

Little

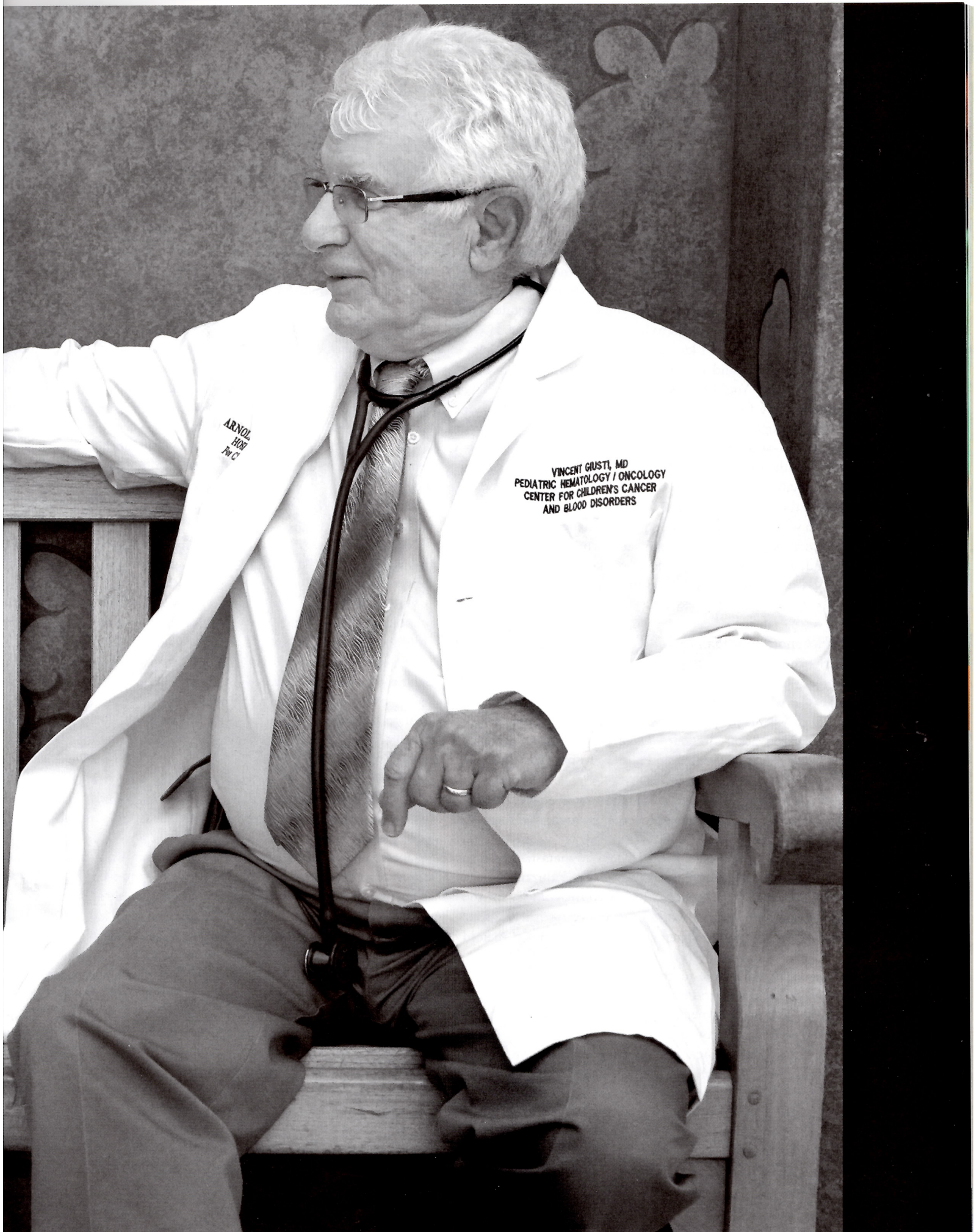
Big Man

CANCER MAY HAVE
SHAPED ME. BUT IT
DIDN'T DEFINE ME.

by Jarred Paluzzi
photographs by Rafael Tongol

Jarred and Dr. Vincent Giusti, the doctor who
saw him through his battles with cancer,
first as a child, then as a young adult.





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I have a part-time job as a waiter. Sometimes, when I approach a table, I notice the customers looking me up and down, their eyebrows raised. Sometimes one of them will grin when I get to the table and wonder out loud if I'm old enough to bring them their wine.

I'm used to it. I know what I must look like to them. At 5-foot-3 and 120 pounds, I could pass for a middle schooler. You'd have to study my boyish face pretty carefully for any clue about how old I really am — or what I've been through.

In truth, I'm a 23-year-old senior at the University of Central Florida. In a few months I'll graduate with a journalism degree. And the reason I'm so small is cancer.

I have beaten the disease twice. The first time around, I was a child, and my growth was stunted by the therapy I had to go through — the chemo, the radiation, maybe both. Years later, when I was in my late teens, a second, entirely unrelated cancer attacked me.

Here's all I usually say when people make comments or ask me questions about my size: "I guess I just got the short end of the stick."

There's a lot more to it than that. I am who I am because of the pain I experienced — not just physically, but mentally. And not just as a boy, but as a young man.

My first battle with the disease began in July of 1993, when, at the age of 2½, I was diagnosed with stage 3 hepatoblastoma, a rare form of liver cancer. Soon afterward I had 70 percent of my liver removed in an operation at the Arnold Palmer Hospital for Children & Women.

The good news after the operation was that my liver was cancer-free and on the mend. In a patient who's young enough, that remarkably resilient organ simply grows back.

The bad news came a year later. The cancer had metastasized into my lungs. It was aggressive. But then, so was Debra Paluzzi.

My mother, who raised me by herself, scoured the country for the best possible treatment for me, working in concert with Dr. Vincent Giusti, a longtime pediatric hematologist-oncologist at Arnold Palmer.

In 1995 she arranged for me to go to Memorial Sloan-Kettering Cancer Center in New York to be among the first young patients to undergo what was then an experimental procedure for my kind of cancer: Autologous Bone Marrow Transplant.

It helped, at first. But the cancer came back again. A doctor told my mother I had six months to live and any further treatment would be "inhumane." She responded with a few choice, unprintable words. Then she persuaded the doctors at St. Jude's Children's Research Hospital in Memphis to take my case. They agreed to perform a radical operation to remove three tumors and a lobe from one of my lungs.

I was 7 years old. I'd been bald for most of my life. Hair, to me, was something that came and went, like the seasons: It started growing back from one round of chemo just in time to fall out for the next one.

My birthday parties had often taken place not at home but at far-away therapeutic way stations like the Ronald McDonald House in New York City. And the guests weren't next-door neighbors and playmates, but doctors and nurses and kids my age from all over the world who might not be around long enough to celebrate another birthday of their own.

The night before the operation, I asked my mother something I'd been wondering about but had never said out loud: "Am I going to die?"

It took her a beat or two to compose herself and find words to reassure me.

No, she promised. I wouldn't die. And she was right. The operation was a success. After three hospitals and 4½ grueling years, I was cancer-free.

When I recovered, I was finally well enough to go to a mainstream school, Heathrow Elementary. But when you haven't had a normal childhood, it's hard to know how to be a normal child.

I tried, though. I tried very hard to fit in. I always kept my shirt on at the pool or the beach to hide the telltale trails of surgical scars on my chest and my back. I hated the ugly blue earphones I had to wear to amplify sounds because the chemotherapy had permanently damaged my hearing, and I begged my mother to let me go to school without them.

She would always do anything she could to help me lead a normal life — and never let me use my illness as an excuse. So she agreed — provided that I sat in the front of the class, paid attention and got good grades. I did.

Doctors had said that because of scar tissue from the operations and the fact that parts of my lungs had been removed, I would never be active in athletics. My mother ignored them and signed me up for soccer. Thanks, Mom.

The great thing about soccer is that you can be small and still compete. And I did. Over the next few years, the game became more and more important in my life. I developed confidence, made friends.

In high school, I even lost some of my embarrassment over my surgical scars, in part because of a funny story about them that started making the rounds and nearly made it into the Lake Mary High year-book.

I'd been attacked by a shark, so the story went, and one of my classmates had saved me. Somehow, the hero of the tale always ended up being whoever was telling the story at the time.

Jarred's mother, Debra Paluzzi, ignored the advice of a doctor who told her to abandon her crusade to save her son's life.





Jarred spent a week of volunteering as a counselor for children with cancer at Camp Boggy Creek. "Cancer is a terrible disease," he notes. "But it's beautiful to see how it draws people together."

When my senior year rolled around, I started looking forward to college. But I also wanted to make sure I closed out my high school soccer career with a flourish.

During one match, after I'd scored a couple of goals, two players on the other team decided to target me. They came at me in tandem, slamming into me so hard it knocked me out.

When I came to, my first instinct was to get on my feet and get back into the game. I couldn't understand why all my teammates started laughing. "Game's over," they said. Because of the blatant foul, we had won on a forfeit.

Later that year, when I was on my way to West Palm Beach with the club team I played for, my left eye began swelling up for no apparent reason. I never made it into the game. By the time we arrived I couldn't see clearly.

I started having other weird symptoms — sinus infections, leg spasms, weight loss. None of the doctors I saw could figure out why.

Then Dr. Giusti came back into the picture, pulling strings so that even though he was a pediatric doctor and I was about to turn 19, he could take over my care.

In July of 2009 he diagnosed me with ALL: Acute Lymphatic Leu-

kemia. Although radiation has been known to cause other forms of leukemia, it has never been associated with this form of the disease, in which lethal hoards of dysfunctional bone marrow cells crowd out the healthy ones.

I had worked so hard to put it all behind me — not just the disease, but the stigma of the disease. I made liberal use of my "short end of the stick" line and kept it a secret.

Especially from girls. One in particular.

She'd seen the scars and asked about them. I didn't want her to know, not yet. "When the time is right," I had told her. The time would be right, I was thinking, when I was sure that she could see me for who I was, not what I was.

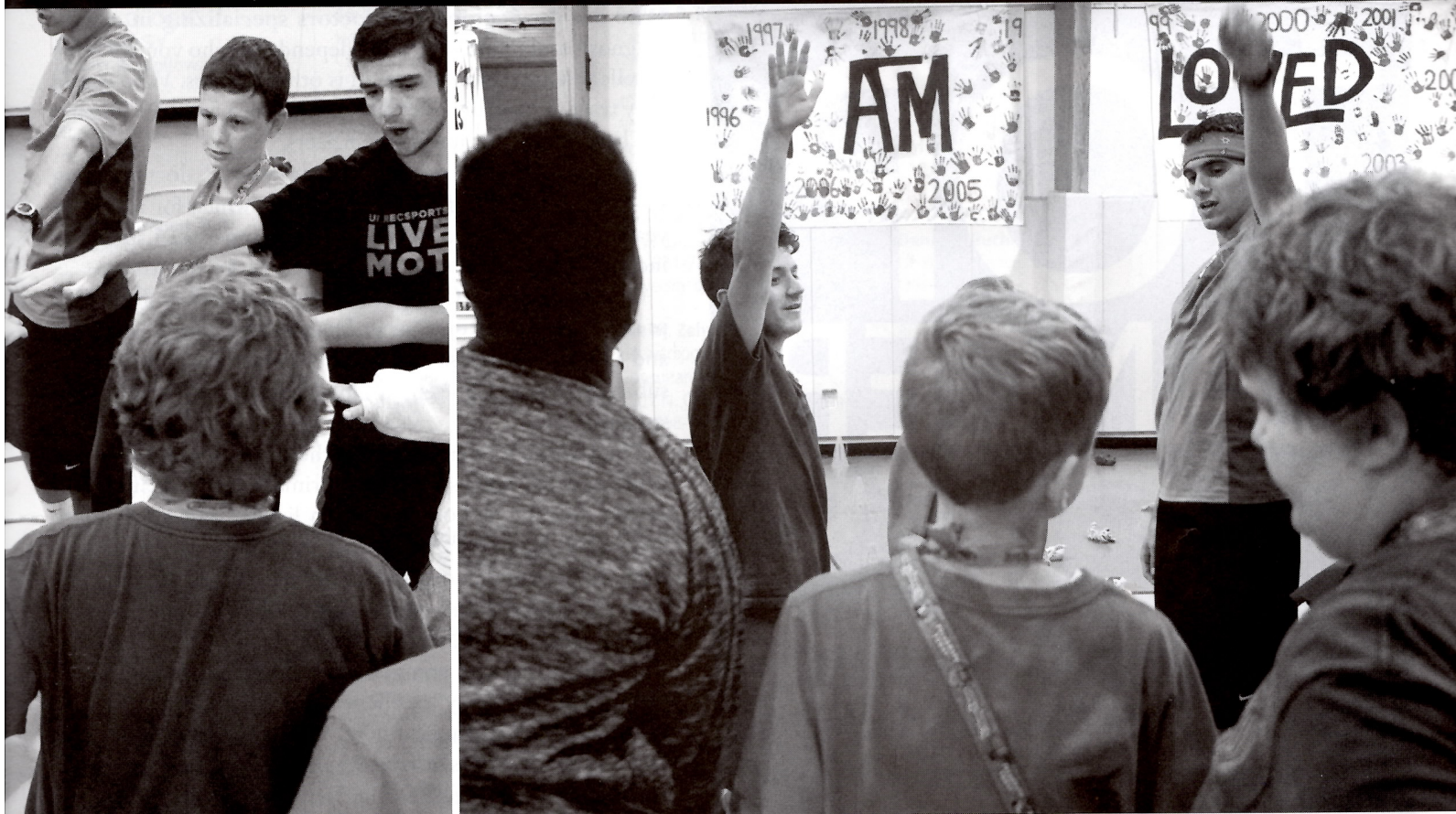
But now the timetable I'd had in mind would have to give way to another.

One year of intense chemotherapy. Two more years of milder chemo — pills, injections and painful spinal taps to check on my progress. I'd get nauseous. I'd be bald. I'd look like crap, feel like crap. I knew what I was in for. Been there. Done that.

I didn't want sympathy. I didn't want my friends to see me go through what I'd be going through. I just wanted to cut myself off from the world.

I begged my mother to let me drop out of classes at Seminole State. But of course, she wasn't having it.

She had bought me Superman underwear when I was younger to infuse me with the idea that I had enough secret powers of my own to



make it through anything.

Now she used different strategies to accomplish much the same thing. She suggested that I keep a journal to record my feelings. She got me a camera and suggested photography as a hobby. She reminded me of friends I'd made at hospitals during my treatment — friends who didn't make it.

There was one stalwart soccer teammate who came to check on me, week after week, as the months of therapy crept by. Other friends disappeared, one by one. So did the girl.

I was just as confused by my emotions this time around as I'd been as a child. I didn't want to be a burden on anyone. I didn't blame them for moving on with their lives while mine was in a holding pattern.

Yet I felt abandoned by them, jealous of them, too. I even lashed out at my younger (but much taller) brother, accusing him of not caring about me as he'd fly out the door to be with his friends.

Meanwhile, though, I was still toughing it out and going to school. I took some classes online. Others I attended. I even gave a talk in my public-speaking class right after my hair — all of it, including my eyebrows — had fallen out.

I had a lot of time to read. I ran across one book that left an indelible impression on me.

It was Jon Krakauer's *Into the Wild*, an in-depth examination of the tragic journey of Christopher McCandless. An idealistic young hermit who thought he could live off the land, McCandless starved to death while living in an abandoned bus in the Alaskan bush.

I identified with his sense of isolation. But what I took to heart the most was a cryptic line from his diary. It wasn't the sort of sentiment you'd expect to hear from a hermit:

"Happiness only real when shared."



It's been two years now since my therapy for ALL ended. My check-ups are good. Meanwhile, that public-speaking class I took has come in handy, as I've occasionally been asked to speak at fundraising events for the Leukemia and Lymphoma Society.

I also spent a week this summer as a volunteer at Camp Boggy Creek in Eustis. All the campers that week were young kids with cancer. The most amazing thing of all was seeing how much they cared about each other, helped each other out.

Cancer is a terrible disease, but it's beautiful to see how it draws people together.

I know that if I ever get the chance again to spend my time with kids like this, I'll jump at it. If anybody knows what they're going through, I do. Still.

I'm a regular fountain of helpful advice, especially when it comes to sports and fashion.

If kids tell me they like playing soccer, I can definitely give them a tip or two.

And if any of them happen to mention an affinity for superhero underwear, I've got a confession to make:

Even after all these years, I wear it, too. ■