Toby Freeman — Robin Cancer Trust

By #Talking Bollocks, Toby Freeman honors his brother through the Robin Cancer Trust.

May 20, 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 Toby Freeman, who founded the Robin Cancer Trust. Enjoy!

My brother, my best friend.

'Is that cancer'? I remember asking the doctor. My brother, Robin, was silently staring at the floor and my Mum was shaking and sobbing… 'Yes, and it's Stage 4'.

That was the moment our lives changed forever.

Rewind just a few months and my brother was in his prime: 23 years old—living healthily, always exercising and at the start of his career—life was good. I mean, he did have a bit of a cough (but it was winter, so it was probably just a virus), and he was really tired (but he was stressed, so coffee would help), and he was waking up in the middle of the night covered in sweat (but it was probably nothing, so it would go away).

It wasn't until his arm swelled up in excruciating pain that my brother finally informed us of his ailments. Needless to say he was rushed straight up to the hospital. Within the week we were informed that he had a 'Mediastinal Germ Cell Tumour'—not a series of words we'd ever heard before, hence my original question… 'Is that cancer'?

My brother had a rare form of testicular cancer. A rogue testicular cell (germ cell) had settled in his chest and grown to the size of a grapefruit, wrapping itself around his heart and lungs.

My brother was rushed to the leading hospital in the UK; he was given seven rounds of intense chemotherapy, two bone-marrow transplants and the best care he could've asked for—but because he ignored symptoms, because he didn't think this could happen to him, because he didn't talk to us or a doctor—10 months after his diagnosis, he passed away, aged just 24.

Never just a photo on the wall.

Courtesy of Justin Birckbichler

In Rob's final weeks, my Mum promised him he'd never just be a photo on the wall – she reassured him we'd never stop talking about him, laughing about the good times and telling our children and grandchildren about their Uncle Rob.

What she didn't envisage is that we'd set up a charity in his name, reach hundreds of thousands of young adults with his story, and campaign across the world for the young adult cancer community in his memory.

We've delivered educational talks to over 25,000 students, handed awareness information to 175,000 young adults at events, music festivals and universities, and reached millions of people online with our life-saving cancer campaigns.

We've sent a pair of testicles into space to launch Testicular Cancer Awareness Month, we've broken the World Record for the most men performing a self-exam by bringing together 260 guys from across 5 continents online, but most importantly we have saved lives. Young men are alive today because they read our leaflets, watched our videos or visited their doctors because we raised awareness and reduced embarrassment – and that's incredible.

It's been 10 years since my brother died and our mission has never changed—we want to prevent another family from going through what we did.

#TalkingBollocks saves lives.

Our #TalkingBollocks testicular cancer campaign has 3 clear objectives: to engage, educate & empower.

We will continue to work towards these goals until every man in the UK knows the signs & symptoms of testicular cancer, is checking themselves regularly and has a clear pathway to get tested early.

Courtesy of Justin Birckbichler

However, the responsibility can't lay solely at the feet of the charities, advocates and survivors—every single one of us has the power to save a life simply by starting a conversation.

I can't tell you how often guys come to me with an 'embarrassing' issue or health problem – they reach out to me because they know I am happy to talk about these issues. Aside from founding the charity, I have shared my own health issues over the years openly and honestly (having a procedure to remove a varicocele, finding a lump and the subsequent scans and tests). This has helped my connections to feel comfortable in asking for my advice (which is always ultimately 'go to your doctor').

We have the power to change the narrative around men's health and to inspire other men to open

up and take action.

It starts in our immediate circle, then out to our wider online communities and if we keep breaking down the stigma, eventually we will create wider societal change in which men feel comfortable engaging in conversation about health issues, are educated on how to check themselves regularly for testicular cancer and empowered to not feel embarrassed about visiting their doctors.

Be sure to connect with Toby by visiting him at @tobytalkscancer. You can watch his TEDx Talk '3 Steps to Surviving Grief' here: https://youtu.be/rxdJMAAx3oY. 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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