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"RARE"  
**BOB PINIEWSKI**

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For the past two years, my right shoulder ached from throwing thousands of footballs to my 14-year-old son AJ, trying to lead him just right on deep post patterns. After the last throw, it would hurt from catching the big lug as he ran and jumped into my arms, yelling "The Bills win the Super Bowl, the Bills win the Super Bowl!" (Just us dreaming.) It hurt from pitching as fast as I could so he wouldn't hit me, but he always did. My shoulder hurt enough that I only slept on my left side -- rolling over on it would wake me in the night. But I didn't care. I loved it.

My shoulder eventually stopped aching. Now what keeps me awake at night is my broken heart. I have no one to throw those passes to. On January 5, 2008, AJ left us -- a victim of childhood cancer.

I will never forget the months I spent in the hospital with AJ. Sometimes it felt like my primary function was to not step on the green-colored tiles on my trips back and forth to the break room. That, to me, was the only thing I could truly control. It was my goal to never, ever step on one; then everything would be okay. Sounds ridiculous, doesn't it? But I bet the nurses knew what I was doing. When you are fighting this war as a parent, it is hard to do much more.

Have you ever been on a pediatric cancer floor? Ever walked the halls and seen the smiles or tears on the faces of the little kids as they play on their Big Wheels? The tiny little masks they wear to ward off infections? How the moms and dads race behind with the ever-present IV pole, how the teens hang together and try to be cool even though they're bald and ready to throw up at any time? Have you ever seen a mom, dad or sibling alone in the break room at 3 a.m. with their heads in their hands, feeling alone, helpless, scared and mad?

I've seen it all and more. In December 2007, my son had to ask me, "Dad, what's hospice?"

I've seen enough. I want a cure for childhood cancer.

Because childhood cancer is often considered "rare," you may not know much about this devastating group of diseases. You may not be aware that federal and private funding

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for pediatric/young adult cancer research and survivorship is woefully inadequate. Breast and prostate cancer receive more funding by an order of magnitude than childhood cancer. In 2007, the [NCI budget](#) for cancer research was \$4.8 billion, with just \$0.17 billion directed to childhood cancers. While pharmaceutical companies devote some money to rare diseases, it's not enough, and it's not specific to the unique challenges of childhood cancers. As a son who has lost his mom and dad to cancer and as a father who has lost his son, I question the distribution of research money. What happened to women and children first?

Childhood cancer may be "rare" compared to illnesses affecting the entire population, but it's not "rare" when it's happening to your child.

Our kids have about a 1-in-300 chance of being diagnosed with cancer before age 20. Cancer is the number-one disease killer of our kids, taking more of them every year than cystic fibrosis, muscular dystrophy, asthma and AIDS combined. While strides have been made, the survival rate has not improved enough in nearly two decades. Each day 40,000 children and adolescents undergo treatment as they struggle to beat the lying, cheating diseases known as childhood cancers.

Pediatric cancers are different than adult cancers and require specialized treatments. And more focus is needed on childhood cancer survivors as they transition from pediatric to young adult care and are faced with [a 60% chance of developing at least one chronic health condition](#) (e.g. secondary cancers, major organ damage, developmental problems or infertility) from the "cure."

But it's tough for parents in the fight to do much advocacy work. Those with children in treatment are advocating every day for the health of their child. Those who've lost a child may be overwhelmed with grief. Those with survivors may be ready to escape from the childhood cancer world. All understandable. And the kids themselves? Well, they can't vote, write checks or pick up the phone to call Congress.

But our advocacy is [desperately needed](#) So we try. In August 2008, my incredible co-founder Lori Keith, a childhood cancer survivor herself, and I created [People Against Childhood Cancer \(PAC2\)](#) We researched reports like those issued by the [American Association for Cancer Research](#)-- Stand Up To Cancer's scientific partner. We spoke to childhood cancer organizations like [CureSearch](#) [St. Baldrick's Foundation](#) [Alex's Lemonade Stand Foundation](#) [Rally Foundation for Childhood Cancer Research](#) and [Hope Street Kids](#) along with doctors, kids and parents.

We knew these organizations and people would be louder and stronger if they spoke as "One Voice United Against Childhood Cancer." That became our motto. So we created [PAC2](#) a free, grassroots, online social network for the childhood cancer community, a place to share news, debate, support and knowledge on pediatric cancer. We focus on raising awareness and uniting the 80 childhood cancer organizations we proudly count as members.

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In January 2009, PAC2 mobilized to ask for increased funding for childhood cancer from President Obama as part of his transition team's initiative to rank issues important to the American people. With over 125,000 requests submitted and 1.4 million votes cast, our request finished #5 in health care concerns, and was presented to President Obama in the [Citizen's Briefing Book](#) (No, we haven't heard back . . . yet.)

After one unbelievable year, our efforts have led us here, to unite with Stand Up To Cancer in raising awareness of childhood cancer and fighting for a cure.

September is National Childhood Cancer Awareness Month and September 12th is National Childhood Cancer Awareness Day. Throughout this month, SU2C will be hosting stories of amazing children and people all fighting childhood cancer. I hope their stories will inspire you to take action. Unfortunately or fortunately, our childhood cancer community is, well, "rare," and we need all the help we can get: help to make sure that every dad's arm aches forever, not his heart; that moms worry about their kids' mischief, not whether kidney damage from treatment will postpone the next round of chemo. For their kids, for your kids, help change the paradigm.

--Donate time and money generously to SU2C.

--Check the [September 2009 Childhood Cancer Awareness Month Calendar](#) and participate in fundraising events by CureSearch, Alex's Lemonade Stand, St. Baldrick's Foundation, The Rally Foundation and others throughout the year.

--Support full funding of the [Carolyn Price Walker Conquer Childhood Cancer Act](#)-- in line with the efforts of the CureSearch Advocacy Network.

Please join with [PAC2](#) and fight childhood cancer.

Thank you for listening. And for acting. Because someday, God forbid, you might be the one who is forced to say, "Childhood cancer isn't so rare after all."

--AJ's Dad

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**Bob Piniewski** is a Project Coordinator, ironically cleaning up Superfund sites and saving bugs and people from risk -- i.e., cancer-causing agents. As [PAC2](#) co-founder, he helped the childhood cancer community collaborate with SU2C to highlight childhood cancer. He lives a [New Normal](#) He dedicates this to AJ, his "favorite" son and best friend forever . . . "AJ, sometimes you'd say something to make me laugh or cry, and I would think, how did you even THINK of that?" -- Sis