Cancer Health™

Ryan Litwin—A Supporter of Ulman Foundation’s 4K for Cancer

Registered nurse and testicular cancer survivor Ryan Litwin works to support cancer patients in a number of ways.

July 19, 2021 By Justin Birckbichler

Welcome to the Band of Ballers! In this series on ABSOT, I’m turning over control to some other ballsy testicular cancer survivors and patients who have inspired me with their work in advocacy and awareness during and after their diagnosis. This month’s feature is all about Ryan Litwin, who uses his experience as a survivor to help others in his career as a registered nurse. He also participated in Ulman Foundation’s 4K for Cancer, which is not four kilometers as I thought, but a 4,000 mile run. Enjoy!

When Justin first reached out to me, my initial thought was, “What do I have to share that other testicular cancer survivors don’t?” The answer is that I don’t have much of anything to share that is unique to me. What I have experienced is no different from those battling their illness now or if they are post-treatment. Much like anyone else, the ways that cancer has impacted my life and how that has led me to become the person I am are infinite.

Ryan (right) with one of his Ulman 4K teammates, TylerCourtesy of Justin Birkbichler

If it wasn’t for my diagnosis everything that I am doing in my life today would not have happened. There is something monumental about a cancer diagnosis that stops you and your family in their tracks and throws you on your back. When you’re able to stand up again, it takes a while to walk, but soon you’ll be running and you’ll be running with a different stride and in a different direction.

That moment when I was thrown on my back was when I was a junior in high school.

During an annual physical for eligibility for my high school track team, I brought up some leg and back pain I was experiencing with my doctor. I requested physical therapy but instead was in surgery the next day. A few days later, I was starting chemotherapy treatment for testicular cancer. It had spread to several different nodules in my abdomen and a couple in my lungs. The largest in my abdomen was almost 7.25 inches long, after it had been shrunk by chemo and removed by surgery. It was pressing on my vital organs, causing my diaphragm to have difficulty expanding, my kidneys to drain inadequately (almost going into failure), and my sciatica nerves to fire constantly down my legs and up my back.

My doctors at Connecticut Children’s Medical Center (CCMC) ended up treating me with the VIP chemotherapy regimen to minimize the damaging effect the more traditional BEP treatment regimen can have on a patient’s lungs. My doctors were shocked hearing that I had run the fastest mile of my life a week before diagnosis. It’s not that I had a remarkable mile time on my track team, but considering the havoc my body was going through. They could hardly believe I could walk.

The VIP treatment was intense.

In a treatment roomCourtesy of Justin Birkbichler

The plan was for six days of inpatient infusions followed by one day of recovery and discharge. Then I would have two weeks of recovery at home and we would repeat this cycle three additional times. Rather than three weeks, each cycle was more like four because of the complications that occurred.

I was in the hospital almost as much as, if not more than I was at home. My main problem was c. diff, a hospital acquired infection that made me have urgent trips to the bathroom. Coupled with the nausea from cisplatin, one of the VIP drugs, I was chronically dehydrated and lost an unimaginable amount of weight. I started treatment at 5” 11” and weighed about 155 pounds. At my lowest, I was 35 pounds underweight. I was skeletal. I also needed the typical blood transfusions, electrolyte repletions, and nutrition support. Some things were more rare like blood clots, hallucinations, and medication interactions. But still, none of what I experienced was unheard of.

Since I had what’s called a mixed germ cell tumor, part of my cancer was responsive to chemotherapy and the other was not.

This meant surgery. The retroperitoneal lymph node dissection (RPLND) was even tougher than chemo. For most of the chemo I was so nauseous and so drugged up, I don’t remember much of my hospital stays. But the RPLND remains a vivid memory in my mind.

The night before the RPLND
Courtesy of Justin Birkbichler

My urologist said he was not comfortable performing such a complicated surgery, so he sent me to a different facility. Rather than a happy and cheerful children’s hospital, I was referred to Memorial Sloan Kettering, a bigger, better, adult hospital. Even though it is a nationally renowned medical center, it was also more grim and bleak to me.

To get to my tumors, they opened up my abdomen like a clam shell. Over the course of eight hours put my vital organs on my chest while they removed the tumors behind them. My surgeon at Memorial Sloan Kettering was able to save my intestine, my spleen, and my kidney. Because of him, I was fortunate to receive some of the best care in the world.

My recovery was complicated by an atypical collection of free air in my abdomen and an intestinal ileus. The problem was I couldn’t eat unless I pooped but I hadn’t eaten so how could I poop? I ended up forgoing pain medications because they made me constipated. Instead, I walked and walked and walked. Towards the end of my stay, I walked enough laps until I had totaled a 5K.

Finally, I pooped.

Shortly after, I left the hospital.

The next step was visiting a lung surgeon. I couldn’t imagine having sections of my lung removed and the idea of this was terrifying. But when we consulted with the surgeon he opted for surveillance of the nodules left on my lung.

Luckily, over five years later, nothing has happened to my lungs and I remain cancer free elsewhere as well.

But it isn’t the medical side of my journey that I typically tell people about.

I am not a hero and I hate being called one. I did nothing. All I did was exactly what my doctors and nurses told me to do. I was lucky it worked. I was lucky to have the endless support of my family who slept in the same room as me. My neighbors who provided my family with dinners. My friends who were always over for a visit even if five minutes was all I had the strength for. My support system was what kept me going. My school, with the support of my closest friends and teachers organized a fundraising run for my family and me. They shaved their heads, including two girls who I hardly knew who completely shaved their heads.

Ryan’s first road race post cancer treatments, the Colchester Half Marathon Courtesy of Justin Birkbichler

The amount of support I received continues to blow my mind even now. It was insane. The race car drivers from the local speed bowl came in to visit one day. Mikey’s Way Foundation gave me an iPod so I could stay connected with friends while in the hospital and stay entertained. Make-a-Wish flew my family and I to Alaska.

I could go on and on but this blog post would be too long. Yet none of it went unappreciated, no matter how small. It’s this stuff I like to talk about. This is the positive side to having cancer, the endless support and how it draws everyone so much closer together. Everything in life is about perspective. When the threat of death is real, priorities change. But I was lucky death remained only a threat.

For others, like my cousin Laurie, this was not the case.

Two weeks after I received my diagnosis, Laurie was diagnosed with ovarian cancer.

We would talk on the phone and when our immune systems allowed it, we would see each other in person. Although we weren’t the type of family to outwardly say it, we both benefited deeply from these conversations. For me, the understanding that Laurie provided for me was something no one else could no matter what they did. She got it. She was the one person who looked at me as normal and as an equal. When we were together it wasn’t like we were battling some terrible illness and our world was crashing around us.

Cancer brought us much closer, but it also separated us forever. Laurie died the summer after I graduated high school. While my treatments were showing clinical improvement, she began trials as a last effort and declined. Eventually, she planned her own funeral while receiving hospice care. Survivor’s guilt is an immensely powerful, insurmountable emotion that took years for me to overcome. Even now there are days where it all comes flooding back.

That fall after Laurie’s death I started school to become a registered nurse.

During the 4K for Cancer, the runners wrote names on their calves in honor of those they were running for.Courtesy of Justin Birkbichler

It was the relationship that I had with my nurses, and the flawless care many of them provided that persuaded me to do what they did. School was difficult, but it was a fresh start. Not many people knew about my past like they did in my hometown. There were no massive fundraising events, no newspaper articles, and no knowledge about my past except with my closest friends. Life was somewhat normal.

I started working as an aide in a nursing home, and it felt great to be making a difference. I hoped that I was making a difference in someone's life like my nurses had with me. The first time I distinctly realized I was doing something was that winter. I remember I sat on a patient's bed one night and went through his family photo album with him. I would point to someone and he would tell me who they were. Just a name, but it was more than he had been talking all week before. He had tears in his eyes and tried to hug me but only had the strength to fall on my shoulder. A few hours after I left that night, he died. His name was Amil.

Amil was the first of many patients to pass. In fact, I lost count how many of my patients passed. Over the course of the next three years or so, I stopped counting after I hit thirty. It sent me into a spiral anytime after it happened, and I would think of Laurie.

Somehow, as I got farther away from treatment, my survivor's guilt remained.

I certainly wasn't as depressed or sad as I had been in the months immediately after Laurie's death, I wasn't in that dark place, but I was still sad. To a certain extent, my experience had traumatized me. Certain smells in nursing clinicals would bring me back to treatment. Even now, as a registered nurse, there are smells and sights that do it. For two days, I had a clinical on the floor I was treated on and that was one of the most emotionally taxing times I have ever experienced. Sometimes I wake up in the middle of the night, thinking I'm back in treatment convinced the dream I just had was real. It takes a moment to get back to reality but it always seems real.

I was quickly learning that survivors' guilt would be the toughest thing to deal with after treatment. I had to do something yet I didn't know what.

That's when I found the Ulman Foundation and their annual fundraising program called the 4K for Cancer.

From the start, I was a fit patient and the doctors wanted to preserve that for me. Since that moment of diagnosis, running has forever changed for me and been one of the most important activities in my life. Now I feel like I have an obligation to utilize my running ability to its fullest.

And they're off...Courtesy of Justin Birkbichler

In the summer of 2019, twenty-seven other runners and I ran from San Francisco, California, to Boston, Massachusetts. Ulman's mission is to support young adults and families diagnosed with cancer. I was running for Laurie. Along the way we fundraised for the foundation and literally connected communities as we ran to them. We ran in relay style, each of us covering up to twenty miles a day. When we weren't running our part of the relay, we took turns driving the vans that held ourselves and our belongings.

At night, a local parish, or community organization would provide us with meals, showers, and or a place to sleep. At four-thirty the next morning, we would move on to the next town. We visited patients in hospitals, Ronald McDonald Houses, and Hope Houses. We spoke to local cancer survivors and patients. We spread hope. We shared stories, and we created a community that I still talk with two years later.

Throughout the forty-nine days it took for us to run to Boston, I went on a transformative journey. The most important thing is not that I shared my journey, but that I listened to others. It gave me perspective and understanding. Hearing how a seventy year old woman dealt with her cancer diagnosis is different from how a mother dealt with the death of her son to cancer.

Talking with people who were going through treatment was different from thinking about my own.

Every situation shared so many of the same complications just from different treatment regimens. It is how someone deals with it that makes the difference. It's their perspective that makes everything and changes their life. It's this realization that made me realize it's okay to be a survivor, even if it means that you survived someone who was important to you. Without this, I wouldn't be comfortable sharing my story today with the hope that you can gain some sort of insight, perspective, or knowledge to help you through your own personal battle. Don't get me wrong, it isn't the easiest thing to say now that I am a cancer survivor, but it isn't impossible and the emotions that come with it are positive now.

It's this new found insight that allows me to work as a compassionate nurse on a transplant floor. A cancer diagnosis is much different from awaiting a transplant or being told that you will die of organ failure because of ineligibility for transplant. There's plenty of death on my unit, in fact too much. More so than in the nursing home. In my first year, I have already had countless stories similar to Amil's. But it's what you do with this knowledge and the emotions that come with it that matter.

It's how you present yourself to those in need and how you make a difference in someone's life.

Looking back, that's what could have sent me on a different life journey. I knew how to perform a testicular exam when I was in high school, but I didn't know what to do with that information. The emotions that came with it clouded my judgement and left me in a state of paralysis until the problem grew so large something had to be done. I felt the lumps months before my diagnosis but I distinctly remember saying to myself "Ehh, it won't kill me, I'm sixteen." I was uncomfortable talking about my problem with any adult, and didn’t realize the severity of the problem.

I’ve talked with high schoolers while in nursing school about the importance of this. I tried to share the importance of this with those I met on our journey across the US, but it’s hard to talk about. For men, it’s even harder to talk about anything personal. But talking isn’t a sign of weakness, it’s a sign of strength. It provides support, healing, and love. It starts the journey to a better perspective.

Perspective means nothing though, if there is no action. So to everyone reading this, go tell someone you love them, and share your feelings with them. Tomorrow, everything could change.

Be sure to connect with Ryan by visiting him at @rlitwin and check out his blog. Until next time, Carpe Scrotiem!

Know someone (or even yourself!) who is supporting TC awareness and would be willing to share their story? Drop their name, contact, and why they should be featured into this Google Form and I’ll reach out to them and/or you!

This post originally appeared on A Ballsy Sense of Tumor on May 13, 2021. It is republished with permission.
