

PARTNERS

Newsletter of the Patient and Family Advisory Program at Moffitt Cancer Center | WINTER 2023

PATIENT'S PERSPECTIVE

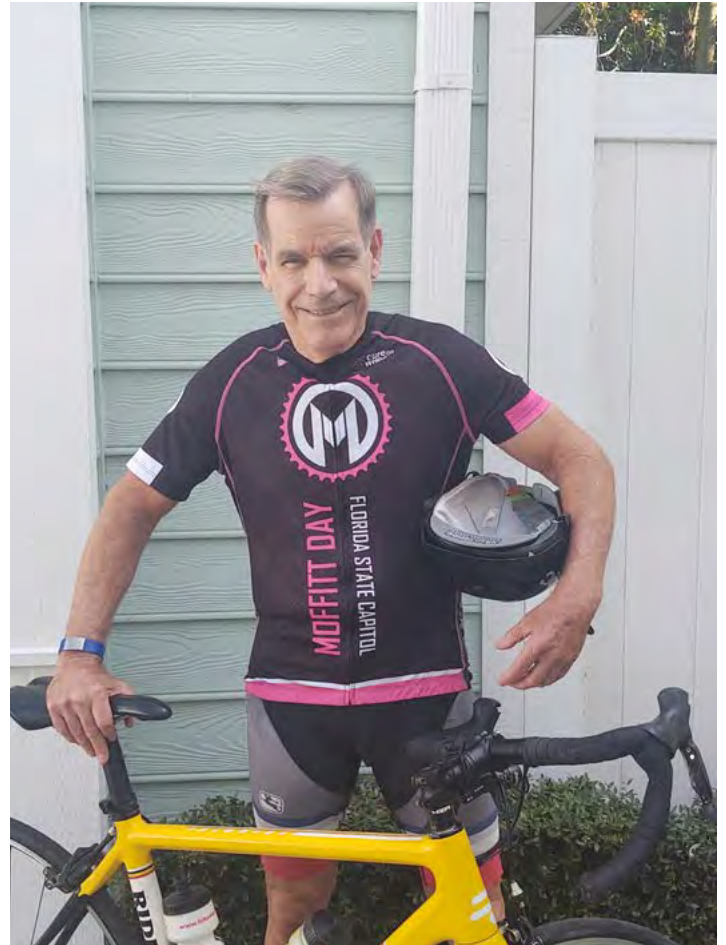
Nearly Four Decades of Survival and Counting

John DesRoches, Patient Advisor, Patient and Family Advisory Program

In 1986, I was a busy engineering student with graduation in sight, but I started frequently getting what I thought was the flu. One weekend, I was talking to my parents on the phone when I started coughing and losing my voice, which was happening a lot by then. When my parents showed up at my place the next day, they took me to the hospital – which, as it turned out, saved my life.

My first day in the intensive care unit, a doctor asked me “John, do you know what cancer is?” Recalling my biology class, I said, “un-controlled cell growth.” He responded, “You’re being very logical about this,” and left. They were trying to tell me I had cancer, but things were happening fast and I just wasn’t getting it. After all, I was 26 years old, strong and couldn’t possibly have cancer!

Continues on page 3



John DesRoches gearing up his bicycle for the annual Cure on Wheels bike ride to Tallahassee.

IN THIS ISSUE

- 1 Nearly Four Decades of Survival and Counting
- 2 It's My Cancer Center, and It's Yours Too
- 4 Moffitt McKinley Hospital's Patient and Family Resource Center
- 5 Moffitt Resources to Help Patients and Caregivers
- 6 Right Size Your Holiday
- 7 Why We're Training Moffitt Team Members on Health Equity
- 8 Chair Yoga: Is It for You?
- 10 Making Moffitt Safer for YOU
- 11 What is a Chaplain?
- 12 Patient and Family Orientation



David Dauman

CO-CHAIR COLUMN IT'S MY CANCER CENTER, AND IT'S YOURS TOO

*David Dauman,
Patient Advisor and Co-Chair,
Patient and Family Advisory Council*

We live in data-driven times. Being questioned for information can feel like an invasion of privacy. Online surveys are my pet peeve. Yet, I do make an exception and share my opinion when I feel a sense of ownership. Moffitt Cancer Center meets this exception. It's MY cancer center, and it's yours too.

Moffitt is driven to maximize the patient experience and have dedicated teams to do this. They carefully use data, including patient and family feedback, to attentively resolve our concerns. As a result, I encourage all of us to respond to each satisfaction survey and share appropriate, detailed information.

I was disappointed to learn that some of us do not share opinions out of fear of being blacklisted, retaliated against, or not wanting to get someone in trouble. Rest assured that sharing feedback is never held against you at Moffitt. Complaints are handled discretely,

quickly, and taken seriously. If you ever feel a change in how you are treated, please let Moffitt's Patient Relations team know by emailing PatientRelations@Moffitt.org or by calling 813-745-3808. The lack of positive feedback can also hurt Moffitt. Affirmations are the purest form of data that can validate an individual's efforts or a new program or initiative.

Being a cancer patient or caregiver makes life much more complicated. The last thing you need this time of year is another request, but please consider the following (with full appreciation); If you see (or feel) something, say something! Moffitt belongs to us, and they are listening.

Visit Moffitt.org/PatientSatisfaction to learn more about the Press Ganey Patient Satisfaction Survey.



We want to hear from you!

If you would like to share your story, provide feedback or subscribe to our newsletter, email

PatientAdvisors@Moffitt.org

or call **813-745-2963**.

Learn About Upcoming Moffitt Events

Moffitt offers a variety of virtual and in person events. These events are here to help you learn and connect with other patients and caregivers. You can find a full list of upcoming events by visiting **Moffitt.org/Calendar**.

Nearly Four Decades of Survival and Counting

Continued from page 1

After a whirlwind of tests and procedures, doctors told me I had a tumor the size of a grapefruit in my chest cavity. I had stage 4 primary mediastinal large B-cell lymphoma (PMBCL), a type of non-Hodgkin lymphoma. I didn't understand most of what they were telling me, but I realized it was bad. A priest administered the last rites, which helped because at least I could sleep at night feeling that I was spiritually prepared to die. Sometime later, I asked my oncologist what my chances of surviving were, and he responded, "We're guardedly optimistic." At the time, this response was incredibly helpful and hopeful – just what I needed. So, a week later, I registered for the fall school term determined to do everything I could do to survive. I wanted to have a life to go back to.

Chemotherapy and radiation were awful but saved my life. However, surviving cancer was only half the battle. Until the Americans with Disabilities Act (ADA), young cancer survivors were legally denied employment because we had cancer. I was born in Canada, so I got a job there after being denied dozens of times in the states. However, after the ADA became law, I found a job in the U.S. and I went on with my life.

I thought I was done with cancer, but I discovered a large lump in 2003. I knew with dread what it was, but an emergency appendectomy revealed diffuse large B-cell

non-Hodgkin lymphoma. When my oncologist told me that I needed chemotherapy again, it was devastating. Chemotherapy had been so awful and almost killed me the first time. He patiently and confidently reassured me that the past chemotherapy regimen was no longer used today because it was too toxic. Sure enough, I was amazed at how much easier chemotherapy had become and it saved my life again.

Nowadays, I continue to benefit from the amazing progress made within cancer research as I receive preventive care and treatment for the long-term consequences of the medicine that originally saved my life four decades ago. I volunteer at Moffitt as an advocate, peer visitor and Comfort Companion. I also ride in the annual Cure on Wheels 326-mile bicycle ride to Tallahassee as a testament to my care. Most of my life has been made possible by the advances in medical science and the amazing care from my nurses and doctors. And I am profoundly grateful. I volunteer at Moffitt to say thank you for saving my life, and to use my experience of cancer and survivorship to help other patients.

DesRoches will be pedaling 326 miles again for the 14th annual Cure on Wheels advocacy ride as part of Moffitt Day in Tallahassee in 2024. If you'd like to support Moffitt's mission to prevent and cure cancer, visit [CureOnWheels.org](https://www.CureOnWheels.org)



MEET THE EXPERTS

Connect with Moffitt experts and learn helpful information for patients and caregivers. Sessions held via Zoom on Tuesdays and Wednesdays at 10-10:30 a.m.

To register please visit
[Moffitt.org/MeettheExperts](https://www.Moffitt.org/MeettheExperts)
or call **813-745-1690**.

Moffitt McKinley Hospital's Patient and Family Resource Center

Laura Bosselman, Manager, Patient Experience Services

At Moffitt Cancer Center, we support patients and caregivers through their journey at our center. We are happy to announce the opening of a dedicated resource center for patients and caregivers within the newly opened Moffitt McKinley Hospital.

Located on the second floor overlooking the balcony, you will find the Styled with artwork created by our Arts in Medicine team, the center is a welcoming space with natural lighting where visitors can sit, relax and unwind. For caregivers arriving prior to the opening of the café and cafeteria, we offer a variety of refreshments, like tea, cocoa, and snacks, while you are waiting. There are computers available for internet access and various needs, as well as a selection of fiction and non-fiction books that are free and accessible at all hours of your visit and stay.

On weekdays from 8 a.m. to 4:30 p.m., our Patient and Family Specialist welcomes patients and caregivers with a friendly smile and hello. Happy to make a meaningful connection with all visitors to the space, our Patient and Family Specialist offers assistance with locating specific resource materials, printing, and faxing documents, or even providing licensed notary services at no charge. During your visit to Moffitt McKinley Hospital, please come in and enjoy all the Patient and Family Resource Center has to offer!

To learn more about the Patient and Family Resource Center, please call 813-745-2873.



MOFFITT RESOURCES

to Help Patients and Caregivers

UPCOMING EVENTS

December – February

Virtual Relaxation/Meditation for Stress Relief **813-745-6052**

Virtual/Zoom, RSVP only
Weds. at 12:15 p.m.
[Moffitt.org/Meditation](https://moffitt.org/Meditation)

Virtual Gentle Restorative Yoga Class **813-745-6052**

Virtual/Zoom, RSVP only
Tues. at 11 a.m. and Thurs. at 2 p.m.
[Moffitt.org/Yoga](https://moffitt.org/Yoga)

Magnolia Open Art Studio | 813-745-8407

In person at Magnolia Campus, No RSVP
3rd floor – Arts in Medicine Studio
Mon.-Fri., 9:30 a.m.-4 p.m.
ArtsinMedicine@Moffitt.org

McKinley Open Art Studio | 813-745-8407

In person at McKinley Campus, No RSVP
1st floor – Patient and Family Center
Mon.-Fri., 8:30 a.m.-5 p.m.
ArtsinMedicine@Moffitt.org

Patient and Family Orientation **813-745-1690**

Virtual and in person, RSVP only
Mon.-Fri., 2 p.m. or by appointment
PatientLibrary@Moffitt.org

Virtual Meet the Experts | 813-745-1690

Virtual/Zoom, RSVP only
Tues. and Weds., 10-10:30 a.m.
PatientLibrary@Moffitt.org

PATIENT AND FAMILY SUPPORT GROUPS

For your convenience, we offer support groups via Zoom. To learn more about support groups or to register, visit [Moffitt.org/SupportGroups](https://moffitt.org/SupportGroups) or call the Social Work office at **813-745-8407**.

General Cancer Support Group

Weekly meeting for patients diagnosed with any cancer type to connect and share mutual support. Meets every Tuesday, 1-2 p.m. via Zoom.

Family and Friends Support Group

Weekly meeting for families and caregivers of patients with any cancer type to connect and share mutual support. Meets every Wednesday, 1-2 p.m. via Zoom.

Metastatic Breast Cancer Support Group

Meet with people who have been diagnosed with stage IV metastatic breast cancer to share mutual support. Meets every Tuesday, 11 a.m.-12 p.m. via Zoom.

Breast Cancer Connection

Monthly support group for anyone who has been diagnosed with breast cancer. Meets the first Tuesday of every month, 6-7 p.m. via Zoom. .

Survivorship Program Support Group

Monthly meeting for Survivorship Program participants to connect and share mutual support. Meets the last Tuesday of every month, 1-2 p.m. via Zoom.

Finding Our Way Through Loss and Grief

This is an 8-week support group for family and caregivers who have lost a loved one to cancer while under treatment at Moffitt.

Right Size Your Holiday

Donna DiClementi, LCSW, OSW-C, Manager of Outpatient Social Work

The holiday season is upon us. What can be a wonderful time of the year can also bring added stress and pressure. People living with cancer and their loved ones may experience holiday planning and events as an added complication to their already busy lives.

This is the year to right size the holiday considering the responsibilities of living with a cancer diagnosis. A conversation with your loved ones about what is important and reasonable this year will reduce stress for everyone and can lead to an enjoyable experience.



The following tips can help guide that conversation:

1. **Set a budget.** The holiday season was never intended to increase our financial burden. Decide what is realistic given all the additional financial responsibilities you have.
2. **Make a simple plan.** Decide with your loved ones the three most important events, traditions or foods that mean the most. Enlist their help to make sure these three things happen.
3. **Put your health first.** It's a busy season. And your health is the priority. Keep your medical appointments; take medications as prescribed, eat healthy foods and get plenty of rest. It is easy to overdo this time of year. Be mindful of how the extra activity and other people's expectations may impact you.
4. **Focus on what you can control.** Not every holiday season goes as planned. Take a deep breath and focus on what you can control. Try not to spend your energy worrying about things outside of your control.

If you need additional support coping with the added stress of the holidays, please call Moffitt's department of Social Work at 813-745-8407.

Why We're Training Moffitt Team Members on Health Equity

Amanda Rivera, Program Coordinator Health Equity Train the Trainer Program

Health equity is achieved when everyone has equal access and the same opportunities to receive quality health care, participate in research, and obtain resources and information through community outreach and education to be as healthy as possible.

The Health Equity: Health Providers Train the Trainer Program is a health equity training program funded by the Florida Blue Foundation and delivered by Moffitt Cancer Center, Orlando Health and United Way of Broward County. The program's purpose is to train professionals that have the potential to impact the patient experience. When health care workers can understand that health is determined by many factors, including social factors, it helps us understand why some groups of people have better outcomes than others. Our goal is to make things more equitable and improve outcomes for everyone by understanding, building trust with patients, and empowering families and communities.



Some of the topics included in this training include health disparities, bias and stereotyping, community strategies, cross-cultural communication, equity in communication, and implementing changes for health equity. The training furthers our team members' understanding and perspective of the challenges that our patients face on a daily basis. The challenges

people face including obtaining social support, transportation, and finances, can directly impact their ability to receive cancer treatment.

Furthering our understanding of the possible challenges our patients face is critical in providing quality and empathic care. Overall, this program provides Moffitt team members with an opportunity to find ways to provide

better, more equitable care for all.

Visit HealthEquityProgram.org for more information.



Chair Yoga: Is It for You?

*Sharen Lock, Yoga Therapist & Patient Wellness Coordinator
Libby Creagh, Yoga Instructor*

Moffitt Cancer Center offers a unique approach to yoga that is accessible to people in all levels of treatment. Chair yoga classes are held on Zoom twice a week and offer a low-impact way to practice yoga without getting onto the floor.

Our gentle yoga classes begin with movements seated in a chair and continue to standing postures with the option of using the chair for support. Traditional yoga movements, breathing, and meditation techniques are adapted so everyone can receive the benefits of yoga regardless of level of health.

As with any yoga practice, we encourage you to listen to your body and only do what feels comfortable. Also, keep in mind the recommendations you may have from your doctor. For example, your providers might advise against deep twists, backbends, or poses that put your head below your heart. Prior to joining virtual classes, our yoga therapists have a one-on-one conversation to discuss your personal needs and goals.

Practicing chair yoga is a gentle way to reconnect with your body during or after cancer treatment. Along with increasing mobility, yoga has a calming impact on your nervous system, which helps you feel more relaxed and at ease. Coming together as a small group for yoga can also build a sense of community and connection. Many people find that yoga is an integral part of finding balance and tranquility during their cancer journey.

Virtual classes are held on Zoom each Tuesday from 11 a.m.-12 p.m. and Thursday from 2-3 p.m. Classes in Spanish are offered on Thursdays from 11 a.m.-12 p.m. Visit Moffitt.org/Yoga to join.



Benefits of Yoga:

- Promotes relaxation
- Increases circulation
- Relieves stiffness
- Stretches muscles
- Reduces tension

For yoga schedule and online resources visit: www.Moffitt.org/Yoga



Set an intention...



roll the head from side to side...



the shoulders...



stretch out the sides...



gently twist... roll out.



Are You a Young Adult Living with Cancer?

Visit Moffitt.org/AYAEvents to check out opportunities to meet other cancer fighters, between the ages of 15-39

TO LEARN MORE:

Moffitt.org/AYA | AYA@Moffitt.org
813-745-4736

YOUR VOICE MATTERS

Moffitt's Patient and Family Advisory Council is seeking members from diverse and underrepresented communities. Help us ensure all voices are represented and heard by Moffitt leadership.

Contact **813-745-2963** or email PatientAdvisors@Moffitt.org to learn more.



Making Moffitt Safer for YOU

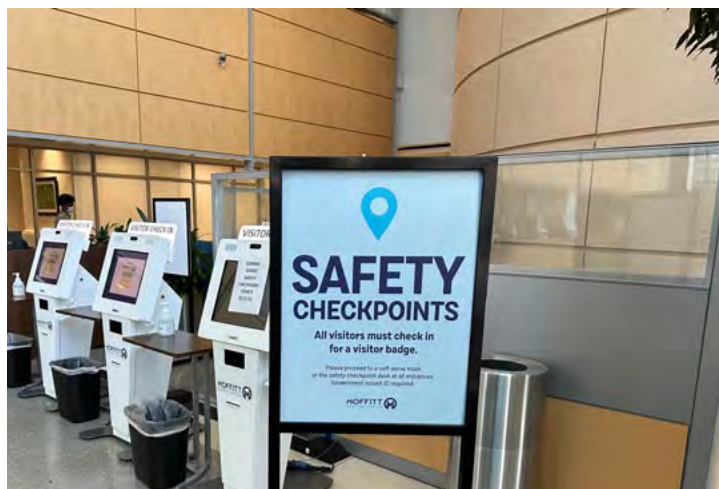
Amanda Sangster, Strategic Communications

The well-being and safety of our patients and visitors are our top priority at Moffitt Cancer Center. With that in mind, we have launched a new visitor check-in process that meets the highest standards for patient and visitor safety.

As you may have noticed at recent visits, this new safety checkpoint system is being used at all visitor entrances of our Magnolia and McKinley campuses. Only visitors, including family members and caregivers, will use the new process. Patients may proceed to their appointment for check in or remain with their visitor.

What you should know:

- ✓ **Safety First:** All visitors, including visitors coming with patients or visiting admitted patients, will need to go through the safety checkpoint. It's all about keeping you safe.
- ✓ **Plan Ahead:** Only visitors are required to check in but please plan extra time for arrival. Patients can proceed directly to their appointment or remain with their visitor. It's totally up to you!
- ✓ **Don't Forget Your ID:** Visitors should bring a government-issued photo ID with them. If you don't have one, no worries! We'll help you at the Security desk for a quick manual check in.
- ✓ **Skip the Line:** Look out for self-serve kiosks at public entrances for added convenience.
- ✓ **Your Visitor Badge:** When you check in, you'll get a visitor badge sticker. Wear it above your waist so everyone knows you're good to go.
- ✓ **Children:** Visitors under 18 don't need a badge, but they should always have an adult with them at Moffitt.



Thank you for understanding and supporting us as we work to make sure everyone at Moffitt is as safe as can be. Your safety is what matters most to us, and we can't wait to welcome you through our new Safety Checkpoints!

Patients, family members and visitors can learn more by visiting [Moffitt.org/VisitorPolicy](https://www.moffitt.org/VisitorPolicy).



What is a Chaplain?

Sandy Eckhardt Harbour, MDiv, Board Certified Chaplain

Two popular responses I receive when I introduce chaplaincy care are, “Am I that sick?” or “What is a chaplain?” One of the reasons I enjoy serving as a chaplain at Moffitt Cancer Center is because the center considers the importance of healing the whole person, which includes the physical, emotional, and spiritual well-being of their patients and families. When the three components work together, the spiritual and emotional balance can enhance the physical outcomes.

Our role as chaplains is to offer a safe, non-judgmental space where someone can wrestle with life’s hard questions and explore their own personal beliefs, while attempting to make sense of their unique situation. A chaplain’s goal is to assist individuals in finding inner strength from their own personal beliefs as they face life’s challenges. As professionally trained chaplains, our role is not to force our personal beliefs, but to encourage the person to claim theirs.

Reasons to seek spiritual support:

- When faced with an unknown challenge
- When learned beliefs, don’t make sense with current experiences
- When overwhelmed by concerns about the future or struggles from the past
- When feeling at a loss of meaning or purpose
- When there is a need for encouragement, in order to strengthen others

Our professionally trained chaplains provide diverse spiritual support for individuals or family members from all faith traditions, even those with no declared faith connection.

To reach an interfaith chaplain, please call (813) 745-8407.





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If you would like to be involved in making Moffitt the best it can be for all patients and families, contact the Patient and Family Advisory Program at PatientAdvisors@Moffitt.org or 813-745-2963.



Patient and Family Orientation

Learn how to:

- CONNECT WITH PROGRAMS AND SERVICES
- PARTNER WITH YOUR CARE TEAM
- FIND YOUR WAY AROUND MOFFITT

- Virtual sessions presented at 2 p.m. on weekdays
- In-person sessions offered upon request
- Each session offers a 30-minute presentation with Q&A
- Presented in English and Spanish
- View online at MOFFITT.org/Orientation

813-745-1690 | Orientation@Moffitt.org

