

The Sarcoma Connection

2019

IN THIS ISSUE

Race to Cure Sarcoma.....	1
Fight the Fight.....	2
Desmoid Tumors	3
Spinal Sarcomas.....	4
Musculoskeletal Oncology and Sarcoma Symposium.....	5
Provider Profiles.....	6
Support Groups	7
Join Us on Social Media	8
Froedtert Hospital Foundation.....	8

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Sarcoma Survivors ~ 2018 Race to Cure Sarcoma™

Sarcoma Community United for Race to Cure Sarcoma™

On July 14, 2018, nearly 900 walkers and runners gathered at beautiful Fowler Park in Oconomowoc to participate in the second annual Race to Cure Sarcoma™ - Milwaukee 5K Run/Walk. Organized by the Sarcoma Foundation of America (SFA), this event raised nearly \$80,000 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.

Weekend athletes, avid runners, stroller riders, sponsors, volunteers and cheerleaders on the sidelines joined together to celebrate and honor those affected by sarcoma.

Following the run/walk, a sunflower was presented to all sarcoma survivors. As part of this ceremony, Meena Bedi, MD, radiation oncologist, MCW faculty member and researcher, reminded everyone that the sunflower is the symbol of sarcoma because it provides a beacon of light and hope for a brighter future even during difficult times, while capturing the resilience and strength displayed by those affected by this disease.

Be sure to join us on Saturday, July 13, 2019 at a new venue for year three of this wonderful event! Please visit froedtert.com/sarcoma or mcw.edu/departments/cancer-center for more details. ♦

Fight the Fight — Find a Cure: Increasing Sarcoma Awareness and Research Efforts for Sarcoma Patients

Clinical trials and translational research are imperative to finding cures for many diseases, including cancer. Each year, it is estimated that 20 to 25 percent of all funds raised for cancer research will go toward breast cancer. In contrast, sarcoma receives less than 3 percent of funding going to specific types of cancer. This is one of the many reasons there has been a barrier to finding a cure.

Because sarcomas are rare, there is a lack of awareness about research efforts and treatment options for patients fighting this disease. However, in recent years, the sarcoma and skeletal tumor teams from the Froedtert & the Medical College of Wisconsin Cancer Network and Children's Hospital of Wisconsin have made an increasing effort to expand the awareness of sarcoma, as well as to increase philanthropy for sarcoma research. In Milwaukee, the inaugural Sarcoma Foundation of America (SFA) Run/Walk in July 2017 raised more than \$17,000 for local sarcoma research, and in 2018, our local team raised more than twice as much. We hope to continue this momentum for the next SFA Run/Walk scheduled to take place in July 2019!

In 2018, we also debuted a new fundraiser: Stronger than Sarcoma: A Soiree for Research. This event took place at the Milwaukee Art Museum on Aug. 3. The event was attended by more than 200 people and raised \$160,000 dedicated to sarcoma research. In addition to the main event, the Stronger than Sarcoma planning committee raised money by volunteering at Cedarburg's Strawberry Festival, hosting a successful bake sale and partnering with Portillo's, which donated a percentage of one evening's proceeds to the cause.

As we continue to progress in philanthropy, our goal remains the same: Fight the fight, and find a cure for sarcoma. To learn more, visit strongerthansarcoma.org. ♦





Desmoid Tumors

by William Lea, MD, Vascular and Interventional Radiologist and MCW Faculty Member

Desmoid tumors, also known as aggressive fibromatosis, represent a rare form of locally invasive, benign tumors that can develop in musculoskeletal connective tissue in any part of the body. Locally invasive means the tumor typically grows in one place without spreading. These tumors usually present spontaneously, but in a small minority of cases, they can be associated with specific genetic abnormalities. When desmoid tumors have a genetic component, they often signify a worse prognosis. Common symptoms include localized pain or complications related to invasion of adjacent structures.

In general, desmoid tumors exhibit a variable natural history, ranging from dormant tumors that have no symptoms to rapidly growing, locally invasive tumors that can threaten limbs and occasionally life, despite having no potential for metastatic spread. As a result, these tumors have long challenged specialists to devise a treatment paradigm that will exact the least harm.

A certain proportion of these tumors will regress spontaneously without treatment, and a “watch and wait” approach with active surveillance can sometimes be appropriate. However, predicting which tumors will follow this favorable course is difficult. For tumors that are symptomatic or actively growing into surrounding structures, treatment is generally indicated.

Historically, desmoid tumors were treated primarily with surgery (resection). Unfortunately, recurrence rates following surgery are quite high — up to 40 percent within five years of diagnosis even with wide resection margins and complete resection by pathologic evaluation. Such operations carry some degree of risk of significant side effects from injury to adjacent structures or from disfiguring incisions that require reconstruction. If a recurrence happens, repeat surgical resection can be more difficult due to the previous surgery.

More recently, interventional radiologists have used two emerging ablation therapies for local control of desmoid tumors

with good results. These therapies have been used as primary treatment choices and after other therapies have failed.

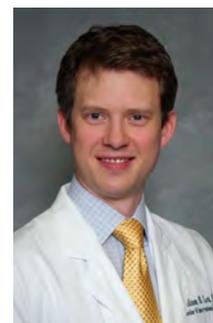
Cryoablation consists of freezing tumor cells using small needles placed through nicks in the skin. Early results at our institution have shown significant effectiveness in reducing patients’ symptoms and the size of the tumor.

Magnetic resonance-guided focused ultrasound ablation (MRgFUS) is a non-invasive technique that focuses ultrasound energy inside the body to destroy tumor tissue while guiding the energy in real time using magnetic resonance imaging (MRI).

These techniques are complementary, with some patients more suited to one treatment than the other, but both techniques are patient-friendly, are usually performed as outpatient procedures and can easily be repeated in the future if necessary. Together, they have largely replaced invasive surgical resections when feasible.

In certain instances, complete surgical resection or ablation of a tumor puts critical structures at significant risk. When these challenges occur, it may be beneficial to add systemic therapy (like chemotherapy or other drug therapies) and radiation therapy to maximize local disease control while avoiding excessive risk. Additionally, several relatively new systemic drugs have been shown to provide some benefit for patients who have desmoid tumors and may offer promising results in the future through cutting-edge clinical trials.

As illustrated, there are many treatment options available for patients with desmoid tumors. Our multidisciplinary team of sarcoma specialists is dedicated to offering the full range of current and emerging therapies, giving patients the opportunity to benefit from our specialty expertise and choose the best treatment option. ♦



William Lea, MD

Spinal Sarcomas

by **Brandon J. Rebholz, MD, Orthopaedic Surgeon, MCW Faculty Member and Researcher,**
and **Hesham Soliman, MBBS, Neurosurgeon, MCW Faculty Member and Researcher**

Sarcomas can affect any part of the musculoskeletal system. When the spine is involved, this results in unique challenges and treatments. Sarcomas that involve the spine can be considered primary when they arise directly from the vertebral segments or discs. Secondary spinal sarcomas originate from a different location and spread to the spine. Identification of the original location of the sarcoma has a substantial impact on treatment options and recommendations.

As with many sarcomas, surgery plays an important role in removing tumors in the hopes of achieving a cure. Surgery is often necessary to attain a complete cure; however, not all patients are surgical candidates. When considering surgical intervention to completely remove a spinal sarcoma, the surgeon has to carefully weigh the risks to surrounding structures, most importantly, the spinal cord and nerves. The unique challenge of removing tumor tissue surrounding the spinal cord can be accomplished with careful consideration and planning. This requires a team-based

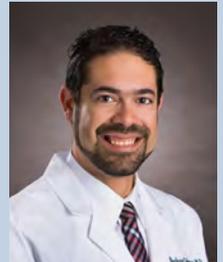
approach involving spine surgeons, vascular surgeons, plastic and reconstructive surgeons, interventional radiologists, hematologist/oncologists and radiation oncologists. The aim is to selectively incorporate chemotherapy, immunotherapy and radiation therapy around the time of surgery. The timing of each treatment can be individualized based on the patient's specific type of tumor, location and size of the tumor and planned surgical resection. These therapies can be given prior to surgery, following surgery or before and after surgery.

Once a decision has been made that surgery should be considered, the surgeon develops a plan for the operation (resection). This typically involves removal of the tumor and affected portion of the spinal column as one section if possible rather than taking small piecemeal "bites," which creates a risk for tumor spill and recurrence. This means that the bones of the spine need to be cut in two and the pieces safely removed from around the spinal cord and nerves. This goal can be achieved by approaching the spinal column from the back, the front (through the neck, chest or abdomen) or both. The approach used depends on the size and location of the sarcoma and surrounding structures. Additional consideration is given to reconstructing the spinal column after surgery. This involves replacing the vertebral bodies or bones with specialized cages or scaffolds that support the weight of the spine and body, along with the addition of stabilizing screws and rods. The goal of reconstruction is to ensure that the spine is stabilized, the spinal cord is protected and that reconstruction will allow the patient to return to near normal activities.

Given the complexity of the surgical approach and need for a comprehensive care plan, the treatment of spinal sarcomas should be reserved for cancer centers where sarcoma specialists treat a high volume of patients with spinal tumors. The Froedtert and the Medical College of Wisconsin Sarcoma Program has a dedicated sarcoma tumor board that meets and discusses patients weekly to ensure the highest possible quality of care. We specialize in the surgical treatment of these challenging tumors. With our comprehensive, team-based approach, we have been able to achieve disease-free survival for many patients, returning them to their lives as quickly as possible. ♦



Brandon J. Rebholz, MD



Hesham Soliman, MBBS





From left to right: John Charlson, MD; Brandon Rebbholz, MD; Christina Roland, MD, University of Texas MD Anderson Cancer Center; William Lea, MD; Meena Bedi, MD; David King, MD; Callisia Clarke, MD;

Vinod Ravi, MD, University of Texas MD Anderson Cancer Center; Nathan Schloemer, MD, Children's Hospital of Wisconsin

Annual Musculoskeletal Oncology and Sarcoma Symposium: Leaders in Musculoskeletal Oncology Collaborating on Coordinated Patient Care

by Meena Bedi, MD, Radiation Oncologist, MCW Faculty Member and Researcher

Each year, the Froedtert & the Medical College of Wisconsin Sarcoma Program holds an educational symposium in which leaders in the field of medicine gather to hear about the latest treatment options for patients with various diseases. On Sept. 7, 2018, we held our Third Annual Advancements in Musculoskeletal Oncology and Sarcoma Symposium at Discovery World in Milwaukee. Here, physicians, physician assistants, nurse practitioners, pharmacists, social workers and dietitians from Wisconsin and Illinois gathered to acquire and provide information that is vital to the entire cancer care continuum.

The educational conference offered providers the opportunity to acquire new knowledge and information that would have immediate clinical application for our patients who have musculoskeletal oncologic disorders. There were dynamic expositions focusing on bone and soft tissue sarcomas and metastatic disease. We had the privilege of hosting two keynote speakers from the University of Texas MD Anderson Cancer Center in Houston. Vinod Ravi, MD, a medical oncologist, presented on the evolution of systemic drugs for sarcoma from non-specific to

histology-based management. Christina Roland, MD, a surgical oncologist, expanded on Dr. Ravi's talk and spoke about the histology-based management of retroperitoneal sarcomas and how therapeutic techniques may be adjusted based on a patient's type of sarcoma.



Meena Bedi, MD

The ongoing goal of the Musculoskeletal Oncology and Sarcoma Symposium is to inform attendees about the current frontiers of this field and to emphasize paths leading to progress. In the short period that this symposium has been offered, new and productive collaborations have developed among colleagues at Froedtert & MCW Froedtert Hospital and their counterparts throughout the nation.

This event will be expanded regionally, and we look forward to the fall of 2019 when we hold the Fourth Annual Advancements in Musculoskeletal Oncology and Sarcoma Symposium at Soldier Field in Chicago. ♦

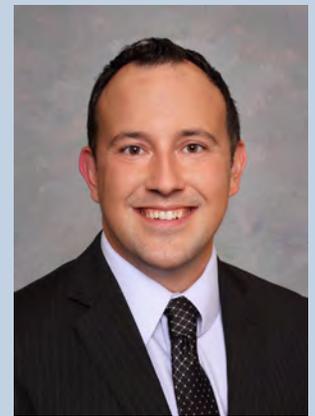
Provider Profiles

Adam Wooldridge, MD, MPH, Musculoskeletal Oncologist and MCW Faculty Member

I'm originally from Columbia, Kentucky – a small town in the south-central part of the state. My education and training have taken me all over. After completing my bachelor of science degree in chemistry and bachelor of arts degree in biology at the University of Kentucky, I lived in Japan for a year working as an assistant language teacher in the Japanese Exchange Teaching Program. I then attended medical school at The Ohio State University College of Medicine in Columbus, Ohio, where I received my medical doctorate and master's degree in public health in 2012. After completing my residency in orthopaedic surgery at the Texas Tech University Health Sciences Center in Lubbock, Texas in 2017, I went on to complete a fellowship in musculoskeletal oncology at the University of Florida, Gainesville, in 2018.

I am excited to be a part of the MCW Department of Orthopaedic Surgery because of the great camaraderie among the faculty, residents and staff. The department has a great deal of energy and a strong vision for advancing the practice of orthopaedics. As a musculoskeletal oncologist, I'm looking forward to the opportunities for multidisciplinary collaboration in patient care and research. Each sarcoma patient presents unique treatment challenges. Our team is here to guide patients and their families through treatment. To achieve a functional and curative limb salvage, a multidisciplinary approach is essential. This collegial environment allows our sarcoma team to individualize each patient's care in pursuit of the best outcomes.

My wife, Kerry Katz, MD, practices general obstetrics and gynecology in Milwaukee. We have two young boys who love Milwaukee as their new home. My family and I have greatly appreciated the friendly Midwestern atmosphere. All of our new co-workers and neighbors have been very welcoming and helpful. We've enjoyed exploring Milwaukee and the surrounding areas. There is always a new event to check out, and our boys have had fun with all the outdoor activities. ♦



Lori Hollingsworth-Burds, PA-C, Physician Assistant

Lori is a member of the Orthopaedic Surgical Oncology team at Froedtert & the Medical College of Wisconsin Froedtert Hospital and has been working with the sarcoma group for the past 12 years. She graduated from the University of Wisconsin-Madison physician assistant program and has her master's degree.

Lori grew up in Wisconsin, and in her free time, she enjoys hiking, genealogy research and traveling with her family. Her favorite vacation was traveling to Glacier National Park. She is married and has a lovely chocolate lab named Lottie.

"Sarcoma is a rare form of cancer that requires a multidisciplinary team collaborating to provide the most effective treatment. I learn something new from my colleagues every day. I feel that the team effort involved is unique: we come together for every patient to create a tailored treatment plan that is just for them and their form of sarcoma." ♦





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

Co-facilitated by a sarcoma survivor

Offered through the Froedtert & MCW Cancer Network:

West Bend

Kettle Moraine YMCA

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.



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, education and 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.

Although it is primarily an open forum, topics of interest are occasionally highlighted.

- 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.



Join Us on Social Media - Three Ways to Stay Connected

We invite you to join the Froedtert & MCW Sarcoma Closed Support Group on Facebook and Twitter 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.

You can also follow our public pages on Facebook and Twitter where you can stay up to date on sarcoma news, and get to know the staff. Please search for @MCWsarcoma on both social media platforms.

For more information, please call Maria Voermans, program coordinator, 414-805-0815 ♦

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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