A Research Study by CACTI

The Center for Advocacy for Cancer of the Testes International did a study on men and their views on testicular cancer and testicular exams — here's my reaction.

July 5, 2018 By Justin Birckbichler

As a testicular cancer survivor, I'm always on the search for fellow Uniballers — both to share ideas about how to spread the word about testicular cancer and to complete my missing half (Kyle Smith of Check15 and June's Band of Ballers feature is the Lefty to my Righty). A few months ago, while browsing Instagram, I happened upon Scott Petinga, a fellow testicular cancer survivor, who was promoting Pariah, a new pair of underwear that benefited cancer research and awareness efforts. While researching further, I saw that he had also founded the Center for Advocacy for Cancer of the Testes International (aka CACTI). As a bonus round, he will be this month's Band of Ballers feature — stay tuned.

Around the same time, I was beginning my research study about men's experiences with testicular exams at the doctor's office and discovered that CACTI had run a survey of 1,000 men in March 2018 about their knowledge of testicular cancer. You can read their full breakdown here, and this is my reaction to their study. I've included CACTI's findings in bullet points and my own reflection after.

What do men know about testicular self-exams?

- Nearly half of those surveyed do not perform testicular self-exams.
- More than 1 in 3 of all men polled have never been told about the importance of a monthly testicular self- exam.
- More than 60% of those surveyed say they would perform a monthly testicular self-exam if someone told them it could save their life.

Honestly, none of this surprised me. I know most of my own personal friends never did (and some probably still don't) self-exams prior to my diagnosis and that I was in the minority as a man who actually did it regularly. My findings from my study regarding doctors talking to patients about self-exams show the percentage is even higher and the Testicular Cancer Society similarly found that 62% of their respondents said that no one had ever discussed self-exams with them. No matter which survey you look at, the findings are clear: all men need to be told about the importance of testicular self-exams.

But it's not all bad news. That last line gives me hope. With any luck, these thousand men they interviewed have now been nudged enough to do a simple life-saving self exam monthly. My biggest question about that stat is, "Why were only 60% convinced?" If someone tells me I can do something to potentially save my life, I'd be all in.

What we can do to change this?

I cannot say it enough — teach the men in your life how to do self-exams, remind them to repeat it monthly, and reinforce the importance of this 2-minute act. If you're uncomfortable talking about it yourself, feel free to send them ABSOT's page on self-exams here.

What do men know about testicular cancer causes and detection?

- Close to 50% of men polled believe testicular cancer is detected during an annual physical exam.
- 40% of men surveyed believe they can get testicular cancer from things like wearing tight underwear, taking a spin class, or having too much sex.

The first stat reminds me of a common excuse I first wrote about in No Time for Excuses: I don't need to do a self-exam every month because a doctor will catch it during my annual exam. Simply put, if I waited the nine months from when I discovered my lump in October until my annual exam in July, who knows if I would be writing this post right now? Additionally, both the Cleveland Clinic and my study have found that many men don't even attend an annual physical exam.

I think we have Lance Armstrong to "thank" for the thoughts of biking resulting in testicular cancer. While cycling doesn't cause testicular cancer, it won't improve your biking ability. I'm not entirely sure where the second two notions stemmed from, but I will say that my urologist actually told me to wear tighter underwear after my orchiectomy.

In addition to those three different "causes" of testicular cancer, I've also heard guys thinking that getting hit or kicked in the balls results. This isn't true, as it's more of a correlation (striking the scrotum will make you feel yourself) than a causation. Either way, it's interesting to know that there are so many guys out there who believe false information about their testicular health.

What we can do to change this?

It's easy — hear something untrue, call it out. Come at it from a place of education and empowering men, and keep it brief. No one needs a lecture.

What do men know about testicular cancer risk and fatality rate?

- More than 63% of men surveyed were not aware that testicular cancer is the most common

form of cancer in men ages 15–44.

- Even though close to 100% of those surveyed believe that testicular cancer is curable, 80% are still afraid of dying from it.

This first point didn't surprise me. Any time I tell someone, regardless of age or gender, that I am a cancer survivor, they immediately say, "Oh, but you're so young." While I am flattered by my youthful good looks, I always tell them that the average age at the time of receiving a testicular cancer diagnosis is 33. Since I was 25 when I received my diagnosis, I also make sure to mention that I am an overachiever! When it comes to awareness about testicular cancer and who it impacts, CACTI's findings solidify the need to reach men far and wide.

In regards to the second point, when a person hears the word "cancer," it's hard not to think of death. I know it's something I struggled with before treatment, during chemo, and while waiting on the results of chemotherapy. However, even from the initial appointment when they told me the cancer had spread, my doctors always reinforced that testicular cancer is a highly curable form. More men need to know this. Sometimes, people put off self exams and doctor's visits since "no news is good news," and then the cancer is allowed to spread to more advanced stages, which isn't as easily cured. Knowing that an early detection can help improve cure rates can help get men to be more on the ball.

What we can do to change this?

This ties into my plan for an ABSOT YouTube channel. Men are the primary demographic of YouTube and are on it constantly. Making these statistics a part of videos will help viewers remember the importance of self exams.

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