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The RACE for Children Act

Thank you for supporting the RACE for Children Act (Research to Accelerate Cures and Equity for Children), a new law requiring novel and exciting cancer therapies to be developed not only for adults, but also for children with cancer. Now, the FDA will require pharmaceutical companies to conduct pediatric studies when the molecular targets of the drugs in development are relevant to pediatric cancers.

This has been a heroic effort and there are many who deserve praise and thanks, including our champions on Capitol Hill, experts at the FDA, NCI and NIH, medical research centers, pediatric cancer advocacy organizations, youth advocates, kids in treatment and survivors — everyone who cares about children with cancer.

With the enactment of each federal law — the RACE for Children Act in 2017, the Creating Hope Act pediatric priority review voucher program (21 U.S.C. 360ff) in 2012 and the reauthorization of the Creating Hope Act in 2016 — we are taking new steps to find cures for kids with cancer.

This Thank You book is our expression of gratitude to all who are changing the landscape of pediatric cancer.

The Kids v Cancer Team
Nancy Goodman, Elena Gerasimov, Jennifer Flynn and
Leika Uzcategui



SADIE

My name is Sadie Keller, I am 10 years old and I just finished 2 1/2 years of chemotherapy treatment for acute lymphoblastic leukemia. I was diagnosed when I was seven, and in the second grade. I never thought something like this would happen to me. I will never forget the day my parents were told I had cancer. I was sitting on my mom's lap and when she started to cry, I whispered in her ear, "Mommy, am I going to die?" while I was crying. I was so afraid. We went straight to the hospital and that day my entire life changed. I started chemotherapy immediately, I had surgery to put my port in the next morning, and the side effects began. I have always gotten the VERY rare side effects; the scary ones that aren't on the side effect sheet.

Some of the things I went through include a reaction to platelets, horrible migraine headaches, methotrexate neurotoxicity, countless chemo fevers and ER visits, an E-coli infection which led to sepsis and my port having to be removed leaving a huge open wound in my chest that took 12 weeks to close.

So as you can see, what children go through is terrible. There is no bike riding, no school, no running and playing with friends, but more like hospital visits, the nurses and doctors become your best friends, and there are more pokes and prods than you could ever imagine.

I always like to not know what to expect and I started making videos explaining what it's like to have cancer as a child.

In 2015, I decided to do a toy drive for all the kids fighting cancer, and named it Sadie's Sleigh. My first goal was to collect 300 toys. This year, I have eight other kids and parents who will be collecting and delivering to their local children's hospitals all over the country!

I also had the opportunity to lobby for the RACE for Children Act with Kids v Cancer and meet with Congressman McCaul (thank you so much for passing this!!!). I loved it and was so happy!

People ask me what it's like to be done with treatment and the thing is, although it is good, right now I don't feel any different. I have to go to PT and OT, I just went through a huge scare that my cancer was returning (thank GOD it hasn't), but that fear will always be there. It's not over, it just changes.

I get asked if now that I am done, if I just want to stop doing all that I am doing and go back to being a normal kid. I won't ever stop! I will always be an advocate and fight for more funding and to one day stop this from happening to more kids.

Kids are dying! How is that ok? Right now, three of my close friends are fighting for their lives.

The thing is we can keep doing more. That is why I am doing what I do and will keep fighting. Together we can make a difference and we are!

Sadie Keller



Kids are dying! How is that ok?



MATILDA

After seven years of clear MRIs, her father accepted a posting to Afghanistan. Unfortunately, only six months into his posting, I had to make the most difficult call of my life.

In July 2009, our world forever changed. Our beautiful 15-month-old, Matilda, was diagnosed with an anaplastic ependymoma, a rare pediatric brain tumor.

When the surgeon told us that nearly all of the tumor was successfully removed, we felt a weight lifted from our souls. However, the best treatment was not curative, but it could give her a fighting chance.

For the next few years we approached every MRI with fear as we watched her deal with the side effects of treatment toxicity. We were told to have faith. Faith in science, faith in the promise of tomorrow. So we set aside our fears.

After seven years of clear MRIs, her father accepted a posting to Afghanistan. Unfortunately, only six months into his posting, I had to make the most difficult call of my life and tell him that her routine MRI revealed a recurrence.

We were shocked that what was presented to us for treatment had hardly changed from her original diagnosis. Over seven years with no cure, no improvement in survival rates, no new effective options? We thought that with all the promising advances in adult cancers, after years of fundraising, and lobbying there must be some kind of curative option or even just a successful treatment...

The RACE for Children Act will widen her access to potential treatments otherwise not available. Time is not on her side, and the RACE Act could save her life.

Lindsay Campbell-Reidhead

JOHN

On August 14, 2004, I was diagnosed with acute lymphoblastic leukemia. I was 4 years old. My family was shocked and frightened.

Since I was only four I was oblivious to the hardships to come. I did not know why my family was huddled around me, praying for my well-being. I did not know why my mother was crying every day. I was able to blindly ride into cancer with all the hope, love, and happiness of a young child, but everyone else knew what was coming.

I went from being an energetic, healthy little boy who loved Thomas the Train, Batman and my red cowboy boots, to a child who would endure five years of treatment. My treatment was hard, like everyone's. Months of chemo, endless blood draws, spinal taps and hours of my crying.

I was lucky. My treatment worked. For many, it does not, and that is what makes the RACE for Children Act so important. It will allow more kids' stories to sound like mine. Hard but not impossible. Difficult but not hopeless. It will give hope to many families like mine and open up futures for many kids like me.

John Ford

I was lucky. My treatment worked. For many, it does not, and that is what makes the RACE for Children Act so important.



AMELIA

On November 20th, 2015, my daughter Amelia had brain surgery and received the diagnosis of glioblastoma multiforme. Amelia underwent radiation and chemotherapy. Her post-radiation MRI showed no signs of cancer, so we held onto so much hope.

Before Amelia started chemotherapy, she had her wish granted through Make-A-Wish Foundation. Amelia wished to be someone who took care of the world by picking up litter. On February 27, 2016, people everywhere were picking up litter in Amelia's honor. At eight years old Amelia made an impact on the world.

Amelia's chemo treatments made her pretty sick but she always bounced back. She started playing soccer. She was a defender and absolutely loved it. As soon as soccer ended, Amelia started playing softball.

Then at her MRI in September 2016 we learned the cancer had shown up in her left ventricle.

We took part in a phase 1 trial at St. Jude in Memphis. We even spent some time picking up trash on the St. Jude's campus.

On October 21, 2016 we learned that the trial meds were not working. Amelia was sent home.

This entire time I was trying to find something to save my daughter. There were some promising trials and I reached out to them, but I was told the trials were for adults only.

Sadly, Amelia passed away on October 26, 2016. She was such a strong, loving, energetic little girl who faced cancer with such heroism. She deserved so much more, she deserved more options.

Jill Meyer

Amelia was such a strong, loving, energetic little girl. She faced cancer with such heroism.



MICHAEL

In a world where most children's biggest choice is macaroni and cheese or peanut butter and jelly, my twin brother, Michael Gustafson, lived amidst quite a different reality.

He didn't choose to be diagnosed with medulloblastoma when he was ten years old. He didn't choose to lose the ability to play the sports. He didn't choose for his cancer to metastasize, dropping his 80% survival rate to just 5%. And he certainly didn't choose to die at the age of 15.

If the RACE for Children Act had been around during his life, maybe he could have chosen a treatment plan instead of being told by his doctors that there were no drugs in the pediatric pipeline available to treat his cancer. It would have been a much harder choice than macaroni or peanut butter, but it would have been a choice nonetheless. Michael didn't get a choice, but I pray the RACE for Children Act will provide other children and families with one.

Bridget Gustafson



If the RACE for Children Act had been around during his life, maybe he could have chosen a treatment plan instead of being told by his doctors that there were no drugs in the pediatric pipeline available to treat his cancer.



I was stunned and angry because I had targeted treatments and an 86% chance of survival while my son had “no known cure” and less than a 10% chance for survival.

BRADEN

Braden was diagnosed with stage IV high-risk neuroblastoma when he was three years old. He fought for nearly a year and a half, but his cancer came back.

Diagnosed with autism, Braden didn't know that he had cancer so he just continued to live and play and love. His neuroblastoma went into a second remission.

Three months after Braden's second relapse, I felt a lump in my breast. It was Stage II invasive ductal carcinoma, a type of breast cancer. I had a double mastectomy.

Braden and I had chemo on the same days. We were bald together, and Braden was my inspiration through my treatments.

I was stunned and angry because I had targeted treatments and an 86% chance of survival while my son had “no known cure” and less than a 10% chance for survival.

Then Braden was diagnosed with leukemia that was caused by the treatments that he had received for neuroblastoma. His then 10-year-old brother Zach was a perfect match and donated his bone marrow. To date, Braden has been in remission from both of his cancers for 3 1/2 years.

My husband and I, and our faithful friends started a nonprofit organization to fund research to find targeted treatments for childhood cancer. This year we will begin to fund three \$1 million research trials.

Deliece Hofen

MELINDA

I was diagnosed with Hodgkin lymphoma on December 18th, 2007 — an inoperable 13 x 9 cm tumor sat in my chest cavity. I had no idea what was going to happen to me. Then, my doctor said with calm reassurance, “We're going to melt it with medicine”. I felt a weight lifted — there were *options*.

I rode the ups and downs of chemotherapy and radiation. My tumor responded.

The experience of a child with cancer is wildly unpredictable. Every second you face the unknown, not having a clue what the next day, or even the next moment, will bring. I was taught that in life, there are always *options*. If circumstances are undesirable, there are *options* that can, if not fully remedy things, bring you one step closer.

Today, I am here because past accessibility of trial drugs for children has increased the survival rate of Hodgkin lymphoma to 97% when, not long ago, it was a certain death sentence. Because preceding children were given the *option* of a second chance, I have been given the opportunity to have a beautiful life beyond cancer.

Melinda Marchiano

Because preceding children were given the *option* of a second chance, I have been given the opportunity to have a beautiful life beyond cancer.





My twin brother Nate is my other half and was my best friend for as long as I can remember. Although very different in our appearance and our interests, we always thought of ourselves as two parts of the same whole. Unfortunately, our world was turned upside down the week of our fifth grade graduation when Nate was diagnosed with a baseball-sized Ewing family tumor in his lung that had metastasized to surrounding lymph nodes and his femur. Nate inspired me as he courageously and optimistically lived life to the fullest while enduring grueling surgeries, harsh chemotherapy, palliative radiation and many hospital stays during our middle school years. On December 9, 2015, my twin brother Nate died during our freshman year of high school.

More must be done to ensure that every child diagnosed with cancer has a chance to live a full life. I am sure that Nate would have been a great doctor - his dream - if *our* 14th birthday had not been *his* last.

Lexi Cavallo

Nate would have been a great doctor - his dream - if *our* 14th birthday had not been *his* last.

NATE

GRAYSON

My name is Grayson. I am seven years old. When I was 2 ½ I started to complain to my mommy (her name is Jackie) that my room was spinning. On Halloween 2012 I was diagnosed with brain cancer, a medullary fibrillary astrocytoma.

I have spent most of my life in and out of hospitals. I have undergone countless craniotomies. I have a permanent shunt in my skull to regulate the pressure in my brain. I have gone through 18 months of weekly chemotherapy.

And I have more friends in heaven than I may have here on earth.

I made four really good friends while on treatment: Lucy, Brielle, Charley and Jillian. Lucy died first. She was 13. My mommy told me that the little light inside of her got very tired and went up to Heaven. I pray to Lucy all the time. I ask her to make sure my tumor doesn't grow.

Brielle died in 2016. I cried and slept with my mommy for a long time after Brielle died because Brielle was the same age as me at the time, six. I planted a tree for Brielle when she died. I call it the "CHOP Tree" because we were all treated at CHOP.

Eight months after Brielle died, my friend Charley died. She was three. I cried a very long time after she died because three years is just not enough time. My mommy says that when Charley died that a giant rainbow painted itself across the sky. I always look for rainbows.

It's just me and Jillian now. We ran the Lemonade Stand at the 5K that we held for Brielle's birthday in heaven. Jillian is five and she is very sassy. Mommy said that Jillian's cancer is growing back and that her little light is getting very tired as well.

No one is sure why the treatment that I had worked for me and why the treatment my friends had did not. My oncologist, Dr. B said that when my tumor wakes up and starts growing again that she has a Plan B.

I am glad there are plans that my doctor and parents have for me, but I still worry about what will happen when there are no more plans.

My plan is to grow up to be either a BMX Biker or a doctor.

Grayson Patrick Savery and mom Jackie



I am glad there are plans that my doctor and parents have for me, but I still worry about what will happen when there are no more plans.



THEA

We have hope that better treatments will be found that are more effective, less toxic, and that give Thea, and all kids with cancer, the chance to thrive, and not just survive.

Ten years. A milestone. Our daughter has a 10-year milestone of her own, but not one that anyone would want. She has been fighting cancer for 10 years.

Thea was just four months old when she was diagnosed with a brain tumor. For 10 years she has endured countless procedures and therapies, about 50 MRIs, 13 surgeries and five different protocols of chemotherapy.

The side effects of all of these treatments have been disabling for Thea. At 10, she still needs help with most of her daily needs like dressing, bathing and just getting around. She has a feeding tube and is legally blind. She struggles with everything that comes easy to most kids.

But she perseveres because we have hope. We have hope that better treatments will be found that are more effective, less toxic, and that give Thea, and all kids with cancer, the chance to thrive, and not just survive.

Trisha Danze

AIDEN

Aiden was the light of my life. As a single mom I was with Aiden almost all the time. After he was diagnosed with cancer that became even more true. We stayed in hospital beds together and he slept in my bed because he was always so sick.

Even when he was sick from chemo or trying to learn to stand on a fractured leg he was still always so happy and smiling. He loved balloons and bubbles and would dance anytime there was music.

Before we found out about his cancer he was just like any other baby. When he started to crawl there was no stopping him, even though he would only use one arm when he moved — we later found out he had a tumor in another arm.

Aiden was diagnosed with stage IV high risk neuroblastoma in June 2015

and started chemo on his first birthday. He faced surgeries, broken bones, stem cell transplant, countless transfusions and so much more.

On December 11, 2015 Aiden went into septic shock and passed the following morning. A child should not have to face such a horrible battle and certainly should not pass away because of it.

My sweet angel Aiden will always be in my heart. He touched so many people's lives as we shared his journey and even still he is making an impact on others.

I now have created a nonprofit in his honor to help other kids his age feel some type of happiness, however brief, while they are facing this battle.

Erica Schneider
Aiden's Army

My sweet angel Aiden will always be in my heart



ELIJAH

Before being diagnosed with cancer, Elijah was a typical nine-year-old boy who enjoyed baseball, basketball, swimming and playing with friends. More than anything, he loved his family, especially his little brother Sam. He had big plans of growing up, going to middle school dances and even playing on The Wheel of Fortune.

I remember a note he left his brother. It said, “Sam, I’ll be back in a couple of days. I’m going to Atlanta to beat cancer.”

Instead, he died in my arms less than a month before his 11th birthday. Despite having virtually no treatment options for his extremely rare form of cancer, epithelioid sarcoma, Elijah never once asked “Why me”, or felt sorry for his situation.

I remember a note he left his brother as we departed for the one clinical trial that would accept him, and it said, “Sam, I’ll be back in a couple of days, I’m going to Atlanta to beat cancer.”

Elijah never once gave up hope, even though the odds were stacked against him. Upon return from Atlanta, we were told we had no more options. Hospice was called.

My son had an amazing heart that should still be shining brightly in this dark world. The world lost so much November 15, 2015 at 10:52 p.m.

Becky Hughes



LILA

My name is Lila Giroux and I am nine years old. I was 15 months old when I was diagnosed with inoperable brain cancer. I don’t remember this time, but my mom told me I hated being at the hospital and that I cried a lot.

The thing that I remember being the hardest about my cancer was when I had a port and it was very hard for the nurses to make it work sometimes. It got me very worried and upset.

Mostly though, I am very happy. I have a lot of friends at the hospital because I have been going for so long that a lot of people know me. I still have to go to sleep for an MRI every three months.

I am going to be in the third grade at St. Andrew Apostle School in the Fall. I love school, my friends, music and swimming.

Lila Giroux



I was 15 months old when I was diagnosed with inoperable brain cancer. I love school, my friends, music and swimming.

COLIN

Colin was a happy, energetic, fun-loving kid. He was diagnosed with autism at three years old. He was always determined, he wanted things his way, he never let anything slow him down.

On New Year's Eve of 2015 we brought Colin to the doctor because of a cough. Scans showed a large mass. Colin had a surgery to remove a 23 cm tumor called undifferentiated sarcoma and his left lung.

He returned to school and began to live just as he did before. But then on the morning of May 7th, 2016 we rushed Colin back to the hospital. He was diagnosed with a very rare cancer known as inflammatory myofibroblastic tumor.

Over 15 months he was at six different hospitals, 10 different trips to the ICU, underwent cardiothoracic surgery, endured multiple rounds of chemo, 15 rounds of radiation, had been eating through a feeding tube for over seven months, was put on a ventilator six times, was in a wheelchair for the last seven months — all the while smiling, laughing, hugging and giving us the “thumbs up”.

Throughout his battle Colin never complained of pain, he continued with endless strength and hope every day. He lost his battle with this horrible disease on March 17, 2017.

In honor of his amazing strength, we have started a foundation in his name, B Colin Strong. Our mission is to continue his legacy of strength, love and courage and to help support other families.

Michael & Diane Woodyshek

Throughout his battle Colin never complained of pain, he continued with endless strength and hope every day.



My illness began in the spring of 2009 when I was just seven years old. I started to fall. I stopped walking and stopped eating. I had a lot of hip pain, abdominal pain, and fevers. My family and I made countless trips to the emergency room and to my family doctor who could not find any reason for my symptoms. “Just eat,” the doctors would tell me since I lost 7 lbs in a week. After two months, my doctors finally sent me to Children’s Hospital of Pittsburgh. I endured several tests and met with endless doctors until the diagnosis was made: acute lymphoblastic leukemia. Chemotherapy started right away.

The good news: I was in remission just 21 days later. The bad news: I still had to endure over three years of chemo. I am proud to say my last chemo treatment was in 2012.

It is so vital to pave a better path for other children with cancer, to make improvements and find cures so one day NO family has to endure what so many already have.

Thank you for your continued support fighting childhood cancer. Please continue to fight for these kids and their families.

Brent Thomas

It is so vital to find cures so one day no family has to endure what so many already have.

BRENT





ALEX

I was doing my 8th grade algebra homework when the phone rang. We learned that my 15-year-old brother, Alex, had a tumor in his brain. My world stopped.

We rushed to the Children's Hospital of Philadelphia. Alex had brain surgery and we were told it was cancer, medulloblastoma.

After radiation, my brother had to be hospitalized for overnight chemo every six weeks for a year, with more chemo in between. Vomiting, infections, multiple bouts of pneumonia, septic shock. The week before his last chemo was scheduled, we learned that his cancer was back.

Alex, my best friend, died during my sophomore year in high school. I was devastated.

He had a subtype of medulloblastoma that not much is known about. Perhaps if we knew more about this particular subtype his doctors could have personalized his treatment. The RACE Act holds the promise that these types of breakthroughs may become available for children.

Prioritizing children should not be a debatable question in our country, it should be our moral obligation.

William Muñoz
UC Berkeley 2021

I was doing my 8th grade algebra homework when the phone rang. My world stopped.

JENNIFER

When I discovered a lump on my 2½-year-old daughter's abdomen I never could have imagined how our lives would be turned upside down. She was diagnosed with hepatoblastoma, a liver tumor.

After major surgery she began chemotherapy. Then the tumor was removed. There would be years of follow-up exams and tests to make sure it did not return. The only long-term side effect of Jennifer's treatment is bilateral high-frequency hearing loss. She has had hearing aids since she was about six years old.

That cute 2½-year-old is now a 24-year-old pediatric oncology nurse on the same unit at Children's Hospital of Philadelphia that saved her life 21 years ago. She is giving back to help other patients that are going through what she did all those years ago.

Jennifer also accompanies me and her younger sister as we attend many events to raise awareness for childhood cancer and to meet with our elected officials to ask for more federal funding for newer and less toxic treatments.

So many children and families are not as fortunate as we were, so we will continue to fight for them until no other parent has to hear those awful words: "Your child has cancer", or worse, "There are no more treatment options left to try".

Gail Toth

That cute 2½-year-old is now a 24-year-old pediatric oncology nurse on the same unit at Children's Hospital of Philadelphia that saved her life 21 years ago.





I am a two-time cancer survivor. I was diagnosed with Ewing's sarcoma, which is a rare cancer of the bone, when I was a 15-year-old freshman in high school. I went from having your normal day-to-day interactions with friends to sleeping every night in a hospital bed. Being diagnosed with cancer created such a drastic change in my life to the point where I had absolutely no idea what to do with myself.

I was pulled out of high school for the remainder of high school years and attended home and hospital teaching. It was so hard because I wanted to be normal so bad just like my peers but I just couldn't.

After a year of treatment I was cancer-free for about nine months before being diagnosed with sarcoma the second time. This time I had to do about half a year of oral chemotherapy and a major surgery to reduce the tumor.

My relapse just showed that the little research that was done clearly wasn't enough to help my disease the first time around. Pediatric cancer only gets a limited amount of funds to do research, and it's just unfair how little we get.

Brittney Etienne

I am a two-time cancer survivor. It was so hard because I wanted to be normal so bad just like my peers but I just couldn't.

BRITTENY



CHRISTOPHER

Christopher and I had a classic sibling relationship, where I often saw him as the annoying little brother and he saw me as the older sister whom he loved to annoy. My favorite childhood memories are easily the ones that Christopher and I shared together, like playing on his Xbox, spending hours on end at the beach, and making the most boring situations fun by making each other laugh.

On August 14th, 2009 my nine-year-old brother was diagnosed with a brain tumor. He underwent surgery, received proton radiation and chemotherapy.

All of the treatment proved ineffective and we had to say goodbye to Christopher on March 31st, 2010.

Anyone that had the pleasure of knowing Christopher would agree that he was exceptionally friendly and had the best sense of humor. He maintained this even throughout his

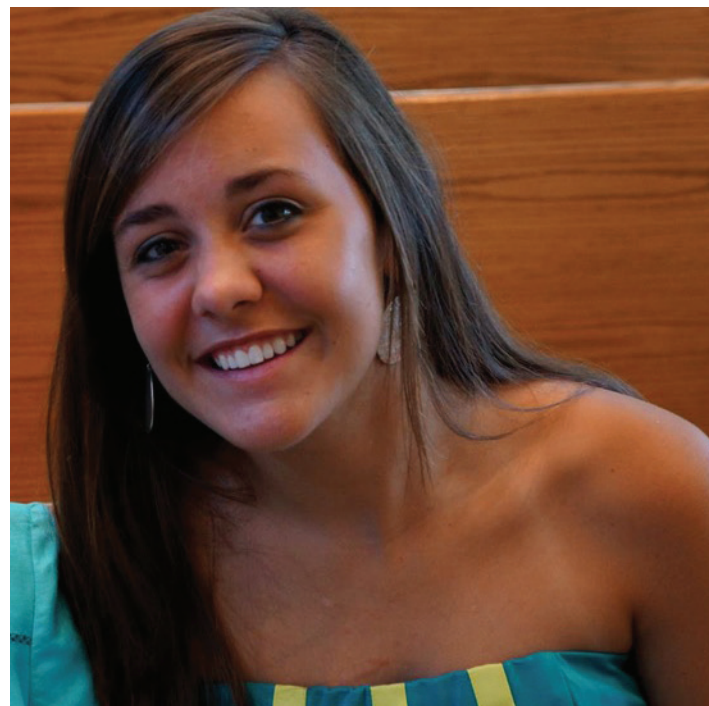
We miss Christopher every single day. My family has found comfort and joy in aiding in the effort to find a cure for pediatric brain cancer.

sickness and faced each challenge with the same happy disposition we had always known him to have.

We miss Christopher every single day. My family has found comfort and joy in aiding in the effort to find a cure for pediatric brain cancer.

Caitie Brandle

Through this whole experience I learned how precious life is. The Lord showed me how to live life not in fear, but in hope.



CORRIE

Twelve years ago I was diagnosed with acute lymphoblastic leukemia. It started with just pain in my leg, bruising, and being constantly sick but this soon became my life for 2½ years. I had all kinds of procedures such as spinal taps, blood transfusions, and chemotherapy in order to cure the cancer.

Through this whole experience I learned how precious life is. The Lord showed me how to live life not in fear, but in hope.

Many of my friends passed away from cancer, and my whole experience with leukemia still affects the way

I see things today. However, I see my cancer as a blessing in my life because of the people who influenced and loved my family and I during that hard time.

Cancer has taken away many important people from me, and that is why I think we need to research drugs for pediatric cancer. Along with my friends, I, too, had to have treatment with adult drugs, and I believe we need to have better options for kids battling cancer. Pediatric cancer is so prevalent, and it needs just as much attention as cancers in adults.

Corrie Hester

“Do you ever get sad and blue? Well, I have a list!” As my daughter Julia and I cuddled in bed, she asked me this question and proceeded to give me a list of ten things to do to make you happy:

“#1 – Grab a friend and have a lunch date...# 5 – Think about puppies...#10 – Give someone a hug...”

A few days after Julia gave me this precious list, she died.

This simple conversation best portrays Julia – an 8-year-old who always put others first. When she was first diagnosed at the age of five, she tried to find ways to make the other children at the hospital happy. From donating all of her birthday gifts to other children at clinic, to insisting that a fundraiser for her go to help others at her hospital,

Julia was so generous and kind. And during her last days, when Julia knew she was dying, she worried about how we would be happy.

Julia was diagnosed with Wilm’s tumor in 2009, shortly after her 5th birthday. When Julia relapsed the last time, we were faced with the cruel reality: There were no options, there were no current trials for Wilm’s, there were no new drugs and ultimately, there was no future for our beautiful daughter.

We dream and work towards a future of “yes” – a future when children diagnosed with cancer have options for safe and effective treatments, and a future filled with happiness for every child.

Janet Miller-Eveland
Julia’s Grace Foundation

Do you ever get sad and blue?
Well, I have a list!

JULIA



Julia's Grace
FOUNDATION



HANNAH

When I was 13, I was diagnosed with a form of brain cancer called medulloblastoma. I was just starting my 8th grade year as an active teenager. We had just moved to North Carolina. I left all my family back in Missouri, other than my mom and dad.

March 14, 2014 was the scariest day of my life. It started early in the morning with an MRI and the next second I was being prepped for surgery. The moment I heard the word “cancer” come out of my doctor’s mouth I thought my life was over.

I was told after getting out of the hospital that I would be going through six weeks of radiation five days a week and about a year and a half of chemo. I felt alone in this fight except for my parents. My family has lost the financial stability we once had, including my college fund. I feel like not only have my teen years been messed up but also my future. Due to treatment, I am now infertile, and I suffered stunted growth. I am very happy to be alive but it comes with a lot of pain.

Hannah Brittain

I am very happy to be alive but it comes with a lot of pain.

Kelsey Taylor Luria, April 12, 1997 – April 18, 2015

“I am more than cancer” – these are the words that Kelsey Taylor Luria wrote just over two years ago, shortly after being diagnosed with acute myeloid leukemia (AML) six weeks into her senior year. During her 5+ months battle against AML, Kelsey showed her friends, family (and even herself), what she was made of.

Those five months Kelsey grew up faster than her peers, as she endured painful procedures, countless chemo treatments, tests, blood transfusions, dressing changes and the frequent indignities that come from fighting this insidious disease called cancer.

Kelsey journaled during her treatment: “Tears aren’t a sign of weakness; tears are a sign of willpower to survive. I know there will be times I want to give up, but I’ll fight with everything I’ve got left”. Kelsey never gave up.

In the midst of her treatment and the fight for her life, Kelsey created a non-profit, Bald Beauties Project, to empower children and young adults with cancer. The Bald Beauties Project is donating to the Children’s Oncology Group to fund the Target Pediatric AML initiative.

Kelsey was far more than cancer.

Maya Luria
Bald Beauties Project

Tears aren’t a sign of weakness; tears are a sign of willpower to survive.

KELSEY



One of the biggest obstacles facing teenagers with cancer is lack of access to clinical trials.



JACK

I currently attend the University of Notre Dame. When I was a freshman in high school (14 years old), I was diagnosed with a pilocytic astrocytoma, a brain tumor.

Because of my fantastic team of healthcare providers at Children's National Medical Center I was able to make a full physical recovery. Despite being physically fine, I struggled for months after my diagnosis with depression and anxiety, largely due to a lack of age-appropriate care in my treatment process.

I currently work with organizations such as Teen Cancer America and the HopeLab, along with hospitals across the country to help establish age-appropriate care for teenagers being treated for cancer.

Through my work, I have noticed that one of the biggest obstacles facing teenagers with cancer is lack of access to clinical trials (even compared to younger cancer patients). Moreover, outcomes in many types of cancers in teenagers have not changed in the last 20-30 years!

It is my hope that one day no teenager cancer patient will be forced to struggle like I did. I implore you to consider teenage cancer patients while supporting or voting on various healthcare bills throughout your tenure in Congress.

Jack Guarino

KORTNEY

Kortney Gillette 11/27/1996 – 4/27/2006

My daughter, Kortney Rose Gillette had a zest for life. She was a daredevil with little fear and a spitfire who knew how to get her way. Kortney's smile and laugh would brighten any room she entered or place she visited.

She was the picture of health at her 9th birthday party. Two weeks later, I noticed that her left eye had become crossed. A visit to an optometrist, an MRI, and our life turned upside down. Kortney had a diffuse intrinsic pontine glioma (DIPG), a tumor in her brainstem. This tumor is a death sentence with no effective treatment. They gave her a less than a 5% chance of living for two years. Kortney died 4½ months later.

When we were thrown into this cancer world we were startled to learn that a meager 4% of NIH funding goes to all types of pediatric cancer research. It's a crime; our children are our future and need to be our priority! We felt compelled to help raise research funding because these kids need answers. Drugs need to be worked on for pediatric cancers and fast-tracked to the sickest of kids!

Kristen Gillette
Founder/Executive Director of The Kortney Rose Foundation



She was a daredevil with little fear and a spitfire.



July 1, 2013 was a day that turned into every parent's and grandparent's nightmare. Hearing that your granddaughter has a brain tumor will be forever etched in my memory. Little did we know at that time, but Millie had a predisposing genetic disease that caused her optic pathway/hypothalamic tumor, neurofibromatosis.

Millie has endured three years of chemotherapy. She spent the last year of treatment in-patient every other week because of the harsh side effects. November 6, 2016 was a great day that we celebrated in style. Millie "rang the bell" at All Children's Hospital and we were looking forward to returning to a normal routine.

Sadly, that normalcy did not last long. In late February 2017, Millie came home from school and told us she had lost the vision in her left eye. She was already legally blind. A scan revealed the tumor had grown.

Millie will have a biopsy in July. A biopsy is risky, but hopefully it will allow us to choose a targeted treatment for mutations the tumor is harboring. There is not an end to this story. We will continue to walk in faith and live by Millie's motto, "Today is the best day ever!"

Yvonne Sica

**There is not an end to this story.
We will continue to walk in faith and
live by Millie's motto, "Today is the
best day ever!"**

MILLIE

OLIVIA

When I was seven years old, I sat in a hospital wing playing games with a family friend until we heard the "beep-beep-beep" of the crash cart and I was summoned into a room where my father and a social worker told me that my sister had died.

I watched my mother hold Olivia, wrapped in her favorite pink comforter, in her arms. My sister's small but powerful body that contained so much energy, light, and laughter, was no longer able to fight the cancer attacking her. There were no more treatments or medicines that could save her.

No child should have to experience the loss and pain that my family went through, but more importantly, no child should have to give her all to fight a disease only to learn that the doctors can no longer help her, and that drug companies have put their profits before saving the life of even one, enormously important, little girl. The fact that my sister, and so many other children with cancer, are treated with 30-, 40-, 50-year-old drugs is a disgrace and a tragedy. They deserve so much more.

Anna Crowley



**When I was seven years old,
I was summoned into a
room where my father and a
social worker told me that
my sister had died.**

ROSS

March 8, 2002 – May 13, 2013

Up until July 3, 2009, our son was “regular Ross”, an upbeat “glass half full” child who loved his family & friends, playing hockey as left wing #33, cheering for the Blackhawks, spending time with his big sister Rachel and his border collie, Augie, and caring and praying for the homeless.

But July 3, 2009 was the last day Ross’ life was anything but regular. That night we heard the word “medulloblastoma” for the first time. Ross began the journey no child should ever have to take.

The next 1,411 days we observed, through Ross, how life really should be lived. He was never afraid. Never felt sorry for himself. He filled every day with family, friends, school, hockey, boxing, cartoons, wings, strawberries and everything he loved. Brain cancer did not take away his joy.

When all available therapies and surgeries had been done, we faced that moment that cannot be described.

In that family conversation Ross asked the three of us to promise that we would “never let another child go through what I’ve gone through”. We promised Ross. And our Foundation is that promise kept.

Kim MacNeill, “Momma”
The Ross K. MacNeill Foundation

The next 1,411 days we observed, through Ross, how life really should be lived.



SARAH

My name is Sarah Smith and I am a 7th grader at Montgomery Ridge Intermediate School in Maryville, TN. I live here with my parents, my two older brothers and my dog Vixen. Today, I am almost six years off therapy for acute lymphoblastic leukemia (ALL).

It all started in June of 2009 with a stomach ache and an ambulance ride to East Tennessee Children’s Hospital. Diagnosed at age four, I began my 2½ year journey of chemotherapy, bone marrow aspirations, lot of shots, pills, blood work, and injections. My room at the hospital became my home as we lived there for what seemed like forever.

We finally came home to try and be normal but our normal had changed. I always seemed to be tired. I couldn’t walk or do stairs. My hair totally fell out. I had no eyelashes or eyebrows. People stared at me.

My dad called September 3, 2011 “the light at the end of the tunnel.” It was going to be the end of pills, meds in my spinal cord, meds in my port. NO MORE MEDS!!!

The five-year “off therapy” celebration last year was a big one. It doesn’t mean that I won’t have long-term issues. It doesn’t mean that I won’t have problems as an adult. It means that I can say cured from my pediatric journey with ALL.

Now my family celebrates every September 3rd. The five of us celebrate with chocolate cake and count our blessings.

Sarah L. Smith



Now my family celebrates every September 3rd. The five of us celebrate with chocolate cake and count our blessings.



SOFIA

Her heart simply gave out.

Sofia was four years old when she was diagnosed with an extremely aggressive form of Non-Hodgkin's lymphoma. Thanks to the doctors at both Baptist Children's Hospital and Miami Children's Hospital, Sofia survived and went through a year of chemotherapy.

Eight months into her treatment she had heart failure which was initially thought to be viral. Unfortunately, it was actually caused by one of the chemotherapy drugs used in her protocol. While Sofia was able to overcome that initial bout and live a full life for several years, the damage was done. Her heart simply gave out and on April 3, 2012, almost a month after her 13th birthday, Sofia died.

Sofia was a pretty, confident yet reserved young lady who was wise beyond her years, extremely smart and also quite funny. She had the prettiest, most expressive eyes. With just one look you could tell what she was thinking and feeling. I think I miss the sound of her voice and her laughter the most!!

Marta Blanco

T.J.

T.J. was diagnosed with acute lymphoblastic leukemia one month after his fifth birthday. He was about a month into his preschool year.

The first month of chemotherapy was horrible. He couldn't walk, he was in so much pain, and worst of all he was scared of what was happening to him. He has overcome so much in the last eight months. Next week he will begin the maintenance phase of his chemotherapy treatment, it will last 2½ years. When treatment is over he will be eight and in the middle of his 2nd grade year at school. For five more years we will be waiting to hear if he is cured.

I am so proud of my son and the bravery he has shown. Every child we have met that has been diagnosed with cancer has shown such strength and resilience. We must be their voice. We must fight for them and never give up.

Becky Lampe

I am so proud of my son and the bravery he has shown.



ASHLEY

My little sister, Ashley, was diagnosed with T-Cell lymphoblastic leukemia at age 13. After complaining of persistent headaches that had an increasing level of pain, we took her to our family doctor for bloodwork. She was immediately rushed to the children's hospital where treatment to lower her white blood cell count started within hours. Within just a couple of hours, her life and our family's life was turned completely upside down.

We had no idea what to expect, no idea what the term "cancer" really meant. Months went by involving extensive chemotherapy that induced much pain and brought her teenage life to a complete halt. For the rest of the family, my mom devoted every minute of her day towards caring for my sister while my dad had to pick up any household activities that my mom was not able to complete anymore.

Ashley reached remission and was back in school for half of her freshman year of high school and most of her sophomore year. God had answered our prayers. She was playing basketball again, regaining her beautiful (what came back as curly) hair and even holding her position as #1 academically in her class. Day to day life was so amazing as things were finally back to normal and we were all able to take comfort in the fact that this beautiful 14-year-old was able to do the normal things that every teenager deserves to be a part of.

Unfortunately, just a couple of months ago we were burdened with the terrible news that my baby sister had relapsed. Yet again, Ashley's life as she knew it was completely taken away from her.

Alexis Wagner

My baby sister had relapsed.



AVA

On March 6, 2017, two months after celebrating her first birthday, we were devastated to learn that our daughter, Ava, had a rare tumor growing on the back of eye, retinoblastoma.

I was even more devastated to learn that the large majority of treatment protocols for children use highly toxic chemotherapy drugs that were invented 50+ years ago to treat adult and not pediatric cancers. This did not leave me very hopeful.

One week after her diagnosis, I was signing consent forms to put these toxic chemicals, that are designed to kill everything else, into Ava's body.

Ava's only mistake is being born in a time when the cures aren't present, the treatments are scarce, and more funding is needed.

The clock is ticking for our children and they cannot afford to wait. Many of them will succumb to their disease over time if new options aren't presented. This is unacceptable and devastating for the families of pediatric cancer patients.

Blair Dunbar

Ava's only mistake is being born in a time when the cures aren't present, the treatments are scarce, and more funding is needed.





Caradine fought cancer with a deep love for others and clung to Jesus.

CARADINE

I met Caradine in middle school. We became best friends our freshmen year of high school. We were teenage girls with nothing but sleepovers, talking about boys, prom, football games, and giggles ahead of us.

Our high school years changed all that. Caradine was diagnosed with rhabdomyosarcoma (cancer of the muscle) in 2008. Caradine fought cancer with a deep love for others and clung to Jesus. She started to get better and then the cancer returned in 2010.

The cancer returned again in 2012. She had to have a stem cell transplant. I remember getting a call that she might not live much longer. My heart was crushed.

Caradine taught me how to live a joyful life even in the worst of circumstances. Praise be to God she lived five years without cancer. She received a cosmetology degree and became a hair stylist. She loved every single person that sat in her chair at the salon.

In January 2016 Caradine passed away. Thank you to those that helped Caradine have a full life of loving people. Please do the same by walking in love and giving in any way you can to pediatric cancer research.

Laurel Dorman
Caradine's forever best friend

Advocacy is amazing because I am able to make a difference and be the change that I wished to see in the world.

CECILIA

My sister was diagnosed with cancer three years ago. Ever since I heard the words, "Your sister has cancer", my family's life has been changed forever. I was overshadowed by my sister's illness because I was the "normal" child while my sister was the "sick" child that needed the most attention. There was little room for me to be a voice and really have a say in what was going on.

I soon realized I was somebody and I had a voice. I turned my pains and sorrows into something much more powerful and beautiful. Advocacy is amazing because I am able to make a difference and be the change that I wished to see in the world.

Valerie Nguyen





CLAIRE

Five years ago I was about to play in my last home softball game of the season. Instead, I was taken from the dugout and to the hospital. Doctors diagnosed me with acute myeloid leukemia and told me that I had about a 30% chance of living.

I have gone back to this specific moment over and over again and sometimes I still can't wrap my head around how fast my life changed. That still blows my mind.

The next day I started chemotherapy. I learned that I would need a stem cell transplant in order to be cured. Thankfully, my youngest sister was a perfect match. And it worked!

Now, five years later, I am healthy as can be and currently have no complications! At my next yearly hospital visit, if my scans remain clear, I will be considered cancer-free!

I am now a junior in college studying to become a nurse. I participate in our collegiate dance marathon to help give back to one of the wonderful hospitals that saved my life.

I am especially grateful that people like you are supporting pediatric research because no child should ever have to experience something like cancer.

Claire Blankenberger

I am especially grateful that people like you are supporting pediatric research because no child should ever have to experience something like cancer.

WILLIAM

When I was seven, I failed a routine eye exam at my yearly check up. An MRI revealed a tumor, an optic chiasm glioma. I began chemo.

Being on chemo is possibly the hardest thing I've had to experience. I was also afraid of what people would think; I didn't want to seem different or sick so I kept my struggle to myself. In elementary school, my friends noticed that I was always absent, but I never told why. One of them said I must be a spy that had to go on secret missions all the time.

My eyesight continued to deteriorate as I moved from one chemo drug to another, none keeping the tumor from regrowing. My peripheral vision had quickly failed, but, when I was in middle

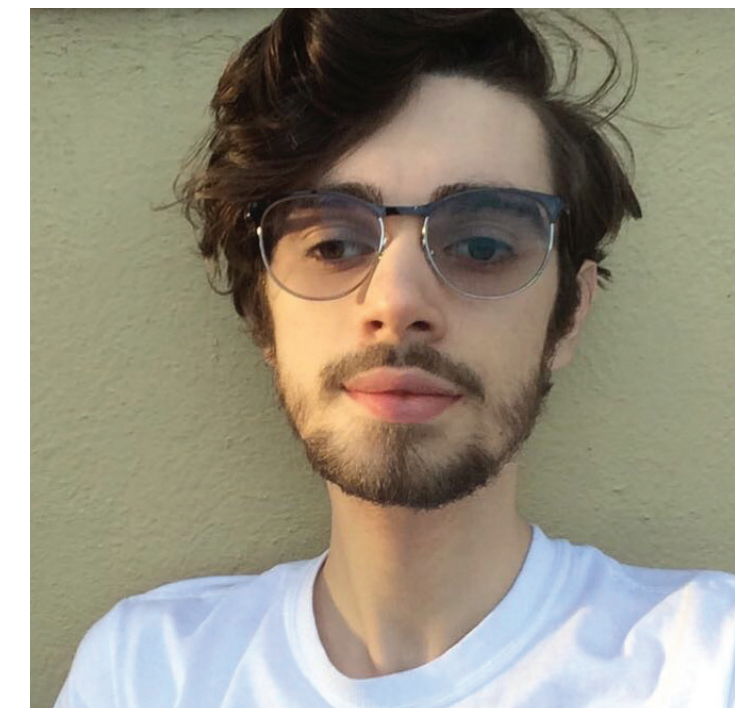
school, I lost all vision in my left eye. I yet again had to return to chemo.

For the next round of treatment, I was put on a new drug in clinical trial. My tumor shrank dramatically and my eyesight has remained stable. If it hadn't been for this trial and this drug I cannot know if I would be here.

It took 10 years for me to get here. With strong research and leadership from those like Congressman Butterfield, who fight for legislation like the RACE for Children Act, my experience need not be what all kids with cancer must go through before cures can be found.

William Morillo

If it hadn't been for this trial and this drug I cannot know if I would be here.





CHRISTIE

Every day I go to work I bring the gift of knowing. Knowing what it feels like to have cancer and what it takes to get to the other side of it.

I am a childhood cancer survivor. I was diagnosed with high risk, acute lymphoblastic leukemia as a teenager. I was placed on an experimental protocol and given three years of intensive chemotherapy. I'll be 40 this year and 25 years in remission.

I have been a nurse practitioner for 12 years, the last seven of which have been in pediatric oncology at Lucile Packard Children's Hospital at Stanford, the very hospital where I was treated as a child. Every day I go to work I bring the gift of knowing. Knowing what it feels like to have cancer and what it takes to get to the other side of it.

After beating cancer, as many as 2/3 of survivors suffer from late effects of their disease or their treatment. I myself spent over two years with a multidisciplinary team of medical providers to eliminate side effects that were the direct result of chemotherapy. Unfortunately, other kids suffer even worse effects of their treatment, including secondary cancers and organ damage.

Cancer treatment can be transformative. We shepherd a patient through a life changing experience and replace a typical teenager with a powerful young adult. When they've completed chemotherapy, we release them back into the world to become the next generation's doctors, nurses, teachers, politicians, and community leaders. I hope I'm around long enough to see what my patients end up doing.

Christie Chaudry, RN, MSN, PNP
Pediatric Oncology
Lucile Packard Children's Hospital at Stanford

The Creating Hope Act

21 U.S.Code 360ff
Section 908 of the Food and Drug Administration Safety and Innovation Act of 2012

The RACE for Children Act

21 U.S.Code 355c
Title V of the Food and Drug Administration Reauthorization Act of 2017

KIDS  CANCER