

thank you for



CHANGING THE LANDSCAPE  
of pediatric cancer

# volume 2

In this book you will find stories of love and strength. You will also find stories of loss and frustration. A common thread of these stories is a serious deficit in pediatric cancer drug development.

We want to thank you for fighting for these children so that others in the future do not have to experience what they have.

It has been and will continue to be a long and grueling journey, but let these stories be a reminder of *why* we fight. We have already made great strides in making transformative changes. Let's get to work.

Sincerely,

The Team at Kids v Cancer



# JACOB

I am grateful to those who have made a difference in creating a world where there is attention to the need to develop new treatment for these children.

Nine years ago on a normal gray February Monday, the telephone rang at 4 p.m. It was Nancy. Jacob, our first born grandson, eight years old, a beautiful, bright redhead with the hugest of hearts had brain cancer and was having brain surgery the following day.

For two years, we witnessed his chemotherapy, radiation, IV's, ports, nausea, anorexia. We pushed his wheelchair, hugged and kissed him. We helped him expend every ounce of strength he had trying to live life as normally as possible. Jacob died two years later, at 10.

The fear and grief and pain of Jacob's loss have marked all our lives. His beloved brother, Ben, has grown tall, handsome, charming, thoughtful and smart. Jacob now has a sister, Sarah, who is five. Babies have been born in the family; people have married. The little jade plants Jacob

and I planted in the hospital while waiting for his chemotherapy, I have lovingly tended, and there are now 12 large plants.

Now, I most often remember his smiling face and fun times rather than his suffering. But when I heard Leonard Cohen's "Hallelujah" last week, it hijacked me and I remembered just after his death, watching a video of his memorial with "Hallelujah" in the background, and I couldn't stop weeping. It's just like that sometimes.

I am grateful to all who have cast a net of care and support around the children and families of those children struck by cancer. I am grateful to those who have made a difference in creating a world where there is attention to the need to develop new treatment for these children.

Judi Goodman  
Grandmother to Jacob

# GABRIELLA

On March 15, 2012, our once normal, playful life came to a screeching halt when we heard the words "Your daughter has cancer". Gabriella was diagnosed with embryonal rhabdomyosarcoma. The world in which we knew, crumbled beneath our feet and we were powerless to stop it.

Gabriella would suffer almost a year of chemotherapy treatments, weeks of radiation, and multiple surgeries – all treatments that could possibly harm her in order to "cure" her of cancer.

My husband continued to work, but I was able to take a leave of absence during most of her treatment. Many days, it was just me, dragging my four year old chemo patient and my two year old baby for chemotherapy, clinic visits, and doctor visits. I would either be holding Gabriella down in order to get her port accessed or comforting Bridget while Gabriella was being treated by the nurses.

I am ecstatic to report Gabriella is currently thriving as a seven and a half year old. She still has scans every 4 months, but she has been clear for 29 months now.

We still live in some fear that her cancer might come back or she will be struck with an ailment from her toxic treatments.

But we have to look and move forward. The journey to fight cancer will always be there.

Kristin Cosner  
Team G Childhood Cancer Foundation



I am ecstatic to report Gabriella is currently thriving as a seven and a half year old. She still has scans every 4 months, but she has been clear for 29 months now.



# ANDREW

January 27, 2007 was a fairly routine day as my 14 year old son, Andrew, helped his team win a Pennsylvania State Championship. Forty-eight hours later, my son would be in cardiac arrest.

The absolutely unthinkable happened at 1:55 pm on July 14, 2007, when my 14 year old son, my best friend, my hero, died in his 16 year old sister's arms. Our perfect life was forever and irreparably shattered!

We took Andrew to the hospital thinking he might have appendicitis or a bad case of the flu. He is Andrew, it can't be anything worse, right? We got the diagnosis of leukemia and after the initial shock and heartbreak of telling him, our family of four buckled down to fight whatever was ahead. But within a few hours, Andrew went into septic shock and his heart stopped. After they resuscitated Andrew in the Pediatric Intensive Care Unit, the attending physician told me "Your son will not live through the night". Of course, he had to be wrong.

And, he was. Andrew lived through the night. Over the next 166 "bonus days", he underwent nearly 50 surgical procedures, four strokes, and a brain aneurysm. Andrew's situation was very atypical for most kids with cancer who go in and out of the hospital. We never left the hospital; we lived virtually every one of those 167 days in the PICU.

While our circumstances may be a little different, all of the families of a child who dies of cancer share so much in common. Our precious, innocent children were robbed of the chance to grow up. Our families will never be the same. We put on false faces for 'regular people' because, quite honestly, you can't handle the truth, the pain that we live. You don't know what to say or do, and I get that.

I was once asked "what can people outside the childhood cancer community do" to help in the fight. "Outside the childhood cancer community"?

If you think that kids should get a chance to grow up, then you are with us and inside the childhood cancer community. Speak up!

Joe McDonough  
*The B+ Foundation*

If you think that kids should get a chance to grow up, then you are with us and inside the childhood cancer community. Speak up!



# JENNIE

For me, September 11th will always be the day I heard the words, "Mrs. Nichols, I am afraid I don't have good news". We learned our beautiful 12 year old daughter, Jennie, had osteosarcoma.

I had thought her knee pain was a growth spurt. Why would I think my healthy sixth grader had cancer? When we started the standard MAP protocol of treatment, I learned it was the same treatment kids were getting in the 1970's! Absolutely no headway had been made in the treatment and possible cure of osteosarcoma in 40 years. We also learned that if the MAP protocol didn't work the first time, there were really no other drugs or therapies that would work for osteosarcoma. The MAP protocol did not work for Jennie.

This year there will be 400 children and teens diagnosed with osteosarcoma. Yet, there have been no new drugs available to help children with osteosarcoma.

Kelly Nichols

I had thought her knee pain was a growth spurt. Why would I think my healthy sixth grader had cancer?



# MICHAEL

Michael Gustafson and his twin sister, Bridget were born on November 16, 1997 in Naperville, Illinois.

Michael was an energetic kid who loved playing basketball and baseball and was a state champion gymnast. Not just an athlete, he was in the gifted program at school.

On April 10, 2008, Michael was diagnosed with a brain tumor and our lives changed forever. Within the week, he was in the operating room. We spent six weeks in Boston so Michael could be treated with proton radiation along with chemotherapy. At home, he completed five more months of chemotherapy.

We learned first-hand that there is no protocol for a relapsed medulloblastoma. We discovered how frustrating the compassionate use process is: more than a year of waiting only to receive a negative response. There's no knowing what would have happened had we gotten the drug through compassionate use, but we can clearly say that the "compassionate use" program failed our beautiful, funny, affectionate, tough guy.

Michael knew that he wanted his life to make a difference and now he would never grow up to be the scientist he dreamt of being. So he donated his brain and spinal tissue to science – "to use him however they could, so that no other child would have to go through what he did". This gave him such peace and was his final gift.

Patti Gustafson  
*Swifty Foundation*

*Michael Gustafson, forever 15*

Michael knew that he wanted his life to make a difference and now he would never grow up to be the scientist he dreamt of being. So he donated his brain and spinal tissue to science – "to use him however they could, so that no other child would have to go through what he did".



# TALIA

The hardest day of my life, was the day we were told the best medical minds in the world had no more answers for us.

I am often asked if the day I lost my beautiful girl was the hardest day of my life, the answer is no. I'm also asked if the hardest day of my life was hearing she had cancer. The answer is no. The hardest day of my life, was the day we were told the best medical minds in the world had no more answers for us. We were out of treatments, and out of hope. A single tear dropped down Talia's cheek, and that moment, was the most difficult moment of the most difficult day of my life.

My hope is that no parent and no person should ever have to feel what I felt that day.

The Creating Hope Act can make my hope come alive. I am now a

part of a charity that is one of the largest funders of neuroblastoma research in the country. When we made our largest grant to date, \$2 million, we insisted that the hospital apply for a Creating Hope Act voucher. This is an amazing way to take limited dollars, and make them into so much more.

In some ways, it reminds me of my amazing little girl Talia. She took limited time on this planet, and made it into an amazing legacy. She took the time to dream, and help the world see the beauty that lies in children stricken by these horrific diseases.

Marc Winthrop



---

My heart breaks from missing my sweet little boy.

---

# TENNEY

My son, Tenney, was a busy, curious, sweet and active little boy. But shortly before his fourth birthday, he was diagnosed with the scariest kind of Wilm's tumor.

Tenney responded very well to treatment at first and we were filled with hope. But after eight months of treatment, the cancer began growing back. His doctor was able to find a trial. It didn't work. We found another drug that might work.

The drug was showing promise disrupting the CD56 pathway in adult tumors, and Tenney's tumor expressed this molecular target. The drug was only in trials for adults.

There was just no way for us to gain access. There was no way to petition for a trial to be opened to a child for a drug that was just emerging, but that might save his life or at least give him time.

My heart breaks from missing my sweet little boy.

My heart breaks watching his little brother miss him.

I have watched other amazing children die from this same type of tumor since losing my Tenney and I cannot help but wonder... what if?

Ashley Little

In 2002, I was a typical seventh grader. I danced multiple times a week, sang in chorus, and played first baseman for a rec-league softball team. Until suddenly I was experienced a host of symptoms that went misdiagnosed for eight months. In July of 2003, 11 days after my 14<sup>th</sup> birthday, leukemia cells appeared in my blood smear and I was diagnosed with Acute Lymphoblastic Leukemia.

I was admitted a couple days later to receive my first chemotherapy, but as they were hanging my chemotherapy, my doctor came in to say they needed to do more tests. A few days later I was told they found another form of leukemia. I had both Acute Lymphoblastic Leukemia and Acute Myeloid Leukemia, also known as BiPhenotypic Leukemia. Only 1% of Leukemia patients a year are diagnosed with this form of leukemia.

My treatment consisted of drugs that were developed 40 years prior to 2003. This treatment left me hospitalized for over 90 days and could have destroyed my heart. I was lucky to only walk away with cognitive effects commonly known as "chemo brain" which would lead me to seek disability services through my school career.

I was in remission for 6 years and 10 months until I went in for my first Late Effects visit. During this visit, they assessed the damage the chemotherapy had done to my body. Instead of talking about preventative measures I needed to take to reduce heart disease, I was told I had relapsed.

I was devastated. My only option was transplant and in order to do that, I had to be in remission. If I had received the same drugs I had been given in 2003, I would have gone into transplant damaged and surely would not have survived. Fortunately, I qualified for a trial drug called Clofarabine. This is the first drug developed to treat pediatric leukemia in almost 50 years. The trial was funded through federal funding and other avenues. Your decision, as a senator or congressman, to support childhood cancer research and funding ultimately saved my life.

Sarah Swaim



# SARAH

---

Fortunately, I qualified for a trial drug called Clofarabine. This is the first drug developed to treat pediatric leukemia in almost 50 years... I am happy to report that I am five years post transplant, fully donor, and healthy.

---



# COLIN

For Colin, we did not have time to wait another five years to begin trials in children for this drug, and luckily, we didn't have to, thanks to the Creating Hope Act.

My son Colin is a vibrant, happy seven-year-old who, like other kids, loves Minecraft, chocolate, and animals. However, on his second birthday, Colin was diagnosed with anaplastic ependymoma, a malignant tumor that wrapped around his brain stem. The surgery that followed took away Colin's ability to eat, talk, and move, and left us lost, hoping for some sort of cure.

While things had begun to look better in the five years after his diagnosis, we were thrown back when we learned of a new tumor.

We looked all over for any sort of help or prospective cure we could find, but for children like Colin, there are very few options. Luckily, hope came in the form of a nearby cancer center that was in the process of opening a trial for a new immunotherapy drug.

For Colin, we did not have time to wait another five years to begin trials in children for this drug, and luckily, we didn't have to, thanks to the Creating Hope Act.

The Creating Hope Act was what saved our son Colin.

Tamiko Toland

# HAYDEN

At 10 years old, our son, Hayden, was an active, smart, funny, carefree, *healthy* kid every day of his life up until the day that he wasn't. The day that he started limping - something all kids do after a harmless bump on the playground. Except that this limp didn't go away but instead started causing swelling and pain in his knee that we soon were told was a bone tumor (osteosarcoma).

Hayden started IV chemotherapy the very next week beginning with three drugs — the most effective drugs with the least amount of side effects — those being hearing loss and damage to kidney, liver, and heart. Just one month into chemotherapy, his tumor was continuing to grow, so his surgery was moved up. After an above-knee amputation, he endured nine more months of IV chemotherapy involving five drugs, three of which were the same ones he took earlier.

After he relapsed, we flew to the hospital top-ranked in the nation for treating osteosarcoma. He was given an oral clinical trial drug and experimental Cyberknife radiation that within a month proved ineffective. At this point, we had no options. The standard treatment protocol had failed. We exhausted all our options because we really *had* no options.

Through two and a half years, Hayden did everything we asked of him — 8-10 surgeries, nine months of IV chemotherapy, physical therapy to learn to walk again on a prosthesis...everything. He did it all with a smile on his face because he was a positive kid who never once believed he wouldn't beat this. As parents, we did everything in our power to save our son, but we still failed him. Our medicine failed him. Hayden didn't fail. We failed. Every day that we don't allow our kids access to different drugs, we continue to fail our children.

Randi White



As parents, we did everything in our power to save our son, but we still failed him. Our medicine failed him.



# ABBY

Abby is a spunky nine year old who has been through a lot. Abby was initially diagnosed with PH+ ALL (Philadelphia Chromosome Positive ALL - Leukemia) at age four and relapsed at seven and a half, just 11 months after her initial treatment protocol ended. Abby had an unrelated donor bone marrow transplant in January 2015 and she is still enduring side effects from that, specifically Graft vs. Host Disease as well as other transplant-related issues.

If it weren't for pediatric cancer research, we wouldn't have Abby here with us today. Abby was on the trial drug Dasatinib, during her initial diagnosis. Dasatinib is one of the few pediatric cancer drugs approved for use. Dasatinib kept Abby's hard-to-treat cancer in remission for over three years, and upon relapse, Abby still had the option of a transplant.

Throughout transplant, Abby has endured several side effects that are life threatening. But at least there were trials and treatments available for her.

We thank you for your understanding that the need for childhood cancer research is great. Our family depends on it.

Patty Furco

**If it weren't for pediatric cancer research, we wouldn't have Abby here with us today.**

# JOEY

Ten year old Joey was a 5<sup>th</sup> grader in Gainesville, Florida. Friends and teachers described him as a funny, kind, caring, gentle, and loving boy. Joey was the award winner of the Florida Math League contest. He loved all things science. Joey played the violin in the Alachua County Youth Orchestra. He was an artist and an origamist. Joey's big dream was to one day play the violin at Carnegie Hall.

On March 20, 2013, Joey was diagnosed with a stage 4 translocation renal cell carcinoma. We were told there was no standard treatment for this cancer. Joey underwent two major surgeries, four different oral chemotherapies, and one chemotherapy. His tumors grew more and spread.

In April 2014, Joey's family started a petition for compassionate use of a new immunotherapy drug called Nivolumab that targets the type of tumors that Joey had. It was already in trials and saving the lives of adult cancer patients, but there were

no trials available for children. The petition was not granted.

On September 4<sup>th</sup>, another immunotherapy, Keytruda, was approved by the FDA for adult patients. Joey started the off-label use of Keytruda. The tumors in his neck shrank significantly and all other tumors were stable.

Joey's family had so much hope. However, his tiny body was too exhausted to fight so much disease. On November 24, 2014, Joey slipped into a coma. Joey passed away two days later.

We wonder if he received access to this drug on a compassionate use basis even just a couple of months earlier, could this have been a different story. The drug had not worked fast enough to save Joey's life, but it had worked just enough to make his mother wonder: What if?

Kathy Liu  
*Joey's Wings*

**We wonder if he received access to this drug on a compassionate use basis even just a couple of months earlier, could this have been a different story.**







# BROOKE

For the first 18 months of her battle with cancer, our little daughter, Brooke, was given terribly harsh chemotherapies and radiotherapies that did not do much other than weaken her bone marrow. None of the drugs Brooke received were specific for childhood cancers. For instance some of her most promising targeted medications were for diseases like Alzheimer's, Parkinson's, osteoporosis, or specific for lung and breast cancer.

Brooke was one of the first children worldwide to ever have the opportunity for genomic analysis for personalized precision medicine (or targeted therapy). Her changing tumor cell pathways were biopsied and analyzed 9 times for targeted pathways inside her tumor cells. No other child and few adults, if any, have ever been genomically analyzed this much.

Brooke was given personalized medicine and targeted drugs for her extremely resistant neuroblastoma cancer through the dedicated work of Dr. Giselle Sholler, NMTRC, TGen and Dell. With each new genomic analysis came new drug options for Brooke to try. And if her cancer became resistant to one drug, another could be pursued. The drugs Brooke received were all drugs approved for use in children but not specifically

for childhood cancers (although some are approved for adult cancers). She did not have a chance to try promising unapproved drugs with her personalized medicine plans because only FDA-approved drugs for use in children could be used.

Brooke was fortunate to have a great quality of life with these personalized medicines. However, Brooke's cancer progressed until ultimately it took her life at the tender age of eight, just this past June 2015. I hope and pray every single day for precision medicine to become up front therapy and for it to happen with drugs designed specifically for pediatric cancers, and not the "leftovers" as Brooke called it.

We grieve the loss of our most remarkable child who in such a short time impacted so many lives.

Hopefully the next generation of kids with aggressive cancers will not have to live to fight, but rather live to be cured.

With Faith, Love and Hope for Cure,

Jessica Hester  
*Brooke's Blossoms*

We pray Brooke's life and fight will save the lives of other children in the future.



# NATHAN

My husband and I have four precious children, but in 2009 our world was forever changed when our then two year old son, Nathan, was diagnosed with brain cancer. He has failed on seven chemotherapies and two surgeries and is currently on a clinical trial. Nathan's cancer had since spread to his spine.

God's hand has been with us through this journey of six years. God has given us so much love, faith, hope and joy. We don't know what our future holds, but for us, it is our faith in Jesus Christ that gets us through each and every day as we enjoy our moments.

Nathan could easily be anyone's child. Like so many children, he is running out of treatment options. There need to be more medicines specifically for pediatric cancer.

All of Nathan's treatments this far have been adult drugs that were passed down for pediatric use.

Please help be a voice to the children battling cancer.

Nathan's Hope

God has given us so much love, faith, hope and joy.



# KYLIE

Kylie was diagnosed with undifferentiated sarcoma with a Ewing's tendency on April 9th, 2014. At the time of diagnosis, the cancer was already metastatic. We immediately began the standard protocol for Ewing's sarcoma.

The treatments were brutal. Constant nausea and devastating mouth sores left her in a state of malnourishment, forcing her to get a feeding tube in her stomach.

All of the drugs selected for Kylie's treatment were old, harsh, and proved to be ineffective in treating her. Fighting the side effects of chemo was every bit as hard as fighting the cancer. We felt our options were always limited to a small range of drugs available for children.

From a parent's perspective, it seems that the medical staff's only recourse was to throw something against the wall and hope it stuck.

In Kylie's case, nothing stuck and we will forever miss her beautiful smile.

Mark Myers  
*Smiley For Kylie*

---

**In Kylie's case, nothing stuck and we will forever miss her beautiful smile.**

---

# AVA

A few weeks before Christmas when Ava was only four years old, our world changed. We went to the doctor for what we thought was an ear infection. It was stage four, terminal brain cancer. We never thought a child, our child, could face terminal cancer. We were shocked and devastated to learn that there were no treatments for her. Her only hope was a handful of clinical trials.

This prognosis is maddening! We wanted to fight for her. She wanted to fight, but there was nothing we could do.

Ava passed away 11 months later.

Why was her illness not important enough to have been the focus of innovative research, like other adult cancers? She was just a child who deserved a chance at life.

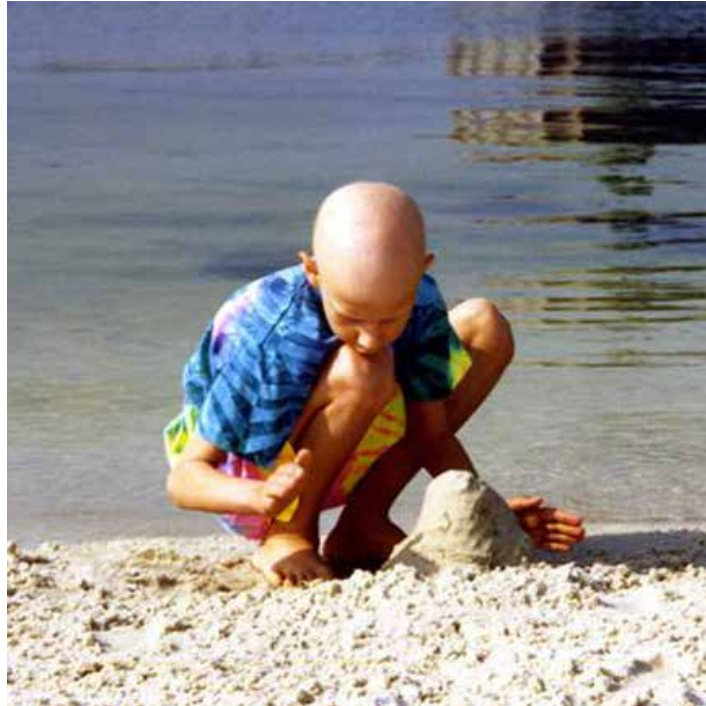
Cynthia  
*The Gold Hope Project*



---

**She wanted to fight, but there was nothing we could do.**

---



## ERIK

We can only wonder what he would have contributed to our world had he lived a full life.

My six year old son, Erik, was diagnosed with high-risk neuroblastoma. He is counted as a “success” in terms of the oft-quoted childhood cancer survival rate of 80%, as he was alive five years later. But he was dead at 24. Somehow the “success” rings hollow for me.

Erik was smart and happy; he was a snowboarding fanatic, amazing graphic artist and techno music composer. He had a full scholarship to study computer engineering and was in his sophomore year of college when his cancer came back.

He endured unbelievable suffering.

His cheerful, kind spirit touched everyone he met. We can only wonder what he would have contributed to our world had he lived a full life.

Donna Ludwinski  
*Solving Kids' Cancer*

## DANIEL

My 12-year old son Daniel has a smile that lights up a room.

Last summer, he started complaining that his leg hurt. Given how athletic he was, we never thought anything of it until we found out that he had osteosarcoma, a very aggressive and highly metastatic bone cancer found mostly in children and adolescents.

Daniel has gone through five surgeries, twenty rounds of high dose chemotherapy, and twenty-four hospitalizations. The chemotherapy drugs he received all date from before 1980. He spent three months in a wheelchair, had many months of physical therapy to re-learn how to walk, and he is now trying to re-learn how to run.

Daniel relapsed and metastasized on treatment. We have learned how few drugs and treatment options there are for children with cancer. After all of the high-dose chemo Daniel has received, he cannot receive more chemotherapy for the rest of his life. If he relapses again, there are no other standard of care treatment options for him; while there may be drugs which would benefit him, they are not available to children.

Through all of this, Daniel smiles and laughs and keeps going, showing a bravery and courage no child should have to learn.

Our children need more cancer treatment options. They need access to better and newer drugs. I pray for no more relapse, and for new treatments and new drugs for Daniel's cancer. I want his smile to continue to light up rooms.

Theresa Beech



I want his smile to continue to light up rooms.



---

I thank God every day for bestowing upon me His angel.

---

January 20<sup>th</sup>, 2005, was perhaps amongst my worst days since my two month old daughter, Sydni, fought through 12 hours of emergency brain surgery for a cancerous tumor. On that fateful day, I discovered that Sydni's oncology team had no new drugs available for consideration because none such medicines existed. I thought: My dear God! What are we facing?

Rather than embracing images of a dazzling future filled with happiness and joy, all I could do was lean upon my faith in the hopes that her fragile body would keep on fighting. I prayed through a father's brokenhearted tears that Sydni would not lose her determined spirit to live. I made a pledge to my dying child that for as long as I had a breath in me, I would be her hands to eat, her feet to walk and her mind to think. All I asked for in return was that she provided me with the opportunity to be a father to her.

Know this, my daughter Sydni is my hero. Her smile is my Northern Star. I thank God every day for bestowing upon me His angel. My daily blessings shall on no occasion be taken for granted. Life may be tough, but thank heavens I've got an angel on earth daughter who is tougher!

My innermost dream is that the Creating Hope Act will foster hope and cultivate opportunity so that future children and families will have a fighting chance to be shown mercy from the harrowing less traveled road which my daughter and our family does daily traverse upon.

Stephen Pecevich

# SYNDI

# BRADLEY

I sat in the ER on November 8<sup>th</sup>, 2011, half expecting the results, and yet shocked as the doctors informed me I had a tumor in my brain.

It was later determined to be medulloblastoma. I spent more than a year receiving chemotherapy and radiation treatment.

My treatment served as the beginning of my faith. Faith has completely turned the direction of my life around not only faith in Jesus Christ, my lord and savior, but in the health care system that saved my cancer-infested body. The work of those before me provided a treatment for my disease. I believed with all my heart that it would work, and it did.

I am over two years out of treatment, completely cancer free, and living a healthy, abundant life. It is my dream to become a pediatric surgeon and a servant of those in need, in part because of the health care professionals that have impacted my life.

Sadly, not all children are blessed with treatment options like mine. While my treatment was anything but pleasant, I have come out of it with minimal lasting side effects. I have friends who have lost the function of their limbs, their cognitive ability, even their life and it is their story that drives me to pursue my God given potential in life. Similarly, I believe that with our nation's support, cancer research has the potential to save even more kids like me.

Bradley Hilliard



---

I have friends who have lost the function of their limbs, their cognitive ability, even their life and it is their story that drives me to pursue my God given potential in life.

---



# ALEXIS

My daughter Alexis Agin was diagnosed with a terminal brain tumor known as DIPG (diffuse intrinsic pontine glioma) at twenty-seven months old. At that time, we were told there were no effective treatments for this tumor. Alexis passed away on January 14, 2011. She is considered a longer-term survivor. There has been no progress made in the treatment of DIPG since her diagnosis to the present time.

It is through the support of initiatives like the Creating Hope Act that parents of children diagnosed with DIPG and every other form of childhood cancer can, in fact, find hope that new, and more importantly, effective therapies will be developed that will save their children. Drug development for childhood cancer, left to its own devices, will rarely occur. Accordingly, your support of the Creating Hope Act and legislation to reauthorize the act through the 21<sup>st</sup> Century Cures Act is beyond critical to providing incentives that drive the focus upon pediatric disease populations such as childhood cancer.

As childhood cancer continues to occupy the undistinguished honor as the number one cause of death by disease of children in the United States, as a country we need to ensure that we are collectively working together for the protection of our children, and more importantly in this case, to foster development of treatments that are less toxic and effective against many of the forms of childhood cancer that have seen little to no progress in the overall survival rate in the last thirty to fifty years.

Thank you for your support.

Jonathan Agin

Drug development for childhood cancer, left to its own devices, will rarely occur.

At the time of her death, Taylor was waiting for an exciting drug that was being used in the same hospital, three floors above, for adults. It was not available to children.

Cancer does not discriminate because of age, but research funding does.

My daughter, Taylor, was diagnosed at 11 years old with a sarcoma. Survival rates and new drug therapies for metastatic sarcomas have not changed in over 30-40 years. Taylor was being treated with medications from the 1970's and 1980's. Taylor's dad sought researchers nationwide and globally.

At the time of her death, Taylor was waiting for an exciting drug that was being used in the same hospital, three floors above, for adults. It was not available to children. Imagine knowing a treatment exists for your child but you cannot get it because it has not been developed for children.

Taylor didn't lose her battle - she just ran out of time. Taylor always had a reason to be happy, a reason to laugh, a reason to love and a reason to LIVE! There is no end to grief and no end to love.

Sue Matthews  
*Conquering Kidz Cancer*  
*A Tay-Bandz Organization*

# TAYLOR





# NIKO

While going through all this, Niko was able to make friends helping others through their treatment, with his big heart.

On January 12, 2014, Niko was diagnosed with B-Cell ALL. Niko faced several complications due to the chemotherapy and the side effects of these toxic drugs. Through it all he has demonstrated such strength it amazes us to this day.

During the beginning of Niko's treatment, Niko had to go 12 days without food, with a drain in his belly and a NG tube and he did so without any complaint. Niko's cancer treatment has caused him to have stroke-like symptoms, which thankfully he has fully recovered from, but it was an incredibly scary time. His shots hurt, his port access procedures hurt, his lumbar punctures hurt, his bone marrow aspirations hurt.

Yet Niko handled everything without a peep. While going through all this, Niko was able to make friends helping others through their treatment, with his big heart.

Niko has inspired us to start TeamNiko. We make backpacks filled with essentials to give to kids and their families within the first 48 hours of diagnosis. We know the nightmare of being told your child has cancer. Our goal is to allow Niko to bring hope to other fighters and help them get through this horrific disease.

Erin Greco  
*TeamNiko*

# SARA

I am a survivor of childhood cancer not once, but twice. At the age of eleven I had T-Cell Lymphoma and after six years of being "cancer free" I was told I had Osteosarcoma. I missed half of my senior year of high school. I was too sick from the chemotherapy to even leave my home.

My doctors had to work hard on a plan to give me the right chemotherapy that would minimize the damage to my body. How funny is that, treatments that are made to cure this disease can cause me life-long problems?

I always thought it was strange to give a sick person medicine that would make them even sicker. I also find it both strange and upsetting that due to the lack of funds — no let me correct that, due to the lack of desire to give childhood cancer research funding, we are still using adult cancer treatments on children.

The effects of these treatments go way past just poor memory and hair loss as if that wasn't enough. I am twenty years old but every time I see my cancer doctor I have to have my dad with me. I am scared to death of relapse. I know I now have a higher chance of getting yet another cancer just because I tried to "cure" the other two!

If there ever was a perfect time to fund a new childhood cancer drug it would be now, all children diagnosed everyday need it. We deserve it.

Childhood cancer is important too. It's time to make it a priority.

Sara Anderson



How funny is that—treatments that are made to cure this disease can cause me life-long problems?



# JOHNNY

Johnny was diagnosed with medulloblastoma when he was 21 months old. He relapsed twice before he died at the age of 7. During those 6 years, Johnny was forced to endure years of chemotherapy, radiation to his brain, high-dose chemotherapy with stem cell rescue, hearing loss, countless lumbar punctures, two brain surgeries and multiple port insertion/removal surgeries.

I still have nightmares about the procedures we forced him to endure with outdated drugs to try to save his life.

One of the most barbaric memories was an oral chemotherapy that we gave Johnny at home - a liquid that smelled, and tasted like gasoline.

Here was a typical scenario: first, he would vomit upon seeing the bottle. Then two or three trusted family members would restrain him while one of us would try to inject the chemotherapy into his throat, bypassing his mouth, via syringe. He would immediately vomit this up. We would repeat this as many times as it took to get the chemotherapy to stay down. Sometimes it took over an hour. The chemotherapy was toxic and would cause the skin around Johnny's mouth and chin to break and bleed.

By the end, Johnny was exhausted, nauseous, terrified, sore and broken.

I think it is time we improved these drugs. Thank you for supporting the Creating Hope Act so that other children don't have to endure what Johnny endured.

Karen Irwin

I still have nightmares about the procedures we forced him to endure with outdated drugs to try to save his life.

She handles all the physical and emotional pain amazingly well and is so strong. I am proud to be her mother.

In February 2013, Brooke was a normal, carefree, teenage girl, finishing her last year of middle school - loving life, art, dogs, friends and family. She started to become very tired all the time and lost weight. Instead of spending spring break at the beach, Brooke spent it in the hospital having tests run. There was a tumor found in her abdomen that was crushing her organs. She was diagnosed with DSRCT, a rare and aggressive cancer.

Brooke underwent a ten-hour surgery to remove the tumors. She was then treated with chemotherapy and underwent another 10 hour HIPEC surgery that left her with a feeding tube in her abdomen.

Throughout the process, I was terrified.

Instead of starting high school with her identical twin Brittney, Brooke had radiation to her entire abdomen five days a week for weeks on end. Radiation was awful – worse than both surgeries and chemotherapy. After radiation, Brooke had almost a year of chemotherapy, but was unable to complete it due to the side effects chemotherapy and radiation had taken on her body.

Today Brooke remains cancer free, but we are left with many questions about her long-term health. Brooke has experienced things that would easily bring an adult to their knees and she perseveres. She handles all the physical and emotional pain amazingly well and is so strong. I am proud to be her mother.

Jamie Braley

# BROOKE





# TREVOR

Take a moment to imagine that you are a nine year old boy. You like to ride dirt bikes and four wheelers. You love sports. You just finished your first year of football and can't wait until baseball season starts. You are in third grade. It is almost Christmas and you can't wait to open gifts to see what Santa brings. Life is exactly how it should be for a little boy.

You wake up one morning with a tummy ache. Your mom takes you to the local weekend clinic. Doctors send you to the local ER and Dad meets you there. The local ER sends you to a larger hospital. You are admitted. Mom and Dad both stay. You just want to go home. Surgery is the next day.

Now imagine, you are the mom and dad. All you can do is put your faith in God and pray for healing. You tell your baby boy he has prostate cancer. He asks you if he is going to die. You look him in the eye, trying to be strong, and tell him it is curable.

You begin the hardest journey of your lives. Trevor underwent 42 weeks of chemo and six weeks of proton radiation therapy. We watched as our child was "poisoned" to save his life. Trevor's chemo worked and he is now cancer free.

Thankfully, Trevor was able to receive two adult medications that worked. But what if he hadn't? We long for the research to find better treatments for our children, so that no child has to be poisoned in order to get better.

Zona Storie

# ALEXANDRA

Alexandra Meyer was just three years old when she was diagnosed with medulloblastoma. The sudden onset of vomiting and an off-balance gait triggered a visit to her pediatrician who ordered an MRI as a precautionary measure. And there it was—an orange-sized mass sitting behind her cerebellum. We were whisked to Children's National Medical Center where a brilliant neurosurgeon performed a craniotomy to remove the mass.

Cells from the mass confirmed it was malignant and aggressive. We chose to enroll our daughter in a clinical trial that would allow us to delay whole brain irradiation which, at the doses needed to cure, would be devastating for her young developing brain. But after only three chemotherapy cycles, an MRI revealed that Alexandra's tumor was growing, and fast. Radiation was needed immediately. There was no time to waste.

She began eight weeks of proton beam radiation, a type of radiation that could potentially spare healthy, adjacent brain tissues and cause the least harm. Alexandra endured three more rounds of high-dose chemotherapy with stem cell rescue. Her body was rendered emaciated, hairless, with extreme pallor. She could not walk or even sit up. She could not eat food. A central line was used to administer nutrition

into her fragile body. But on New Year's Day 2012, Alexandra's treatments were completed. We could now enter the "survivorship phase". The heroic battle had ended; it would all be worth it.

One month later, Alexandra's first post-treatment MRI revealed a significant enhancement of cancer lesions. With no treatments left to offer her, Alexandra was now deemed terminal. Her oncology team arranged hospice care and we were blessed with five weeks alone to hold her, kiss her, smell and touch our precious daughter, while her body slowly declined.

Alexandra passed peacefully in our bedroom on Good Friday, April 6, 2012. Her brother Samuel, only seven at the time of his sister's death, placed a soft Easter bunny rabbit on her chest as a way to say goodbye. She had always loved stuffed animals. We never traveled anywhere, without a least a few by her side.

Alexandra's loss has left a gaping hole in our hearts. No parent should ever watch their child die from cancer. Alexandra's valiant fight must be met with an equal resolve to combat brain cancer. There is so much room for improvement.

Jennifer Cullen



Alexandra's loss has left a gaping hole in our hearts.





# CONOR

Thank you very much for passing the Creating Hope Act and your continuous support to change the desolate therapeutic landscape for America's children that have received a cancer diagnosis and will receive one in the future.

Your support is extremely important to our family, because at the age of 16 months, our very energetic, full of life son, Conor, was diagnosed with high-risk neuroblastoma, a solid tumor that is derived from the sympathetic nervous system. Conor's tumor was located in his chest and it had wrapped itself around the main vein in his body that was delivering blood to his heart. His treatment options were limited, a combination of decades-old drugs that are highly toxic and nonspecific. As cancer researchers in prestigious research institutions in Southern California, we were shocked about how little was available for our little boy and how little progress had been made in moving promising discoveries for pediatric cancers out of the halls of academia, through drug development pipeline in industry, and into the clinic.

There was only one option for Conor and if it failed, there wasn't anything else on the shelf. He had only one shot, it either worked or didn't. Luckily, the tumor responded, allowing for the remaining tumor to be surgically

removed. Conor continued on several rounds of chemotherapy to mop up the remaining tumor cells.

These decades-old drugs did save Conor's life, but not without causing permanent damage. Chemotherapy is effective on adults because it targets rapidly growing cells and induces significant damage in cancerous cells opposed to slow growing normal cells. However, a child is made up of rapidly growing normal cells. In addition to damaging the child's cancerous cells, every normal cell in the child's body will have received some damage too. These "normal" cells are now more likely to become cancerous or simply, may not function properly causing severe health conditions. Children must have safer, effective targeted therapies that will eliminate the cancer without jeopardizing a long, healthy life.

Today, Conor is a typical 11-year-old boy that lives to skateboard and mountain bike. Our biggest fear is hearing the words "your child has cancer" again.

Thank you for supporting the development of more treatment options for the kids, America's future.

Beth Anne Baber, Ph.D. and  
Michael N. Boddy, Ph.D.  
*The Nicholas Conor Institute*

Today, Conor is a typical 11-year-old boy that lives to skateboard and mountain bike.



# TARA

She says she will continue to fight for better treatments for kids like her.

Our daughter Tara was diagnosed with Astrocytoma Grade II Brain Cancer nine days after her eighth birthday, on February 26, 2013. No parent should ever have to tell their child they have cancer and then tell them they have to endure horrible chemotherapy treatments. Tara underwent 70 weeks of IV chemotherapy and ended her treatment July 2014. We thought "great, now Tara can move on to being a normal kid". Well, that was short lived. In January 2015, we got the news that one of the three tumors in Tara's brain had grown and now we are going through another year of oral chemotherapy.

Tara struggles daily with short-term memory issues as well as issues in school. It is a killer on her father and me to see her struggle with normal

daily activities. Having to watch her lose her hair twice was gut wrenching. When she asks me why she has cancer and I can't tell her, it makes it so unfair. When she has watched several of her friends die of cancer and then she asks me if she is going to die, I have no words. I tell her that she is not supposed to die and I pray every day that we don't have to go through what other friends have.

She says she will continue to fight for better treatments for kids like her. Our kids should not be the last on the food chain to get better treatments. Tara's treatments are over 25 years old and this is just not right.

Thank you,

Tammy and Craig Sankner  
*Parents of Tara Sankner*



---

The first thing she ever heard in this world was also the last: my heart beat.

---

My daughter, Ambrosia, was diagnosed with cancer when she was just five months old. Even harder than hearing the word “cancer,” was reading the pathology report that identified us what kind of cancer she had: Malignant Rhabdoid Tumor of the Liver.

We were hopeful and went ahead with treatments. Ambrosia went through six rounds of chemotherapy. Then she had a stem cell transplant; the transplant could not stop the growth of her tumors. At this point in her treatment, we were left without any more options.

The first thing she ever heard in this world was also the last: my heart beat.

Anya Hopper

# AMBROSIA

# SKYYLER

Skyyler was always a mama’s boy. He was attached to my hip. He would be so happy when I picked him up like that was all he was waiting for all day. At two he was saying, “Oh mom, I love you so much!”

At three, he had a horrible tummy ache. I took him to the ER. After multiple doctors, we found the source: neuroblastoma. Our worst nightmare had come to life.

Eight years of treatment for our Skyyler. All the way through, this boy was courageous, positive, happy, and funny, with the many tears and fear. We had the, “You are going to heaven” talk several times. Skyyler was on hospice three times; he graduated twice.

For 11 years and 5 months, Skyyler was our precious gift. Not long enough, but the best gift for 11 plus years of his family’s life. He wanted to name a book of his stories, “Skyyler’s Sky High Cancer Scare”. He loved cats and dreamed of having a cat shelter when he grew up.

Neuroblastoma and the gargantuan amount of pain meds given him to try unsuccessfully to control his pain took his life on February, 26<sup>th</sup> 2011. He did not have adequate access to new adult cancer drugs. He did not want to say goodbye. He was still a mama’s boy.

We miss him so much. Our only comfort is knowing he suffers no more and we will see him later.

Angie Barron  
*Skyyler’s Mom*



---

He was still a mama’s boy.

---



# MARK

I am 41 now and thrilled to be cancer free, but the side effects of treatment and radiation have left me unable to work.

My name is Mark Kelly and I was diagnosed with rhabdomyosarcoma on December 12, 1990, when I was 16 years old. Back then cancer treatment was barbaric. I had a very aggressive protocol of chemotherapy and radiation I had to undergo a bone marrow transplant, due to the radiation damage, after my bladder wall ruptured.

After barely surviving the transplant, I have been cancer free since. However, the treatment later caused IBS, Colitis and now finally Crohn's disease, while also causing Lymphedema in my legs. I am 41 now and thrilled to be cancer free, but the side effects of treatment and radiation have left me unable to work.

I am hoping more can be done to help make treatments more focused and with less side effects. I also hope something can be done to recognize people who have given their life to this disease and are dealing with lifelong disabilities. Something needs to be done. Do whatever you can to help these kids so they don't have to suffer through what I do.

To help other survivors who deal with permanent side effects, I started a website called ckmagicsports ([www.ckmagicsports.com](http://www.ckmagicsports.com)).

Mark Kelly  
*CKMagic Sports*

Jackson gave us strength, he was an inspiration, and, most importantly, he gave us hope.

On June 26, 2014, Jackson, our son, was diagnosed with T-Cell Acute Lymphoblastic Leukemia. Doctors found a large cancerous mass in his airway and lungs. The life we had planned came crumbling down.

Jackson passed away on August 11, 2014. His battle with cancer lasted only 47 days. During this time, Jackson endured chemotherapy, blood transfusions, CT scans, daily X-Rays, continual renal therapy, and failure in his liver, kidneys, and lungs. He suffered from severe infections, uncontrollable fluid build up, and malnourishment. Jackson had to fight every second of every day, but ultimately, the cancer was too much.

Jackson gave us strength, he was an inspiration, and, most importantly, he gave us hope.

To this day, we continue to feel all of these things, but to us, hope is the thing we hold onto the tightest - hope for better treatment, hope for better research, and hope for better awareness for children who fight cancer every day. We are very thankful to Kids v Cancer and their Creating Hope Act for helping children and families across the country the hope that Jackson gave us.

Anna Ertz

# JACKSON





# SCOT

We promised Scot we would do everything in our power for the rest of our lives to help find a cure so no one or no family would ever have to endure what we did.

Scot fought hard against a rare and aggressive childhood cancer, Rhabdomyosarcoma for two and a half years. At the time of diagnosis, he was already at Stage IV. Scot entered a 54-week trial program that included chemotherapy and radiation. He was cleared of RMS November 12, 2013, and relapsed one month later in December. He entered another trial program February 6, 2014, for more chemotherapy and radiation.

I quickly realized there was no cure for this disease. UCSF Benioff Children's Hospital had done all they could. We had no chance to beat this from the get-go. This experience was heartbreaking for me, his dad, our families, and friends. But it was even more devastating when we found out there was nothing being done to fight this terrible disease.

Scot gained his Angel Wings September 28, 2014, at 1:17 pm at the age of 22. We promised Scot we would do everything in our power for the rest of our lives to help find a cure so no one or no family would ever have to endure what we did.

Scot was adamant we continue the fight to help raise awareness for childhood cancer through fundraising, advocating, and research support. He made sure to leave behind a great gift for both his doctors and for patients battling RMS. Scot donated his tumor for research.

Scot's Mommie Forever, Trae Sieczko  
*Team Scot*

# ROSIE

I can't really remember a time when I didn't have cancer or when I haven't been on chemotherapy. Sickness, treatments, blood tests, MRI scans, needle pokes and long car rides to and from the hospital have been what I've known as normal for years. I have grown up at my hospital. I started going there when I was just 10 months old. I was diagnosed just a few weeks after turning three and I've been seeing doctors and nurses almost weekly for years ever since. My journey has been long and hard and I still have a long way to go, but I'm not giving up!

Sick kids like me make up more than half my friends. Kids connected to feeding tubes, in wheelchairs, using walkers, with ports and who ride their IV poles for fun. They are bald and beautiful and we have faced some really hard days. I don't know what a spinal tap feels like, but I do know what a shunt tap feels like. I've never needed a blood transfusion, but I know the importance of giving blood. I know that anyone can die no matter what his or her age is. I know what it's like to see a child die too young. I have had to say good-bye too many times; it hasn't been an easy life.

Cancer and illness are not what my whole life has been about. Through my cancer journey, I have learned to take the negative and make it a positive. I have learned to make the best of a moment, no matter where I am, no matter what I'm faced with or how hard it may be. It won't defeat me! I've learned that attitude is everything. I won't ever give up, until giving up is all I have left and that's when God says so and not before.

I believe in the power of prayer. I believe in having a strong faith and reminding myself that God loves me and He is always with me. No matter what I'm faced with I can find my strength in God.

I have learned that one person can make a difference and that person can be me! People will help if you just ask. I have learned a lot from having brain cancer, but most of all I have learned that love is what matters most. If you have love you have everything!

Rosie Colucci  
*Age 11*



I have had to say good-bye too many times; it hasn't been an easy life.



Fighting cancer is staring death in the eyes and saying “Bring it on”.

# BEAU

The day I learned I had stage 4 Ewings Sarcoma with a 5-7% chance of survival for the next 5 years was the scariest moment of my life. I asked my Dad how hard fighting cancer would be, on a scale of 1-10, he said 11. For me, that statement meant death.

When we started the rigorous treatment, a positive attitude was the medicine I didn't even realize I had that kept me fighting. This support system I encountered was vital to my optimism and it became my compass through the mountain crossing that cancer is. My friends even shaved their heads in solidarity, and everyone rallied behind me.

My chemotherapy worked for six rounds but then my primary tumor began to grow again. I thought this was the last straw. When my entire world seemed dark, my mom worked tirelessly to find answers until she found the light: Memorial Sloan-Kettering Cancer Center. They operated on my tumors when everyone else had said the tumors were inoperable. After an eight-hour surgery,

half my right lung had been removed, a metal rib had replaced the rib that was eaten by my cancer, and most importantly, there was no evidence of disease with clean margins. The surgery was followed by a year's worth of maintenance chemo and six weeks of radiation.

Fighting cancer is staring death in the eyes and saying “Bring it on”.

This experience matured me at an accelerated rate. I focused this maturity on Cancer awareness through Curesearch. Almost 6 years later, cancer has given me a broader perspective on life.

I know life will be hard for me as I become an adult due to the side effects, including 67-degree scoliosis from the cancer and treatment. I also know that I will lead my life focused on the positives, as my friends that have lost their battles would have wished me to.

Beau Swallow

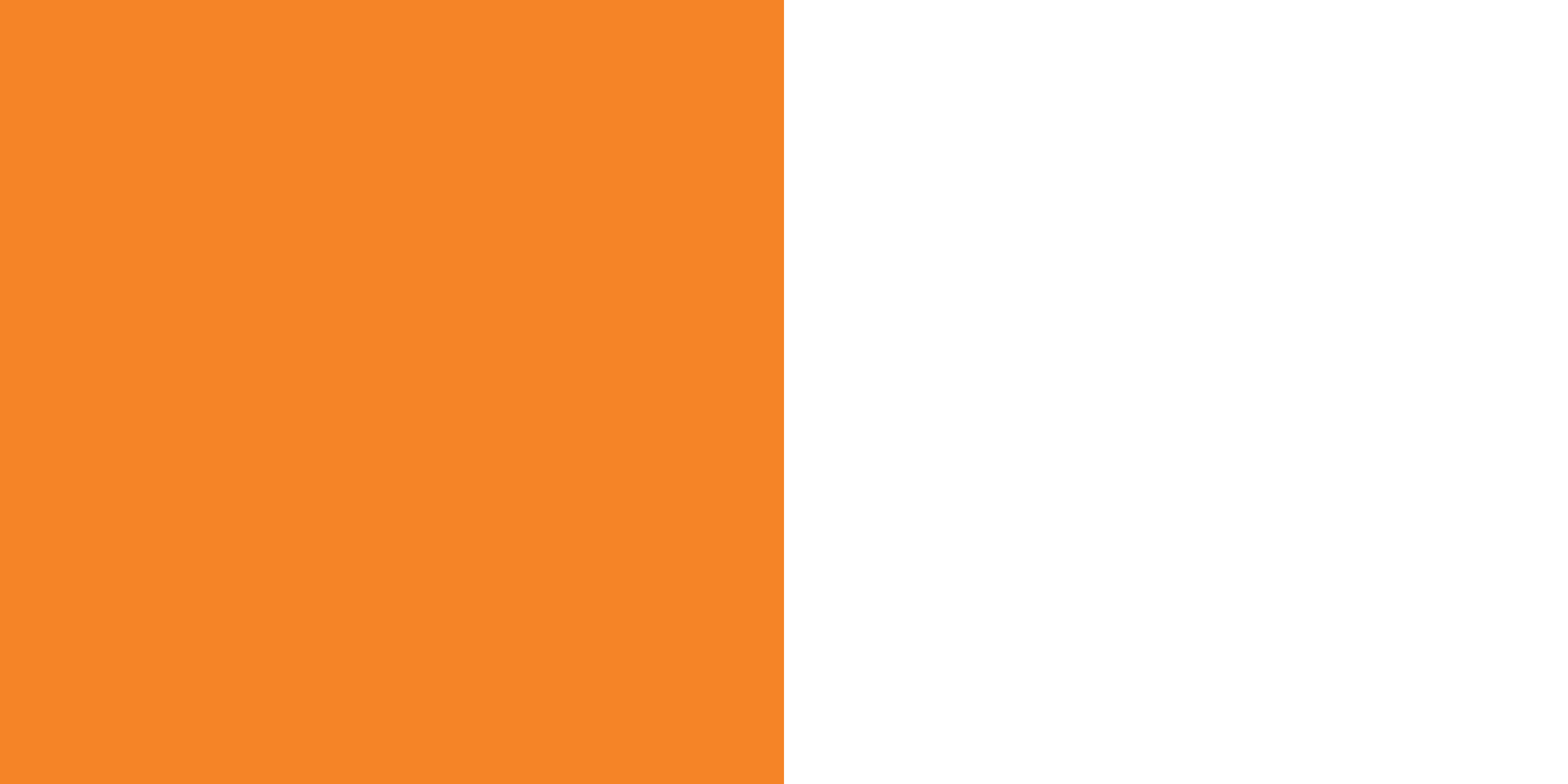
Thank you for supporting the Creating Hope Act, passed in 2012 as 21 U.S.C. 360ff, and the Advancing Hope Act, H.R. 1537, S. 1878, to reauthorize the Creating Hope Act.

Thank you for supporting the Kids' Innovative Drugs Initiative (KIDS Initiative) to update the Pediatric Research Equity Act (PREA), to protect American children with cancer and pediatric cancer researchers, and to bring PREA into alignment with European regulations.

Join us as we change the landscape of pediatric cancer drug research.

Nancy Goodman  
Executive Director

Kids v Cancer



KIDS **V** CANCER

[kidsvcancer.org](https://kidsvcancer.org)