

Changing the Face of Young Adult Cancer Care In West Virginia

Chris Ryan January 17, 2018



Walking Miracles Childhood Cancer

**"My passion to help young cancer survivors & fight for these families because we had no one fighting for us, rose up in me like a brushfire"
Brett Wilson**

([Newswire.net](#) -- January 17, 2018) -- Charleston, W.Va. – Brett Wilson is a 2 time 35 year childhood cancer survivor of ALL Leukemia and Non-Hodgkin's Lymphoma, and Founder of [Walking Miracles Family Foundation](#). He was diagnosed in 1974 at the age of 2 with his Leukemia, and had 5 years of

chemotherapy radiation and cranial radiation to battle his childhood cancer. After being in remission a year and a half he was diagnosed with Non-Hodgkin's Lymphoma at the age of 9 after 3 more years of treatment including more chemotherapy and radiation to his chest, during his battle he blue coded 2 times due to having a difficult airway and anesthesiologists could not get an intubation tube down his throat, Wilson finished his treatment in 1982 and became then what was then known as a childhood cancer survivor because he was no longer getting treatment at 12.

[Wilson states](#) the toughest part of the journey wasn't getting treatment you got used to being isolated and you built up a pain tolerance to it, but the side effects of those treatments years later and the lack of resources he and his family had during their journey was the worst part. " My mother was the one who knew all my medical history and she had great support while we were in the hospital, but outside of it we were supposed to figure everything out ourselves and we had no survivorship plan and very little information back then as they were just learning themselves.

 **Chris Ryan**
34 minutes ago 



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Fundraiser for WALKING MIRACLES Family Foundation by Chris Ryan

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You just dealt with the cognitive, physical, psychosocial and other long term effects as they came.” I’ll never forget what the nurses told me that day Wilson said they told me to go be normal” Normal whats that, I was lost. For 12 years I had been going to treatments day in and out had no friends, was bullied and made fun of in school and on the school bus, had difficulties with school subjects, was smaller than other kids and I was tired and I was supposed to be normal. “I told my mom that I would build a center one day to help families like ours so they would never go through what we did by themselves.”

“Today the definition of cancer survivorship has changed its now from the time of diagnosis through the continuum of care, however long that may be said Brett Wilson. “In 2006 I started having long term complications for the treatments I had as a child, I had my gallbladder removed because it was crystallized and my first pacemaker at 35 in NC and had no insurance and came back to WV.” I joined the WV state cancer coalition and was on the survivorship committee and the patient navigation committee.

Jim Keresztury the President believed in my passion to serve families like mine and gave me a place where I could learn about the cancer issues in our state but no one had experience with childhood, adolescent or young adult cancer but me. I have always been an advocate for childhood, adolescent and young adult cancer survivors, I was the state volunteer Livestrong leader and had spoken at many events asking why there were no survivorship support systems in rural communities, I even helped develop the state patient navigation conference and brought pioneer Harold P. Freeman a breast surgeon who founded the Patient Navigation Institute in Harlem NY for poor women who had breast cancer so he could provide support for them and Chris Dammert who was the director of the Livestrong Patient Navigation Center in Austin Texas to Flatwoods WV and people said it would be impossible Wilson said but I made it

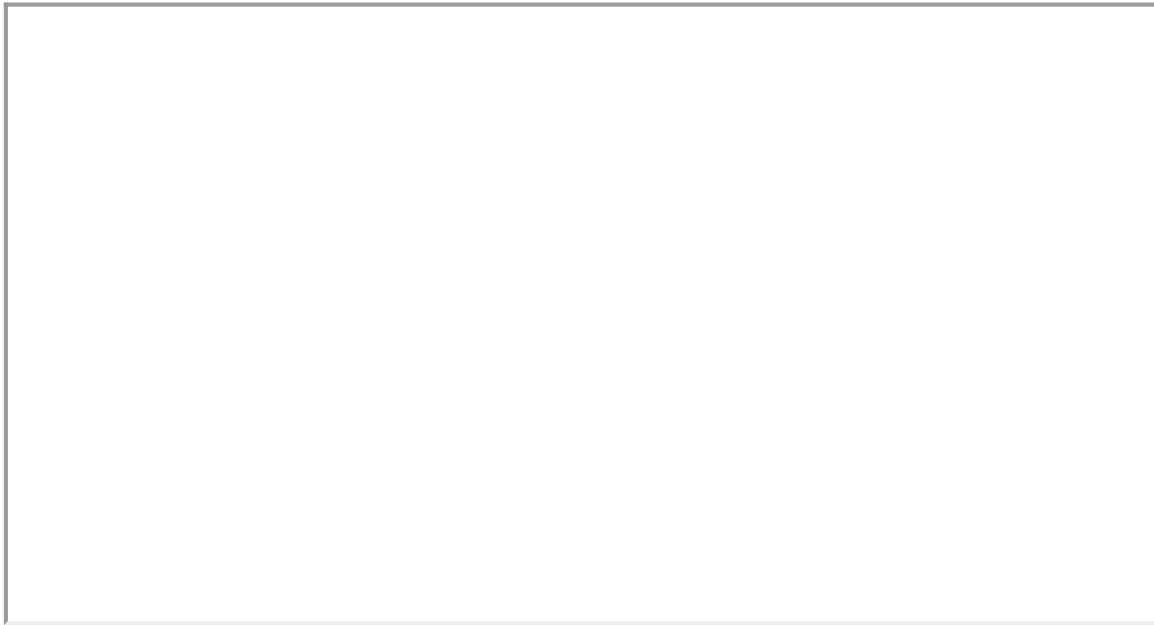
happen.

"I tried to implement the program where I had been treated. It took 6 months for a meeting and I gave a presentation to hospital and cancer leadership. I was asked to leave my presentation with them, but I couldn't do it. It was the the only thing I felt I had to help me further my career. I had worked in the social work department at a local cancer center in 1995 visiting and counseling patients during my internship at Marshall University. I then moved to Durham NC as part of my graduate internship in 1998 and worked in the cancer patient support program and counseled families and went with them to their treatments. I then was hired by the pediatric oncology division by Dr. Phillip Rosoff to help in the new cancer survivorship program they were building and begin researching the long term side effects that would years later effect my health. That was a grant funded program and I moved on adding disciplines and advocating to build my resume.

I have always believed after I saw the patient navigation program at the Ralph Lauren Cancer Center in action that the program needed to be implemented here in rural WV because it provided outreach, connection, communication and support to the families and survivors it served. When I saw that and later saw the standards set forth by the College of American Surgeons for cancer care that have to be implemented in cancer centers across the country in the areas of patient navigation, survivorship education and psychosocial oncology (counseling) for cancer patients I was amazed that it was being done for adult cancer but not for pediatric cancer. After those went into effect I had advocated that I could help with that program at a local cancer center. The program had gotten grant support and was implemented and when I asked to be a part of it they had already developed it. That's when all the past memories flashed back in my head at the lack of support my mom and I had and I said this can't continue.

My passion to fight for these families because we had no one fighting for us rose up in me like a brushfire and that's when I founded the center I had spoken about so long ago Walking Miracles Family Foundation in 2012. Our mission is to help our families and survivors impacted by childhood adolescent and young adult cancer in WV. We help connect them to resources and referral networks and to help defray the travel costs during their cancer journey.

God has blessed me and my organization and I am happy to announce the organization and our board have hired Jennifer Bass a former Patient Navigator from a local Charleston WV cancer system. "I helped develop, implement, and maintain a Comprehensive plan to manage the financial burden caused by the diagnosis of cancer.



This program saved patients over eight billion dollars in out of pocket cost. Says Bass” The program garnered national recognition with the airing of the PBS documentary “Cancer: Emperor of all Maladies” Our goal along with our board of survivors and business leaders is to help our families navigate the cancer journey and walk with them and reach out to our families and survivors of childhood adolescent and young adult cancer in our state to provide the best patient centered care and support we believe all our families deserve. We have a goal in 2018 to add a director and another navigator and could use our communities support.

Respectfully,

Brett Wilson
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Patient Navigator
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[Any donations can be made HERE](#)

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