



AMANDA RAMOS
SURVIVOR

Photography: Ray Reyes

“CANCER REMINDS YOU TO TELL EVERYONE YOU LOVE THEM.”

By Janan Talafer

THE TERM “SUPER MOM” MUST HAVE BEEN INVENTED FOR 36-YEAR-OLD AMANDA RAMOS.

When this bubbly, energetic mom is not busy driving her teenage daughters, nieces and nephews to sports events, band practice or school, she works full-time as a paralegal at a Sarasota law firm.

At home, on her farm in rural East Sarasota County, she cares for an assortment of horses, cows, chickens and dogs. She also loves to cook, and whenever she can, she finds time to paddle board, ride horses, fish and play football or softball with her large extended family.

It’s a dizzying pace that many would find hard to juggle. But Ramos does it with a smile and a kind word for everyone.

Now she has added knitting to her list of activities, thanks to new friends she met at Hope Lodge, where she stayed while undergoing treatment at Moffitt Cancer Center.

A RARE SARCOMA

Last year, Ramos was diagnosed with epithelioid hemangioendothelioma, a very rare malignant tumor of her hip. It’s so rare that only about 20 cases are diagnosed in the U.S. every year. Children and young adults are those primarily affected.

Classified as a vascular sarcoma, epithelioid hemangioendothelioma can appear anywhere in the body, but it commonly grows in the soft tissues and bones. In her case, the tumor appeared at the top of her thighbone — the femur. It also affected the ball of the femur where it attaches to the hipbone.

Today, both her doctors — Odion Binitie, M.D., an orthopedic surgeon specializing in bone and soft tissue sarcomas, and Jacob Scott, M.D., a radiation oncologist and section chief of sarcoma — consider Ramos well on the way to recovery. But getting there certainly had its ups and downs.

Ramos is grateful for the tremendous support she received from everyone — her family and friends, her co-workers, her Moffitt health care team, and also the people she met at Hope Lodge.

A diagnosis of cancer or any traumatic experience reminds you what life is all about, Ramos says. “It makes you realize how much you mean to people and how much they mean to you. And it reminds you to tell everyone you love them.”

Last September, on her birthday, she received what she calls “the best birthday present ever.” A biopsy of her lymph nodes showed no sign that the cancer had spread.

BROKEN BONES LEAD TO A CANCER DIAGNOSIS

A series of accidents involving her leg and hip were complicated by a diagnosis of a rare cancer.

“It all started about three or four years ago,” Ramos says. “We were at the softball field. Being the rambunctious person I am, I ran over and jumped on a good friend I had not seen in a while. That’s when I dislocated my hip.”

A friend who was a physical therapist helped ease the hip back into place, and a doctor later prescribed physical therapy. But the hip never fully healed and was always uncomfortable, Ramos says.

Two years ago on a dare, Ramos, who is only five feet tall, jumped over a fence. “Don’t ever tell me I can’t do something because then I have to try it,” Ramos jokes. “I cleared the fence, but when I landed I heard a snap. I knew right away that I had broken my leg.”

The break was severe enough to require surgery to place a metal rod in her tibia, followed by weeks of bed rest. But even after a year, she was still in a lot of pain, especially at the top of her leg near her hip. “I kept thinking, I don’t have time for this,” Ramos says.

Then one night, she woke up hot and kicked the covers off the bed. Just that small action was enough to break her femur, quite a shock considering that the thighbone is the strongest bone in the body. “The pain was so severe I couldn’t breathe,” Ramos says. Her youngest daughter called 911.

When X-rays showed a suspicious mass, local hospital officials called a medical helicopter service to transport her to Tampa General Hospital. Doctors there confirmed she had a tumor and arranged for her to be transferred to Moffitt.

“God sent me to Tampa General so I could go to Moffitt,” Ramos says. “It was there I met Dr. Binitie and Dr. Scott, the most compassionate doctors I have ever met. They were my angels.”

At Moffitt, Dr. Binitie temporarily stabilized the fracture with an external fixator. A more permanent fix would have to wait until biopsy results determined whether the tumor was malignant.

“The fixator looked like a little metal cage on my leg with pins sticking out about a foot,” Ramos says. “It was crazy.”

During the wait, Ramos moved back home to Sarasota, but not to the farm, where she couldn’t take care of herself. Instead she moved in with her brother and sister-in-law and their children.

“I am a very independent person, and I could not do anything for myself,” Ramos says. “On top of everything, my sister-in-law was seven months’ pregnant. My family gave me such amazing support. Everyone, including my mother and my other brothers, pitched in to help.”

When biopsy results came back that the tumor was cancerous, Ramos was in shock. “These are words you never want to hear,” she says. “I was in disbelief.”

Dr. Binitie recommended surgery to remove the malignancy in the top of her femur, including the ball that attaches to the hip joint. She wasn’t even 40 yet and would need a hip replacement to accommodate an artificial joint.

“Another doctor might have said we are going to amputate, but Dr. Binitie specializes in rebuilding, protecting and preserving limbs. He said, ‘I can fix this for you,’” Ramos says.

After the surgery, she underwent an additional six weeks of radiation therapy overseen by Dr. Scott. Rather than drive back and forth to Sarasota, she stayed at the American Cancer Society-sponsored Hope Lodge located next to the Moffitt campus. During this time, she also received physical therapy to help her regain mobility after the hip replacement.

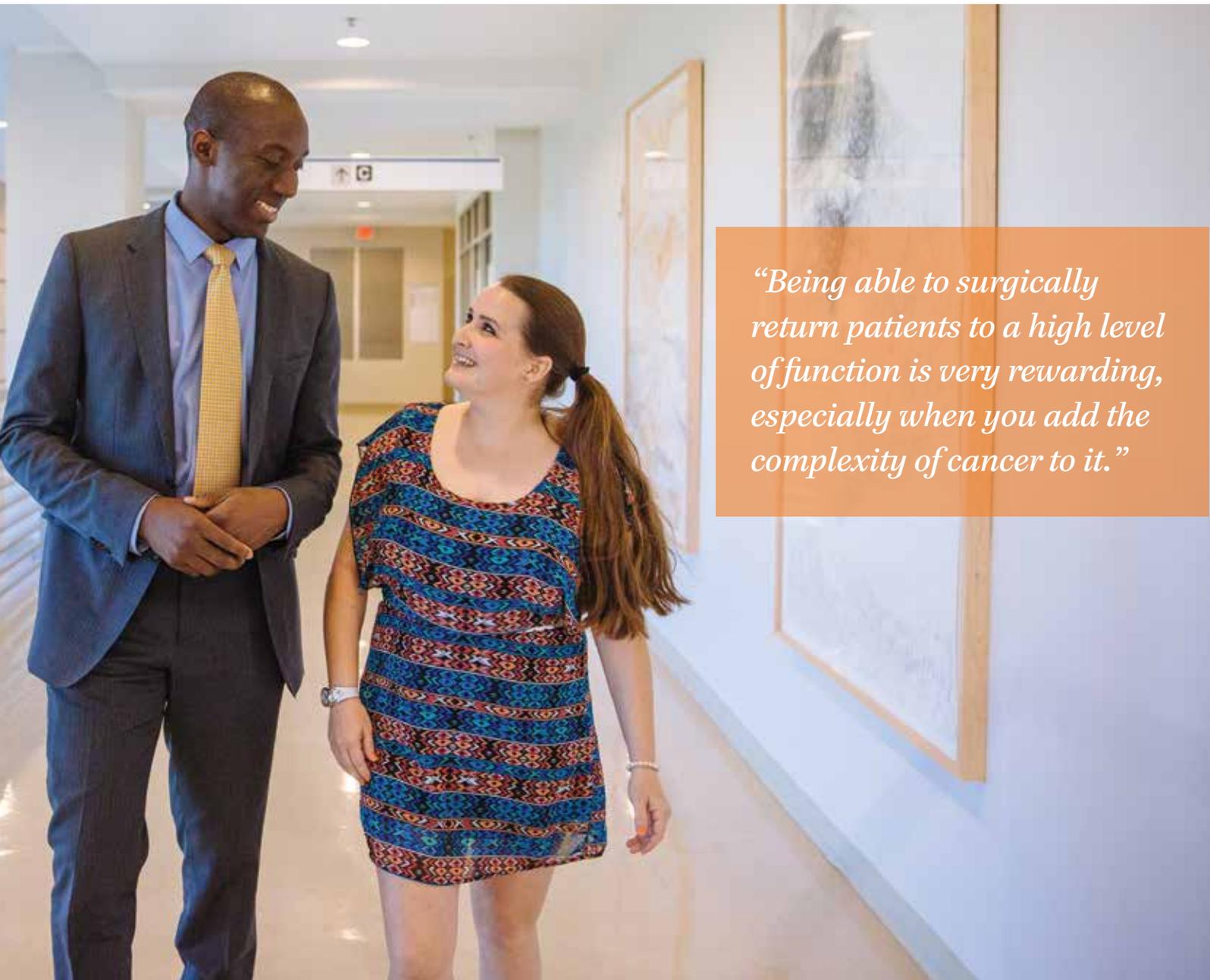


A COMPLICATED DIAGNOSIS

“Amanda’s cancer was a very complex diagnosis,” Dr. Binitie says. “If a surgeon had treated it as a straightforward fracture, there might have been unforeseen consequences. For example, if he or she had used a rod to treat the fracture and placed it into the tumor without realizing it, that could potentially have allowed the tumor to spread or even placed the entire femur at risk.”

That’s the advantage of coming to a National Cancer Institute-designated comprehensive cancer center, Dr. Binitie says. “At Moffitt, we have an entire multidisciplinary team of medical oncologists, radiation oncologists and surgeons all devoted to sarcoma, which is a rare diagnosis and requires a certain level of expertise and experience.”

Dr. Binitie was born in the United Kingdom, grew up in Nigeria and came to the U.S. when he was 16. After completing college at Florida State University, he came to Tampa to attend medical school at the University of South Florida and stayed to complete a residency in orthopedic surgery. He graduated in USF’s first group of orthopedic surgery residents.



“Being able to surgically return patients to a high level of function is very rewarding, especially when you add the complexity of cancer to it.”

His next step was additional training at Children’s Hospital in Philadelphia, where he completed a pediatric orthopedic fellowship, followed by a second fellowship at Moffitt Cancer Center in musculoskeletal oncology. Dr. Binitie currently treats adolescents and young adults in Moffitt’s Sarcoma Program and pediatric patients at Johns Hopkins All Children’s Hospital.

“I asked Dr. Binitie if he would pray with me before the surgery,” Ramos says. “I prayed that God would guide his hands. He is my hero. He can just walk into a room and you feel better.”

“Being able to surgically return patients to a high level of function is very rewarding, especially when you add the complexity of cancer to it,” Dr. Binitie says. “The technology is continually advancing and allowing us to save extremities.”

With her leg saved, Ramos is anxious to get back to exercising. In fact, she had considered going skiing with her daughters during Christmas break last year. “My doctors immediately vetoed that idea,” she says. “Maybe this year.” 🍷



ODION BINITIE, M.D.