room, after surgery, and with treatment. They underscore the value of a multidisciplinary approach to review and discuss difficult, unusual, and routine cases. And also from the operating room, Dr. Nagib provides information about the importance of technology and neuronavigation, specifically the use of iMRIs during surgery. All of this, a multidisciplinary approach along with state of the art equipment and techniques, leads to better management of brain and spinal cord tumors and longer lives. These physicians share their pride by agreeing that Abbott Northwestern Hospital is well equipped to continue to be the leader in managing the treatment of brain and spinal cord tumors in the Twin Cities. We hope you agree, too.

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Meet staff at the Givens Brain Tumor Center

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Our research team, another integral part of our multidisciplinary approach, provides an update on current clinical trials, specifically the Denovo and the GBM Agile trials; and the team's goal to continue to provide cutting edge, innovative clinical trials.

Following my column is a letter of introduction from Dr. Andrea Wasilewski, Neuro-oncologist, who will be joining the Givens Brain Tumor Center in February, 2022. Dr. Wasilewski has had a diverse life experience and training leading to her board certification as a neuro-oncologist. When you read her letter you will be impressed with her accomplishments. I am very proud to have Dr. Wasilewski join the Givens Brain Tumor Center and look forward to you meeting her in the coming months!

And, we recognize Patti Bruns, our Certified Nurse Specialist, who was awarded the 2021 March of Dimes Heroes in Action Critical Care Award in Oncology. Congratulations, Patti!

Wishing you a healthy, peaceful year!

Dr. John Trusheim

Welcome Dr. Wasilewski!



Hello everyone,

It is an honor and pleasure to be joining Dr. Trusheim and the incredible team at the Givens Brain Tumor Center in February 2022. As a board-certified neuro-oncologist my passion is providing

the highest level of comprehensive care to patients with primary brain cancer, central nervous system lymphoma, brain metastases and neurologic complications of cancer. My treatment philosophy emphasizes evidence-based treatments and multifaceted approaches to cancer care including lifestyle medicine and alternative practices. I completed my Neurology and Neuro-Oncology training at the University of Rochester in Rochester, New York where I remained on faculty at the Wilmot Cancer Institute for several years. I have extensive experience with research and clinical trials and am excited to participate in the many exciting and ground-breaking research studies enrolling patients at Abbott Northwestern Hospital. My research interests include developing new and innovative approaches for the evaluation of older patients with brain tumors and supportive care interventions for patients with glioblastoma.

I have a diverse background from growing up in my hometown of Toronto, Canada to completing my medical education at Jagiellonian University in Krakow, Poland. Having lived, trained, and worked in multiple cities and countries allows me to bring a wealth of experience and perspectives to this new position at Allina Health. I look forward to setting down roots in this community and calling the amazing city of Minneapolis home.

I am humbled to join the wonderful team here at the Givens Brain Tumor Center and Allina Health and look forward to partnering with and guiding you and your loved ones along your brain and spinal cord tumor journey. Together we will ensure you and the community we serve are heard, helped, supported, and deeply cared for.

See you soon!

Welcome to Gray Matters

Editor's column

DEBORAH JONES, LIFECOURSE CARE GUIDE



Welcome to 2022! We hope your 2021 holidays were healthy and happy and you were able to be with those you love.

We have another newsy issue for you! We are proud of the collaboration we do here at Abbott Northwestern Hospital with our partners. Our focus is multi-disciplinary care and we work hard to be in communication with each other so that you get the best whole person care you deserve. Read on to learn more about our neuroscience partners.

We have information about the CERN Foundation and the Epilepsy Foundation of Minnesota. The CERN (Collaborative Ependymoma Research Network) Foundation's focus is for persons who have an ependymoma type of brain or spinal cord tumor. Both organizations are dedicated advocates in each of their areas offering support, resources, and education. Both organizations care very much about people who are living with an ependymoma or seizures or epilepsy.

And we have two patient stories to share with you. We love learning about you and how you and your loved ones are living with a brain or spinal cord tumor. Your story is unique and it also offers courage and hope to others. As we always say, we learn from you, you are guiding us along this journey.

Please feel free to contact me or anyone else at The Givens Brain Tumor Center if you would like to share your story or have ideas about what to include in the next issue of the Grey Matters Newsletter.

In the meantime, stay safe and stay strong!

Deborah

651-424-1076

deborah.jones@allina.com



Mike and Linda Givens

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 as a member of the Abbott Northwestern Hospital Foundation.

Neuro-oncology community

Neuro-oncology research



KELSEY JACKSON
RN, BSN
SENIOR NURSE RESEARCHER

Neuro-Oncology research at Givens Brain Tumor Center is supported by the Allina Health Neuroscience Research Department. The research team consists of experienced research nurses, coordinators, a project manager, and regulatory specialists who work with our Abbott Northwestern team of specialists and technicians to provide whole-person care.

With our current research portfolio, we offer multiple drug and device treatment trials for people with primary brain tumors. These clinical trials are focused on immunotherapy, individualized medicine protocols, and adaptive platforms to bring our patients the most innovative treatments available. Our research team has been actively enrolling eligible patients in our available clinical trials and is currently screening eligible patients seen in the clinic.

One of our current research studies, Denovo Biopharma (ENGAGE) (ClinicalTrials.gov Identifier: NCT03776071) enrolls patients with newly diagnosed glioblastoma and gliosarcoma. The study sponsor has identified a unique marker in individual human genes, called a biomarker, which they are evaluating with an investigational agent, Enzastaurin in combination with the standard of care treatments.

A second clinical trial, GBM AGILE (ClinicalTrials.gov Identifier: NCT03970447) is open to both patients with newly diagnosed and recurrent brain tumors in a unique clinical trial design evaluating which treatments work best for each tumor type and biomarker subtype. GBM AGILE maintains several "treatment arms" and utilizes adaptive randomization to allow for dynamic adjustment within the trial model. If one treatment arm outperforms another, a higher portion of new enrollees will be assigned to that treatment arm. This cutting-edge trial design is made possible by the partnership and collaboration of clinicians, researchers, governments, regulatory agencies, pharmaceutical companies, and patient advocacy groups. While GBM-AGILE plans to test multiple drugs from different companies over time, three treatment arms are currently open for patient enrollment at the Givens Brain Tumor Center and we look forward to opening new arms in 2022.

Allina Health is dedicated to staying on the front line of cancer research. We believe that everyone deserves excellence in comprehensive care and hope that through research and innovative clinical trials we can help to improve the quality and longevity of life for our patients.



KATRINA STREMSKI
RN, PHN, MN, MA
NURSE RESEARCHER

Neurosurgery



MAHMOUD NAGIB, MD



NEUROSURGICAL ASSOCIATES, LTD.
affiliated with Allina Health

INTRAOPERATIVE MRI APPLICATION IN NEUROSURGERY (iMRI)

An intraoperative magnetic resonance imaging (iMRI) refers to an MRI done during surgery while the brain is still exposed. This gives the neurosurgeon the opportunity to take high resolution scans or images of the brain during surgery to see the exact location, size and shape of a tumor and if any tumor is left that can still be removed. The brain can shift during surgery making pre-surgery MRIs inaccurate and iMRI helps differentiate the edges of a brain tumor and normal tissue from abnormal tissue during surgery. iMRI has been used for primary brain tumor removal in an attempt at optimizing the extent of tumor removal during surgery.

The addition of iMRI to the neurosurgical toolbox allows real-time evaluation of the extent of resection in the case of primary brain tumor and the instant identification of unexpected findings including complications. Therefore, early corrective action can be pursued minimizing adverse events and optimizing patient outcome. The more tumor removed during surgery, the better the patient's chances are for living a longer life.

Other examples of computer assisted technologies which help guide neurosurgeons during surgery are the introduction of cutting edge neurophysiologic monitoring with the inclusion of cerebral, cortical and subcortical mapping and spinal cord neurophysiologic monitoring. These further refine the ability to optimize the surgical outcome and can be addressed in another issue of this newsletter.

Intracranial and intraspinal neuronavigation, or computer assisted technologies, have been an intricate part of the surgical toolbox for brain and spine surgery.

Since the institution of the iMRI at Abbott Northwestern Hospital in 2006, the applications have evolved and extended into multiple neurosurgical areas including patients with brain / spine tumors as well as birth defects in the brain. The Abbott Northwestern Hospital team have been leaders in the state of Minnesota with the development of these state of the art techniques.

Precise localization and treatment of deep-seated lesions with minimal side effects can be accomplished. Extensive reconstruction of the spine and correction of craniospinal deformity with minimal risks are also accomplished.

Multidisciplinary care at Givens Brain Tumor Center



KYLE NELSON, MD

Clinical research has repeatedly shown that high-volume centers and multidisciplinary care lead to improved patient outcomes. This is especially true for complex disorders of the brain and spine. At Abbott Northwestern Hospital, we have routinely utilized a multidisciplinary panel of experts from many disciplines to review and discuss challenging and routine cases.

This collaboration extends into the operating room itself. Intraoperative pathology consultation helps direct the appropriately aggressive or conservative treatment of brain tumors. Intraoperative neuromonitoring with neurologists and physiatrists helps minimize damage to eloquent and functional neurologic tissue that otherwise would be at high risk of permanent injury. The neuroradiology team regularly provides real-time diagnosis during surgery to aid in complete resections using our intraoperative MRI scanner.



JOSEPH KAPURCH, MD

After surgery, close collaboration between the surgical team and the medical oncology/radiation oncology teams is key to effective and efficient adjuvant treatment of often aggressive tumors. This team work is all part of the experience at the Givens Brain Tumor Center.

Our multidisciplinary team also includes research coordinators, which give our patients the ability to enroll in many national research studies. This offers cutting edge treatments and the opportunity to help advance the field of tumor treatment. These research protocols often require participation from neurosurgery, oncology, and radiation, which we are able to provide using our team approach.

At the Givens Brain Tumor Center, we meet every other week to discuss patients and all agree on treatment plans. This is the definition of multidisciplinary care.

As one of the busiest hospitals in the metropolitan area for neurosurgery, Abbott Northwestern Hospital is well equipped for the most complex tumors of the brain and spine. The volume and collaboration of different specialists make this the premier place for treatment of these tumors in the Twin Cities.



Chicken and white bean soup recipe

Perfect for those cold winter days especially if you have the sniffles!

Be sure to wash all fruits and vegetables thoroughly to avoid infection.

Recipe courtesy of:



Nutrition

Per Serving (for 6 servings)

Calories	235
Calories from Fat	45
Total Fat	5.0 g
Saturated Fat	1.0 g
Trans Fat	0.0 g
Polyunsaturated Fat	1.4 g
Monounsaturated Fat	2.3 g
Cholesterol	60 mg
Sodium	675 mg
Total Carbohydrate	17 g
Dietary Fiber	5 g
Sugars	5 g
Protein	28 g

A store-bought rotisserie chicken offers incredible versatility at mealtime. Here it makes a quick and flavorful “homemade” chicken soup. Instead of traditional noodles, this soup is made with protein-packed beans. Choose a rotisserie chicken with mild seasoning—both plain and lemon-pepper work well. Adding the wings and some bones to the broth adds richer flavor. For a burst of green, add a few handfuls of baby spinach or 2 tablespoons chopped fresh parsley right before serving. For classic chicken noodle soup, substitute ½ cup of egg noodles for the beans.

Serves: 6 to 8

Prep time: 15 minutes or less

Total time: 1 hour or less

Ingredients

- 1 rotisserie chicken breast section
or 3 cups chopped white chicken meat
- 1 tablespoon canola oil
- 3 carrots, sliced
- 2 celery stalks, sliced
- 1 onion, chopped
- 2 cups water
- 6 cups reduced-sodium chicken broth
- 1 (15-ounce) can Great Northern beans, rinsed and drained
- Salt and freshly ground black pepper

Directions

Remove wings from chicken and reserve. Remove skin from breast and discard. Shred the meat from the breast and break off breastbones.

In a stockpot over medium heat, add oil. Sauté the carrots, celery, onion, chicken wings, and breastbones for 8 to 10 minutes, or until vegetables soften.

Add water and chicken broth and bring to a boil, stirring to combine. Reduce the heat, cover, and simmer for 15 to 20 minutes. Add beans and chicken meat and cook for 5 minutes. If too thick, add additional broth or water. Discard bones and wings before serving. Season with salt and pepper.

Patient stories

Jenn Swenson



I have always had drive and motivation, but sometimes life can be ripped away from you and come crumbling down around you.

I was 27 years old, working as an airline pilot, and married with an 18 month old child. Through an incident of what was believed to be food poisoning, I was shocked to learn I

had a brain tumor! To this day, I have never had any symptoms nor have I had to take anti-seizure medication. This was 2012. Dr. Uittenbogaard removed the tumor and we learned it was an oligoastrocytoma. Eventually I went back to work flying for a major airline.

Five years later, now 2017, during my routine MRI scans, we learned I had another tumor. After the surgical removal of the second tumor, I opted to undergo 32 treatments of chemo and radiation followed by another six months of chemo to increase the amount of time between the second resection and when the tumor will come back. I voluntarily stepped away from the cockpit and plan to reapply for my medical certificate in 2023.

After the second tumor, I ran a half marathon with a friend. Those years of my life were out of my control but running a half marathon gave me back that control. As a

pilot, you can understand the desire to be in control. That's what inspired my attempt to run the next Chicago Marathon in support of the American Brain Tumor Association. The Chicago Marathon was canceled due to COVID-19 but I was ready to complete a full marathon. Since there was nowhere to run and no way to raise funds for the American Brain Tumor Association, my friend and work partner Brian said he would host a marathon for me to run. I ran a solo 26.2 marathon on October 10, 2020, starting at my house in Minnetonka, running around the north side of Lake Minnetonka ending at the Flying Cloud airport. More than 100 supporters and members of the community along with a formation of airplanes greeted me! The community support was overwhelming.

Brian, a veteran previously serving overseas, understands the struggles that service members overcome after sustaining traumatic brain injuries. We both have a passion for raising awareness about brain disease, each focusing on a different aspect of brain disease. This resulted in the two of us getting involved with the initial formation of the BRAIV Foundation. The BRAIV Foundation is focused on fundraising for research on brain cancer and for traumatic brain injuries suffered by veterans. The Foundation, supported by aviation and aerospace executives, seeks to provide funding to innovative research in these areas and to provide direct support to families and those suffering from these injuries.

I also recently formed my own aviation consulting business with Brian. /www.myjetevents.com. We help independent FBOs scale for large business aviation events such as managing all airport operations at Sheboygan for the Ryder Cup or Augusta for the Masters.



That's me running with a formation of airplanes!

Patricia Bride's story – by Tim and Patty Bride



How about a game of cards?

Patty was born in Los Angeles and grew up the first of 4 daughters. When she was about a year old, they moved to a farm in Dannebrog, Nebraska. When she was in third grade, they moved back to California where her father pursued another business and moved back to the Midwest in eighth grade to Staples, MN, to a dairy farm. After graduation, Patty earned her AA in Accounting and started working at Bang Print Shop in Brainerd where she met her husband, Tim.

Patty was a 51-year-old mother of two when she was diagnosed with a brain tumor on Christmas Day 2013. After an initial 3-day stay in the hospital she was released as we sought consultation and second opinions on what to do. It was

made clear that the tumor - anaplastic astrocytoma 3 - had to be removed which was located deep in the pineal region of her brain.

Patty had brain surgery on February 24, 2014. Over the next 24 hours her condition worsened as she suffered from severe edema on the brain. Patty became unresponsive for two weeks, was on life support, and by mid-March we realized she would have significant disabilities. Patty remained in rehab facilities for six months and while she received excellent care, our lives were turned upside down.

Patty continued with radiation and oral chemotherapy for 18 months. She came home in September 2014 after her sister, Christy, and husband, Tim, were trained on caring for her and her limitations. She made great progress but cannot walk on her own, lost 50% of her vision, one eye is crossed, has labored speech, perpetual dizziness, difficulty swallowing, and compromised short-term memory.

Christy, played a key role in her weekly care schedule until we hired an in-home caregiver. She achieved several milestones including getting to and from the bathroom using a walker, getting up, getting dressed and to the couch on her own.

Patty has had roughly 30 MRI's over the past six years, all of them with no new tumor growth. She had two serious falls in the past two years and has had some setbacks. She has a great sense of humor, loves to play cards, and continues to be known for her accuracy and detail orientation. Tim, retired a year ago, is now the primary caregiver for Patty.

We are positive and faithful people, and we give thanks every day for what we have. We have each other and that is a lot to be thankful for. Thanks for allowing us to share our story.

For more patient stories and to see previous issues of our newsletter visit us online at allinahealth.org/givens

Staff congratulations

Heroes in Action 2021



Celebrating Nurses and Maternal and Infant Health Providers



Patti Bruns, Clinical Nurse Specialist, was recently awarded the 2021 March of Dimes Heroes in Action Critical Care Award in Oncology! We are very proud of Patti here at the Givens Brain Tumor Center for receiving recognition for all the work she has done for patients through the years. Congratulations, Patti!

SLIPS, TRIPS AND FALLS PREVENTION

Ice and snow? Remember to go slow

BEING AWARE HELPS YOU AVOID POTENTIAL SLIPPING HAZARDS:

- Walk like a penguin on snow and ice
- Watch out for icy spots
- Walk only on cleared paths
- Don't text and walk
- Leave the snow outside—wipe your feet on your way in

Allina Health 



Brain tumor support groups

During the COVID-19 pandemic, many local support groups moved to virtual support, where you meet with others on your screen, tablet or phone in a safe and confidential place in your home. Here are a few support groups to explore:

GILDA'S CLUB BRAIN TUMOR SUPPORT GROUP

4th Wednesday of Month 6:30-8 p.m.

Orientation required

gildasclubtwincities.org

MHEALTH FAIRVIEW

4th Monday of the month, ; 6-7 p.m.

Email Katie Pearson to receive link to online group

Kpearson11@umphysicians.umn.edu

CANCERCARE.ORG

Brain Tumor Patient Support Group Online

Information and registration for 15 week online support group for people with a primary malignant brain tumor.

BRAIN TUMOR CAREGIVER SUPPORT GROUP ONLINE

Information and registration for 15-week online support group for people caring for a loved one with a primary malignant brain tumor or brain metastasis.

Learn more about both groups:

cancercare.org/support_groups

BRAINS TOGETHER FOR A CURE

3rd Saturday of the month; 10 a.m.-12 p.m.

Monthly zoom / online meeting

Mayo Rochester

Registration required

info@brainstogetherforcure.org

NATIONAL BRAIN TUMOR SOCIETY

Brain tumor conversations attended by and run by patients and care partners who have had firsthand experience with the challenges and effects of a brain tumor diagnosis.

Online monthly sessions

To sign up:

braintumor.org/take-action/brain-tumor-support-conversations/

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**

Brain and spinal cord tumor resource highlights

Ependymoma is a type of tumor that can form in the brain or spinal cord. It begins in the ependymal cells that line the passageways of the brain and spinal cord where cerebrospinal fluid nourishes your brain. This tumor constitutes less than 2% of other primary brain and spine tumors and can occur at any age, although more often in young children. Most that occur in adults are more likely to form in the spinal cord and cause weakness in the part of the body controlled by the nerves affected by the tumor. (The Givens Brain Tumor Center sees 3-5 adult patients each year).



Kimberly Wallgren, Executive Director of the CERN Foundation

Established in 2006, the CERN Foundation is a 501c3 nonprofit organization dedicated to improving the lives of those affected with ependymoma. The CERN Foundation, a designated program of the National Brain Tumor Society, offers outreach programs, and support efforts to this community. We provide educational resources, such as the Ependymoma Guide

and referral support to patients and caregivers. We also help bridge the gap between providers and the patient and caregiver community by partnering with other organizations and neuro-oncologists who specialize in ependymoma diagnosis and treatment and to find better treatment options for those with ependymoma. We also engage this unique community through research efforts, clinical studies, and awareness activities.

Thanks to the efforts of an international network of collaborators, the CERN Foundation has been responsible for the publication of over 50 peer reviewed papers in leading medical journals. This body of research has greatly advanced our understanding of ependymoma and has left a lasting legacy for future investigators to build upon. Today, the CERN Foundation continues to advance

ependymoma research by supporting scientific fellowships, clinical trials, sponsoring professional conferences and symposia, and investigating risk factors for the disease. The CERN Foundation is currently engaged in a range of community outreach programs and support efforts designed to have a positive impact on the lives of children and adults living with ependymoma, as well as their families and caregivers.

Ependymoma Guide

The CERN Foundation Ependymoma Guide is a guide for patients, caregivers and advocates. The guide gives readers the basic facts about ependymoma, its diagnosis and treatment. We hope this information gives you a better understanding of ependymoma. Keep in mind that your specific case may be different from another person with ependymoma.

cern-foundation.org/education/ependymoma-guide

Ependymoma Awareness Day - Butterfly Release

On Ependymoma Awareness Day, an annual event in the Spring of the year, butterflies around the world are released to honor loved ones with ependymoma, recognize care partners and medical workers, and to support ependymoma research efforts. The delicate and beautiful butterfly was chosen to represent the spirit of the ependymoma community as a symbol of hope through change. The butterfly is a symbol to represent hope. Just as a butterfly dramatically changes its shape, so does the meaning of hope along this journey.

EPILEPSY FOUNDATION OF MINNESOTA

1 in 26 people will develop epilepsy in their lifetime



Founded in 1954, the Epilepsy Foundation of Minnesota (EFMN) offers services for people with epilepsy and seizures across Minnesota. EFMN

is a patient advocacy organization offering programs and services to support individuals impacted by epilepsy to help improve their quality of life. We operate a successful social enterprise in used clothing collection and its resale to thrift stores. Our programs educate, connect, and empower people with epilepsy, their family, and caregivers no matter where they are on their epilepsy journey.

It is our solemn responsibility to prioritize equity and inclusion in our programs and services. We are committed to serving all people with epilepsies and seizure disorders by addressing disparities of stigma, uncertainty, and wellbeing through equities of normalcy, therapies, and well-being.

"Epilepsy is a cruel humbler that can easily strip away one's confidence of ever gaining an upper hand. Marcia and I share the disappointment when spirit-crushing seizures occur. The moments immediately following a seizure are the most trying for us. This is when we are most vulnerable and saddened by yet another setback. However, that is the time where we focus on defeating epilepsy and not letting epilepsy defeat us. As difficult as our journey has been at times, we know that we are not alone. We have sought and received great counsel and support from the wonderful staff of the Epilepsy Foundation of Minnesota."

– Dean K, spouse to someone who has epilepsy.

Learn More About our Services:

Information Services

From diagnosis through treatment, our Information Services staff offer free, one-to-one, customized support for all people impacted by epilepsy to help them overcome the challenges they face and answer the questions they have. This includes medication side effects, transportation, employment, and more.

Connect Groups

People impacted by epilepsy meet others on a similar journey to share experiences in a safe and supportive environment.

Shining Stars

Children with epilepsy face unique challenges, and the Shining Stars program helps these families connect with others, make friends, and have fun with family-focused events and activities.

Camp Oz

Camp Oz is a week-long overnight experience for youth with epilepsy. For many, it's the first time they've been away from home for an extended period. Along with the importance of making new friends, Camp Oz includes traditional camp activities, teamwork-building skills, and personal growth.



Local and national organizations offering support and programs

(Due to COVID-19 availability of programs may change.)



GILDA'S CLUB TWIN CITIES

Offers free cancer support for everyone impacted by cancer. Learn how you can be part of our community today. gildasclubtwincities.org



ABTA (AMERICAN BRAIN TUMOR ASSOCIATION)

abta.org

Patient and Family Meetings - free virtual events

abta.org/about-brain-tumors/brain-tumor-education/patient-family-meetings/



CANCER CARE

cancercare.org
800-813-HOPE (4673)



CERN (Collaborative Ependymoma Research Network) Foundation

E-mail at administrator@cern-foundation.org or call 844-237-6674.
cern-foundation.org



AMERICAN CANCER SOCIETY

cancer.org/about-us/local/minnesota
651-255-8100



NATIONAL BRAIN TUMOR SOCIETY

National Brain Tumor Society unrelentingly invests in, mobilizes, and unites our community to discover a cure, deliver effective treatments, and advocate for patients and care partners.

617-924-9997

braintumor.org



OPEN ARMS OF MINNESOTA

A nonprofit that cooks and delivers free, nutritious meals to people living with life-threatening illnesses in the Twin Cities.

openarmsmn.org/aboutus/

612-872-1152



CANCER LEGAL CARE

A non-profit resource for patients and survivors diagnosed with cancer at any stage or diagnosis, living in the state of Minnesota, looking for answers about legal rights on a wide variety of issues such as estate planning, wills, healthcare directives, power of attorney, employment, housing, applying for social security disability, health care insurance, and more.

cancerlegalcare.org
651-917-9000

SeniorLinkAge Line®

SENIOR LINKAGE LINE
mnaging.org/advisor/SLL
800-333-2433



DISABILITY HUB
disabilityhubmn.org
1-866-333-2466



VETERAN'S LINKAGE LINE
macvso.org
1-888-546-5838



MINNESOTA BOARD ON AGING

(Excellent resource for persons of all ages!) Seven area agencies (For example: Arrowhead, central Minnesota, southeastern Minnesota, etc.) that provide assistance and resource information to seniors, local agencies, and communities within their area.

mnaging.org/en/Administrator/AAA



A Healing Center

Pathways' mission is to provide resources and services for people with life-threatening or chronic physical illness—as well as caregivers—to explore and experience complementary healing approaches. Virtual Programming available.

pathwaysminneapolis.org



HELP AT YOUR DOOR.

Helpatyourdoor.org
651-642-1892

Supports seniors or individuals with disabilities living in Minnesota’s seven-county Twin

Cities Metro area. Helps seniors and individuals with disabilities to maintain their independence and continue living in their homes. Store To Door grocery assistance, home support and transportation services provide help with in-home tasks and chores. Services can be bundled. Service area includes Anoka, Carver, Dakota, Hennepin, Scott, Ramsey and Washington counties.



WILDER FOUNDATION

Wilder is committed to improving the lives of older adults; adults with mental, physical and chronic health conditions;

and their caregivers who age in place and live where they feel most comfortable, whether in their own home or connected to their community. Access to a variety of healthy aging and caregiving services, support and resources to help maintain health, well-being and independence.

Committed to addressing complex challenges that will advance equity in Saint Paul and across Minnesota.

wilder.org/about-us



POWERFUL TOOLS FOR CAREGIVERS

Caregiver classes provide tools and strategies to better handle the unique challenges faced by caregivers of adults

with chronic conditions and also of children with special health or behavioral needs. Caregiver classes meet once a week for six weeks. Currently virtual classes. Registration required. There may be a \$30 requested donation for the class manual.

powerfultoolsforcaregivers.org/class-type/caregiver-classes



PENNY GEORGE INSTITUTE FOR HEALTH AND HEALING

Offers classes and services to help you be your healthiest. Whether you

want to manage chronic illness or pain, lose weight, reduce stress, quit smoking, or stay healthy. Treat the whole person – mind, body, spirit and community.

allinahealth.org/georgeinstitute

FINANCIAL RESOURCES

Allina Health

allinahealth.org
612-262-9000 or 800-859-5077

MNsure

mnsure.org
1-855-366-7873

Medicare

Website: medicare.gov
800-633-4227

Social Security

ssa.gov
800-772-1213

County Programs

Check with the county you live in to learn about programs you and your family may be eligible for.

Angel Foundation

mngel.org
612-627-9000

Transportation

(Due to COVID-19, availability of programs may change.)

Taxi Services

1010 Taxi

Provides taxi service with cell phone for texting. Rates vary. Affordable taxi rate.

1010taxi.com/minneapolis-metro-area

Transportation Plus (formerly Airport Taxi)

Full-service transportation company offering the best and most convenient ways to get around the Twin Cities and surrounding areas. Call, book online, text, or use iHail app. Vans available for transporting patients with wheelchairs.

tplusride.com

612-888-8888

Wheelchair transport resources

In the event patient is not able to transfer from car.

- Transport Allegiance 651-207-5211
- AT Transport 612-729-1156
- Transportation Plus 612-888-888

Veterans Travel

1. VTS - Veterans Transportation Services:
va.gov/healthbenefits/vtp/veterans_transportation_service.
2. DAV transportation (Disabled veterans)
612-467-2768 – No charge for vets who do NOT need w/c or oxygen assistance in the seven-county metro area. Two pickups each day for 9 am or 1 pm appts. Service provided Monday – Thursday. Call 2-3 weeks in advance. For Shakopee / Prior Lake contact the VA County Officer at 952-496-8176.
davmn.org/transportation

Metro Mobility

Metro Mobility is a shared-ride public transportation service for certified riders who are unable to use regular fixed-route buses due to a disability or health condition. Trips are provided for any purpose. To learn more and to apply, which requires your physician's input, see their website.

metro council.org/Transportation/Services/Metro-Mobility-Home

County Public Transportation

Many counties around the state have public transportation options for the general public. Check your county to learn about public transportation options. Rides may be curb to curb, within a specific radius, provide transportation for specific reasons. Some are listed below.

Dakota County

dartsconnects.org/GoDakota

Scott and Carver Counties

scottcountymn.gov/516/SmartLink-Transit

Transit Link

Transit Link is a shared-ride public transportation for the Twin Cities metro area where regular route transit service is infrequent or unavailable. It's for trips that can't be accomplished on regular transit routes alone.

metro council.org/Transportation/Services/Transit-Link

651-602-LINK (5465)

SW suburbs of Chaska, Chanhassen, and Eden Prairie

swtransit.org/about

Raising awareness and dollars for brain and spinal cord tumors

Below are some organizations that work tirelessly to raise awareness about brain and spinal cord cancer by raising money to help find cures, 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. Gratitude!



BT5K Your Way

BT5K Your Way: anyway, anyhow, anywhere! You can walk, run, bike, or even kayak your 5K—solo or with friends and family. Join folks across the country to raise critical funds for brain tumor research and patient support services.

Watch here for information on 2022 in-person events.
abta.org/get-involved/bt5k

We can't wait to see you!



Bowling for Brains

A successful outdoors Mini Golf edition and silent auction in place of Bowling for Brains was held on September 26, 2021. Rumor has it bowling will be back in 2022! Stay tuned to the website for more information!
bowlingforbrainsmn.org



walk.talk.connect

WalkTalkConnect is a non-profit dedicated to building a "peer-to-peer" mentoring community that

connects patients and caregivers facing the unique challenges rare brain & spinal cord tumors present. Watch for events here: walktalkconnect.org

Note: We are working with the CERN Foundation who is publishing the book *Reconnected - Stories from Spinal Cord Tumor Survivors* this Spring, 2022! Copies will be available for sale on our website.



Humor to fight the Tumor

Dedicated to funding research and patient services to improve the lives of patients by raising

awareness, providing support and encouragement, and offering uplifting events to provide a sense of community and hope to affected individuals and families.

humortofightthetumor.org

Collective effort towards support and healing

Allina Health is dedicated to caring for the physical and mental well-being of our employees, our patients and all members of our community. We recognize the additional stress that many of us are experiencing – whether it is from the busyness of season, the stress felt by the prolonged pandemic or feelings related to current events in our community.

As an organization, we share in the sadness, pain and frustration being felt throughout our community. Allina Health is dedicated to caring for the physical and mental well-being of our patients, our staff and all members of our community. During these difficult times, we are committed to supporting healing for all of our employees.

Our unwavering commitment to safety and Whole Person Care is our touchstone and will continue to guide our actions as an employer, care provider and community partner.

Givens Brain Tumor Staff

John Trusheim, MD Neuro-Oncologist, Medical Director
Andrea Wasilewski, MD Neuro-Oncologist
Patti Bruns Clinical Nurse Specialist, MSN, APRN, CNS
Alexandra Arakawa Nurse Practitioner, DNP, APRN, CNP
Margaret Callan Social Worker, LSW, ACM
Lani Hoese Clinical Support Specialist

Tankia Barnes Medical Assistant
Megan Elia Nurse Navigator, RN, BSN
Emma Sacco Nurse Navigator, RN, BSN
Karen Holmseth Nurse Navigator, RN, BSN
Deborah Jones Care Guide, MA



ABBOTT NORTHWESTERN HOSPITAL
Neuroscience Institute

allinahealth.org/givens