

# PARTNERS

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

## YOUNG ADULTS LIVING WITH CANCER

### A Daughter's Perspective: Growing Closer Through Cancer

*Grace Halula, 17, Daughter of Patti Halula*

From the outside, it seems like I grew up with a normal childhood. In actuality, things felt a lot different in life as I was growing up with a mother who has cancer.

My mother never really had to break the news to me. It was just something that was talked about since the first time I could comprehend words. In my earliest years, my mom's cancer wasn't active. My developmental years were relatively easy. When I was 6, her condition started to worsen. I would ask to play outside and the answer turned from yes to no. What was commonly spoken about in my household had become actually quite serious.

From that time on, I took everything with my mother seriously and carefully. At least, I tried to as best as a child could. I would always feel anxious every time my mom said she had doctor's visit or when the call came at school telling me my mom would be late to pick me up.

*Continues on page 3*



*Grace Halula poses for her senior photos at Fred Howard Park.*

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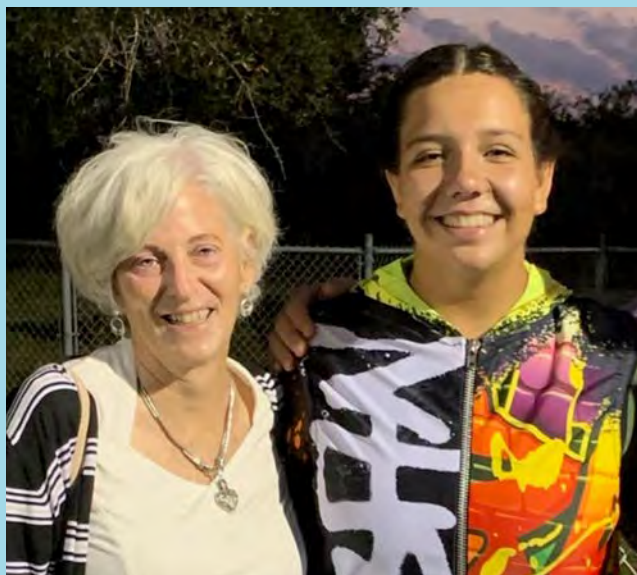
## CO-CHAIR COLUMN

### A MOTHER'S PERSPECTIVE: PARENTING WITH CANCER

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*Patti Halula, Patient Advisor and Co-Chair,  
Patient and Family Advisory Council*

Living with metastatic breast cancer brings its own set of challenges and emotions that show up every day in the most random ways. Being a parent raising children takes those challenges and emotions to another level. When I was first diagnosed, I was in shock. At the time, I was living my best life with my husband Michael and our 5-year-old daughter Grace.



*Patti and Grace Halula at Grace's senior night.*

For three weeks, I couldn't put Grace to bed because I found myself crying at the thought of not watching her grow up. I would miss all the celebratory milestones in life, like the first day of school, her first serious relationship, her graduation and more. The list just went on and on in my head.

During those three weeks, I decided I was going to teach her as many life lessons as I could. I focused on her and threw myself into volunteering at her school. In many ways, that little 5-year-old had no idea how she was lifting her mom up. The days

were long during my chemotherapy. At the end of the day, Grace went to bed by 7 p.m. and I followed behind her only an hour later, feeling physically and emotionally exhausted.

When you have cancer, you worry. You want to protect your loved ones from sadness. And for your child, you worry all the time. Are they scared? Are their grades low because they are hurting and too afraid to say? I was always open with Grace. I felt that doing so would help her not be so scared, especially as my looks changed. Maybe if she saw me every day at school, it would bring a sense of normalcy to this new life.

When she was in 5th grade, she asked for a cell phone and I said no. My intelligent girl went to her room and within an hour, she created a presentation of all the reasons she should have a phone. Her last reason sent me right over the emotional cliff that I was already delicately hanging from.

"Mom, do you know what it is like for me when you go Moffitt?" asked Grace. "When the teacher tells me you're running late to pick me up, I don't know why. Is it because you are stuck in traffic? Was the doctor late? Is it because your cancer is back?"

After all my efforts to maintain transparency with her, it turned out she was worried every time I had an appointment. After some tears and hugs, we got Grace a cell phone to ease her mind.

There is no rule book when it comes to raising children, especially when you have cancer. You get up and do the best that you can. As I have told Grace many times through her own struggles as a young adult, some days are diamonds and some days are stone. The gift is choice – a gift so great that not even cancer can take it away. If she learns that lesson, then I have given her the one tool that will get her through life.

## A Daughter's Perspective: Growing Closer Through Cancer

*Continued from page 1*

I often wore a locket with her photo in it and I would wear it each day she had an appointment.

As I grew older, my mom and I grew closer as I fully grasped the situation. There would be times where my mom wouldn't be there for major events and memories, like my first marching band performance or first band competition. It would be a little sad for me. I lived with the anxiety that something would happen to her and I was going to miss out on those moments with my mom. It made it better knowing that I would still get to see her and tell her everything once I made it home.

I grew even less dependent on her as I started driving and spending more of my time with friends. Growing apart felt a bit more guilt-filled as I would run out the door at the last second and forget that locket. I would always be able to come home and talk about her day and appointments though. I never really grew farther away from her due to my understanding and appreciation of the time we have together.

Though it's a dreadful thing to consider – having to tell a child or family member about cancer – I am thankful she told me. It has given me the opportunity to be a lot closer with my mother and really value all the time we spend together, whether it's typical mother-daughter arguments, the emotional moments or all the happy ones. Every moment with her is one I will never take for granted.

Living with my mother and her condition definitely affected my childhood experience, but I still had my childhood with my mom, and I wouldn't trade that for anything.

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*Moffitt offers many resources to assist with communicating about cancer in the family. For more information, please contact the **Social Work office** at **813-745-8407** and ask to speak with a social worker.*



### **FAMILIES FIRST**

Families First is a special program at Moffitt designed to help parents and their children adjust to the changes that occur within the family when a parent has cancer. Education, preparation and support enable families to cope successfully in the face of a serious illness.

To learn more visit **Moffitt.org/FamiliesFirst** or call **813-745-8407**.



# How Well Do I Understand My Health Information?

*Vicki Vann, Patient Education Specialist  
Prado Antolino, Manager of Language Services*

Health literacy is being able to find, understand and use information and services that will help you make health-related decisions about your care. Only 12% of adults in the United States have the health literacy skills needed to use and understand our health care system.\*

Health literacy skills include:

- **Being able to use printed and electronic health care information**
- **Knowing how to fill a prescription or read prescription instructions**
- **Being able to make appropriate health care decisions**
- **Being able to read and understand health care instructions**

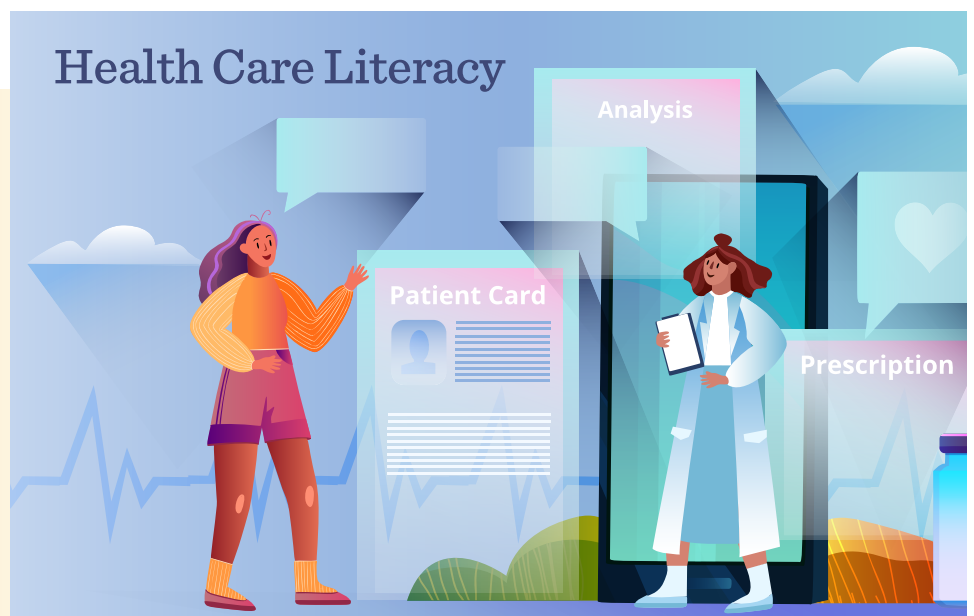
Not having these skills increases health care costs and is directly related to:

- **Longer hospital stays or emergency department visits**
- **Medication errors**
- **Missed appointments**
- **Inability to manage treatment side effects or make treatment decisions**

Health care professionals have a responsibility to keep information and instructions simple. They may ask you to repeat instructions to make sure you clearly

understand them. This is a process called teach-back and is a way of confirming you understand.

It is important that health care professionals consider language barriers when providing patient information. Low health literacy skills combined with a language barrier could possibly cause misunderstanding of information you receive. If English is not your first language, using an interpreter through our Department of Language Services (in-person or remote interpretation, as well as written translation) is an important service we offer to help you fully understand the information and instructions you



receive. You or your caregiver can request interpreting services or written materials in a language you prefer.

If you do not understand any information you have received, please let your health care team know. It is very important to clearly understand your diagnosis, treatment options, procedures, medications and any written/verbal instructions you have received. We are here to help!

*\*Reference: US Dept. of HHS: Healthy People 2020*

*Visit [CDC.Gov/HealthLiteracy](https://www.cdc.gov/HealthLiteracy) to find more information about health literacy. To find easy to understand educational materials visit Patient and Family Libraries on the Magnolia and McKinley campuses. Call 813-745-1690 for hours and locations.*

# MOFFITT RESOURCES

## to Help Patients and Caregivers

### UPCOMING EVENTS

*March – May*

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

Virtual/Zoom, RSVP only  
Weds. at 12:15 p.m.  
[PatientWellness@Moffitt.org](mailto:PatientWellness@Moffitt.org)

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#### **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](mailto:PatientWellness@Moffitt.org)

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#### **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.

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#### **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.

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

Virtual and in person, RSVP only  
Mon.-Fri., 2 p.m. or by appointment  
[PatientLibrary@Moffitt.org](mailto:PatientLibrary@Moffitt.org)

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#### **Virtual Meet the Experts** **813-745-1690**

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

#### ***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.

# Breast Cancer Survivors Are SOARing Back to Their Kitchens

*Diane Riccardi, MPH, Registered Dietitian, and Sonya Pflanze, MPAS, RD, CCMS, PA-C*

The Survivors Overcoming and Achieving Resiliency Program (SOAR) is offered to breast cancer survivors and funded by a generous donation from The Giving Girls Charity. The program is hoping to expand to other clinics in the future.

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*Moffitt's expert team leads survivors through activities such as art, meditation, mindful eating, medical management discussions, yoga and physical activity. But at its heart, SOAR is a program that provides patients with the kitchen skills they need to permanently change their eating habits to prevent cancer.*

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The link between diet and cancer is clear. However, more and more health care professionals are recognizing that it's difficult for their patients to meet their goals, like eating more fruits, vegetables and whole grains, when they're not eating home-cooked meals.

Despite the popularity of cooking shows and farmers markets, we spend less time cooking and more time eating meals prepared away from home. What's so bad about staying out of the kitchen? Although some restaurants provide high quality food, those meals tend to be higher in calories, fat and salt, and lower in fruits, vegetables, whole grains and protective nutrients, such as fiber and antioxidants.

That's why the Survivors Overcoming and Achieving Resiliency Program (SOAR) has been helping breast cancer survivors master the art of healthful cooking since 2018. The program strives to support the emotional and physical health of patients as they transition from active treatment into the recovery or survivorship phase of cancer. Moffitt's expert team leads survivors



through activities such as art, meditation, mindful eating, medical management discussions, yoga and physical activity. But at its heart, SOAR is a program that provides patients with the kitchen skills they need to permanently change their eating habits to prevent cancer.

The teaching kitchen component of SOAR starts simply with preparing recipes while using pantry staples like canned beans, whole grains, olive oil, garlic and herbs. Rather than just saying, "Eat more vegetables," we teach survivors how to make a variety of plant-based dishes such as a spinach, tomato and goat cheese stuffed portobello. At the completion of the program, participants can master multiple recipes and cooking techniques that are not only healthy, but delicious. This translates into feeling confident and competent in preparing home-cooked, plant-based meals for themselves and their families.

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*SOAR meets virtually via Zoom for nine consecutive weeks during spring and fall. Breast cancer survivors who have completed active treatment are welcome to join us by calling 813-745-6506.*

# Searching for Answers, Finding Experts

*Jacqueline Beaushaw, Patient Library Supervisor*

When I was first diagnosed with mesothelioma, I found myself at the computer a lot. I searched Google, WebMD and more. I was looking for answers. How long do I have? Is this pain normal? Are other people my age diagnosed with cancer? I had so many questions and the internet had even more answers. However, the problem with asking the internet any question is that you don't always get reliable answers.

I could easily find information about treatments, diets offering miracle cures and more. I received even more advice from well-meaning friends and relatives. The problem was that I couldn't decide what advice was true and what wasn't. This experience resonates with many people affected by cancer. It can be overwhelming looking for answers while also dealing with a new medical diagnosis and all that comes with it.

Twelve years since my diagnosis, I now know about resources that could have answered these



questions. One of Moffitt's greatest programs for seeking out information is the Meet the Experts series. Patients and their families can join these twice-weekly live sessions and learn directly from Moffitt's world-class professionals. Experts, like physicians, social workers and registered dietitians, host 30-minute sessions on a wide variety of topics.

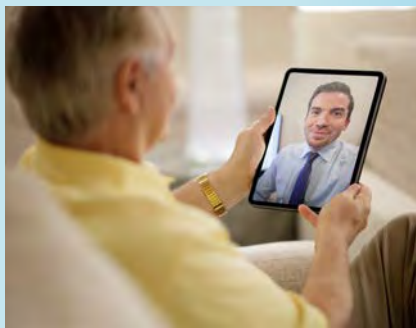
The best part about these Meet the Expert sessions is that they're interactive and you can ask questions in real time. Patients can listen to experienced oncology nurses share their best tips for managing chemotherapy side effects or talk with a social worker

about tools to cope with a cancer diagnosis. If you want to know if sugar feeds cancer, you can actually discuss this with a registered dietitian.

If I could travel through time and give advice to my newly diagnosed self, it would be that there are resources and answers out there that can help you. I'd tell my 18-year-old self to ask every question and attend a Meet the Experts session.

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*For more information and to view select past sessions, visit [Moffitt.org/MeetTheExperts](https://www.moffitt.org/MeetTheExperts) or call 813-745-1690.*



## 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.

# Comfort Companion Program

*Ken Susalla, Patient Advisor, Patient and Family Advisory Program*



*Volunteer Services Starburst Award recipient Ken Susalla brings a burst of energy and sunshine to his volunteer work at Moffitt.*

I have been a Moffitt volunteer for 10 years, serving as a peer visitor primarily in the Radiation Oncology Program to support patient and families.

Being a peer visitor is really rewarding. When I was contacted by a member of the Comfort Companion Program to see if I might be interested in assisting patients who are terminal, I jumped at the chance. It seemed that this opportunity would round out my volunteer experience.

Moffitt provided insightful guidance to help me prepare to be a Comfort

Companion, but when the time came to sit with a patient, I actually felt kind of inadequate. I thought that I might have overextended myself. Maybe I bit off more than I could chew. Before this, my only experience with a dying person was when my wife, Marlys, was at the end of her battle with cancer. Her daughter was with us during Marly's final weeks, and we had plenty of time to plan and make critical decisions.

Being with a stranger who was nearing the end of their life was much different than being with my wife and family. I sort of played it by ear; just be with him and for him. Quietly, I encouraged him to guide me through his wishes. I just wanted to be a comfort for him. It made me feel good and was rather peaceful. I felt some comfort in being able to fill this need until his close friends arrived to be with him.

My second experience was much the same, yet different in some ways. She was more agitated, but I did my best to meet her where she was while remembering that my job was to comfort her within her frame of mind at the time. These two experiences showed me that each person is different no matter their stage of life. Each person had different life experiences, diverse needs and unique coping skills.

I am glad that I accepted the invitation to be a Comfort Companion. I hope to continue as this is a vital service provided by Moffitt at a critical time in a person's life when family has not arrived yet, or in some cases, there is no family member or even a friend.

*“Moffitt’s Comfort Companion Program (CCP) offers trained volunteers who provide a compassionate presence to patients who are alone at the end of life. While this companionship isn’t needed for all patients, the goal of the program is to provide companionship when requested by the patient, family members or the care team. CCP volunteers work in 2 to 4-hour shifts and also offer support for family members who may need respite from the dying process, or need to leave their loved one to arrange for hospice care. For more information on becoming a CCP volunteer, please contact [VolunteerServices@Moffitt.org](mailto:VolunteerServices@Moffitt.org).”*

— LaWanda Byrd,  
Director of Volunteer  
and Retail Services

*Do you want to get involved and give back? Visit [Moffitt.org/Volunteer](http://Moffitt.org/Volunteer) or email [VolunteerServices@Moffitt.org](mailto:VolunteerServices@Moffitt.org) to learn about volunteer opportunities at Moffitt.*



# The Convenience of Virtual Care

*Cristina Naso, Director of Virtual Care*

The pandemic didn't just change the way we live and work. It also changed the way we receive health care. At Moffitt, providers across all specialties quickly adopted telemedicine in April 2020. Learning new technology can be a little uncomfortable for everyone, but patients and providers worked together to connect in new ways.

Fast forward to today. Moffitt providers continue to offer virtual care when suitable. Providers determine clinical appropriateness before scheduling a visit. This helps ensure the quality of care for patients won't be compromised. If the visit would include a physical exam, labs or imaging a patient may be required to come on site.

Moffitt recognizes that sometimes we all need a little help. A dedicated virtual care team is available to help you get started at Moffitt, set up care visits and even connect patients with interpreters. Patients have shared that they find telemedicine visits efficient and



convenient. The service has helped to reduce barriers and increase access for patients that find accessing care difficult.

Virtual care can save patients time and money. Dr. Krupal Patel, a surgeon within Moffitt's Head and Neck Oncology Program, has studied the impact of telemedicine. He used real patient data to determine savings. At Moffitt, he found that virtual care patients were able to save an average of 148 miles per visit. The time savings was significant too. Patients saved an average of 1.2 hours of time by connecting from home. Patients saved money as well. They saved \$147 to \$186 on gas, travel and lost wages per visit by connecting virtually.

Virtual care is equitable to in person care. It isn't a second-class experience and does not jeopardize a patient's ability to receive appropriate and adequate care. It is only a different way to connect. This means that services like live interpreters and nursing education are still offered to every patient.

## *Are You a Young Adult Living with Cancer?*

Check out opportunities to meet other cancer fighters, between the ages of 15-39.

**Networking Socials:** Connect with other young adults in the Tampa Bay area.

**Meet the Experts AYA Edition:** Learn more about topics relevant to young adults as well as resources available to you.

**To learn more: [Moffitt.org/AYA](https://www.moffitt.org/AYA)  
[AYA@Moffitt.org](mailto:AYA@Moffitt.org) | 813-745-4736**

*At Moffitt Cancer Center, we believe in patient- and family-centered care. A virtual care visit must be clinically appropriate and agreed upon by the patient and care team. Learn more at [Moffitt.org/VirtualVisit](https://www.moffitt.org/VirtualVisit) or ask your care team if you're eligible for a telemedicine visit.*

# Relapser Recovers in More Ways Than One

Mary Sansone, Patient Advisor,  
Patient and Family Advisory Program

I was living in a sober living home with two other recovering addicts. I was fresh out of rehab after an ugly relapse on alcohol that broke 20 consecutive years of sobriety. I was looking for a new job. I had been through a lot but was eager to experience sober life again. I then went into Moffitt for my six month checkup and came out with a cancer relapse diagnosis. I would need a bone marrow transplant (BMT).

In reference to the moment that my acute myeloid leukemia was confirmed through a bone marrow biopsy, Dr. Sallman, my hematologist, thoughtfully reflected, "That was such a bad day." I still shiver when I recall his authentic compassion. Dr. Perez, my BMT physician, delivered a wealth of information on what to expect



*A painting of Mary (left) and her sisters Julie and Amy – painted at Moffitt in 2020.*

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*You don't know  
how strong you  
are until you  
have no choice.*

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with the transplant. She was not shy of delivering the likely side effects, like the details on graft-versus-host disease and the morbidity rates. This would be rough.

My siblings were not a match for the transplant. The pandemic put a hamper on the search, but four months after induction, a donor was finally found. I later learned that she was a 23-year-old lady from Israel. On June 5, 2020, I received my transplant.

You don't know how strong you are until you have no choice. The treatment kicked me in the butt, but I had a strong support team with my family, Moffitt's people and their resources. Thank God!

What blew me away about my experience at Moffitt was that these busy experts acted like they had all the time in the world. Before each step of the treatment process, a physician or member of Moffitt's clinical staff clearly explained what was to be done, why and how it could affect me physically. They would often use whiteboards in my room to draw pictures and define terms so I could comprehend complicated treatments. They were never patronizing while educating me. I felt like I mattered.

I am now two years post-transplant and am doing remarkably well while also remaining sober. Yay!

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*If you're interested in using your lived experience as a patient or caregiver to make a difference the Patient and Family Advisory Program may be right for you. To learn more please email [PatientAdvisors@Moffitt.org](mailto:PatientAdvisors@Moffitt.org) or call 813-745-2963.*

## 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](mailto:PatientAdvisors@Moffitt.org) to learn more.

## The Best Laid Plans...

*Catherine Wood, Moffitt Caregiver*

**“One day, you will see how hard it was and how brave you were.”**

– *The Boy, the Mole, the Fox and the Horse*

If there was one thing I could go back and tell myself, it would be this quote. When my husband was diagnosed with stage 3 brain cancer my world was turned upside down. We had everything going for us, a loving relationship and a perfect two-year-old daughter. In March of 2019 when Kyle got the diagnosis, I was nine months pregnant with our second child. Cancer was not in our plan.

With no local family to help, I became the primary caregiver to two small children and my husband. My days were full with scheduling appointments and providing medical care while also changing diapers and potty training. I have always taken pride in my independence. As someone who never asked for help, I was quickly overwhelmed carrying the weight of three other lives on my shoulders.

I did my best on my own, but I was struggling. Kyle and I were extremely private about his diagnosis, which limited my available outlets for stress relief. With the suggestion of a dear friend, I sought professional help. This gave me a safe place to openly and honestly share my thoughts and fears. This became, and remains, my main form of self-care. It is how I continue to cope with not only Kyle's diagnosis and what that means for our family, but the normal things that life throws at me that I would not have been able to handle almost four years ago.

Throughout this journey, I learned a lot about myself. Although I am capable of a lot, I need to be open and ask others for help. In being open about my struggles, I have gained such a supportive community of local moms. I have developed a close friendship with another mom who is also the caretaker of a husband with brain cancer. When they say it takes a village, they really mean it.



*Catherine and Kyle Wood renewing their vows with their children Donnie and Colette.*

*Moffitt recognizes that caregivers are a vital part of a patient's care team. We offer many services, including support groups. Visit [Moffitt.org/Caregivers-Families](https://www.moffitt.org/Caregivers-Families) to find more resources for caregivers.*

## 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](mailto:PatientAdvisors@Moffitt.org)**

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



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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](mailto: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](https://MOFFITT.org/Orientation)

**813-745-1690 | [Orientation@Moffitt.org](mailto:Orientation@Moffitt.org)**