

Senator Thomas Carper
513 Hart Senate Office Building
Washington, DC 20510

November 14, 2009

Dear Senator Carper,

Because your job is to well- represent the citizens of Delaware, I am hoping you'll take in to consideration what I have to say, as a fellow Delawarean.

My name is Ali McDonough. I graduated from Ursuline Academy in 2008 and I am currently a 19 year old sophomore at the University of Delaware.

You attended a fundraiser at Salesianum School for my family while my brother was sick and you know my aunt, Mary, so I know you've been introduced to my family's story and the importance of funding for childhood cancer, but I'm sure you've forgotten as the life of a senator must be so hectic. With that being said, please allow me to refresh your memory as this issue is unbelievably important.

January 27, 2007 my 14-year-old brother and best friend, Andrew, played 4 soccer games, winning the state championship for his elite travel soccer team, FC DELCO. Forty-eight hours later, he was in cardiac arrest at AI DuPont Hospital, in Wilmington, as you know, with a diagnosis of Acute Myeloid Leukemia and Septic Shock. In case you aren't aware, septic shock is when there are toxins, often infections, in your blood stream. Andrew went from weighing a healthy, 130 pounds to 190 pounds within hours due to the amount of fluids they needed to pump into his body in order to keep his blood pressure at a level that could keep him alive. My parents and I weren't allowed inside his hospital room in the Pediatric Intensive Care Unit during this time because the doctors were doing everything they could to keep Andrew here, on Earth, with us. The doctors told us to start saying our "good-byes" as Andrew wouldn't make it through the night. How were we supposed to take that? Naturally, we were absolutely shocked. The next emotion I remember was determination -- determination to prove the doctors wrong. They didn't know Andrew and they didn't know the fight and will to live he had inside of him. True to form, Andrew made it through the night. Unfortunately, the rollercoaster of a journey was just beginning. Day after day Andrew fought. He fought like a champion.

Andrew went through intense rounds of chemotherapy in an effort to rid his body of the Leukemic cells. However, because of the lack of funding given to Pediatric Cancer Research, children's bodies get infiltrated with "watered down" chemotherapies used in adults. Over the past two decades, only ONE new cancer drug has been approved for pediatric use. Now tell me, how does that make any sense? How is it that a full-grown adult and a child get the same level

of toxic chemicals pumped into their body, as their only chance of survival simply because of a lack of funding? I just don't get it. If you understand the reason, please enlighten me as I would love to hear a plausible explanation. Chemotherapy doesn't simply wipe out the "bad" white cells, it takes them all. The patient is left with zero white cells, in a state called neutropenia, in which they get injected with shots to boost their cell count. As you know, a person's white cells make up their natural defense system, their immune system. Without a natural defense system, there is nothing to stop infections from setting in and taking over the body. That's just what they did in Andrew's body.

After a round of chemotherapy, Andrew's fevers started to spike, an immediate sign of infection. Cultures were taken and they came back positive for an absolutely dreadful fungus called Fusarium. The thing is, bacterial infections can be combated with antibiotics. Fungus, on the other hand, is a whole 'nother ball game. There was absolutely nothing Andrew, or anyone for that matter, did wrong to put the Fusarium in Andrew's body; it simply was because of the lack of white cells as an immune system. As we soon learned, antibiotics can't touch Fusarium. Our next goal was to stop the spread of the Fusarium. Andrew's Infectious Disease doctors at A.I. communicated with an amazing man, Dr. Walsh, at the National Institute of Health and tried to come up with an attack plan against this beast of a fungus. They worked tirelessly and truly cared about Andrew and for that, I am eternally grateful. The Fusarium was out of anyone's control and spread to Andrew's eyes for which the Ophthalmologist told us Andrew would no longer be able to see. Are you kidding me?! What more can this innocent boy go through? And it's all because of a lack of funding for research that could work to find better chemotherapy treatments and look for a cure for these pediatric cancers. As life changing as that news was, we could deal with it if that ended up being the situation as long as Andrew was still here with us. Andrew underwent multiple eye surgeries and the amazing doctor was able to repair his retina and remove the infected area. We're in the clear, right? Nothing more could go wrong, right? Very wrong. The Fusarium spread to Andrew's brain. Andrew experienced multiple hemorrhages, a stroke, an ultimately an aneurysm that would force him to be airlifted to Jefferson Medical Hospital in Philadelphia for emergency brain surgery. Andrew didn't leave A.I. Hospital once. Since he went to the Emergency Room for an expected Appendicitis that turned into a cancer diagnosis, Andrew never returned home to our house on Rockland Circle. After 167 days in A.I. DuPont Hospital for Children, Andrew went to Heaven on July 14, 2007.

Andrew's story is one of, literally, millions. Are you aware that each school day, 46 children are diagnosed with cancer? Do you know that, on average, 12,500 children and teens will be diagnosed with some form of childhood cancer each year in our country? How about that in the U.S. almost 3,000 children do not survive childhood cancer each year? I bet you don't know that Cancer remains the #1 disease killer of America's **children** - more than Cystic Fibrosis, Muscular Dystrophy, Asthma and AIDS combined. There are 15 children diagnosed with childhood cancer for every one child diagnosed with pediatric AIDS. Yet, the U.S. invests approximately \$595,000 for research per victim of pediatric AIDS and only \$20,000 for each

victim of childhood cancer. Isn't it devastating that currently there are between 30-40,000 children undergoing cancer treatment in the U.S.?

One fact I do know you are aware of, because it's your job as the government to decide is that: research funds are scarce for pediatric cancers as most money is diverted to well-publicized adult forms of cancer, such as breast and prostate. The National Cancer Institute's (NCI) federal budget was \$4.6 BILLION. Of that, breast cancer received 12%, prostate received 7%, **and all 12 major groups of pediatric cancers combined received less than 3%**. The above figures are absolutely appalling and unacceptable.

Savannah Pauley (www.caringbridge.org/visit/savannahpauley1),
Matthew Faulkner (www.caringbridge.org/visit/matthewfaulkner),
Erin Brennan (www.caringbridge.org/visit/erinbrennan),
Lara Phillips (www.caringbridge.org/visit/laraphillips),
Zackary Adamsky (www.caringbridge.org/visit/zackaryadamsky) and sadly, many, many more innocent, beautiful children from your state of Delaware who passed away because of a disease that is highly lacking in funding and awareness. These kids are true heroes who didn't lose ANY fight. They won the battle, just in a different way than we as families had hoped.

Thankfully, not all children diagnosed with cancer pass away. However, three out of five children diagnosed with childhood cancer suffer from long-term or late onset side effects.

Delaware heroes like Joey Borowski (www.caringbridge.org/visit/joeyb),
Pearce Quesenberry (<https://www.carepages.com/carepages/PearceRock>),
Drew Koenig (www.caringbridge.org/visit/drewkoenig),
Evan Nickle (www.caringbridge.org/visit/evannickle),
Molly Anderson (www.caringbridge.org/visit/mollyanderson),
Molly Zahner (www.caringbridge.org/visit/mollyzahner),
Hayden Godwin (www.caringbridge.org/visit/haydengodwin),
Sydney Lysinger (www.caringbridge.org/visit/sydneylysinger),
Zackarey Turner (www.caringbridge.org/visit/zackareyturner),
Sammy Bradly (www.carepages.com/carepages/Bradly),
Noxah Palomo (www.carepages.com/carepages/Noxah) are fighting and surviving their childhood cancers each day.

Right now, this second, somewhere in America, there are 7 children fighting for their lives who won't live through the day. In the second that you just read the line above, a child was fighting to live; an innocent child that won't make it through the day because there aren't sufficient funds for research into the horrid pediatric cancers.

I'd hate to think that a lack of funding could cost someone their life, but think about it....it CAN, it IS, and it HAS.

Congress passed the Caroline Pryce Walker Childhood Cancer Act in 2008, however it has not yet received any funding!! The House of Representatives included \$10 million in their version of the bill as a first step to partially fund the Caroline Pryce Walker Conquer Childhood Cancer Act. The Senate Labor Health and Human Services Appropriation bill is in conference. PLEASE DO THE RIGHT THING.

I'll never be able to put into words how extremely heartbreaking it was to watch my absolute best friend, my only sibling, go through such pain, such Hell. The memories of doctors rushing into Andrew's hospital room to try to resuscitate him multiple times will forever be with me. The memories from his battles in the hospital are engraved in my mind. The memories of his tears running down his face because the pain was unbearable, but no once did he complain, will always be with me.

My life has been forever changed, but one thing is for certain, I HAVE a brother. Andrew IS my best friend. I WILL carry Andrew with me where ever I go.

As I sit here, literally, shaking reliving this awful journey in an effort to portray this heinous disease to you, I hope that you understand the point of this letter. I hope that at least one piece of it had an impact on you. I hope that you will represent YOUR citizens in Delaware who are fighting for their lives in A.I. DuPont Hospital for Children this minute and bring to the Senate the dire NEED for funding for Pediatric Cancers.

I pray to God for you and your families that you never have to go down the road that my family and so many others have been unwillingly led down. I would not wish this awful journey on anyone, but I'm on this journey now. My rollercoaster isn't over and it's not going to be over until we have a cure so no other family experiences what I have.

I hope you will fight as hard for these kids as they fight to live.

Please make Delaware proud.

Sincerely,

Alison McDonough

"Andrew's Sister"

101 Rockland Circle

Wilmington, DE 19803

www.caringbridge.org/visit/andrewmcdonough