



MEET EMILY WHITEHEAD

VIDEO TRANSCRIPT

This is the story about 5-year-old Emily Whitehead.

After being diagnosed in 2010 with leukemia, relapsing twice, not responding to any treatments... and ultimately facing hospice and weeks to live--- her parents Tom and Kari pursued a highly experimental treatment called CAR-T-cell therapy.

Tom Whitehead: They told us this new experimental CAR-T cell therapy had just been approved the day before and that Emily could become the first child in the world to have this type of treatment.

CAR-T cell therapy means Emily's T-cells were collected and genetically reprogrammed to recognize and attack the cancer cells in her body.

Tom: April 17, 18 and 19th of 2012 she received her modified CAR T cells back, which made her very sick and she ended up in the intensive care unit for two weeks on a ventilator breathing for her, but she just kept fighting. And the doctors all worked together and figured out a way to treat the side effects and they said her system became overwhelmed with sidocaramelised syndrome because over 3 and a half pounds of her body weight was cancer.

Barry Heavey: That kind of fighting spirit, how do you feel about that now, looking back?

Emily Whitehead: That was really important to me and my dad always told me we need to stay positive and find something to smile about every day and I think that does have a big effect on ---especially when you are in the hospital.

Tom: She woke up from a 14 -day coma on her seventh birthday - which would have been May 2 of 2012 and then 8 days later, 23 days after her first infusion, they checked her again and she was cancer-free.

Barry: The clinical and scientific community were essentially taking your immune cells and bringing

them to a lab, genetically engineering them and turning them into super T-cells, right? And then giving them back to you and then your own T-cells essentially fought back. Were able to fight back cancer and it's been working ever since.

Emily: it's been 10 years and I have been waiting for my B-cells to come back because I have to do a medicine every two weeks because I don't have any, but 10 years later the T-cells are still in there."

Tom: I posted one day, you know, I believe I am witnessing a miracle with Emily's treatment because, you know, they told us she couldn't survive and here she was becoming the first child in the world to have her immune system trained to beat her cancer and it sparked the cancer immunotherapy revolution.

Emily: I think it is important to tell other kids how important it is that they believe in themselves.

Emily is a medical rockstar. People want to meet her and hear her story.

Tom: We were receiving letters from soldiers that said, you know Emily, people tell us we are heroes, but to us, you are our hero.

Emily: We met President Obama a couple of years ago and he asked me...

Barry (background) President Obama met Emily Whitehead

Emily: He asked me, what can I do for you since you came all this way, and I told him that I had missed school. So he wrote me a school excuse that said 'Emily wasn't in school today because she was with me.'

Barry: You've met Lada Gaga and other celebrities, but to me, you guys are celebrities right, I am a pharma Geek. I geeked out when I heard your story. I feel like you know, you are rockstars.



Barry: You've been on the cover of The New York Times. You are about to launch a movie at the Tribeca Film Festival.

Emily: I got to spend a day on the set with Steven Spielberg whenever he was filming West Side Story. And that was probably the day I realized, that is what I want to do.

Barry: But it is not just about the Whitehead family and what you've gone through, you've also been really generous and giving of your time to other families in similar situations and you've established the Whitehead Foundation.

Tom: Along with that media attention came parents calling. So we finally started the Emily Whitehead Foundation to try to pay it forward every day and help other families have the same outcome as us and provide assistance when they need to travel or just advocate for them so they can find these trials.

Emily: For me, my main goal is to get less toxic treatment options closer to the frontlines, especially the effects from radiation can be really harmful and my parents were more scared of that than they ever were of CAR T-cell therapy. But just getting kids back to school, back to their normal lives, is really important. For me now I would like to see better, more on the mental health side, better care for patients especially pediatrics. Even adults too.

Tom: We were kinda put into this...forced into it, but since Emily was first and we saw the power of what her story could have, we've kinda been, we've taken the reins and tried to do whatever we can and to drive this revolution forward.

Emily: It really is a medical revolution, and we feel incredibly grateful to be a part of it and be driving it forward.

Copyright © 2022 Accenture
All rights reserved.

Accenture, its logo, and High
Performance Delivered are
trademarks of Accenture.