

The Sarcoma Connection

2018

IN THIS ISSUE

Tie Up Those Sneakers	1
Spindle Cell Sarcoma.....	2
Stronger Than Sarcoma Soiree	3
Elekta MR-linac for the Treatment of Soft Tissue Sarcomas: The Future of Radiation Therapy ...	4
Chasing the Dream: Insomnia after Cancer....	4
Moving Closer to a Cure for Retroperitoneal Sarcomas	5
Support Groups	6
New Interventional Radiology Suites	7
Join Us on Facebook	8
Together, We Are Strong Blog	8
Froedtert Hospital Foundation.....	8



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Sarcoma Survivors ~ 2017 Race to Cure Sarcoma™

Tie Up Those Sneakers - Race to Cure Sarcoma™ Milwaukee 5K Run/Walk Returns in July

On a picture-perfect Sunday morning last July, 665 walkers and runners gathered at beautiful Fowler Park in Oconomowoc to participate in the first-ever Race to Cure Sarcoma™ Milwaukee 5K Run/Walk. Organized by the Sarcoma Foundation of America (SFA), this event has raised more than \$50,000 to date for sarcoma research — nationally through the SFA and locally through the Froedtert & the Medical College of Wisconsin Cancer Network and Children’s Hospital of Wisconsin.

The family-friendly event in 2017 provided opportunities galore for everyone: weekend athletes, avid runners, stroller

riders, sponsors, volunteers and cheerleaders on the sidelines. Music, food and photo opportunities helped link everyone together to celebrate and honor those affected by sarcoma.

“The first Race to Cure Sarcoma™ Milwaukee was an incredible success,” said Michaela Mueller, senior manager of events for the SFA. “The number of registrations for a first-year race was the highest ever in one of the many cities where we hold these events.”

Be sure to join us on Saturday, July 14, 2018, for year two of this great event! Learn more or register: curesarcoma.org/Milwaukee ♦

Spindle Cell Sarcoma

by Terry Visocky

August is usually busy with end-of-summer fun, unless you discover a golf ball-sized mass under your upper arm. No warning signs, no pain — just a huge lump that literally appeared overnight.

My journey began the next day, Aug. 4, 2016, with a visit to my general doctor. A computed tomography (CT) scan confirmed his diagnosis — a sheath nerve tumor. I was referred to a neurosurgeon because the tumor was very involved with the brachial plexus nerve bundle. That nerve bundle controls the feeling and function of my right hand, arm, shoulder and neck.

The neurosurgeon was extremely confident about removing it, telling my husband and me before and after the Aug. 27 surgery, that it was “no big deal.” It turned out that wasn’t the case! When we met with him for the post-surgical appointment, he handed me two business cards and told me to see the specialists noted on them. I saw the word oncologist on the cards and was speechless; then, I began to cry. The doctor simply remarked that there was more involved than expected. Never once did he say I had cancer!

The next few days were filled with fear, disbelief, tears and determination; How could I have cancer? I’m not sick!

We met with the two oncologists I was referred to. They confirmed I had cancer. Now, I could move forward. We learned that the first surgery didn’t get all of the tumor, so cancer was still in me. I had spindle cell sarcoma, a very rare and aggressive form of soft tissue cancer. I was then referred to Donald Hackbarth, MD, an orthopaedic oncologist at the Froedtert & the Medical College of Wisconsin Clinical Cancer Center at Froedtert Hospital, part of the Froedtert & MCW Cancer Network. The oncologists explained that the surgeon would be key, and Dr. Hackbarth was the best!

Meeting with Dr. Hackbarth was the next step. He examined my arm and showed us the CT scans and magnetic resonance (MR) images. Next, he calmly explained the severity of my case and his concern for the future use of my arm. Our minds were swirling with questions. We learned that Froedtert Hospital uses a multidisciplinary approach and has a cancer conference for sarcoma — a group made up of various specialists who meet weekly and discuss patient cases. Because my sarcoma was so rare, and the previous surgery did not remove all of the tumor, my case was discussed numerous times.

We soon met Dr. Hackbarth’s colleagues, Meena Bedi, MD, a radiation oncologist and John Charlson, MD, a medical oncologist. They thoroughly explained their roles, answered all of our questions and reassured us we’d be in good hands.

Now, the plan was set: Radiation therapy, followed by a second surgery and chemotherapy.

My radiation therapy would include five visits a week for five weeks, beginning in October 2016. Molds were made of my shoulder/upper arm area to provide exact measurements. Treatments were simple: I lay within the mold on the table while technicians checked that the positioning was correct. I’d hear the machine hum, see the colored light beams, get a CT scan, and then, that session was over.

My body tolerated radiation therapy well — no extreme tiredness — so, I continued to work. As treatment ended in mid-November, my skin reacted. Dr. Bedi provided gel pads, cream and dressings. My skin recovered after a short time.

Then, it was time to meet and discuss surgery No. 2 with Dr. Hackbarth. He suggested including John LoGiudice, MD, a plastic and reconstructive surgeon, due to extensive nerve involvement, adding that the incision would be about seven inches long, extending into my armpit. We met Dr. LoGiudice, and surgery was scheduled for Dec. 21, 2016.

Dr. Hackbarth and Dr. LoGiudice worked diligently to peel the remaining tumor off my nerves, while maintaining the functionality of my arm and hand. Later that evening, I was amazed to find I had as much strength and mobility in my hand as I did before the surgery!

The next week, we saw Dr. Hackbarth to remove sutures and discuss his findings. We didn’t hear exactly what we expected. Two of the three tumor margins were still positive. Radiation therapy had shrunk the tumor about 20 percent, but the only way to completely eliminate the cancer was to amputate my arm at my shoulder. What?!

In the following two weeks, we consulted at three other well-known cancer treatment hospitals to explore options. We never doubted our team at Froedtert Hospital, but needed as much information as possible to make the best decision for me. Losing my right arm was just not an option!

The other specialists concurred with Dr. Hackbarth: More surgery wasn’t possible because radiation therapy had melded everything together inside my arm. Only then, did I realize I’d been holding out for a miracle cure. Sadly, there wasn’t one.

Now, it was time to talk chemotherapy and that terrified me! Putting poison into my body, losing my beloved red hair and feeling sick were not things I was looking forward to. My mantra became, “kill the beast — whatever it takes!”



Terry Visocky

I had a double port placed on Thursday, Feb. 2, 2017 and began chemo four days later. I'd undergo five rounds, each round three weeks apart. It was the second toughest cocktail there is, consisting of three drugs, so I'd be hospitalized for very close monitoring. Each round of chemo would run for 66 hours, non-stop.

Round 1 was uneventful. I ate anything I wanted, visited, walked around and watched TV. On the fifth day, I was released. About a week later, I started losing my hair. I had already purchased a wig, but I was still shocked after my neighbor shaved my head for me.

Round 2 brought nausea, and eating became less appealing, resulting in my spending a couple hours receiving IV fluids. I began losing weight and lying around more. I was becoming weaker. One day at home, when trying to get back into bed after a bath, I slid onto the floor. I called family and left them voicemails. I eventually made it back into bed. When they arrived home and tried to help move me, I started convulsing. A call to 911 brought paramedics, and I experienced my first ambulance ride. I don't remember most of that, except that hearing my blood pressure was 70/40. After a few days in the hospital, I recovered and returned home.

Round 3 proved to be brutal! Being sick most of the time, I had no desire to eat or drink. My determination waned and was replaced by questioning how much more my body could take. Most of the time, I just wanted to sleep, so I lost most of the muscle tone in my legs.

I developed neurotoxicity, affecting my brain and nervous system. It was during this "crazy time" that I managed to pull out the access wires of my port, causing the chemo to spill and burn the skin on my chest. Luckily, after receiving an anecdote, I fully recovered within a couple days. My medical

team monitored the burn, and my skin also recovered.

My husband and Dr. Charlson had been discussing the continuation of my chemotherapy. By this point, I'd lost 35 pounds and wasn't strong enough to walk. Chemo had definitely taken a toll on me, and I was no longer sure what my future held. The three of us decided I would not continue chemo.

Even after returning home, I wasn't interested in food, felt very sick and weak and withdrew from the army of friends that had given me so much strength. I felt I had failed! I had another MRI and CT scan, and we had an appointment with Dr. Charlson a couple of days later.

I thought we'd discuss an alternate treatment. Dr. Charlson pulled up the images and reports. To our amazement, the scans were clear. The cancer was gone! Little by little, my taste buds returned, making eating possible again. I also went to physical therapy to regain some leg strength. By May 2017, I realized I was feeling better every day!

I'm not sure I believe it still, but ... countless appointments, two surgeries, many CT scans/MRI's, 25 radiation treatments, five multiple-day hospital stays, two ambulance rides and 198 hours of chemotherapy later – I survived! I am cancer free!

It's nothing short of a miracle! From the bottom of my heart, thank you for giving me my life back! I've returned to the full-time job I love as a special education teaching assistant. I have no restrictions, need no medication and can do anything and everything I want to do. Thanks to God, the experts at Froedtert Hospital and all of my Terry's Troopers, I made it, and I am a survivor! ♦

Stronger than Sarcoma: A Soiree for Research

Bone and soft tissue sarcomas are rare but deadly diseases that account for about 1 percent of all cancers in adults and 20 percent of all cancers in children. Each year, about 14,000 new patients are diagnosed with bone and soft tissue sarcomas and about 6,000 people die as a result of sarcoma. Because sarcomas are rare, research has been limited; thus, improvements in treatment have been slow.

Each year, it is estimated that about 6 billion dollars will be raised in the name of breast cancer research. In 2011, almost 20 percent of the site-specific research funding was dedicated to breast cancer. In contrast, sarcoma received less than 3 percent.

To increase awareness for funding for sarcoma research, multiple philanthropic efforts have been initiated through

Froedtert & the Medical College of Wisconsin Froedtert Hospital and Children's Hospital of Wisconsin. In addition to the Sarcoma Foundation of America run/walk, we are pleased to announce our inaugural Stronger than Sarcoma: A Soiree for Research fundraiser. The event will be held on Friday, Aug. 3, 2018 from 6-10 p.m. at the Milwaukee Art Museum in downtown Milwaukee.

Our goal is to not only increase the funding for research in hopes of finding a cure but also to improve awareness of this uncommon disease. ♦



Elekta MR-linac for the Treatment of Soft Tissue Sarcomas: The Future of Radiation Therapy

by Meena Bedi, MD, Radiation Oncologist

Patients with soft tissue sarcomas are often treated with radiation therapy. Radiation therapy is typically delivered with a machine called a linear accelerator (linac) which has a computed tomography (CT) scanner attached to the machine to allow visualization and accurate delivery of radiation therapy each day for several weeks.

Many times, my patients ask me, “Do you see the tumor shrinking or dying?” or “How is my tumor responding to radiation?” Unfortunately, I am unable to give my patients much insight into how their tumor is responding, as CT scans (unlike magnetic resonance imaging or MRI) provide little detail about a patient’s sarcoma. Up to now, we have been unable to assess if the tumor is shrinking or if it is responding to radiotherapy without having the patient undergo MRIs on separate scanners in the hospital several times during their treatments.

On Sept. 16, 2017, a new technology called the Elekta MR-linac or high-field magnetic resonance radiation therapy (MR/RT) system was delivered to the Froedtert & the Medical College of Wisconsin Clinical Cancer Center at Froedtert Hospital, part of the Froedtert & MCW Cancer Network.

The MR-linac integrates, for the first time, an ultramodern radiotherapy system and a high-field MRI scanner with novel software. It incorporates the function of an MRI device and linac treatment device together without disrupting the function of either machine. Elekta’s MR-linac system was specially engineered to contain magnetic fields and radio frequency waves within each unit. This allows both technologies to function optimally in a single machine.

It may surprise many to know that the location, shape and size of tumors change daily. For example, soft tissue tumors in the abdomen may move from day to day depending on

what a patient has eaten and how full the bowel is. The MR-linac enables a physician to capture diagnostic-quality images of tumors and surrounding tissues during radiation therapy delivery. It’s designed to improve targeting of tumor tissue while reducing exposure of healthy tissue to radiation. It could allow physicians to precisely target a tumor and lock onto it during treatment, even when tumor tissue is moving during treatment or changes shape, location, size or composition between treatment sessions.

One of the exciting features of the MR-linac is its potential to identify actively growing portions of a patient’s tumor which could allow physicians to escalate the radiation dose in these specific areas, while minimizing radiation dose to other areas that are not actively growing.

Currently, there are seven academic medical centers worldwide that are examining MR-linac technology and just two of them are in the United States – at MD Anderson in Texas and at the Clinical Cancer Center at Froedtert Hospital. The goal among members of the Elekta MR-linac consortium is to provide patients with improved accuracy of treatment while minimizing side effects.

Over the years, there has been much advancement in the refinement of radiation therapy delivery systems. The MR-linac is one of the foremost revolutionary concepts in radiation therapy and will allow for constant monitoring of each patient to enable the most precise targeting of tumors. As with any technology, it is crucial to continue to refine the delivery of radiation therapy for the future, and that is exactly what the MR-Linac may offer: More effective and accurate treatment with limited side effects. ♦



Meena Bedi, MD

Chasing the Dream: Insomnia after Cancer

by Lyndsey Wallace, PsyD, Clinical Psychologist, Psycho-Oncology Program

Insomnia is an inability to obtain adequate sleep which manifests as difficulty falling asleep or staying asleep. Whether you lie in bed for hours before falling asleep or experience restlessness throughout the night, it’s important to know that occasional bouts of insomnia are normal, and insomnia is an almost inevitable reaction to significant life events such as loss of a job, family stressors, divorce and health problems. In fact, data have shown that most adults experience insomnia at some point in life.

What about prolonged stress? For many, being diagnosed with cancer brings uncertainties and fears about the future. You are faced with making big life decisions in a short amount of time, which can be emotionally distressful. We operate on a set of assumptions about the self, the world and others that are founded on logic and



Lyndsey Wallace, PsyD

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our own sense of justice. We think “everything happens for a reason.” When diagnosed with cancer, these assumptions can be shattered. Instead of living in a predictable, structured world that made sense, you are now living in a world that feels random and meaningless. Research shows that up to 80 percent of cancer patients have sleep problems over the course of treatment, and these problems can persist long after treatment.

While insomnia is triggered by significant life events, it is our reaction to short-term insomnia that can lead to a chronic sleep problem. For example, after a few weeks of lying awake at night, you can start to dread sleep, feeling frustrated and anxious. Anticipation of insomnia creates a negative association with the bedroom and can lead to an anxious preoccupation with the effects of insomnia on your ability to function during the day. These are appropriately called negative sleep thoughts. For example, “I must get eight hours of sleep” or “I won’t be able to function tomorrow if I don’t sleep well tonight.” These negative sleep thoughts are often inaccurate and distorted but the body doesn’t discriminate between a physical threat and a psychological threat. Thus, if you are anxious going to bed, you ignite an arousal response in your body which reduces your ability to fall asleep.

To improve sleep, start by looking at your sleep routine and environment. Sleep serves a major biological restorative function by reducing and restoring our physical energy, so it is crucial that your bedroom is comfortable, cool and dark. One of the best ways to train your body to sleep well is to establish a regular sleep and wake time, even on weekends and days off. By establishing a regular rhythm, you will feel

better, and your body will have an established schedule.

Recognizing, challenging and replacing negative sleep thoughts with more accurate sleep thoughts can help to short-circuit the cycle of emotional arousal. Instead of thinking “I can’t take another night of poor sleep,” you can say “this is only temporary,” or “occasional nights of poor sleep are normal.” There are some faulty assumptions out there about sleep including that less than eight hours can have dire effects on daytime performance. While this can be problematic with prolonged periods of insomnia, the truth is, that we can maintain performance with 5.5 hours of core sleep for short amounts of time. This is because for adults, all of our deep sleep or restorative sleep occurs in the first half of sleep.

Not only are you faced with emotional side effects with cancer, but there are many physical side effects that interfere with sleep quality. Cancer patients are twice as likely to experience insomnia as people without cancer. Often, chemotherapy drugs and radiation therapy cause fatigue, while medications prescribed to combat side effects of chemotherapy can be stimulating (e.g., corticosteroids). It becomes a balancing act with regards to symptom management. In situations where insomnia persists despite adequate management of side effects (e.g., pain) hypnotic medication can be of benefit.

Regardless of the cause, insomnia affects up to 50 percent of cancer patients and can have a profound impact on quality of life. So, the next time you are asked, “how are you sleeping?” — be honest. There are many interventions the Psycho-oncology Program offers to improve your sleep! ♦

Moving Closer to a Cure for Retroperitoneal Sarcomas

by Callisia Clarke, MD; Surgical Oncologist

Soft tissue sarcomas are rare tumors that account for less than 1 percent of all adult cancers. These tumors can arise from various types of connective tissues such as fat, muscle, nerves or blood vessels. While sarcomas can occur anywhere in the body, about 20 percent will arise within the retroperitoneum, the posterior compartment of the abdomen that is separated from the anterior compartment by a thin lining called the peritoneum. Because these tumors start in the “back” of the abdomen, they often grow to rather large sizes over a long period of time before they cause symptoms. Surgery to remove these tumors, when possible, is the only chance for a cure. Involved organs or blood vessels may be removed with the tumor to avoid leaving tumor tissue behind. For this reason, sarcoma surgery should be performed at centers with high volume experience treating these challenging tumors.

Not all retroperitoneal sarcomas are created equal. Some tumors are aggressive and can metastasize to other organs. Other tumors recur (come back) after surgery in the same space they originated or in adjacent areas. In these cases, surgery alone is often ineffective at treating the disease and radiation therapy and/or chemotherapy before (neoadjuvant) or after (adjuvant) surgery is used. Definitive/palliative care may be offered in cases where surgery offers no benefit for patients. Fortunately, there has been progress in research aimed at better understanding and treating sarcomas.

In recent years, two drugs have been approved by the FDA

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Callisia Clarke, MD

for treatment of soft tissue sarcomas in select patients. Trabectin was approved at the end of 2015 for use in unmanageable leiomyosarcoma and liposarcoma, two common subtypes of retroperitoneal sarcoma. The drug targets tumor cell DNA to stop tumor growth and kill cancer cells. The second drug, Olaratumab, is an antibody that blocks platelet-derived growth factor receptor PDGFR-alpha to block tumor cell growth. Research is ongoing to investigate the role of the immune system in sarcoma development and progression. Trials of immune-modifying drugs are underway, and we hope to see similar success with these drugs in patients with retroperitoneal sarcomas as seen in patients with other cancer types such as melanoma and colorectal cancer. Another exciting development in the sarcoma world is the discovery that cyclin-dependent kinase-4 (CDK4), a cancer-linked gene, is

overexpressed on some subtypes of retroperitoneal sarcomas. This discovery was made after many years by doctors and researchers who studied these rare tumors. The identification of this gene as a potential target for cancer drug development led to the creation of CDK4-directed therapies targeting this CDK4. New drugs are in early phase trials. New therapeutic options and scientific findings show progress in retroperitoneal sarcoma research.

Within the Froedtert & the Medical College of Wisconsin Cancer Network, our sarcoma doctors and researchers are dedicated to continuing the work needed to understand the disease and find new and better therapies. I am optimistic that as patients, doctors and researchers from all over the world stand together to raise awareness and fund research, a cure is on the horizon. ♦

Support Groups

Journey to Wellness Support Group

This monthly support group is for anyone affected by a cancer diagnosis. Please join us for an opportunity to share information and experiences, as well as to receive encouragement and support. Spouses, family members, significant others and caregivers are also welcome to attend.

- This monthly support group offers speakers and is also intended as an open forum.
- No matter where you are in your cancer journey, please join us.

Journey to Wellness is offered at these Froedtert & the Medical College of Wisconsin Cancer Network locations:

Menomonee Falls
Cancer Care Center at Community Memorial Hospital
New Berlin
Moorland Reserve Health Center
Wauwatosa
Clinical Cancer Center at Froedtert Hospital

Offered through the Froedtert & MCW Cancer Network:

West Bend
Kettle Moraine YMCA

Young Adult Oncology Group

The Young Adult Oncology Group is for cancer survivors (on or off treatment) ages 18 to 39. This group provides survivorship support and education and offers social activities.

- Meets monthly
- Dates and times vary
- Sponsored by Children's Hospital of Wisconsin, the Medical College of Wisconsin and the Froedtert & MCW Cancer Network.

For more information contact Kristin Bingen at 414-955-4148 or kbingen@mcw.edu.

Cancer Caregivers Support Group

This support group is for friends, family members or others caring for people with cancer. It promotes open communication of feelings and shared experiences. Occasionally topics of interest are highlighted but it is mostly intended as an open forum.

- Meets fourth Tuesday of each month from 5:30-7 p.m. (no meeting in December)
- Clinical Cancer Center at Froedtert Hospital, Lobby Level, Conference Room J
- This group is made possible by donations to the Froedtert Hospital Foundation.

For more information about our support groups, please visit froedtert.com or call 414-805-3666 or 800-272-3666.

New Interventional Radiology Suites Provide Enhanced Patient Care

by William Lea, MD; Vascular and Interventional Radiology

The summer of 2017 brought substantial changes to the division of Interventional Radiology. After nearly two years of planning and construction, Froedtert & the Medical College of Wisconsin Froedtert Hospital's integrated procedural platform expansion finally opened. Interventional Radiology moved to a new location housing nine new procedure rooms with state-of-the-art capabilities within a beautiful new patient care area in the Center for Advanced Care building.

Many patients battling sarcoma will visit Interventional Radiology at some point during their care. Interventional radiologists are physicians dedicated to caring for all patients fighting cancer by providing a wide range of minimally invasive, image-guided procedures. Our new space has had a substantial impact on our ability to provide an enhanced patient care experience.

Because of the image-guided nature of our specialty, maintaining state-of-the-art technology is extraordinarily important, and our new location has allowed for several technological advances.

One of these advances is a new type of procedure room, called a Miyabi suite. One of only a handful in the United States, this room combines a computed tomography (CT) scanner with a traditional fluoroscopic imaging machine to provide even more precise imaging guidance, improving

procedural success and safety.

For example, from time to time, treatment targeting a specific area of cancer is necessary. Interventional radiologists frequently use a variety of needle-based therapies performed through tiny skin incisions, including procedures to kill tumors (ablation), block nerves and reinforce weakened bone. For these procedures, precise needle placement is critical for success, and the enhanced imaging in our new combination Miyabi room has allowed us to safely perform increasingly complex procedures through truly minimally invasive techniques, allowing patients a quick recovery with minimal downtime.

Patients who need other therapies, such as magnetic resonance (MR) guided focused ultrasound (MRgFUS) ablation, have also benefited from our new location. MRgFUS technology allows for targeted tumor killing in a completely non-invasive manner using ultrasound waves originating from outside the body. With the transition to our new space, MRgFUS technology was combined with a larger MR scanner, allowing interventional radiologists to offer this promising therapy to even more patients.

We are, perhaps, most excited about the improved patient experience our new home will provide. As just one example, cancer patients often visit Interventional Radiology for the placement of a chest port, which can be used for chemotherapy and blood draws. These are placed in the outpatient setting using small skin incisions, light sedation and the guidance of X-ray imaging to ensure optimal positioning. While a relatively straightforward procedure, many patients receiving a chest port have only recently been diagnosed with cancer and are understandably anxious about their procedure and the long road ahead. We are fortunate that our new Interventional Radiology suites are optimally located for patients, situated directly adjacent to the patient preparation and recovery area in the Center for Advanced Care. This allows us to provide a seamless experience throughout the procedure experience, from check-in to check-out, providing patients some small measure of reassurance in an uncertain time.

Despite these many physical changes within Interventional Radiology, our unwavering commitment to caring for our patients remains the same, and we look forward to providing the same exceptional patient care in our new home for many years to come. ♦



William Lea, MD





Join Us on Facebook

We invite you to join the Froedtert & MCW Sarcoma Support Group on Facebook to:



- Connect with and learn from others affected by sarcoma
- Receive information about sarcoma events, meetings and classes
- Continue discussions from monthly in-person support group meetings

Ask to join at: facebook.com/groups/froedtertsarcoma

Please note: You must be 18 years of age or older to participate. Before welcoming you to this group, we will send a verification message via Facebook which requires your response. This message is most often delivered to the “other” message folder. Please be sure to check there.

For more information, please call Tracy Erlitz, RN, BSN, OCN: 414-805-6001. ♦

Together, We Are Strong



What does the word “cancer” mean to you? Your cancer experience is different from that of others, but we can learn and take comfort from one another.

Visit our cancer blog, Together, We Are Strong, where a community of patients, family members, friends, physicians and researchers have started a conversation about cancer.

Join us and subscribe: froedtert.com/together. ♦

Froedtert HOSPITAL FOUNDATION

Many donors support the Froedtert Hospital Foundation because of their patient care experience. Their gifts reflect the compassionate care provided by our nurses, physicians and others. We all stand in partnership with our patients in fighting cancer.

The annual “Living with Sarcoma: Facing Today with Hope for Tomorrow” event is made possible through the generous support from these grateful patients and donors.

Gifts to the Froedtert Hospital Foundation support patient care, clinical research and education initiatives for staff and physicians. Tributes can be made in honor or memory of a loved one, and they can be directed to a special interest area.

If you would like to learn how you can support this program, please contact the Froedtert Hospital Foundation at 414-805-2699. ♦

Froedtert & the Medical College of Wisconsin Sarcoma Program

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