

PARTNERS

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

PATIENT'S PERSPECTIVE

A Survivor's Flowers

*Charlie Agurcia, Patient Advisor,
Patient and Family Advisory Council*

A dozen white orchid blooms sit in front of me. They symbolize survival. Orchids normally bloom once a year, but last year a gecko attacked the buds. I had to wait more than 24 months to see these rare flowers come out again. While that doesn't seem like a long time to most people, it's an eternity for those of us with small-cell lung cancer.

I was diagnosed with the disease in Tegucigalpa, Honduras when I turned 40. Treatment options for my inoperable tumors were limited there, and after a cycle of chemotherapy and a failed attempt at radiation, my family brought me to Florida and Moffitt Cancer Center.

I was sick, frightened, and helpless when I first went through the doors of the lobby. I thank my family for giving me the strength to get there and follow through. From the first face that greeted me (Gina is awesome) to the nurses, doctors,

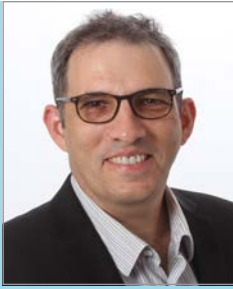
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Charlie and his dachshund, Toby

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David Dauman

CO-CHAIR COLUMN A BIGGER LIFEBOAT

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

It is my honor to become Moffitt’s Patient Family Advisory Council’s (PFAC) newest co-chairperson after working with these dedicated volunteers for six years. I replaced the awe-inspiring Shani Parkin, whose tireless commitment set a high watermark. Luckily, I have the support of one of the strongest people I know, Patti Halula, as my senior co-chairperson.

This year also marks my 10-year anniversary as a Moffitt patient. I arrived stunned with aggressive multiple myeloma thinking Moffitt was the last stop before a premature death, soon to realize I had instead found a seat on a lifeboat. From the Hematology/Oncology and Blood Marrow and Transplant clinics, I saw the shores of recovery on the horizon.

Moffitt enlists the best tools and people to fight cancer. It also nurtures the humanity of patients, families and caregivers. I think Moffitt is the perfect combination of Rambo and Mr. Rogers (you may need to be my age to get that one). Like

most rescue movies, there are limited seats in the lifeboats. But Moffitt is expanding to build more lifeboats to offer the gift of health and optimism that my family received several times over to the growing number of people needing a seat.

With growth comes change and adjustment. And sometimes change can be disruptive. How can Moffitt build more lifeboats and still have all its passengers feel uniquely cared for and attended to? I offer PFAC as part of the solution.

We are seen as the eyes and ears of the collective patient family at Moffitt. We are in a perfect place to funnel feedback to leadership to ensure a consistent, clear, and compassionate dialogue is maintained between Moffitt and those of us on the lifeboat (and hoping to be assigned a seat). So please help us share feedback and suggestions.

Please let Moffitt’s Patient and Family Advisory Council know how we can keep the lifeboat as steady as possible at PatientInput@Moffitt.org.



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](https://www.moffitt.org/Calendar)**.

A Survivor's Flowers

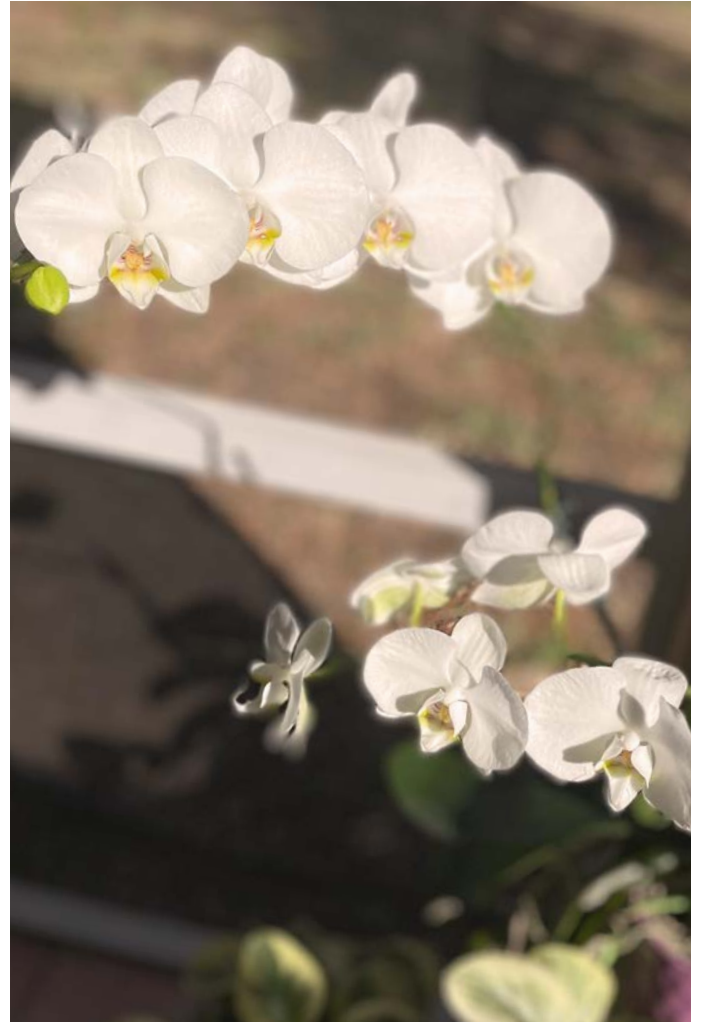
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technicians, and everyone else in this place, I discovered a bustling hive of healing and support. Moffitt Cancer Center and my caregiver team of friends and family saved my life.

When I rang the bell to celebrate my last infusion, I still felt sick, frightened and helpless. A month later, when we ran the first scans and verified that there was no evidence of disease (NED), I felt less bad. Fear of its return wouldn't let me be happy.

Recovering from chemotherapy and radiation is not easy. It has taken a lot of time, an immense amount of patience, and the persistence of my dachshund to recuperate my body. I started walking and moved on to swimming. Slowly, but steadily, I got more lung function back and reduced the attacks of fatigue. I found the mental strength and sanity to do this by going to therapy. Looking death in the face is a big deal, and my therapist has guided me on how to process that.

I'm about three and a half years NED, checking regularly to make sure it stays that way, and staring at these beautiful orchids that remind me that I'm a survivor.



*Moffitt offers support groups where you can talk with people who have experienced cancer. Please call the department of Social Work at **813-745-8407** or visit [Moffitt.org/SupportGroups](https://www.moffitt.org/SupportGroups) to learn about the support groups that are available.*



Virtual Relaxation & Meditation

Every Wednesday 12:15 – 1 p.m.

Meditation can help:

- Reduce stress
- Manage symptoms such as pain and fatigue
- Improve mood and sleep

Class is free; all are welcome.

To register, visit [Moffitt.org/Meditation](https://www.moffitt.org/Meditation) or call **813-745-6052**.

Don't Forget About You

Esther Marshall, Family Advisor, Patient and Family Advisory Program

One day, my coworker walked up to me and said, "You look great, you've lost so much weight!" Little did she know I did not lose weight on purpose. It was a few months after hearing my family member's diagnosis, one in which we were told she may not survive. My weight loss was a result of my support for her and showed that I had stopped taking care of me.

Nothing prepares you for news like cancer. We had no guide on what to do and nothing to compare it to. It was immediate survival mode. She was dealing with a lot of quick life-changing choices and I was doing research and trying to quickly learn how to help. I was fully connected to every part of her journey through appointments, treatments, labs and scans, to making sure she ate, took her medication and got organized. My mind planned and prepared at night (which meant I wasn't sleeping) while my heart had me at her side during the day.

You may be getting the picture that I am painting. You may even be in a similar situation where all you know to do is to give everything that you have while they fight for their lives. There is nothing wrong with that hope and it's a worthwhile fight. Keep both but add in time to take care of yourself.

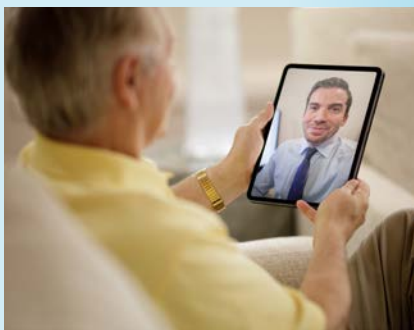


Esther Marshall



Thinking back to our journey, I know that I didn't handle this right. I was a mess the entire time! I now know that although it helped her, it worried her. As a caregiver, consider taking time to recharge your personal battery. Eat, sleep, and set aside moments to breathe and do an activity that builds you up. It will be worth it for all of you.

At Moffitt, we offer many services to help caregivers, including the Family and Friends Support Group. To learn more, visit [Moffitt.org/SupportGroups](https://www.moffitt.org/SupportGroups) or call 813-745-8407.



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 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.
PatientWellness@Moffitt.org

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

Virtual/Zoom, RSVP only
Tues. at 11 a.m. and Thurs. at 2 p.m.
PatientWellness@Moffitt.org

Magnolia Open Art Studio

In person, Moffitt's Magnolia Campus
3rd floor – Arts in Medicine Studio
Mon.-Fri., 9:30 a.m.-4 p.m.

McKinley Open Art Studio

In person, Moffitt's McKinley Campus
1st floor – Patient and Family Center
Mon.-Fri., 8:30 a.m.-5 p.m.

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://www.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.

Families First: Parenting During Cancer

A support group for parents raising young children and teens while living with cancer. Meets every Wednesday, 4-5 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.

Staying Safe in the Summer

It's summer and the hot, humid weather is here in full force! For cancer patients and survivors, the heat can really take a toll. Those who have undergone cancer therapies can be at greater risk for dehydration and skin sensitivity to sun exposure. Below are some tips to beat the heat this summer and stay safe. Please keep in mind that not all recommendations in this article may be appropriate for you. Please consult with your care team.

Be mindful of what you eat:

- Consume a variety of fruits and vegetables to stay hydrated and replenish electrolytes lost with increased sweating in hot weather.
- Fruits with high water content include watermelon, cantaloupe, strawberries and grapefruit.
- Avoid caffeine and alcohol to help maintain the body's water balance.

Plan your day around the sun:

- Schedule appointments early in the day to beat the midday sun when the heat index is highest.
- Park in shaded areas, whenever possible.
- Wear clothing that covers as much skin surface as possible. Use sunscreen for what can't be covered.
- Unless otherwise directed by your care team, bring water, healthy snacks and any medication needed to help with side effects of therapy.

Stay safe outdoors:

- Prior to sporting events, confirm in advance if there will be shaded areas.

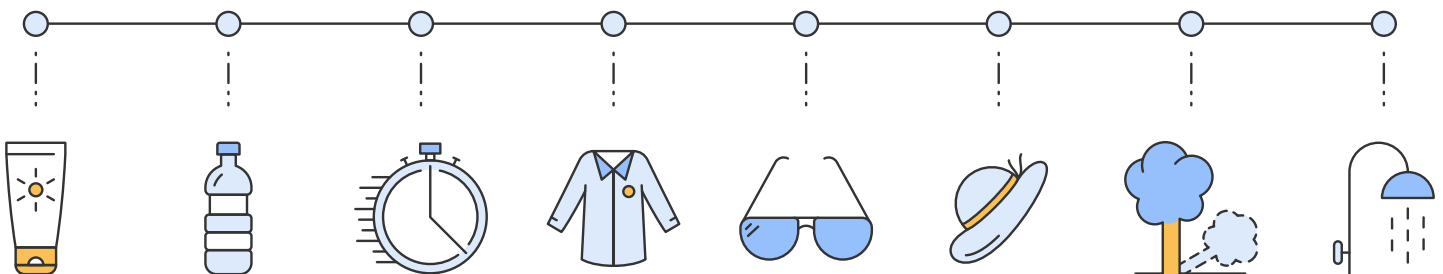
- Pack a lightweight folding lawn chair and an umbrella to protect against the sun.
- Bring plenty of water, other fluids and healthy snacks.
- Have a backup plan for an early ride home or relocation to a cool indoor location.



Exercise with caution:

- Always discuss plans with your primary care provider or oncologist before starting any activity.
- If eligible for physical activity, be mindful of where and when one is exercising during summer months.
- Activities such as water aerobics or exercising in air-conditioned areas are options for staying cool while being active.
- Exercise earlier in the day or later in the evenings, if possible.

Moffitt offers free skin cancer screening at Mole Patrol events. For more information, visit [Moffitt.org/MolePatrol](https://www.moffitt.org/MolePatrol) or email MolePatrol@Moffitt.org.



The Moffitt Survivorship Clinic

Sherri Huang, MD



After completing cancer treatments, patients may experience treatment side effects and anxiety about the risk of cancer recurrence. “Will my cancer return?” and “How can I live healthier so I decrease the chances of future cancers?” are just two of the common questions. The Survivorship Clinic at Moffitt Cancer Center helps patients navigate their post-cancer treatment journey.

Directed by Dr. Smitha Pabbathi, the clinic provides a care plan that is personalized and unique to each patient. The clinic monitors for recurrence of cancers through follow-up tests and imaging as well as common side effects each patient may experience. The clinic also helps patients with regular recommended screenings of other cancers.

The clinic also provides patients with resources about healthy diet and exercise. Many studies have shown the numerous benefits that a healthy diet and regular exercise can provide cancer survivors. Benefits range from reducing the degree of long-term treatment side effects to decreasing the risk of new cancers or the return of preexisting ones.

At the start of each clinic visit, a nurse asks the patient about their lifestyle habits. Based on the patient’s responses, the team creates a care plan for each patient that may include diet suggestions, referral to a dietitian and/or exercise program and suggestions on questions to ask the patient’s own primary care provider.

One endeavor the clinic has started is a program called Survivors Overcoming and Achieving Resiliency (SOAR). SOAR helps breast cancer survivors achieve a healthy lifestyle through nutrition, exercise, yoga, meditation and stress management. Recently, the program was awarded a grant to expand a nutritional support program which teaches survivors how to prepare healthy meals. Through programs like SOAR and Survivorship Clinic visits, cancer survivors receive the guidance and support they need to navigate their post-cancer treatment journey.

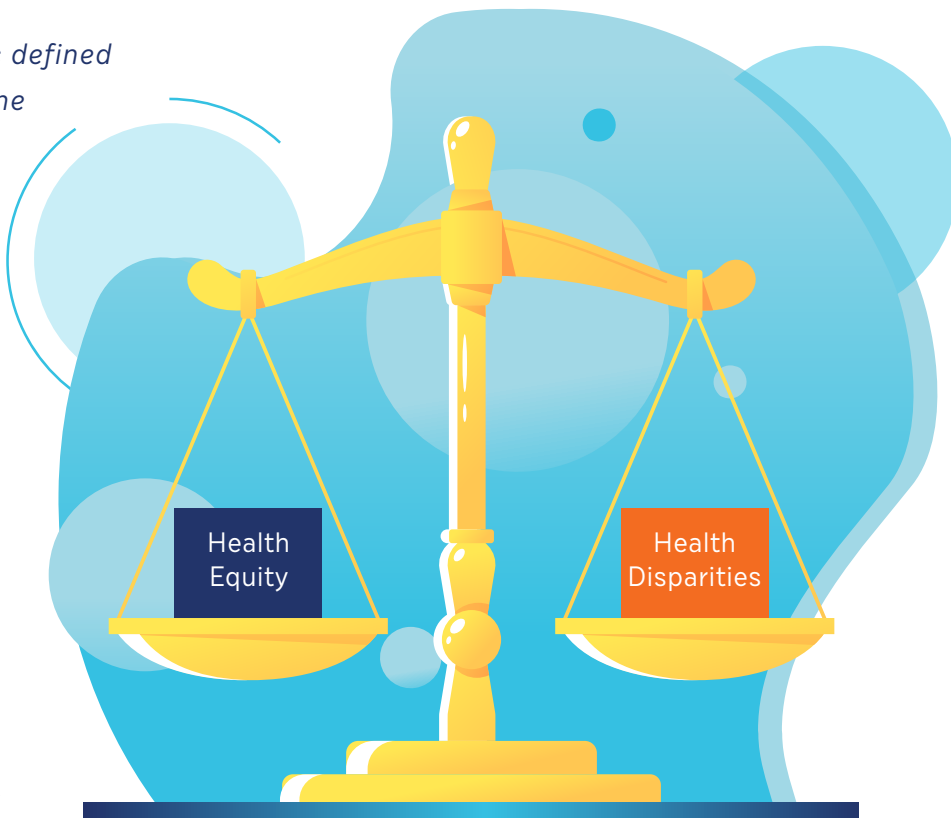
For more information, visit [Moffitt.org/SOAR](https://www.moffitt.org/SOAR) or call 813-745-8000 to speak with a Survivorship program expert.



Are Health Equity and Health Disparities the Same Thing?

Kenisha Avery, Manager, Office of Community Outreach, Engagement and Equity

Short answer, they are close cousins! As defined by Moffitt, health equity is 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. Whereas health disparities are the metrics used to measure progress towards achieving health equity.



What is Moffitt doing to show their commitment to reducing health disparities and achieving health equity?

- **Increasing access to cancer screenings of preventable cancers.** Moffitt physicians, advanced practice professionals, nurses and other team members routinely do community screenings for skin and oral cancers. Moffitt's screening access program provides no-cost screenings for breast, lung and colorectal cancers to uninsured community members. Please visit Moffitt.org/Screenings for more information.
- **Offering language services.** Moffitt has a team of professionally trained, certified translators and interpreters readily available to assist patients and providers when they do not share the same language. Interpreter services are provided remotely (via phone or video) or in-person. Visit Moffitt.org/LanguageServices to learn more.
- **Supporting health disparities research.** Health disparities research covers a wide range of focus areas and includes Moffitt getting to know the

populations they study through community partnerships. Through the George Edgecomb Society, funds are raised to support researchers working on reducing cancer disparities in the Black community. Moffitt is also working to increase enrollment of diverse patients to clinical trials that offers innovative therapies for patients. Visit Moffitt.org/GeorgeEdgecomb to learn about this fund or donate.

- **Fostering and sustaining community partnerships.** Moffitt's Office of Community Outreach, Engagement and Equity (COEE), oversees a network of 29 diverse community partners of the Tampa Bay Community Cancer Network to help increase education and access to care; works with a variety of community organizations to conduct outreach and education; and partners on research to assess disparities and ensure more equitable care. Visit Moffitt.org/COEE to learn more.

Moffitt McKinley Hospital: What Can Patients Expect?

Amanda Sangster, Strategic Communications

As Moffitt Cancer Center prepares to open its new inpatient surgical hospital, many patients are left wondering how this new facility will impact their cancer care. Will my appointments be at the new hospital? Is my doctor moving? What does this mean for my clinic appointments? Where will my surgery happen?

The nearly 500,000-square-foot hospital, located across from the Richard M. Schulze Family Foundation Outpatient Center at McKinley Campus, will serve only as a surgical hospital for solid tumors. This means that only patients who require surgery services will be treated there. Moffitt Cancer Center's existing Magnolia facilities, located on the campus of the University of South Florida, will remain a centralized hub for our life-saving clinics, programs and research.

For many Moffitt patients, surgery and inpatient stays won't be needed. Their diseases will be cured by the treatments that will continue to be provided by our Magnolia facilities, McKinley Outpatient Center and our many ambulatory centers in the greater Tampa Bay area.

For the patients that will have surgery at the new hospital, they will receive the same world-class care that Moffitt is known for. On opening day, Moffitt McKinley Hospital will house 19 operating rooms, 96 inpatient beds and 60 recovery rooms, with the capacity to expand as patient demand grows. The new facility is outfitted with state-of-the-art technology that will enhance the inpatient surgical experience and improve patient outcomes. This includes new imaging technology, virtual assistant technology within patient rooms and a new digital platform for patient registration.

The last surgery performed at our Magnolia Campus will be on July 25. The first surgery at Moffitt McKinley Hospital will occur on July 31. Patients scheduled for surgery will be notified upon scheduling as to which facility they will receive care from.

Check out Moffitt Cancer Center's social media channels for the latest updates on Moffitt McKinley Hospital ahead of our opening day on July 31, 2023.



Transforming the Inpatient Surgical Experience

Amanda Sangster, Strategic Communications

In order for patients to fully heal and recover from surgery, they need environments that empower and enable them to do so. The moments in a patient room following a surgery can be just as vital as the surgery itself. When Moffitt Cancer Center embarked on building a new hospital and envisioning a new inpatient surgical experience, we invited the best experts to help us: our patients and families.

Alongside architects and through multiple design sessions, Moffitt patient and family advisors provided feedback about their own inpatient surgical experiences. Our advisors emphasized that one of the biggest areas for improvement was the technology within inpatient rooms. Based on this feedback, the inpatient rooms at Moffitt McKinley Hospital will be unlike any other hospital before it.

The patient rooms will be equipped with virtual assistant technology, integrated pillow speakers and voice controls. Additionally, each room will be equipped with large television screens that will offer entertainment options and educational resources. Digital screens will also replace the standard dry-erase whiteboards known

throughout all hospital systems. Information on the digital whiteboards will update in real time according to the patient's medical records, allowing for patients and families to easily view dietary restrictions, allergies, medical concerns and more.

Another concern that patient and family advisors raised was around providers entering the room. Moffitt patients see a multidisciplinary team of providers and it can become confusing for them to keep track, especially

as they're recovering from surgery. The digital screens will also display the names of the Moffitt staff entering the room, so patients and families will always know the names of those treating them. Digital door signs will also be installed outside every room and updated in real time to display any precautionary measures.

While technology plays an important role for patients, we realize that caregivers are also essential to their

healing. To make accommodations more comfortable for caregivers, we have increased the size of the guest beds within the patient rooms. To help caregivers recharge, the new hospital also features family showers, laundry facilities, a spiritual room, resource center, and expansive waiting areas with private alcoves for times of respite.

With these enhanced features, our hope is that Moffitt McKinley Hospital provides a healing environment that offers patients and families the same comforts of home.



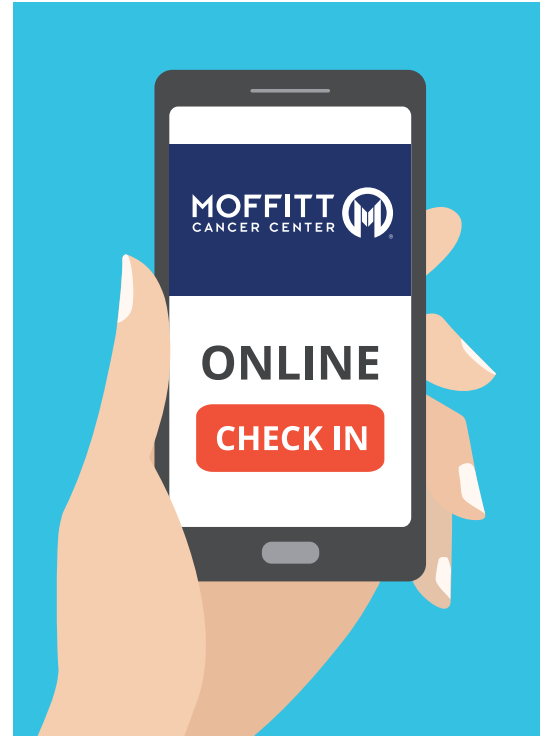
Online Registration, My New Best Friend

Walter Inman, Patient Advisor, Patient and Family Advisory Program

Moffitt now offers you the ability to register online before your appointments, giving you an opportunity to complete your paperwork at your convenience.

I have been a Moffitt patient for eight years so I was accustomed to the old registration process. I have several monthly appointments for labs, doctor visits and chemotherapy. With the new online process, I enjoy the ease of doing my paperwork at my own leisure. I can complete it from my home computer or my phone.

Sometimes, I don't feel very well when I arrive for my appointment. I appreciate how the new online registration process makes my arrival easier. The online program saves all my personal information and insurance. This means I don't have to spend time on the phone when I'm not feeling well. The new system also sends me reminders. This improvement has created a faster registration experience and more enhancements are in the works! I think once people get used to registering online they will really like the change.



For questions about online registration please call 813-745-8111 and select option 1.

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.



Are you a patient that has been prescribed a new chemotherapy to take home?

Great news! Moffitt Cancer Center's Specialty Pharmacy focuses on providing these medications with excellent customer service and expert support by our technicians. We can serve as an integral part of your treatment team.

To learn more:

PHONE **813-745-7354**
TOLL FREE **866-409-6670**

EMAIL **PharmSpecialty@Moffitt.org**
WEBSITE **Moffitt.org/Specialtypharmacy**



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

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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.

