PARTNERS

Newsletter of the Patient and Family Advisory Program at Moffitt Cancer Center | SUMMER 2024

PATIENT'S PERSPECTIVE

No Longer Alone

Amy Bondon, Patient Advisor, Patient and Family Advisory Program

Most of my life I've been self-sufficient, self-employed and comfortable being alone. In January 2019, I came down for my annual Florida visit from New Jersey. I was looking forward to the Florida sun. My first day in Florida I remember feeling the sun on my face while I was riding my bicycle 30 miles on the Florida Greenway. I was healthy and happy. I never would have guessed that two days later I would be in the emergency room with excruciating pain.

I had always been able to take care of myself, and it was shocking to be in a position where that was no longer the case. I had some very hard weeks filled with pain, an inability to eat and medical tests. Eventually I came to Moffitt Cancer Center with concerns that I had cervical cancer and needed surgery right away.



Nearly five years after being diagnosed with cervical cancer, Amy Bondon gives back as a patient advisor at Moffitt Cancer Center

I was scared the day of my surgery, having never been sick or hospitalized or having had anesthesia. I woke up from surgery and was told that it was more complicated than initially expected, so they kept me for observation. My gastrointestinal tract shut down. Emergency surgery followed nine days later, and I was very sick and very alone for a long time. Thankfully my deep faith gave me the peace in the midst of this to hang on.

Continues on page 3

IN THIS ISSUE

- 1 No Longer Alone
- 2 Co-Chair Column
- 3 Chaplains... A Part of the Interdisciplinary Team
- 4 To Look or Not to Look: That is an Important Question
- 5 Moffitt Resources to Help Patients and Caregivers
- 6 LUNA Offers Education, Emotional Support to Latino Patients and Families

- 7 My Annual Mammogram Saved My Llfe
- 8 Oncology Rehab Services
- 9 Moffitt, Suncoast YMCA Offer Wellness Classes for Cancer Survivors
- 10 Moffitt Partners with Patients to Enhance the Scheduling Expereince
- 11 Knowing Your Moffitt Scheduling Options
- 12 Patient and Family Orientation

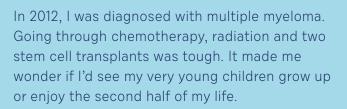




David Dauman

CO-CHAIR COLUMN

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



Looking back 12 years later, I drew so much strength to fight my cancer by talking to other people who have experienced the disease. Their perspective was different from the doctors and nurses I relied on for medical advice. They were my big brothers and sisters. They validated my fears and confusion. They made me feel that I was not alone, and I could draw from their courage. It was support from people whose sole bond with me was a shared enemy. We were comrades in arms.

The support of others who understood was invaluable to my physical and emotional recovery from the darkest days of my family's cancer fight.



Weirdly enough, there is an opportunity that can come with going through cancer. If you are comfortable in doing so, share your experiences with others. You have a lot to offer. Call it cancer cred (short for credibility). Whether casually, through Imerman Angels or as a patient family advisor, there are ways to help others. You are probably too humble to realize how important your thoughts and time are to other patients and their families.

Hang in there, fellow patient. Let me know how I can help.

Imerman Angels is an organization for those impacted by cancer who are seeking support or looking to support others. Visit **ImermanAngels.**org to learn more about connecting one on one with someone who has experienced cancer.

Want to talk with someone who can relate?

Imerman Angels is a community organization that provides free, personalized one-on-one cancer support for cancer fighters, survivors, previvors and caregivers.

To connect with support, please visit ImermanAngels.org or call 866-463-7626.



We want to hear from you!

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





No Longer Alone

Continued from page 1

I endured many surgeries, treatments and life-threatening complications that put my life at risk. At Moffitt, I didn't feel alone. The thing that made my recovery bearable were the amazing connections with the nurses and medical assistants. It meant so much to me that they would take the time to visit and talk with me. I got to know them as people, and one day a nurse even suggested that I become a patient advisor. I was very sick at the time, and I had no idea what a patient advisor was, but that idea stuck with me.

After recovering, I remembered that advice and I looked into becoming a volunteer with the Patient and Family Advisory Program. I was compelled to give back some of the lifeaffirming love, support, care and empathy that all of the Moffitt team gave to me. As a patient advisor I would have the opportunity to connect with other people who have had cancer too. Despite being mostly on my own, I inherited the

gift of gab from my dear dad. I love getting to know people and hearing their stories. These dear ones melt my heart and give me purpose.

Almost five years out of treatment, I now spend my time visiting people in clinics and the inpatient nursing units at Moffitt. I'm so grateful to be in a position where I can use my experience to provide company, support and encouragement to people who are going through a hard time. Volunteering at Moffitt is the joy of my life.

Have you experienced cancer as a patient or caregiver? Would you like to give back like Amy? Email PatientAdvisors@Moffitt.org or call 813-745-2963 to learn about Moffitt's Patient and Family Advisory Program.

CHAPLAIN'S CHAT

Chaplains ... A Part of the Interdisciplinary Team

Garth Battick, MDiv, Staff Chaplain

All great recipes have a number of ingredients. Moffitt Cancer Center is similar with a multifaceted team of trained health professionals to walk with patients and families through the physical, emotional, and spiritual hills and valleys of their journey as they seek to understand their options and make informed decisions about their health and lives.

Combining these ingredients of doctors, nurses, techs, dietitians, physical therapists, social workers and chaplains creates a strong interdisciplinary care team.

Each discipline possesses a unique set of skills that integrate and complement one another. As part of the interdisciplinary team, chaplains work side-by-side with other team members. Chaplains bring to

the table a nonclinical perspective, active listening, spiritual insights and religious resources. They are important to the overall team effort to create a safe space for patients and families from diverse

backgrounds to come together to discuss treatment options, goals of care and at times end-of-life wishes

As one of the ingredients in the interdisciplinary team, chaplains are there to help bring about a sense of inner peace and spiritual strength, which like your favorite dish, can be very satisfying.

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

To Look or Not to Look: That is an Important Question!

Sean T. Powell, MSW, LCSW, CCM, OSW-C

Senior Director, Care Management



Part of any patient's journey is undergoing different types of tests, such as blood work, CT scans and MRIs and then awaiting the results. The results of these tests can indicate if the cancer is in remission, further treatment is needed to control the disease or the cancer has progressed. Obviously, any of the possible scenarios can create a great deal of anxiety while awaiting the test results.

Patients now have access to information contained in their electronic medical record. Through the Patient Portal patients can easily access notes from their physicians, upcoming appointment schedules, treatment regimens and test results. In the past we had to wait for a call from the physician's office telling us what the latest test results were. However, that information is now at our fingertips and available to us once the test results are ready.

"Reviewing your labs in the portal can provide valuable insights," said Timothy Hembree, DO, PhD, vice president of Quality at Moffitt. "It empowers you to stay informed about your health and enables more meaningful discussions with your doctor. Actively participating in your health care means taking ownership of your well-being, asking questions, making informed decisions and following through with

recommendations. Working together, the patient and the doctor can achieve optimal health outcomes."

This may lead you to ask, should I look at it before my doctor calls?

There is no right answer, and there are pros and cons to looking and not looking. For newly diagnosed patients who have not had experience with the health care environment, trying to interpret test results without a provider to explain them may cause misunderstanding, fear, anxiety and frustration. In these circumstances it may be best to wait for your upcoming appointment or phone call so you have a full understanding of what is going on.

However, many patients develop a level of understanding of what the results mean, particularly blood work. If you understand what the results mean and it will reduce your anxiety to check the portal before discussing them with your doctor, it is generally OK to review them. However, any questions and concerns should be directed to your care team. Your Moffitt providers are the best at interpreting how these results apply uniquely to you and your diagnosis and treatment.

You can always have a conversation with your provider about checking the test results in the portal. If you find you become anxious or fearful right before tests or while awaiting the results, there are ways to cope. Talking with a friend or family member, distracting yourself with hobbies or past-times, and meditating are great ways to help manage the worry. Moffitt offers peer advisors, social workers, chaplains and support groups that offer safe spaces for you to discuss your feelings and find ways of coping.

To connect with these programs, please call 813-745-8407.

MOFFITT RESOURCES to Help Patients and Caregivers

UPCOMING EVENTS

June - August

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

Virtual/Zoom, RSVP only Weds. at 12:15 p.m. *Moffitt.org/Mediation*

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*

Magnolia Open Art Studio | 813-745-8407

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

McKinley Open Art Studio | 813-745-8407

In person, Moffitt's McKinley Outpatient Center 1st floor - Patient and Family Center Mon.-Fri., 8:30 a.m.-3:30 p.m. ArtsinMedicine@Moffitt.org

Patient & Family Orientation | 813-745-1690

In person, RSVP only 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** 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 4 metastatic breast cancer to share mutual support. Meets the first and third Tuesday of every month, 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. .

Ostomates

Twice monthly meeting for patients with a colostomy, ileostomy or urostomy. Meets the first and third Monday of every month, 1-2 p.m. via Zoom.

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**.

LUNA Offers Education, Emotional Support to Latino Patients and Families

Viviam Sifontes, LUNA Executive Director

The mission of Latinos Unidos por un Nuevo Amanecer, or LUNA, is to provide health education and emotional support to Spanish speaking cancer patients, survivors and their families in the Latino communities in the Tampa Bay and Central Florida area.

LUNA offers free support groups, health navigation, emotional counseling, cancer camps and educational support. Considering the needs of Latino patients, the purpose is to fill the gaps in the provision of health services in our communities.

LUNA transforms lives by empowering patients to develop strengthened knowledge and a positive attitude. This will help them make confident, educated and hopeful decisions.

We embrace the new findings of science without forgetting the emotional aspect of the cancer journey. Our support groups are designed to implement unique supportive teachings with two important components: an educational session and a personal, heart-to-heart session.

Patients often do not know where to begin in the cancer



journey process. The health navigation we offer is designed to guide patients who need personalized care.

Through our counseling and coaching sessions, we address emotional health, anxiety and depression and offer self-management tools so patients can continue the path of treatment with their emotions under control.

We also hold Camp Alegría, our biannual, three-day retreat for survivors and patients under cancer care, where they can make new connections and lasting bonds with other patients and survivors. At Camp Alegria, we offer up-to-date scientific educational information, emotional support groups, entertainment and self-care and pampering.

Our organization is run by volunteers, including our executive director of 10 years, Viviam Sifontes. Viviam and the board of directors serve our community with passion, professionalism and dedication.

For additional information about our services, call Viviam Sifontes at 813-956-2978.

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.

My Annual Mammogram Saved My Life

Norma Martinez, Breast Cancer Survivor, BMT-CI Faculty Administrative Coordinator



Norma Martinez is thankful her yearly mammogram found her breast cancer early. She's able to enjoy traveling, including to



I have been a team member at Moffitt Cancer Center since August 2020. In October 2021, I went for a routine mammogram at Moffitt. I had no symptoms, no pain and no lumps. During my appointment, Dr. Dana Ataya discovered a suspicious mass. I needed a biopsy.

Then I met with Dr. John Kiluk and his nurse Jayne Cartwright and nurse practitioner Carly Pabon. To my surprise, I was informed that I had early-stage invasive lobular carcinoma in my left breast. Invasive lobular carcinoma is a breast cancer that begins in the milk-producing glands (lobules) of the breast that have the potential to spread to the lymph nodes and other areas of the body.

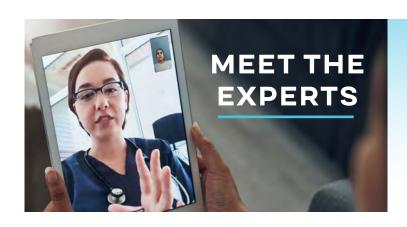
I heard the words "breast cancer" and going through fear, anxiety and a lot of emotions was something I did not expect. I had to make the biggest decision of my life. Do I undergo a lumpectomy, which would require possible chemotherapy, or do I undergo a mastectomy? I prayed and immediately knew what I needed to do. You are never ready to hear shocking

news. However, it was the support from Dr. Kiluk that made me feel peace and I knew that I was in the right place at the right time and in the best hands at Moffitt. Surrounding myself with family and friends was one of the best factors in the healing process. I have a family history of breast cancer and that is the reason for having early mammograms.

After surgery, reconstruction and recovery, I have a strong commitment and desire to spread the word of cancer awareness to others. Not everyone is comfortable talking about breast cancer or mammograms. Having a yearly mammogram, eating healthy, exercising, having faith and a support group helped me tremendously through this journey.

Thank you to the entire team at Moffitt for being compassionate and loving. I am very grateful for every person who touched my life during my journey.

Visit Moffitt.org/Screening to learn more about screening appointments, including mammograms, available at Moffitt.



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
or call 813-745-1690.

Oncology Rehab Services

 $Ron\ Jennings,\ Director\ of\ Rehabilitation\ Services$

The oncology rehab services at Moffitt Cancer Center include physical therapy, occupational therapy, speech and swallow therapy, and nutrition therapy.

Physical and Occupational Therapy

Physical therapists focus on improving a patient's ability to move their body. Occupational therapists focus on improving the patient's ability to perform activities of daily living like getting dressed and using the bathroom. Both therapies help patients regain strength, mobility and a sense of independence. They provide care for muscle loss, falls and weakness; offer caregiver training for home; and recommend equipment such as a walker. They also may make discharge recommendations for people leaving the hospital to determine if it is safe for a patient to return home or if they may benefit from being admitted to a long-term care center for continued rehabilitation.

Speech Pathology

Speech language pathologists address issues with swallowing and communication. They perform various swallowing studies, which help determine the safety of eating food. Speech language pathologists may make recommendations for special diets or thickened liquids if a patient can't safely swallow regular solid foods or thin liquids. They are also available for consultations for patients needing their voice box removed. They can meet before surgery, as well as teach ways to communicate after surgery.



Nutrition Services

Registered dietitians provide nutrition care including diet education, tube feeding recommendations, diabetes education and parenteral nutrition, or receiving nutrients through a vein. Dietitians can provide education on several topics including cancer prevention, prevention or treatment of malnutrition, nutrition for different cancer treatments, management of feeding tubes, special diets, and nutrition and cancer survivorship.

How to access our services

All of these services are available both inpatient and outpatient. To make an appointment with these specialties, ask your health care provider at Moffitt for a consult.

For more information call the Rehab Department at 813-745-3609.



Moffitt, Suncoast YMCA Offer Wellness Classes for Cancer Survivors

Jennifer I. Vidrine, PhD; Assistant Center Director, Research Community Partnerships; Senior Member, Health Outcomes & Behavior

Morgan Lael, MS, Research Partnerships Program Manager



What is the program and how will it help cancer survivors?

The YMCA Survivorship & Wellness Program Powered by Moffitt is a 12-week exercise program. It is designed to help cancer survivors live healthier lives. Cancer survivors work with Y staff and other survivors two times each week.

David Dauman completed the program through the Suncoast YMCA. "After a year of intensive treatments for multiple myeloma, I needed physical and emotional healing. I needed to trust my body again," Dauman said. "I discovered the YMCA program. It offered me guidance, a group of fellow patients for mutual support, and the structure to start active recovery. I credit the program with being the catalyst for my fitness recovery."

Participants may also be invited to take part in separate cancer survivorship research studies. Such research could improve the lives of countless survivors across the nation. Participation in research studies is voluntary. Eligibility to participate in research studies differs from study to study.

We are excited to bring opportunities like this to cancer survivors in our community.

Who can access the program?

The program is available to all cancer survivors who live in the Suncoast YMCA area who have not already previously participated in the LIVESTRONG Program or the YMCA Cancer Survivorship & Wellness Program Powered by Moffit. We hope to expand opportunities for past participants and caregivers in the future.

The Tampa Metro YMCA offers support through the LIVESTRONG Program. Please contact your local Y for details

How much is the program?

The YMCA Survivorship & Wellness program is 100% free. Participants and caregivers also receive a free three-month membership to the YMCA.

Email Kari Grassia at **KGrassia@suncoastymca.org** to find the program closest to you and enroll today!



Moffitt Partners with Patients to Enhance the Scheduling Experience

Rae Sawyer, Family Advisor and Co-Chair, Patient and Family Advisory Council

Corrie Wassum, Senior Instructional Designer of Patient Access

Moffitt Cancer Center's Patient and Family Advisory Council (PFAC) is a diverse group of patients, family members, clinicians and key administrators who meet monthly to enhance the patient experience. Over the past year, PFAC has witnessed increasing concern among patient and family advisors regarding Moffitt's ability to schedule a growing demand for appointments in a timely and efficient manner.

In response, the council formed a PFAC Scheduling Subcommittee to support Moffitt team members and improve the patient experience throughout the scheduling process. This new subcommittee includes Moffitt's Process Excellence team, Moffitt leaders, and patient and family advisors. The group kicked off with several sessions designed to hear concerns and gather information before defining the priorities of the project. These initial sessions culminated in a two-day brainstorming event that focused on streamlining the process for scheduling patients. This unique event brought patient and family advisors together with Moffitt administration, clinical staff and schedulers to identify key obstacles to more efficient scheduling.



The PFAC Scheduling Subcommittee identified multiple solutions that could be instituted immediately, initiated for further work and planned as long-term endeavors. Perhaps the most notable adoption has been to change the scheduling process for outstanding appointments through the Instant Scheduling Initiative.

Instant Scheduling is a process that does not rely on contact with each patient prior to scheduling. Moffitt team members work to document each patient's scheduling preferences, such as days, times and locations that are most convenient for them, and schedulers use these details to reserve a time for the patient's care before calling the patient with details about their upcoming appointment. After a patient is instant scheduled, they will receive notification via a phone call, text, and/or email.

"Instant Scheduling is a unique opportunity to minimize touchpoints and ensure every patient is scheduled in a timely manner, all while continuing to meet the needs and preferences of our patients. In transitioning from a reliance on telephone contact to greater use of Instant Scheduling, we have significantly reduced the number of outstanding appointments with minimal complaints, requests to reschedule or missed appointments," said Derek Herring, senior director of Patient Access at Moffitt.

Clearly, the partnership between PFAC and Moffitt team members is a win for patients as we've worked diligently to collaborate, seek action-based solutions, and implement significant changes to improve the patient experience, all within two months!

Need to cancel or reschedule an appointment? Call our scheduling team at 888-663-3488 for assistance.

Know Your Moffitt Scheduling Options

 $Patty\ Kim,\ Director\ of\ Public\ Relations$

At Moffitt Cancer Center, we recognize that a cancer diagnosis affects not just our patients, but their caregivers and families as well. That's why we do everything we can to offer personalized scheduling options that fit the needs of each patient.

Did you know you have the flexibility to schedule appointments at several locations? Or you can have labs and imaging done a few days before your provider visit? For those who travel long distances, you can stack appointments in a single day? And if weekdays are not convenient, labs and imaging can be scheduled over the weekend?

If you need imaging, choose from our Magnolia, McKinley and International Plaza locations. Blood draw and infusion services can be done at any campus. Radiation oncology treatment can be scheduled at Magnolia, Wesley Chapel and International Plaza. All inpatient surgeries are at Moffitt McKinley Hospital. Starting in January 2025, Moffitt at SouthShore will be our newest satellite location offering screenings, radiology, blood draw, infusion, radiation therapy and oncology visits.

Here you'll see all of our Moffitt locations. We want to empower you to use these options to best meet your needs.

Moffitt Cancer Center, Magnolia Campus 12902 USF Magnolia Drive Tampa FL 33612

Richard M. Schulze Family Foundation Outpatient Center at McKinley Campus 10920 N. McKinley Drive Tampa FL 33612

Moffitt McKinley Hospital 10901 N. McKinley Drive Tampa FL 33612 Moffitt Cancer Center at Wesley Chapel 2590 Healing Way Wesley Chapel FL 33544

Moffitt Cancer Center at International Plaza 4101 Jim Walter Blvd. Tampa FL 33607

Moffitt Cancer Center at SouthShore (coming in January 2025) 2709 E. College Ave. Ruskin FL

If you have scheduling preferences, please tell us. Our schedulers will work with you in person, by phone or through a patient portal message to accommodate your requests. It's one of the many ways we strive to provide patient- and family-centered care in all that we do.

For more information or to schedule an appointment, please call 888-663-3488. Select option 1 for established patients or option 2 for new patient scheduling.





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

PARTNERS

EDITORIAL BOARD

Managing Editor
Jacqueline Beaushaw

Graphic Design Moffitt Strategic Marketing

Editorial Board Members
Patti Halula (Patient Advisor)

Prado Antolino

Kenisha Avery

Anne Bidelman

Ana Carlson

Pam Duncan

Patty Kim

Shani Parkin (Patient Advisor)

Cristina Pérez

Sean Powell

Cathy Schaffer (Patient Advisor)

Alexis Youdelman

PATIENT & FAMILY ADVISORY COUNCIL

Charlie Agurcia

Susan Brill

Bárbara Cruz

David Dauman (Co-Chair)

Amanda Dugger

Kerrijo Ellis

Danni Gallagher

Ron Giovannelli

Yvette Gray

Patti Halula

Randy Isaacson

Barney Morris

Shani Parkin

Mark Pizzo

Rae Sawyer (Co-Chair)

Vondalyn Wright

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.







