

Teen Cancer America— All Aboard!

BY SIMON DAVIES



I was a six-foot and five-inch 16-year-old and they had to make an extension to my hospital bed on the children's ward. Steve, 18, Los Angeles

I had a type of bone cancer called Ewing's Sarcoma, and I looked up the drugs they were giving me. They were 30 years old. Nothing new in 30 years! I couldn't believe it. Emily, 17, Boston

I had just turned 18 and the average age of patients on my ward at the adult hospital must have been about 60. I felt strange and isolated. Daniel, 21, Chicago

The doctor in my hospital said that he had only ever seen one other patient with my type of cancer and that he wasn't sure how to treat it. There was a bigger hospital with more expertise, but my insurance company said they wouldn't pay for me to go there. My Dad ended up taking out a loan to pay for my treatment. Ellie, 16, Daytona

These are just some of the stories voiced by teenage and young adult cancer patients in the United States.

Teenage Cancer Trust

For more than 20 years the U.K. (United Kingdom) charity Teenage Cancer Trust has single handedly battled for specialist services for this sometimes “forgotten tribe” of patients. Such that now the British National Health Service (NHS) has standards and measures that require every major cancer center to provide age appropriate facilities and expert multidisciplinary teams specifically for teenagers and young adults. Furthermore there is a national research group focused solely on this patient population and a national intelligence service that clearly marks these patients in comprehensive data collection.

And now the movement has come to the United States.

Teen Cancer America

After acting as CEO of Teenage Cancer Trust for 13 years, I was recently appointed executive director of Teen Cancer America, a charity founded by Roger Daltrey and Pete Townshend, legendary frontmen of The Who. Daltrey has been a passionate patron of Teenage Cancer Trust and, with the help of Chairman Rebecca Rothstein, Daltrey and Townshend set up the charity and brought me in to build on the U.K.'s success.

Teen Cancer America has big ambitions. We want to work in partnership with all of the major cancer centers in the U.S. to develop both facilities and multidisciplinary teams to meet the unique needs of this patient population. We work specifically with young people aged 13 to 25 because

that is where all the “action” happens—late onset pediatric cancers, early onset adult cancers, growth spurts, hormonal activity, acute psychological challenges, educational and employment issues, and most significantly, a lack of medical and scientific understanding about many of the rare cancers that affect those in this age group.

The charity has hit the ground running. I have a list of more than 30 hospitals in 20 states that are in communication with Teen Cancer America about developing services. This list includes some of the top teaching hospitals in the world, such as UCLA, the Dana-Farber Cancer Institute, and MD Anderson.

There is a lot of interest and enthusiasm out there demonstrated by a small but



Left: Young people with cancer at the Long Beach Grand Prix where TCA launched Hernan's (in the driving suit and wheelchair) Road Rebellion tour. Above: Teen lounge within the specialist AYA facility at UCLA. Below: Teen Cancer America logo.

growing number of champions. The American health system is, of course, complex and different from the U.K., but the challenges are by no means insurmountable. In fact the natural entrepreneurialism of the American culture is what should make our goals achievable. It will take courage, investment, collaboration, and communication. For example, meeting the needs of teenagers and young adults with cancer requires pediatric and medical oncology to combine their efforts.

A Time for Change

The message from the U.K. and increasingly here in the U.S. is that these specialist services are what teenage and young adult patients and families want. Or, as Daltrey so succinctly puts it, “[this type of care] is the right thing to do for the young people who are our future.” So, let’s make this a time for change.

How do we do this? In addition to the larger, academic teaching centers, I truly believe that community programs have an important part to play in bringing about success for this patient population. While Teen Cancer America believes in centralizing complex treatments in major cancer centers that see enough of these patients to conduct clinical trials and deliver the best outcomes, the organization has a commitment to seeing well-developed partnerships with community programs that can deliver some of the most important aspects of care and support.

Rare disease requires specialist input and

teams that treat young people and understand their needs. These programs need to be the coordinators of the cancer pathway. But we are increasingly able to treat cancers in outpatient settings, and the less complex aspects of medical support can be effectively given closer to home in



community programs. These community programs can deliver first-class treatment by collaborating closely with their academic and tertiary counterparts.

Imagine a hub and spoke arrangement where the specialist cancer centers “design the treatment packages” and then share the delivery of these treatments with community cancer programs and primary care physicians. At the center of this hub are the multidisciplinary cancer care teams who have specific expertise with teenagers and young adults and the cancers that affect them.


Get Involved!

I recently met a young American woman who had survived cancer and is now training to become an oncologist. She told me that the isolation she felt during her cancer treatment at both the pediatric and adult cancer programs—not meeting one other

person her own age—had been the single motivating factor in her desire to study medicine and bring about change. She is now determined to be a part of changing cancer treatment for those young people.

Teen Cancer America is embarking on a major initiative to draw attention to these issues. And we are joined by some amazing individuals. Hernan Barrangan survived two episodes of cancer in his teens. The last treatment (not the cancer) caused him to be paralyzed from the waist down. Undaunted, Barrangan has become an expert filmmaker and he has developed a specialty in telling the story of young cancer survivors. I have seen a thousand charity films but none compare to the quality of Hernan's. He is an exceptional talent.

Teen Cancer America is sending Hernan to every state in the U.S. to capture the stories of young people with cancer. We will then have the voice of the nation captured on film, and Teen Cancer America will use this to influence and bring about change. You can follow Hernan's “Road Rebellion” journey on the Teen Cancer America website, www.teencanceramerica.org/hernan/the-plan.

The teenage and young adult cancer train is here and healthcare professionals need to get onboard or be left behind. Find out more at www.teencanceramerica.org or contact me at simon@teencanceramerica.org if you want to help make a difference. 

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