“For somebody that’s always on the go,” Leonel says, “not being able to walk, to need help getting out of bed – I felt like the least important person in the world.”

JUST ONE MORE OPPONENT

A former kickboxer lays a counterpunch on cancer

WHEN MOMENTUM CAUGHT UP WITH LEON LEONEL, HE WAS GETTING HIS 2000 HONDA CIVIC READY FOR THE IMPORT ALLIANCE CAR SHOW IN ATLANTA. SO FAR, LEONEL’S SWAPPED OUT THE ENGINE AND MODIFIED THE TRANSMISSION FROM AUTOMATIC TO STANDARD. “IT’S ALL RIGHT,” LEONEL SAYS, “BUT I STILL HAVE A TON TO DO.”

Doing a lot on swapped-out parts is nothing new to Leonel. In 2012, when he was 21, Leonel had half his tibia, his knee and 10 inches of his femur replaced with metal prostheses. The culprit: osteosarcoma. A type of cancer that starts in the bones, osteosarcoma is the most common bone cancer in children. It also is common in people over age 60.

A runner, kickboxer and inline skater, Leonel thought at first that the swelling in his knee was just another torn ligament. By the time he started visiting doctors, the pain was excruciating, but no one would see him “without crazy amounts of money.” Then his dad, Rolando, took him to Moffitt – determined not to leave until someone saw his son. There, David Cheong, M.D., an orthopedic oncology surgeon, took one look at Leonel and said, “Be in my office at 6:30 tomorrow morning. We’re doing a biopsy and placing a port.”

What followed was 18 months of surgery, chemotherapy and rehabilitation. There were the typical indignities – pointing children, people mistaking his missing eyebrows for a practical joke, the protective mask, the feeding tube – but worst of all was the feeling of uselessness. “For somebody that’s always on the go,” Leonel says, “not being able to walk, to need help getting out of bed – I felt like the least important person in the world.”

To overcome this, Leonel learned to “eat that pain.” The average time patients take to walk again after a surgery like Leonel’s is six to eight months. Leonel ran in Richard’s Run – a cancer charity 5K in Ybor City – less than seven months after he got a new knee. “I didn’t care how much pain there was. The whole world deserves to be able to walk. So I put my mind to it and I ran.”

One of his nurses, Marris Smith, ran with him. She and the other nurses on Five North “were like family,” Leonel says. They talked to him at night when he couldn’t sleep. They laughed with him. They were positive. Six months after his treatment ended, Leonel stays in close contact with them. “They remind you of that tough time,” he says, “but they also remind you of how lucky you are to have met them.”

This level of personal investment is typical of the Adolescent and Young Adult (AYA) Program at Moffitt. Damon Reed, M.D., medical director of Moffitt’s Sarcoma Department, created the AYA Program in 2011 to address the age-specific challenges of having cancer while developing as a young adult. At first, Dr. Reed thought “we would get patients on clinical trials and get them talking about science and meeting the investigators.” Noticing a lack of enthusiasm for this among his patients, however, Dr. Reed and his team of medical and psychological experts in AYA care shifted gears to address the less tangible needs specific to AYA patients. Developmentally, they are seeking independence, training for their future careers and fostering relationships with their peers. Social interactions, which can be stressed by a cancer diagnosis, are critical to their well-being. One attempt at helping this vulnerable population navigate an unfamiliar medical (and emotional) maze that can seem overwhelming and unfriendly was creating Meet-Ups – “support groups that we don’t call support groups” – to bring AYA patients together and combat the loneliness pervasive among them.
“We need more Leons.”
It worked. The meetings, Leonel says, are “a place to go express yourself, if you have pain in you, if you want to talk to someone who’s been through what you’re going through.” Their common experience makes the advice and motivation the patients share ring true, and, in Dr. Reed’s view, it’s this identification that’s made the AYA Program such a success. Leonel and his nucleus of friends created an atmosphere that was inclusive and energetic. “Cancer is trying to destroy these young people,” Dr. Reed explains. “A natural human response to that type of threat is to withdraw, to make a shell around you. But Leonel didn’t do that. If you were getting chemo and Leonel was around, he was going to walk up to you and talk to you, maybe about having cancer and how much it sucks, or maybe about what you’re going to do after cancer. Whatever it was, you were going to talk together. It was probably therapeutic for him to talk to as many people as possible, but it was also therapeutic for them to share.”

To that end, Moffitt is planning to build a lounge for AYA patients to foster the sense of community that Leonel helped create. But most of all, Dr. Reed says, “We need more Leons.”

Leonel does plan to continue being a part of the AYA Program and Meet-Ups. “A lot of them are survivors that are having my same problems,” he says of the group attendees. “A regular person is going to feel pity for you. But not them [in AYA]. They’re going to feel your pain because they’ve been through it. They’re the only people I can talk to about my experience.”

Aside from his quarterly checkups, prior to which he can get fairly nervous, Leonel’s biggest challenge is figuring out – and overcoming – his physical limitations. “I started kickboxing again for a few months after treatment, but realized it just wasn’t for me anymore. I had to think about the use of my leg.” That doesn’t mean he babies the metal knee, though. “The doctors told me the only time I’m allowed to run is when there’s a fire. But I didn’t go through 18 months of hell to just sit around.” In fact, Leonel is constantly on the move. He still runs and enjoys inline skating – and sends his doctors pictures and video of him doing so. “Just to rub it in,” he says with a laugh. Metal prostheses can handle a finite amount of wear and tear, and Leonel’s active lifestyle will likely require they be replaced earlier than normal. “But,” Leonel says, “I’d rather have the surgery in 10 years instead of 20 and know that I enjoyed life.”

To Leonel, doing so remains straightforward. “The key is to surround yourself with really positive people, with a positive vibe. Giving up without a fight isn’t the right thing to do, because there is light at the end of that tunnel.”
Leon Leonel
Survivor