

PARTNERS

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

PATIENT'S PERSPECTIVE

From Remission to Research

Ryan Gebert, Acute Lymphoblastic Leukemia Survivor, Moffitt Research Associate

"I'm not superstitious, but I am a little stitious."- Michael Scott, "The Office"

The day of Friday the 13th is synonymous with bad luck and misfortune, and in my case, it is the date that changed everything. It was 2018 and I was 32 years old. I was working as a biologist in coral propagation and genetics research toward coral reef restoration practices. Always keeping busy between the laboratories and work, it was not a shock to me that I was tired and fatigued by the end of the day, but the fatigue never subsided. I unfortunately ignored it and kept working, not getting it checked out until Friday, July 13, 2018.

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Ryan Gebert in the lab where he does cancer research

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Patti Halula

CO-CHAIR COLUMN

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

My time as co-chair of the patient and family advisory board has come to an end. I first came to the council as a patient advisor five years ago, but back then, I did not have a true understanding of the Patient and Family Advisory Council (PFAC). All I knew was that it had to do with patients and helping them have the best possible experience at Moffitt. I only knew I wanted to be a part of that and to make a difference and give back.

When I was invited to be co-chair of the council, I was motivated to see what a difference I could make with these wonderful people who give their time so freely to make the patient experience the best that it can be. Over these past two years, PFAC has partnered with all levels of leadership at Moffitt and contributed to improving processes and policies. Along the way, I have met some of the most compassionate, kind and talented people who have inspired me every time I walk through the doors of Moffitt.

As I close out my tenure as co-chair, I am excited to introduce PFAC's newest co-chair, Rae Sawyer. Rae knows how challenging it can be to navigate the health care system and has a passion for sharing the family member perspective to help make enhancements that benefit all patients and families. Rae partnered with Moffitt to help design Moffitt McKinley Hospital and leads subcommittees on patient scheduling and parking. I am excited about Rae's leadership abilities, and I know she will help Moffitt continue to strengthen its strong patient- and family-centered culture.

Moffitt offers flexible options for joining the Patient and Family Advisory Council, including attending meetings virtually. To learn more, please email PatientAdvisors@Moffitt.org or call 813-745-2963.



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)**.

From Remission to Research

Continued from page 1

I was diagnosed with Philadelphia-positive acute lymphoblastic leukemia (Ph+ ALL), a rare subtype of the most common childhood cancer, acute lymphoblastic leukemia (ALL). Like ALL, Ph+ ALL is a cancer of a type of white blood cell called lymphocytes. What makes this subtype rare is a mutation that fuses two genes together, the BCR and ABL genes. This BCR-ABL gene, also known as the Philadelphia translocation, can cause the white blood cells to become cancerous.

The journey to recovery was peppered with obstacles of pain and uncertainty. However, I had a coping mechanism in light of all this. I was able to find humor in my struggles. More than just a respite from sadness and pain, laughter gave me the strength to get through the rounds of chemotherapy

and stem cell transplant. Cancer had set hurdles before me. My ability to laugh and make others laugh in the face of this challenge allowed me to overcome them.

Now – to state the obvious – there is nothing funny about cancer. However, in my situation, it has diminished my anger and fear, and kept me grounded, focused and alert. Cancer is different in every case; each person finds their own path to overcoming it. My experience has taught me how patient, resilient and stubborn I can be.

I am relieved and happy to report that after nearly five years of battling, I am in full remission. I currently apply my background and experiences working at Moffitt Cancer Center to give back to the research community to transform health and improve quality of life.



*Did You Know
Moffitt Has an
AYA Lounge?*

If you are a patient between the **ages of 15-39**, the Swim Across America Adolescent and Young Adult (AYA) Lounge was created for you! The AYA Lounge is located on the fourth floor of the main hospital, near Elevator C and is open 24/7.

If you want to use the Lounge, visit the Red Valet information desk or visit the inpatient nursing station on your floor to sign out an access card. When you're done, sign it back in to your floor when you go back to your room or drop the card off in the drop box next to the Lounge.

PEP Talks: A Patient Experience Podcast

Robin Gordon, Patient Advisor, Patient and Family Advisory Program, and Kathi Barden, Moffitt Patient Experience Liaison

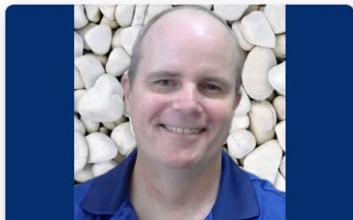
Moffitt Cancer Center has released a patient- and family-centered podcast called PEP Talks. Thoughtfully curated and crafted by the Department of Patient Experience, each episode showcases the personal story of a Moffitt patient, caregiver or team member. These stories are intimate, immediate and powerful. Only fifteen minutes long, each episode carries a healthy dose of enlightenment and inspiration.

One episode tells the story of a woman who went through treatment for cancer while simultaneously battling addiction. Another tells the journey of a family from Ukraine seeking treatment for their father's cancer and finding support at Moffitt. After being encouraged by a Moffitt nurse, one young man discovered his voice and was empowered to make his own decisions for treatment.

Detailing the small gestures that can make all the difference for people with cancer and their families, the podcast showcases how Moffitt builds a culture of connection and care for everyone. By creating an environment where patients and their families feel heard, respected and empowered, we ensure that their journey through cancer treatment is as comfortable and hopeful as possible.

Listen to a short episode to learn how simple acts of respect, kindness and exceeding expectations have the potential to make a world of difference in the lives of those living with cancer and those who care for them.

Visit [Moffitt.org/PEPTalks](https://www.moffitt.org/PEPTalks) to listen to the impactful moments that make all the difference during cancer. New episodes are released monthly.



[My Positive Experience at Moffitt Became My Stronghold](#)

A cancer diagnosis can be overwhelming. Hugh Hedley shares how team members helped him feel supported and empowered.



[You're Fighting But You're Not Alone](#)

After a lengthy journey to get her parents out of Ukraine, Julia's father was diagnosed with cancer. Julia speaks to her gratitude for Moffitt for...



[Grace, when I needed it from Moffitt](#)

Robin Gordon, shares how her Moffitt physician was able to respond to her with grace and respect during a difficult moment.



[My Dignity was Preserved at Moffitt](#)

Mary Sansone learned that sometimes, to the patient, facing cancer is not their only or biggest challenge.

PEP Talks

Stories of Cancer, Connection & Care

MOFFITT RESOURCES

to Help Patients and Caregivers

UPCOMING EVENTS

March - May

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.

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.

Adolescent and Young Adult Health Disparities

Amber Skinner, Adolescent and Young Adult Program Administrator

According to the Centers for Disease Control and Prevention, the definition of health disparities means preventable differences and outcomes within the same disease experienced by a disadvantaged population. Since multiple cancer screenings are above the age range (40 or over) for adolescents and young adults, and because cancer detection is typically overlooked for this age group, it is common for adolescents and young adults living with cancer to experience health disparities.

Research has shown that adolescents and young adults with cancer are more likely to have preventable differences in care. These include delays in diagnosis, increased financial stress and age-specific challenges, like maintaining employment and insurance throughout treatment. These patients are also at risk for having more aggressive stages of cancer. There are also disparities in race, gender, economic status and

education level within this age group that follow cancer disparity trends.

The Adolescent and Young Adult (AYA) Program at Moffitt Cancer Center was created in 2011 to address the unique needs of AYA cancer patients (aged 15-39) and assist them in connecting with other AYA cancer patients who can relate. The mission of the AYA Program is to improve the cancer care experience and long-term outcomes for young adults with cancer by ensuring that all adolescent and young adult patients and survivors have access to resources, services and events specific to their age.

To learn more about the AYA Program, please email AYA@Moffitt.org or go to Moffitt.org/AYA.



SEXUAL HEALTH, INTIMACY & CANCER

Fertility Preservation

Amber Skinner, Adolescent and Young Adult Program Administrator

As part of Moffitt's Adolescent and Young Adult Program's mission, it is important to improve the cancer care experience for people between the ages of 15-39 to ensure their best quality of life, and it's equally as important to improve the long-term effects that cancer can cause. The ability to have a biological child is one of those long-term effects that can be high-risk depending on the type of cancer treatment a patient receives.

It has been a top priority to educate all people of child-bearing age on the risk of infertility associated with cancer treatments. There are resources available

for patients who may want to save their reproductive samples for the future. With new technology, resources for freezing samples have expanded and opened a new opportunity to have a biological child even after treatment is complete. For people who need it, grants may be available to cover some of the costs associated with fertility preservation.

If you are an AYA patient and interested in fertility resources, reach out to your social worker at 813-745-8407. Visit Moffitt.org/Fertility to find out more information on your options for fertility preservation

How I Became an Adolescent and Young Adult Ambassador

Megan Wing, AYA Ambassador

My husband (boyfriend at the time) and I moved to Florida in 2007 for a new adventure. After landing a dream job in 2008, we married in 2011. I was diagnosed with Ewing Sarcoma in 2013 at 32 years old. I thought I could hide my diagnosis from my employer and coworkers. That was until we sat down with Dr. Damon Reed, and he explained the treatment plan that included 14 cycles of inpatient and outpatient visits using five different chemotherapy drugs.

Dr. Reed explained my immune system would be compromised and I would be unable to work until after treatment. I would be out for 7 to 12 months. I was afraid I would lose my job or not be well enough to return when all of this was done. I was afraid I wouldn't have the choice to have children. I was afraid of how much treatment was going to cost and what kind of debt we would have hanging over us if I made it through. For readers' immediate peace of mind, I made it! We are okay. I still have my dream job. I am strong and healthy. I have made peace with not having children and our debt is under control.

What I really want to talk about is my time with the Adolescent and Young Adult (AYA) Program at Moffitt. I did not get involved until after I finished treatment. I had spent so much time at Moffitt that it felt sad to not be there as often. Everyone showed me such compassion and care, including my doctors and nurses, the receptionists and volunteers. I wanted to be a part of that and to give back. I started volunteering and getting involved with AYA events. I realized every time I shared my story or experiences with someone, the weight of all I had been through lifted a little bit.

I joined the AYA ambassador committee to help others. The AYA ambassadors are a group of young adult cancer



Megan Wing poses with the Thunder Bug at Miles for Moffitt

patients and survivors who volunteer their time to provide feedback on AYA Program resources and plan peer-to-peer events. I have had the opportunity to speak at fundraisers, sit on panel discussions, help design a lounge for AYA patients, and give back to the place and people who took such good care of me.

To learn more about how to become an AYA Ambassador like Megan, email AYA@Moffitt.org.

AYA Resource Packet

In 2021, the AYA ambassadors reviewed and shared resources that have been helpful along their AYA cancer journey. These resources were compiled into a packet to share with other young adults with cancer to assist them along their journey. The packet is categorized with different AYA specific needs such as emotional support, events to connect with other young adults, and fertility preservation to help those reading find the appropriate resources they need easily and quickly.

To obtain a physical copy of the AYA Resource Packet, ask your social worker or visit the Patient Library at the Magnolia or McKinley campus. Contact AYA@Moffitt.org to request an electronic copy. Visit [Moffitt.org/AYA](https://www.moffitt.org/AYA) for additional resources and to sign up for the monthly AYA newsletter.

Families First: Helping Families to Cope

Jolene Rowe, LCSW, Manager of Inpatient Social Work

They may seem deeply engrossed in their computer games or glued to the TV, but kids are always listening. They may not hear that call to wake up for school, clean their room, or come to dinner, but kids are always listening.

As a parent, it is normal to want to protect your children from any distress or worry. You may find that it is harder than you realize to keep the news of your cancer diagnosis from them. Without accurate information, children will often draw their own conclusions about what they are hearing and seeing.



Early communication with your children about your diagnosis and treatment is key, especially because it allows you to be in control of what is communicated and how it is communicated. An open and proactive approach to communication will create a safe space for discussion about what is happening to you and your family.

Most importantly, when telling your children about your diagnosis, be honest. Don't hesitate to share your distress or sadness about the diagnosis, but at the same time, share your hopefulness about getting better. If the

question of death comes up, reassure them that you are seeking treatment for your cancer and doing everything possible to get well.

Additionally, recognize that children of different ages have different capacity to understand what is happening medically so adjust your communication accordingly. Younger children may only need information about changes they see. These include physical changes, such as hair loss, or changes in their routine, like having to ride home from school with a friend because of your treatment schedule. Older children may need more details. Regardless of age, remember to keep it simple and use language that they can understand.

Finally, check in regularly. Don't be afraid to ask kids what they know about cancer so that you can dispel any myths, such as the fear that your cancer may be contagious. Encourage them to ask questions and express their fears and worries. Set up a weekly time to connect as a family to see how they are doing. Engage others in your support system to be available to them as well, such as close family members, friends, or trusted teachers.

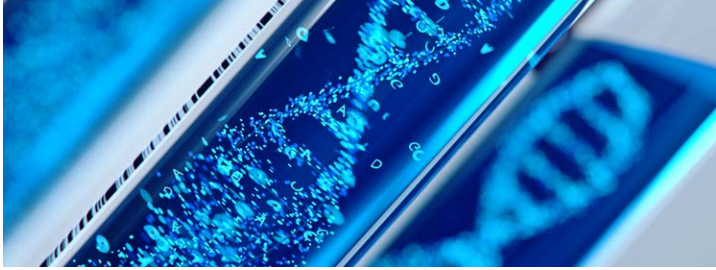
Taking steps to communicate in these ways will help kids to know that they are included and a part of your recovery. Information can be empowering for kids and help reduce their anxiety. It can be empowering for you as well.

Take charge of communication and remember - kids are always listening.

If you would like assistance in finding ways to best communicate the news with your children, contact the Social Work office at 813-745-8407 and ask to speak with a social worker. We have numerous resources to assist patients in communicating about cancer in the family.

Genetic Testing

Jennifer Pickard Brzosowicz, Genetic Counseling Supervisor



Genetic counseling and genetic testing are a part of cancer care. Information from genetic counseling and testing can be helpful for learning about cancer risk and informing treatment decisions. For example, someone might start having cancer screenings at a younger age based on their test results. Genetic testing can also help with surgery recommendations. It can help determine what medication may be best for someone (targeted therapy) or what information can help family members.

Moffitt Cancer Center has a team of nine genetic counselors. We meet with patients to review their chances of having a genetic risk for cancer. We talk about what genetic testing is and how it may help someone. If you have cancer, your Moffitt doctor may send you to meet with a genetic counselor. Genetic counselors can help a person decide if genetic testing is best for them while also discussing their cancer and family history. Genetic testing is usually done by blood or saliva sample and may be covered by insurance. If insurance does not pay for testing, the self-pay price for a test is \$249.

Genetic counselors also meet with people who don't have cancer, like family members. Anyone can ask for a visit with a genetic counselor. Genetic counselors offer both in-person and virtual appointments. While your provider may suggest genetic counseling, you can always ask your provider if seeing a genetic counselor could be helpful for you. You can also self-refer for an appointment.

*To schedule an appointment, please call
1-888-663-3488.*

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
or call **813-745-1690**.



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.



Practicing Sun Safety

Gina Corsanico, Cutaneous Nurse Practitioner; Ashley Culbreth, Cutaneous Physician Assistant; and Kathleen Cunningham, Cutaneous Physician Assistant

One in five people in the United States will develop skin cancer throughout their lifetime. The most common is basal cell carcinoma, followed by squamous cell carcinoma, melanoma and Merkel cell carcinoma.

Sun safety and prevention of skin cancer involves a sun-safe lifestyle, routine dermatologic follow-up, and self-skin checks. At least 90-95% of skin cancers are caused by ultraviolet (UV) radiation exposure to the skin. Sunlight and tanning beds are examples of UV exposure. Tanning beds emit 2-3 times more UV radiation than the sun.

Consult with your doctor if you have any moles with the following features described by the acronym ABCDE. A is for asymmetry when one half of the lesion does not match the other half. B is for irregular or uneven borders. C is for a variety of colors within one lesion. D is for a large diameter greater than ¼ inch. E is for evolution or change in the size, shape or color of a lesion over time.

Protecting your skin from sunburn is key to skin cancer prevention. Stay out of the sun as much as



possible during peak UV hours between 10 a.m. and 4 p.m. Cover up with physical barriers, including UPF clothing with long sleeves and long pants, and utilize wide-brimmed hats and sunglasses. Apply broad spectrum (UVA/UVB) waterproof sunscreen of at least SPF 30 strength and reapply every two hours. Do not use indoor tanning machines and be sure to check your skin regularly for changes.

The Mole Patrol skin cancer screening program offers free skin cancer screenings and cancer education to the public. Visit Moffitt.org/MolePatrol for more information and to find upcoming events.



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**.

Cancer in College

Rick Czaplewski, 27-Year Hodgkin's Disease Survivor



Rick Czaplewski, 27-Year Hodgkin's Disease Survivor

"Son, you have cancer," my mom told me as she arrived unannounced in my dorm room. "You have Hodgkin's disease."

I did not know then that this moment would kick off three years of treatment. I felt scared and ashamed, and I tried to hide that I had cancer.

Soon after taking a series of tests, I started radiation treatments at a hospital near campus. I would get up in the morning and have a small breakfast before walking to my classes. After lunch, I would walk over to the hospital for radiation. I would then come back to the dorms to study and eventually eat a small dinner. No one knew I had cancer.

Radiation burned my skin and caused some hair to fall out. Feeling ashamed like I did not fit in, I tried to hide it, but I couldn't. After 48 treatments, my cancer went into remission.

Only 18 months later, cancer returned. This time, I dropped out of college and went home for chemotherapy. After eight months of treatment, it went into remission again.

When I returned to college bald, everyone knew me as the "cancer guy." I felt out of place and people would stare at me. When my hair grew back and I could blend in more, the stares eventually stopped.

I graduated two years after finishing chemotherapy. Now, I am a 27-year survivor. I have a son and a career as an author and speaker. I even climbed Mt. Rainier! If you are a young adult, I understand the feelings of fear and shame. I know what it is like to not fit in anymore.

To work through those feelings, I turned to sports to "reclaim" what cancer took from me and started running and swimming. As I healed physically and rebuilt my body, those feelings changed to gratitude for a second chance.

It helped to talk to other survivors for support and you can do the same by searching for "cancer one-on-one support." As a new survivor, I recommend that you lean on your loved ones and into activities you enjoy. Pursue them with a new joy and you will find yourself healing from those difficult feelings.

You are not alone! Keep fighting. Work on getting to tomorrow and to your next treatment. Life has a way of turning around and you will get there. Have hope and faith. Good luck. You got this.

Imerman Angels is a free community resource that can connect you with someone who understands. For more information or to connect with a mentor, please visit ImermanAngels.org or call 866-IMERMAN (463-7626).





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.

