When I first heard the news that my mother, Lydia, had cancer again, I couldn't believe it. She had just been declared clear of bladder cancer, and now she was diagnosed with a rare form of cancer, spindle cell sarcoma, in her foot. I had so many thoughts and emotions going through my head. I knew I needed to get her to Milwaukee from her home in Illinois so she could get the best treatment. My partner and I did a lot of research and decided that Froedtert & the Medical College of Wisconsin Froedtert Hospital was the place to be.

As an only child, you rely a lot on family and friends to get you through tough times, and my mother and I had many. We had our first appointment at Froedtert Hospital in May 2015. David King, MD, orthopaedic oncologist, put together the best team of doctors and nurses for us. My mom went through in-patient chemotherapy, radiation therapy and multiple surgeries. She was in the hospital or in the rehabilitation facility from October 2015 to May 2016. We made sure my mother had everything she needed and tried to make sure she was as comfortable and as happy as she could be. We made sure to decorate her rooms for each holiday and season change. I visited her nearly every day, often for 10 to 12 hours. Even though I wasn't the person who was ill, I felt as if my life was put on hold, too. My vacation time was spent at the hospital or the rehab facility. Even though I wasn't physically able to do anything, providing emotional support was important for her recovery.

When she was finally discharged from the rehab facility, we turned our living room into a rehab room just for her. She continued to need post-surgical wound care, which I provided after getting training from the nursing and wound care teams. If anything looked unusual or if I had concerns, there was always someone available for me, especially Leeann Essig, RN, who works with Dr. King. I was fortunate to have an employer that was flexible in allowing me to attend all of my mother's follow-up appointments.

continued on next page
It’s so hard to see a loved one lying in a bed and not able to get up. There were many times when I put my daughter role on the back burner and became the best advocate I could be for her. My advice to other caregivers: never give up; all questions are good questions; don’t underestimate the value of your presence in being there for your loved one.

Having great, supportive teams at home and at Froedtert Hospital helped us get through this experience. ♦

Read more about Lydia in the January 2017 issue of “Froedtert Today” by visiting froedert.com: go to Health Resources and choose Publications and Health News.

Most of the people around us who have cancer are older adults, and many of these patients are experiencing improved outcomes and expanded treatment options. Likewise, children with cancer are significantly more likely to survive cancer now than children of 20 to 30 years ago. However, in recent years, it has become apparent that adolescent and young adult (AYA) cancer patients, defined as ages 15 to 39 years, have not seen the same survival improvements.

Factors contributing to the lagging treatment outcomes in this age group include limitations in access to care, delayed diagnosis because AYA patients see doctors less regularly and cancers are not suspected in this age group, and lack of standardized, research-based treatment protocols. The reasons for lack of progress are complex and are not yet well understood. An underlying problem is that AYA cancer treatment has not had as much attention from researchers as treatment for other age groups.

Supportive and psychosocial care, aimed at ensuring that cancer treatment outcomes and quality of life are maximized, are important components of cancer treatment. Here again, AYA patients can find themselves in a sort of “No Man’s Land” between pediatric and adult cancer centers. Issues unique to this age group such as school, new careers, dating, young families and the impact of treatment on fertility require attention as we guide our patients through their cancer treatment.

Since early 2016, at Children’s Hospital of Wisconsin and the Froedtert & Medical College of Wisconsin Cancer Network, we have been working on developing robust AYA cancer programs. Our vision is that we will provide the best possible care for our AYA patients, and that our expertise in this area will be a valuable resource for patients throughout Wisconsin. We initially focused our efforts on patients with sarcoma, leukemia and lymphoma, since these are cancers common to this age group. Eventually we plan to roll the program out to AYA patients with all cancer types.

We have taken a number of steps forward on this mission. Educational materials and information about resources are provided to AYA patients starting treatment. Programs to educate cancer care teams and other health care providers about AYA issues are being prepared as well. Care pathways have been developed to make sure key components of initial treatment and supportive care are addressed for every patient. We’re also working to standardize and streamline access to Froedtert & MCW fertility preservation experts for patients whose ability to have children may be affected by their treatment.

Our researchers are helping to fill in the knowledge gaps that have held AYA cancer care back. Clinical trials are available at the Froedtert & MCW Froedtert Hospital campus for various cancers that affect this age group. Ehab Atallah, MD, medical oncologist, is part of a small group of physicians designing a nationwide clinical trial focused on AYA patients with acute myelogenous leukemia. Jeanne Erickson, MD, from the University of Wisconsin - Milwaukee College of Nursing, is collaborating with investigators at Froedtert Hospital and Children’s Hospital to study innovative ways of using technology to improve communication and supportive care for AYA patients. In addition, Children’s Hospital is a member of the Children’s Oncology Group, which offers clinical trial opportunities to adolescents and young adults with a variety of cancer diagnoses. This includes early phase clinical trials for patients with relapsed or refractory cancers.

There is work to be done, but we are excited about the opportunity to improve on the great care we provide for our patients with sarcoma and other cancers. ♦
“I have a sarcoma.”
“A what-oma?”
“A SARcoma.”
“Oh, is that a type of breast cancer?”
“Nevermind.”

The frustration that accompanies the diagnosis of a rare cancer can be overwhelming at times. Imagine being in a room with 99 other cancer patients, all of whom have at least one other person to talk with and relate to in terms of their cancer type. But you are off on your own; no one else shares your diagnosis. That is what it is like to have sarcoma. Welcome to the 1 percent club.

When you receive a sarcoma diagnosis, it can often feel like you are stranded alone on an island, except that instead of talking to a volleyball named Wilson, you consult “Dr. Google” for any and all information you can find about this new rare label you have, since you can’t seem to find anyone else who knows what you are talking about. This terrifies you.

Then, one spring, you are invited to attend an event called Living with Sarcoma: Facing Today with Hope for Tomorrow. You roll your eyes and think, “Yeah, ok. What, have they scrounged up five people from across the country with sarcoma?” or “Just what I want to do: Spend a day talking and hearing about cancer.” But you decide to go because even if you could talk to just one person who also has a sarcoma, it might be worth it. You arrive at the event, not really knowing what to expect. All of a sudden, you see members of your care team: your nurses, your medical oncologist, your surgeon and your radiation oncologist. They know you — you feel like the guest of honor. Soon, you start talking with other attendees (while indulging in delicious food) and find that the question, “What is a sarcoma?” to which you have become so accustomed, has been replaced by questions like “Which subtype do you have, soft-tissue or bone?” or “Chemo? Radiation? Surgery? All three?” Suddenly, you realize you are no longer in the 1 percent club; you are now in the 100 percent club. Literally, 100 percent of the people around you at the event know what sarcoma is.

You listen to the medical team give an update to the group, and you are filled with hope when you learn about all of the brilliant minds working to find better ways to treat your type of cancer, while searching for a cure. Then the patient speakers are introduced. You listen in awe as you hear them recounting their symptoms and the day they received their diagnosis. You think, “That is just like my story,” or “I reacted the same way!” You hear about their treatment and their fear, nodding your head knowingly because maybe you, too, remember those chemo days when you didn’t feel the best, or the surgery that took a limb (or salvaged one) or the day you heard “No, you don’t have an injury, you actually have a cancerous tumor called a sarcoma in your (insert body part here).” You are filled with emotion, as you realize that you are not alone in this.

You visit the booths and learn about all the support that is out there, and you just cannot believe so much effort has been put into this rare, 1 percent cancer that you thought nobody knew of. You leave the event feeling so supported, so understood, so ready to ‘face today with hope for tomorrow.’
The First Annual Musculoskeletal Oncology and Sarcoma Symposium: Bringing Together Leaders in the Field of Musculoskeletal Oncology to Improve Patient Care

by Meena Bedi, MD, Radiation Oncologist

Each year, the Froedtert & the Medical College of Wisconsin Cancer Network hosts educational events or symposiums in which leaders in the field of medicine will gather to hear about the latest treatment options for patients with various diseases. On Sept. 16, 2016, the First Annual Advancements in Musculoskeletal Oncology and Sarcoma Symposium was held at Miller Park, where physicians, physician assistants, nurse practitioners, pharmacists, social workers and dietitians around the state gathered to acquire and provide information that is vital to the entire cancer care continuum.

The symposium offered providers the opportunity to acquire new knowledge and information that would have immediate clinical application and bring about changes in care for patients with musculoskeletal sarcomas. Dynamic presentations focused on bone and soft tissue sarcomas and metastatic disease. Leaders in Wisconsin discussed advances in systemic and targeted therapies as well as various evolving interventional and surgical techniques that may improve patient outcomes. In addition, there were valuable discussions on implementing a statewide registry for all sarcoma patients. David King, MD, orthopaedic oncologist and chair of Orthopaedic Surgery, highlighted the need for continued resources and collaboration to facilitate improved access to cancer care, effective prevention strategies and innovative research. Sarah Dobrozsì, MD, medical oncologist, also spoke to the need for standardized quality of life measures for each patient providers encounter.

The inaugural Musculoskeletal Oncology and Sarcoma symposium aimed to inform all attendees regarding the current frontiers of our knowledge and to highlight paths leading to future progress. We hoped by holding this event not only to share information but also to encourage the development of new and productive collaborations.

We look forward to the fall of 2017 when we hold the second annual symposium at Lambeau Field in Green Bay, Wis.

A Network of Coordinated Sarcoma Care

by Candice Johnstone, MD, MPH, Radiation Oncologist

Being treated by nationally known cancer experts at a location close to home is just one advantage of the Froedtert & the Medical College of Wisconsin Cancer Network, which includes four locations. For sarcoma patients, who truly require multidisciplinary, coordinated care, this is especially important as initial diagnostic steps may impact the chance of success.

This network of cancer care also offers:

Patient convenience

“At our cancer centers, patients see medical, surgical and radiation oncologists, often during the same visit. That is not typical with cancer care,” said Candice Johnstone, MD, MPH, a radiation oncologist and associate director of the cancer service line.

This is truly multidisciplinary and integrated care. Specialists see patients in the same clinical area and work together to develop treatment plans, often on the same day.”

The power of collaboration

The Froedtert & MCW Sarcoma Program team convenes weekly to discuss a patient’s care plan or any issues that crop up. Team specialists include radiologists, pathologists, radiation oncologists, medical oncologists, surgical oncologists and research coordinators, all of whom have specialized knowledge about sarcoma treatment. “It’s a meeting of the minds among all the experts who have input into the care of a patient,” Dr. Johnstone explained.

Seamless transitions

Some patients may be able to receive some of their care at their community hospital, while others need specialized testing or complex surgeries available only at the academic medical center, Froedtert & the Medical College of Wisconsin Clinical Cancer Center at Froedtert Hospital campus. They then return to their community location for follow-up care. The same electronic medical record is used throughout the Cancer Network to ensure smooth collaboration of care.

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Extensive services
The Cancer Network offers on-site resources such as: nutritional support, genetic counseling, physical therapy, occupational therapy, psycho-social support, oncology nursing, palliative care and survivorship planning. “Patients receive the benefit of multiple expert opinions and individualized treatment plans. We also offer the ancillary services that are critical to the care of the whole patient,” Dr. Johnstone said.

Cutting-edge resources
“One of the advantages of our Cancer Network is the high-quality care no matter where you are treated,” Dr. Johnstone said. “Because our network includes an academic medical center, patients have access to clinical trials and physicians who are doing state-of-the-art research, teaching our next generation of physicians and implementing the newest approaches for our patients.”

Access to clinical trials
Our Sarcoma Program offers patients the opportunity to participate in clinical trials. These trials are open at Froedtert Hospital and some are available at locations throughout our Cancer Network. Three current clinical research initiatives include:
- Participation in the tumor tissue bank: Participation allows researchers to advance our knowledge of sarcomas to help increase cure rates and determine the best treatment for patients.
- Short-course of radiation therapy prior to sarcoma surgery: This novel approach condenses five weeks (25 treatments) of radiation therapy into five treatments.
- Precision radiation therapy for lung tumors from sarcoma.

Froedtert & MCW Cancer Network
- The right care at the right time, in the right place.
- A complete range of cancer specialists and support services
- Fourteen disease-specific cancer teams
- Positive, healing environments for patients and families
- Four Froedtert & MCW locations: Community Memorial Hospital, Menomonee Falls Moorland Reserve Health Center, New Berlin St. Joseph’s Hospital, West Bend Froedtert Hospital, Wauwatosa

Step Up to Volunteer or Participate in the First Annual Race to Cure Sarcoma Milwaukee 5K Run/Walk

Have you ever thought about the power of one step?

On Sunday, July 16, 2017, individuals in the Milwaukee area will have an opportunity to take a step toward a cure for sarcoma in the first Race to Cure Sarcoma Milwaukee 5K run/walk. This family-friendly event will provide a way for anyone affected by sarcoma to join friends and family members in raising funds for research and providing greater awareness of this often devastating disease. Sponsored by the Sarcoma Foundation of America, the event will benefit sarcoma research at Froedtert & the Medical College of Wisconsin Froedtert Hospital, Children’s Hospital of Wisconsin and across the country.

Specific details about the inaugural Race to Cure Sarcoma Milwaukee are being finalized and will be updated on the website. There will be opportunities for everyone to take part, as sponsors, volunteers, participants, donors or as cheerleaders on the sidelines.

To learn more, contact the Sarcoma Foundation of America at milwaukeerace@curesarcoma.org.

Or watch this website for details about registration coming early in 2017: http://curesarcoma.org/race ♦
Management of Unplanned Excisions for Soft Tissue Sarcomas

by Meena Bedi, MD, Radiation Oncologist

Soft tissue sarcomas (STS) are rare cancers that have diverse presentation and unpredictable clinical behavior. The mainstay of treatment for localized STS of the extremity and chest wall is surgery and radiation therapy with or without chemotherapy. Alternatively, some sarcomas that are small and not as aggressive may be treated with surgery alone. With these methods of treatment, local control rates are excellent.

Sarcoma surgeries are usually performed by cancer surgeons, as these physicians are trained at appropriately dissecting a tumor along the correct surfaces to acquire wide margins. During these operations, sarcoma surgeons pay careful attention to the casing of the tumor which may harbor cancerous cells.

Due to the rare nature of this disease and the high likelihood of any soft tissue mass being benign (non-cancerous), it is rather common that these tumors are removed by general surgeons. It is estimated that up to 40 percent of patients with STS undergo non-cancer surgeries (unplanned excision). Unfortunately, patients who undergo unplanned excisions for their STS have a higher risk of recurrence. Thus, referral to a sarcoma center for further cancer management is important, as it allows for optimal management of this disease and decreases the risk of recurrence.

The appropriate management of STS that are not removed by surgeons who specialize in sarcoma is controversial. Re-excision (a second operation to remove the remaining cancer) can be done. However, even with re-excision, there are relatively high rates of recurrence. At Froedtert & the Medical College of Wisconsin Froedtert Hospital, a study was performed by the Froedtert & MCW Sarcoma Program group to assess which treatments afford the highest rates of disease control. The study looked at patients who had re-excision alone by a sarcoma surgeon, re-excision followed by radiation therapy, pre-operative radiation therapy followed by re-excision and radiation therapy alone. The results of this study showed that patients who had pre-operative radiation therapy followed by re-excision had the lowest risk of recurrence and the highest rates of disease control. Thus, the Sarcoma Program group’s typical recommendation for patients who undergo an unplanned excision is for radiation therapy followed by re-excision by a sarcoma surgeon.

Regardless of excision type, recommendations of additional therapies should involve a discussion by a multidisciplinary team of experts where options for management are assessed and then provided to the patient. Ultimately, it is up to the patient which treatment he or she chooses to pursue.

Within the Sarcoma Program, we are continually attempting to improve patient care and outcomes, even for patients who may not have had the most optimal initial treatment. As we study and discover more about these types of tumors, we are confident in our ability to provide excellent care to any patient we see.

Support Groups

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, 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, as well as providing relaxation and stress relief. Various topics of interest to the caregiver will also be presented.

- Meets fourth Tuesday of each month from 5:30-7 p.m. (no meeting in December)
- Clinical Cancer Center at the Froedtert & MCW Froedtert Hospital campus, 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.
Journey to Wellness Support Group

This monthly support group is for anyone affected by a cancer diagnosis. The open forum provides an opportunity to share information and experiences, as well as to receive encouragement, education and support. Educational topics vary. Family members, significant others and caregivers are also welcome to attend. 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

The following are comments from sarcoma survivors who have “been there and done that.” They invite you to join the Journey to Wellness support group. Here is what they had to say about the support group.

Our group is made up of individuals who have been declared cancer-free, those recently diagnosed and those presently in treatment. Most of us have been through chemotherapy and/or radiation therapy and/or surgery. Are we medical people with extensive medical backgrounds? No. We are people who have “walked the walk and talked the talk.” We are good listeners and will listen to what you have to say. We are optimistic about our recovery. We are empathetic. We care.

We who are now cancer-free can share with you what we have been through. We know the effects of chemotherapy and radiation therapy and the feelings that go with so many surgeries. We have had lengthy stays in the hospital.

Is our cancer support group a true-confession facsimile? Does everyone need to tell his or her life story? The answer is “no.” One speaks if one wishes to speak. One listens if one wishes to listen. No one is compelled to share a story if he or she chooses not to. Listening can be a strong learning experience. After all, we have two ears and one mouth.

If you want to go fast, go alone.
If you want to go far, go together. (African Proverb)
If you join us, we will be pleased to call you friend. Welcome aboard!

- Joseph A. Vitale, Myxofibrosarcoma Survivor

I attend the Journey to Wellness support group for the educational content, and because I know I will meet others who have or had a cancer diagnosis.

I remember feeling very isolated when I was diagnosed and treated. Sarcoma can feel that way, because it is such a rare diagnosis. I hope the support group helps others feel understood and not so isolated at this time in their lives.

It helps to hear the stories of others and know you are not alone. And, if you choose, telling your story is a way of coping with the stress of what you are going through. The understanding and educational offerings of the group, facilitators and speakers are ways to connect with others and learn some great coping strategies.

- Kathy Cervenka, Sarcoma Survivor

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/froedtersarcoma

Please note: You must be 18 years of age or older to participate. Before admitting 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.
Make a Difference by ‘Bowling with Grapatin’ While Raising Funds for Sarcoma Research

The annual Bowling Fund Raiser in Memory of Scott Grapatin will be held Sunday, April 23, 2017 at Riviera Lanes in West Allis, Wis. Proceeds benefit research to help find a cure for soft tissue sarcoma at Froedtert & the Medical College of Wisconsin Froedtert Hospital.

The activities begin at 1 p.m. The cost is $25, including lunch. Lane sponsorship is also available for $100 and features your company or family name. Register by Sunday, April 16, by calling Danny at 414-774-2274, or register in person at Riviera Lanes. Bowlers and non-bowlers alike are encouraged to join the event, which also includes auction items and fun! Riviera Lanes is located at 8600 W. Greenfield Ave. in West Allis, Wis.

For more information about fundraising events, please contact Peggy LeBrun, Director of Development for Volunteer and Event Fundraising at 414-955-4503 or email plebrun@mcw.edu.

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.

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Froedtert Hospital Foundation

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Froedtert & the Medical College of Wisconsin Sarcoma Program

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