



CHANGING  
**A SOLITARY  
BATTLE**

MOFFITT'S ADOLESCENT AND  
YOUNG ADULT PROGRAM  
CONNECTS YOUNG PATIENTS

*By Ann Miller Baker*

「  
CORRINA COUTANT  
SURVIVOR  
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*Photography: Ray Reyes*

## IT WAS ENOUGH TO DRIVE A SELF-DESCRIBED POSITIVE PERSON INTO HER SHELL.

In 2011, when Corrina Coutant was diagnosed with Hodgkin lymphoma at the age of 33, she was understandably shaken but intent on making a wise treatment choice. Moffitt Cancer Center was high on her list, and not just because her then-boyfriend (now husband) worked in Moffitt's Molecular Oncology and Drug Discovery Program. After meeting with hematologist/medical oncologist Celeste Bello, M.D., she knew Moffitt was the right place for her – “much more pleasant, and more current with research on the best Hodgkin treatments,” she recalls.

But the reality was still daunting. Every Friday, she faced eight hours of chemo, scheduled around her full-time job as a teacher. “In infusion clinic, just seeing what others were going through would make me cry,” she remembers. “So I tried to stay to myself. I had my iPad and my music.”

*“I was just passing through, not planning to be there long enough to make friends.”*

As medical director of Moffitt's Sarcoma Program and a board certified pediatric oncologist, Damon Reed, M.D., has seen many young patients face their treatment in exactly the same way. They retreat into their smart devices, Dr. Reed says, “and leave the hospital thinking not another patient under the age of 40 was seen at Moffitt that day.”

In fact, 20 patients age 15-39 years old are hospitalized at Moffitt on any given day. Another 100 are seen in Moffitt's outpatient locations. They are dealing with their cancer diagnosis while still developing as a young adult – seeking independence, fostering relationships with peers, planning for careers. Some are raising young children. Others wonder if they'll ever be parents after all the treatments they need to survive cancer. And for many, their only prior health care experience has been going to the dentist and getting vaccinations – a far cry from the life experience of most Moffitt patients, 92 percent of whom are over 40.

Addressing the age-specific needs of teens and young adults with cancer led Dr. Reed to spearhead Moffitt's Adolescent and Young Adult (AYA) Program, serving patients age 15-39 years old with any type of cancer diagnosis. “Moffitt leadership understood that young adults are different

than the typical cancer patient here,” says Dr. Reed, “and that we should try a different approach to meet those needs.”

## RESEARCH BRINGS OUT AYA CHAMPIONS

AYA oncology is a relatively new field in the United States, with seminal works published in the early 2000's by Archie Bleyer, M.D., of the Knight Cancer Institute in Oregon. They brought attention to the fact that survival rates for cancer patients aged 15-39 had been stagnant for more than two decades, while cancer survival had improved markedly in both children and older adults during that same time interval. Figuring out why this was happening – and how to change it – led to several key initiatives in the mid-2000's, including the development of clinical practice guidelines for AYA programs by the National Comprehensive Cancer Network of which Moffitt is a member.

In 2011, Dr. Reed set out to establish Moffitt's AYA efforts within his Sarcoma Program. “We intended purposely, once we built this initiative within the Sarcoma Program, to take any opportunity we could to be lateral and branch across the institution,” he explains. One key would be the ability to identify AYA champions within each Moffitt diagnosis-related program. Dr. Reed knew he could draw out his colleagues if AYA could fund their research related to why young adults with a given cancer don't do as well as older adults with the same diagnosis.

Donations have enabled studies that are already yielding results. Dr. Reed points to an article published in the Sept. 15, 2016 issue of the journal *Cancer* that characterizes unique genetic alterations in AYA patients with colorectal cancer. It took massive amounts of existing data, “and just looked at it from a different



*The AYA Lounge gives a sense of belonging.*



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DAMON REED, M.D.  
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*Photography: Ray Reyes*

perspective - age,” says Dr. Reed. “With under \$20,000 of philanthropic funding, we came up with a really rather amazing finding that got the attention of the major cancer centers in the country and the National Institutes of Health.”

Another study pending publication from Moffitt’s cutaneous cancer program looks at the possible relationship between clinical trial enrollment rates and melanoma survival in the AYA population. Studies show the vast majority - 98 percent - of young adults diagnosed with cancer don’t go on clinical trials. Says Dr. Reed, “With those numbers, you won’t have many treatment advances.”

“So we looked at our melanoma AYA patients’ clinical trial

enrollment rates and overall treatment response, from 2007 to 2014. The overwhelming majority of stage 4 melanoma AYA patients who did not go on a clinical trial did not survive. But for those who enrolled in clinical trials, the chance of survival went up to 30 or 40 percent. And our rate of AYA melanoma patients going on trials was nearly 20 percent - ten times higher than what’s shown in the literature for this population.” Dr. Reed says the credit for the high trial enrollment rates and improved survival figures goes to Moffitt’s Cutaneous Oncology Program staff. “It was the fact that the Cutaneous Program understands AYA. You have a dedicated group of physicians and staff who believe in young adults, and take the extra time to teach them about clinical trials and obtain their consent.”

*“When I was in middle of my cancer treatment, I didn’t want to talk about details. The AYA staff will introduce you to others you’re most likely to connect with - people with similar attitudes, similar cancers.”*

#### AN UMBRELLA OPENS IN A RAINSTORM

But research opportunities aren’t the only draw, notes Dr. Reed. “When the AYA program opened, it was like an umbrella in a rainstorm. We created this space, and team members from throughout Moffitt were drawn to it because they want to contribute to the cause. I’m passionate about the research, but the clinical aspect of dealing with this patient population is heart-wrenching and also very important to address.”

To that end, Moffitt’s AYA Program includes an AYA Patient Navigator, Cathy Elstner, R.N. Elstner is a seasoned nurse with the experience to help eliminate barriers across the entire continuum of cancer care and ensure that these young patients get needed information and services, including fertility preservation resources. Additionally, the program is recruiting a dedicated coordinator.

But the most visible resource thus far, Dr. Reed says, has been the Swim Across America AYA Lounge on the hospital’s fourth floor. Opened in April 2015, it’s named in honor of its funding source, a national organization that holds swim events to raise money for cancer research and prevention. Within the past six years, Swim Across America events have raised \$1 million for Moffitt Cancer Center. Those funds have benefitted Moffitt’s Melanoma, Sarcoma and AYA programs, including the AYA Lounge.

Dr. Reed says the AYA Lounge is more than just the physical location of the program. “It’s the spot for weekly “meet-ups” – informal sessions that we don’t call support groups. It’s also somewhere for hospitalized AYA patients to play video games, watch movies or just hang out with friends. Most importantly, it gives them a sense of belonging.”

And the AYA efforts continue long after they walk out Moffitt’s doors.



#### INVITATION ACCEPTED AND FRIENDS DISCOVERED

**Now 38-years old, Coutant views her cancer experience through the rear view mirror of her life. She completed treatment at Moffitt in 2012 and remains cancer-free. She and her husband have been doubly blessed with two precious, healthy children. But Moffitt still keeps in touch, regularly sending invitations to events for the AYA program that got its start just months before her Hodgkin diagnosis.**

Last year, one such event caught her attention. It was at Ulele, a restaurant she’d wanted to try. “So I figured, why not?” Coutant discovered it wasn’t “just people talking medical ‘doom and gloom.’ We had time to mingle. And I found out, these people are really cool. I wish I’d done this sooner.”

Thanks to Swim Across America program funding, Moffitt’s AYA group is able to offer several events every year at locations throughout the bay area. There have been outings to Tampa Bay Rays games, an annual wellness fair, spa days, holiday parties, even a trip to 3 Daughters in St. Petersburg – a family friendly craft brewery where Coutant’s kids enjoyed games with other survivors’ children as a local band played.

“The people who brainstorm places to go are super positive,” says Coutant. And that’s another important point to this self-described positive person. “When I was in middle of my cancer treatment, I didn’t want to talk about details. The AYA staff will introduce you to others you’re most likely to connect with - people with similar attitudes, similar cancers. If you don’t want to talk about your cancer, you’ll find others like you. The same goes for people who want to share all the details and discuss options.”

Perhaps best of all, young people still going through treatment see peers like Coutant who have survived – and thrived.

Dr. Reed says his favorite part of any AYA outing is the ending. “It’s pretty rare not to wind up with at least two people who never met before that just won’t leave,” he says with a smile. “And then, it’s like they’re best friends forever. That’s a pretty good feeling at the end of the day.”

For more information about Moffitt’s AYA Program, visit [www.Moffitt.org/AYA](http://www.Moffitt.org/AYA). 



*Corrina Coutant and her husband Ronil Patel  
enjoy time with their daughters.*

*Photography: Ray Reyes*