Cancer Health™

Mike Craycraft — The Testicular Cancer Society

Mike Craycraft founded the Testicular Cancer Society to help raise awareness and improve care for testicular cancer.

December 20, 2018 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 Mike Craycraft, who founded the Testicular Cancer Society. Enjoy!

When I first heard the doctor say, "It looks like you have cancer," I wasn't shocked at all. In fact, unfortunately, I was all too well prepared for it. I had felt a lump on my left testicle some seven months previous and immediately "knew" it was cancer. However, instead of going to the doctor I remained silent, not sharing my concerns with anyone.

During this time of "silence" I convinced myself that I was going to die from metastatic disease and even "made peace" with it. I took a long hard look at my life and realized that, although I didn't want to die, that I had lived a great life already with incredible friends and family and that I was way more fortunate than others have been. I even went as far as to throw a party in my hometown of Cincinnati during Thanksgiving weekend but didn't tell anyone that it was my "going away" party. I figured in a few months that my friends would find out that I was dying of cancer. They'd realize that me buying some beer and getting people together was my feeble attempt to see everyone one last time.

I should have known that going to the doctor immediately was my best option when I suspected testicular cancer

As a clinical pharmacist, you'd think I would be smarter than I was being. However, I specialized more in cardiac, critical care and infectious disease medicine. Besides knowing that testicular cancer existed, I knew little about the disease.

Miraculously, despite the seven month delay, I was diagnosed with stage I seminoma. At the time, three weeks of radiation therapy, just to make sure that the cancer did not return, was the gold standard of care. However, a wait and see approach, called Active Surveillance was beginning to come into favor and a single dose of carboplatin chemotherapy was an option too but was still a bit too investigational for wide acceptance in the U.S.

Being a clinical pharmacist, I believed in primum non nocere (first do no harm) and decided that Active Surveillance was the correct approach for me. I chose to defer radiation therapy or chemotherapy until if I relapsed and definitively knew it was needed.

Amazingly, 12 years on and I have not faced a relapse. Today, Active Surveillance is now the preferred approach for stage I seminoma so perhaps I was a bit ahead of my time in selecting this as the best option for me.

Once I was diagnosed, I opened up about testicular cancer and have never stopped doing so

I reached out to whomever I could find that had been affected by the disease and started asking about their experiences and how they made treatment decisions. I began to learn of the journey of others and more specifically what resources were missing from that journey. When I was diagnosed, some 12 years ago, there was very little, even on the internet, about testicular cancer.

Given my experience as a survivor and my knowledge as a medical professional I figured that I was uniquely positioned to help change the world of testicular cancer for the "next me" that was diagnosed.

To achieve this, I founded the Testicular Cancer Society. Originally, I envisioned it as kind of a hub in a tire and figured that I could easily point people down the spokes in the direction of what few resources were available and then develop resources that didn't yet exist.

Today, we focus on reducing the burden of the disease by simultaneously working to increase early detection, access to care, and quality of care. We strive to make sure that those affected by testicular cancer (the fighters, survivors, and caregivers) are not facing things alone and have the best support and resources available to help assure positive outcomes.

I am often asked, "What does the Testicular Cancer Society do?"

My best answer is that until you contact us in need you'll never really know exactly what we do. I know that is a horrible elevator pitch, but it is the truth. Fellow "Band of Ballers" Dave Fuehrer once said that we helped people "go from overwhelmed and unable to cope to having a new perspective and hope." (Editor's Note: Seeing one Uniballer reference another survivor is a heartwarming feeling. Mike and Dave are two of my favorite people in the cancer space, with one nut between them.)

I like to believe that this is indeed the case and each person we connect with differs in what they need.

In medicine, I was trained to give the answer that is needed and not necessarily the answer to the question that is asked. I do this all the time in helping those affected by testicular cancer. While I can answer their direct question, I more impactfully provide the answers they need and help avoid pitfalls in their care. For example, the answer to, "Where can I get financial assistance for my care?" is that none really exist unfortunately. However, given my experience in health care I can usually make some calls and get the care that is needed.

In fact, not once have we been unable to find care for someone, regardless of the patient's insurance status, ability to pay, or our limited resources as an organization. It is somewhat amazing that some of the largest cancer organizations in the nation, those that raise tens of millions of dollars a year, refer patients to us. They have no resources for testicular cancer and yet we are able to help overcome any access to care issues.

I am frequently asked why I continue to do what I do with testicular cancer

Hopefully, I'm not risking sounding braggadocious, but it is because I am not sure who else can or would. I do believe I am unique in having the sincere empathy as a fellow survivor, the in-depth medical knowledge to converse with world-experts on the disease, and the communication skills of a pharmacist to be able to explain things to the patient and caregiver.

I have developed relationships with experts across the globe to help advance the access to quality care. I have published articles in medical journals, have developed research partners for further publications, reviewed other's articles for publication, and even review proposals for cancer research funding. Most importantly, I have continued to have the compassion and open ears to listen to those newly diagnosed, to those mothers, wives, and girlfriends that are scared for the man in their life and console each the same.

One of the best ways to reduce the burden of testicular cancer and save lives is via early detection and treatments. If diagnosed with stage I disease, the 15 year-survival rates are almost 100% and most men can avoid chemotherapy, radiation and more aggressive surgery.

However, getting the attention of young men and having them realize that they are most at risk for the disease and convincing them to do monthly testicular self-exams is like herding cats

While our social media and web properties reach several million people a year, this post from the Super Bowl reached over 1.7 million individual users on its own, we have come up with some unique ways to achieve our awareness goals.

We developed a mobile app, Ball Checker, with a few facts about testicular cancer, instructions on how to do self-exams, and the ability to set monthly reminders. To date, the app has been downloaded in over 140 countries. (Editor's Note: That means a minimum of 280 testicles have been checked… give or take a few!)

Beyond the app, we also have a monthly text reminder program where people can text @selfexam to 81010 and then once a month we send a reminder to do their self-exam with a link to instructions. We don't use the system except for the monthly reminder and the person's cell number is never revealed to us.

Furthermore, we have also forged partnerships with other non-profits and industries to help raise awareness. A perfect example was our partnership with Patient Point this fall that delivered our awareness video message into over 4,500 primary care physician offices.

We also have partnered with the movie Funeral Day, not only to have the rights to show the movie for educational purposes, but they have also graciously helped with some Testicular Cancer PSAs that we are currently releasing.

While we can’t prevent testicular cancer, we hope that by simultaneously increasing early detection, access to care and quality of care, that future guys diagnosed will be minimally impacted by the disease and get back to living their their lives immediately.

Be sure to connect with Mike and the TCS:

- Mike Cracraft on Facebook
- @pharmacistmike on Twitter
- mike@testicularcancersociety.org
- Testicular Cancer Society
- Testicular Cancer Society on Facebook
- @TCSociety on Twitter
- @TCSociety on Instagram

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!

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