

GREY MATTERS

NEWSLETTER OF GIVENS BRAIN TUMOR CENTER

FALL 2019
VOLUME 1 | ISSUE 1

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Medical Director's Column

JOHN TRUSHEIM, MD

Hello everyone,

I hope you all enjoyed the summer and fall months and that you are appreciating this transition to winter. We are excited to offer our first ever edition of "Grey Matters," a Givens Brain Tumor Center newsletter that will bring you the latest

information about our programs and services, research and clinical trials, upcoming events, community resources that we think you'll find helpful and information about our team.

We plan to offer this newsletter two times per year as a supplement to our website and other venues of communication with our patient and family community.

Please feel free to reach out to our team with any questions or interest based on this issue and we will be happy to help you get involved in whatever services or resources that may interest you. If you have feedback for additional topics you would like to see us discuss here, please contact Deborah Jones (deborah.jones@allina.com, 612-424-1076) and we will be happy to consider including it in an upcoming issue.

Sincerely,
Dr. Trusheim

Givens Brain Tumor Center
Part of Abbott Northwestern Hospital
Neuroscience Institute | Piper Bldg 304
800 E 28th Street, MR 39304
Minneapolis, MN 55407
allinahealth.org/givens


Allina Health
ABBOTT
NORTHWESTERN
HOSPITAL

Neuroscience
Institute

Welcome to Grey Matters



Editor's Column

DEBORAH JONES
LIFECOURSE
CARE GUIDE

Welcome to our maiden "Grey Matters" newsletter! A heartfelt welcome from all of us

at The Givens Brain Tumor Center. We welcome the opportunity to work with each and every one of you and your loved ones as you experience your journey with brain or spinal cord tumors and cancer. It is our mission to serve and support you in the best way possible!

Our focus at Givens Brain Tumor Center is to support and understand what matters most to you beyond your physical condition. We respect that many of you have busy, chaotic lives along with days and nights where you feel just plain lousy, and live with uncertainty about the future.

With each publication we will highlight community resources, keep you informed of any changes or new services we offer, and share other relevant and interesting information about brain and spinal cord tumors. And, of course, we will provide resources helpful to you and family.

The Givens family

Mike Givens was a hero in every sense of the word when he lost his battle with brain cancer in 2015. He, along with his wife, Linda, were the co-founders of the 501(c)3 MG Charities and events run by MG Charities around the country. Mike and Linda Givens were self-made entrepreneurs in the Midwest and the driving force behind raising and donating more than \$10 million to charities around the country over the past two decades.



Mike and Linda Givens

In three years MG Charities has donated \$1.6 million to The Givens Brain Tumor Center. Their annual Mind over Matter charity golf event at the Wayzata Country Club has raised money to benefit brain cancer research and patients being treated with brain cancer. MG Charities has also provided funds to MD Anderson's Laser Interstitial Thermal Therapy (LITT) research and for research at UCSF Medical Center in San Francisco, Calif. Mike Given's legacy lives on through this continuing charity work.

To learn more about MG charities or to make a donation, check out the MG Charities website, mgcharities.org.

Meet Our New Staff Members!

Welcome Kia!

TANKIA BARNES
CERTIFIED MEDICAL ASSISTANT



Tankia (TAN + kia), or Kia Barnes, Certified Medical Assistant, joined Givens Brain Tumor Center in June. Barnes is one of the first people you'll meet because one of her duties is to guide you to your exam room. She completed her medical assistant program at Rasmussen

College while working full time and, as a single mom, raising her 4-year-old daughter, Trinity. Kia loves music and dance and continues to take online courses as a prerequisite to entering a nursing program.

Barnes most recently worked at South Lake Pediatrics as a medical receptionist and scheduler. Most of her career has been spent in health care, working in home care at Univita Health and Corner Home Medical.

Ask her to share news about her daughter or ask her how to pronounce her name: "It provides something to laugh about and makes things calmer," she says.

Welcome Karen!

KAREN HOLMSETH, RN,
CANCER CARE COORDINATOR



Karen Holmseth joined us in February and works alongside Emma Sacco, RN, and Kathy Gilliland, RN, our other cancer care coordinators. Nursing is Karen's second career. After college, she worked for non-profit organizations in development, marketing and event planning. She decided

to pursue nursing after her mother was diagnosed with a glioblastoma 13 years ago. Soon after the diagnosis, she took a year off of college to move home to be her mom's full-time caregiver for a year. While, Holmseth and her husband were living in Nashville, she enrolled in an accelerated nursing program.

"I always wanted to provide care for patients and families who were living with a similar diagnosis as my mom."

After completing her nursing degree Holmseth worked in inpatient renal, medical-surgical and kidney transplant units at Abbott Northwestern Hospital as well as in oncology at the University of Minnesota's blood and bone marrow transplant program.

"It's been a big change to move from seeing patients at the bedside into the role of a Care Coordinator here at Givens Brain Tumor Center. I find the team to be very rewarding to work with. We are small, but we accomplish so much together."

Karen and her husband, Owen, are big Minnesota United soccer fans and love the outdoors, especially camping, fishing and kayaking. Regrettably, Karen's mother died in the spring of 2015. Her father live in southern Minnesota, and she is also close to her brother and two sisters.

Community Resource Highlights

The Richard M. Schulze Family American Cancer Society

HOPE LODGE, MINNEAPOLIS

The Richard M. Schulze Family American Cancer Society Hope Lodge, which opened in 2007, is located about four miles from Abbott Northwestern Hospital. Funding for the land and facility was provided through the generosity of several foundations. Hope Lodge facilities are sponsored by the American Cancer Society in several states including Minnesota.



The local Schulze Family Hope Lodge is for patients, and one caregiver, undergoing cancer treatment who live more than 40 miles or one hour away. Hope Lodge has 42 hotel-style rooms with a bathroom, TV and WI-FI. Added features include kitchens on the main level; a new theater; shared community spaces; a meditation room and chapel; library; craft, yoga and exercise room. Laundry facilities and housekeeping is available on each floor.

Transportation to treatment is available at little to no cost.

To learn more about The Richard M. Schulze Family American Cancer Society Hope Lodge contact your social worker.

Cancer Legal Care: What are my rights?

Cancer Legal Care is a non-profit resource for cancer patients and survivors who live in Minnesota, who are seeking answers about a wide variety of legal rights and issues. Cancer Legal Care can provide you answers and referrals for estate planning, wills, healthcare directives, power of attorney, employment, housing, applying for Social Security Disability, health care insurance, and more.



Most questions can be answered on the phone, but attorneys are also able to meet with you in their office or in your home, hospital room or hospice facility.

Cancer Legal Care was founded as Cancer Legal Line in 2004, and began providing legal services in 2007. If you are wondering "what are my rights," give them a call! It's free!

To learn more visit cancerlegalcare.org or call 651-917-9000.

Neuro-Oncology Highlights



Nilanjana Banerji, MS, PhD
DIRECTOR, CLINICAL RESEARCH

Neuro-oncology research at Givens Brain Tumor Center is supported by Allina Health Neuroscience Research Department. The research team includes experienced research nurses, project and regulatory managers, and research scientists.

Through our current research, you have access to multiple cutting edge drug and device treatment trials for people with brain tumors. These clinical trials are focused on immunotherapy and individualized medicine protocols. There also is a robust menu of investigator-initiated clinical trials that have the potential of research discoveries which could be translated into advances in patient care.

One current research study evaluates the routine clinical treatment of patients with glioblastoma at Givens Brain Tumor Center to determine the success and outcome of standard treatments. This study is allowing us to benchmark our performance to national standards for glioblastoma care.

A second research study explores quality of life for patients with glioblastoma, and their caregivers. Questionnaires can only capture pieces of the experience, and experiences change over time as available treatments, resources and care patterns change. In this study, we are interviewing patients and family caregivers. The study will examine these interviews for themes and how they relate to existing quality of life assessment tools. We hope our findings will guide future research into ways we can improve quality of life for patients and families dealing with a diagnosis of glioblastoma.

Supportive Offerings

PROVIDED BY THE GIVENS BRAIN TUMOR CENTER

Brain Tumor Support Group

Abbott Northwestern Hospital's Givens Brain Tumor Center offers a support group for adult brain tumor patients and adult caregivers. The sessions are held on the second Thursday of each month. Social workers, clinicians and staff gather to offer education and support to people affected by brain tumors.

WHEN:

Second Thursday of each month
5:30–7 p.m.
Light meal: 5:30 p.m.
Group session: 6 – 7 p.m.

WHERE:

Abbott Northwestern Hospital
913 E 26th St.
Minneapolis, MN
6th floor classroom of the Piper Building

*For questions or more information,
please call 612-863-3732.*

Powerful Tools for Caregivers

This six-week series of classes is geared towards caregivers of all backgrounds, at any stage of their caregiving role.

Conducted by certified trainers, the weekly, 2-hour classes aim to educate caregivers and improve overall health and well-being.

At Powerful Tools, you will learn how to:

- Reduce stress.
- Communicate more effectively during challenging situations.
- Prevent caregiver burnout.

Classes will be held from 10:00 AM - 12:00 PM on the following dates:

Wednesday, January 22
Wednesday, January 29
Friday, February 7
Friday, February 14
Wednesday, February 19
Wednesday, February 26

CLASS INFORMATION

Classes will be held at the Heart and Vascular Center within Mercy Hospital, 4040 Coon Rapids Blvd NW #120, Coon Rapids, MN 55433.

Enter through the Heart and Vascular Center and take the elevator down to the lower level to find the classroom. Signage will be present.

Parking is free.

The class costs \$25 for the 6-week session and includes a workbook that you will keep.

Pre-registration is required. Call Anushka at 651-241-8297 to learn more or to register.

Supportive Offerings

PROVIDED BY THE GIVENS BRAIN TUMOR CENTER

Coping with brain and spinal cord cancer program



Givens Brain Tumor Center is partnering with Tiatros to offer a free online program to patients and caregivers experiencing brain and spinal cord cancer. The program is designed to nourish your mind, body and spirit during this challenging time of life.

PROGRAM FEATURES

- Eight weekly sessions you can access whenever it works for your schedule
- Join classes on our secure and HIPAA-compliant platform from any electronic device
- Separate online groups for patients and caregivers
- Activities include light journaling, sharing and reframing your story, meditation exercises, gratitude practices, reflecting on personal health and resilience objectives.

If you are interested in participating in the next online program or would like to learn more, please contact Deborah Jones, deborah.jones@allina.com, at 612-424-1076.

“I cannot believe how lucky I am to have the opportunity to be part of this. I am extremely grateful and thankful.”

–PATIENT PARTICIPANT

“I found it beneficial. I learned ways to reframe my story in a different way.”

–PATIENT PARTICIPANT

“It was a blessing to share this time with the group. I enjoyed the encouragement I got from sharing. I felt close like I would with family and friends.”

–PATIENT PARTICIPANT

Supportive Offerings

PROVIDED BY THE GIVENS BRAIN TUMOR CENTER

CHOOSE WHAT YOU EAT NUTRITION CLASSES

Learn more about how nutrition can optimize your well-being through a monthly nutrition class at Givens Brain Tumor Center. Topics include:

- How food can support and nourish you during treatment
- How to manage your symptoms through diet
- Understanding your weight concerns
- Will supplements help me?
- other nutrition resources.



NUTRITION SUPPORT FOR PATIENTS AND FAMILIES

What you choose to eat is an area of life you can control. Are you interested in learning more about how nutrition can help you optimize your wellbeing? Join us for a free session designed just for patients with brain tumors and their families.

We'll cover topics like:

- How food can support and nourish you as you go through treatment
- The best and healthiest foods that protect your body AND taste delicious!
- Popular diets
- Supplements
- Unintended weight gain and weight loss issues
- Managing symptoms through food choices
- Additional resources for optimizing nutrition

Class will be led by Maureen Rose Doran, RDN, LD from Penny George Institute for Health and Healing.

When: Second Wednesday of each month from 12:00 – 1:00 p.m.

Where: Givens Brain Tumor Center
Abbott Northwestern's Neuroscience Institute
Piper Building, Suite 304
913 East 26th Street
Minneapolis, MN 55407

Cost: FREE

Register: Sign up at the Givens Brain Tumor Center front desk or call the clinic at **612-863-3732**.

Note: Each class session can accommodate one family member or guest per patient attending. Each class will cover the same topics.

Community Resources

RAISING AWARENESS AND DOLLARS FOR BRAIN AND SPINAL CORD TUMORS!

Here are some of the organizations who work tirelessly to raise awareness about these serious conditions along with raising money to help find cures to 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 – Como Regional Park, October 12, 2019

It was a snowy, rainy, windy, bitter day on Saturday, Oct. 12, 2019, but 1,700 amazing people signed up to run or walk around Como Lake in St. Paul to support The American Brain Tumor Association (ABTA). The ABTA has funded more than \$1 million in critical research grants to Twin Cities-based scientists. Supporters have helped the ABTA create and provide patient and caregiver-focused programs as well as explore new local programs and relationships. As of this printing \$244,600 had been raised toward a goal of \$260k.



Bowling for Brains

The goal of this annual April event is to bring people who have been affected by brain tumors together to raise awareness of brain tumors, the work of the American Brain Tumor Association and the Givens Brain Tumor Center at Abbott Northwestern Hospital through participating in the bowling games, silent auction and sharing stories of brain tumor patients and survivors.



Annual Fun Walk in Excelsior in May

WalkTalkConnect is a non-profit dedicated to building a "peer-to-peer" mentoring community that connects patients and caregivers facing the unique challenges presented by rare brain and spinal cord tumors. Their close relationship with The Givens Brain Tumor Center and Courage Kenny Rehabilitation Institute allow them to connect with patients and families and provide support alongside their continued medical advancement. Watch for the next fun walk in May 2020, or other events such as the Spin Sweat Connect! walktalkconnect.org

Support and Classes



American Brain Tumor Association
Website: www.abta.org



American Cancer Society
Website: cancer.org
651-255-8100

American Cancer Society – Road to Recovery
Website: cancer.org
Get a ride to cancer treatment.
800-227-2345



Website: cancercare.org
800-813-HOPE (4673)



Disability Hub
Website: disabilityhubmn.org
866-333-2466



Minnesota Board on Aging

Website: mnaging.org
Seven area agencies who provide assistance and resource information to seniors, local agencies, and communities within their area.

Pathways

A Healing Center

Pathways Minneapolis

Website: pathwaysminneapolis.org
Pathway's 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.



Powerful Tools for Caregivers

Website: powerfultoolsforcaregivers.org
Caregiver classes provide tools and strategies to better handle the unique caregiver challenges you face. PTC classes are available for caregivers of adults with chronic conditions and also of children with special health or behavioral needs. Registration required.

Support and Classes



PENNY GEORGE
INSTITUTE FOR HEALTH
AND HEALING

Penny George Institute for Health and Healing

Website: allinahealth.org/georgeinstitute

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.



Senior Linkage Line

Website: mnaging.org
800-333-2433



Veteran's Linkage Line

Website: macvso.org
888-546-5838



Wilder Foundation, St. Paul, MN

Website: wilder.org

Wilder is committed to improving the lives of individuals who age in place and live where they feel most comfortable, whether in their own home or connected to their community. Seniors, older adults, adults with mental, physical and chronic health conditions and their caregivers have access to a variety of healthy aging and caregiving services, support and resources.

FINANCIAL RESOURCES

Allina Health

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

MNsure

Website: mnsure.org
1-855-366-7873

Medicare

Website: medicare.gov
800-633-4227

Social Security

Website: 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

Website: mnangel.org
612-627-9000

Twin Cities Metro Area Support Groups

Givens Brain Tumor Center

Abbott Northwestern Hospital – Piper Building
913 E. 26th Street, 6th Floor classroom
2nd Thursday of the month, 5:30-7 p.m.
612-863-3732

Brains Together for a Cure

Sandra Schultz Hope Lodge
411 Second St. NW, Rochester
3rd Saturday of the month, 10 a.m.-noon

Gildas Club Brain Networking Group

GCTC
10560 Wayzata Blvd., Minneapolis
4th Tuesday of the month, 6:30-8 p.m.
612-227-2147

Health East Neurosurgery Brain Tumor Support Group

St. Joseph Hospital
Call Kathy Maiers at 651-232-3987 to register
1575 Beam Ave., St. Paul
3rd Monday of the month, 6 p.m. dinner
6:30-8 p.m. meeting

M Health University of Minnesota

Hope Lodge
Contact: Katie Pearson, 612-273-7437
2500 University Ave., Minneapolis
4th Monday of the month, 6:30-8 p.m.

For more community and financial resources contact your care coordinator or social worker.