JUST SUPPOSE
JIMMY'S STORY
THE PEDIATRIC CANCER PROGRAM AT THE SидNEY KIMMEL
COMPREHENSIVE CANCER CENTER AT JOHNS HOPKINS
THE STORY IS TOLD OF A LITTLE BOY WHO FINDS THOUSANDS OF STARFISH WASHED UPON THE BEACH AFTER A BIG STORM. HOW COULD HE SAVE THEM ALL? AFTER ALL, WHAT DIFFERENCE COULD ONE PERSON POSSIBLY MAKE?

HE REACHED DOWN AND THREW ONE FISH BACK IN, THEN ANOTHER. “I MADE A DIFFERENCE TO THIS ONE, AND THIS ONE,” HE SAID.

JUST SUPPOSE OUR COMMUNITY SAW CHILDHOOD CANCERS THE SAME WAY. HERE IS A STORY OF THE DIFFERENCE IT CAN MAKE.

A NOTE FROM DR. DONALD SMALL
Director of Pediatric Oncology

Every child has a story. And, every child should be promised the time to live out that story. Cancer is one of the cruelest diseases, not only because of the physical pain and suffering it causes, but because it threatens to rob children of their futures. We understand that when we cure a child of cancer, we not only save a life but a future filled with possibility and promise.

Cancer strikes more than 12,000 children each year. While pediatric cancers are rare, they claim the lives of more children than any other disease. But, there is good news. We understand the urgency that pediatric cancers demand. With world-class expertise, a culture of cross-disciplinary collaboration and a proven track record of successfully bringing therapies from the laboratory to patients, our researchers are leading the field in developing treatments and cures for childhood cancer.

Our researchers are the ones finding the genes, studying what they do in terms of the biology of pediatric cancers, and developing the targeted therapies to fight them.

In the following pages I share with you the story of one of my patients. It is an example of the power of research.
IT WAS AUGUST 1996 and the third birthday for the Berents triplets. It should have been an exciting time for Jimmy Berents and his sisters, but he didn’t feel like celebrating. He sneaked away from the festivities and hid, curled up under the kitchen table. He was pale and clammy, and had a fever. “It’s probably the flu,” the pediatrician told Jimmy’s mother by telephone.

A few days later, with no signs of improvement, his doctor admitted him to the local community hospital. Jimmy’s parents Ginny and Ken recall the doctor sitting at the nurses’ station throughout the night. Neither one of them could sleep. As they worried at Jimmy’s bedside, hour after hour they saw the doctor looking through books and searching on the computer trying diligently to find an explanation for Jimmy’s high fevers. The next day, the answer remained elusive, and he decided Jimmy should go to a teaching hospital near the family’s home in Virginia. Nine days and nine specialists later, Jimmy was sent home with a diagnosis of a virus called mononucleosis that seemed to fit some of his symptoms.

Days passed, and Jimmy had not improved. In fact, he was getting worse. Jimmy’s parents decided it was time to take him to Johns Hopkins. This wasn’t the first time the Berents had turned to the experts at Johns Hopkins. Jimmy and his sisters were born prematurely, and Jimmy suffered a serious complication. “He was rushed to Johns Hopkins when he was 8 days old. The doctors there saved him then. I wanted him back there now,” says Ginny.

While there was no definitive answer, his pediatrician suspected cancer, so he referred him to the Johns Hopkins Pediatric Oncology Clinic. Dr. Donald Small was the pediatric oncologist in charge the day Jimmy arrived. Dr. Small trained at Johns Hopkins and was considered one of its rising stars. From the exam area, he could hear Jimmy coughing continuously. He walked out to the waiting room and called him back to a private room immediately. Dr. Small instinctively knew it was bad. He admitted Jimmy that day.

Dr. Small gathered all of the experts in a conference room just down the hall from Jimmy’s room. He told Ginny and Ken, “Before you put your head on your pillow tonight, we will have answers for you.” Dr. Small and the doctors who gathered to review Jimmy’s case stayed in that conference room, all working together, until they figured it out, recalls Ginny and Ken. “There was such a feeling of teamwork,” says Ken. “Jimmy was the priority, not their egos. It was the complete opposite of our experience at the teaching hospital in Virginia. I knew Dr. Small and the others were doing everything within their power to save my son.”

That night, as promised, Dr. Small delivered the news to Jimmy’s parents. It wasn’t good. Jimmy would need a biopsy to confirm the diagnosis, but Dr. Small was fairly certain he had anaplastic large cell lymphoma, a cancer of immune cells called T cells. Two days later during surgery to biopsy a swollen lymph node under his arm, Jimmy’s heart stopped.

The doctors were able to revive him, but his small, diseased-ravaged body was weak. They transferred him to the pediatric intensive care unit in a drug-induced coma, hoping his body could recover but aware that the odds were against him.

The pathology report confirmed Dr. Small’s suspicion of anaplastic large cell lymphoma, and there was worse news. Jimmy’s lymphoma was stage 4, the most advanced form of the cancer. It was killing Jimmy quickly, and he desperately needed chemotherapy. After all he had been through in recent days, Dr. Small
wasn’t sure Jimmy’s body was strong enough to handle chemotherapy.
In Jimmy’s weakened condition, the potent anticancer drugs could
kill him. Without them, however, he would certainly die. Ginny and
Ken remember feeling terrified

“WE TRUSTED DR. SMALL FROM THE BEGINNING, AND
IF HE WAS RECOMMENDING CHEMOTHERAPY, WE
KNEW THAT WAS WHAT WE HAD TO DO.” — Ginny Berents

and hopeful at the same time.
“We trusted Dr. Small from the beginning, and if he was
recommending chemotherapy, we knew that was what we
to do,” says Ginny. Jimmy
started his chemotherapy
on Halloween. His pediatric
oncology nurse came to the
intensive care unit dressed in
cowgirl costume to give him
his first treatment. He was
still in a coma.
It took two weeks for Jimmy
to wake up. When he finally
came to, it was reminiscent of a scene
out of the Wizard of Oz. His family,
doctors, and nurses gathered around
his bed. For the entire time he had
been on the unit, they had never seen
him awake; never heard his voice.
His condition was dire, and they were
jubilant that he was improving. But
beyond that, they wanted to talk to
him and get to know the patient they
had taken care of for the last two
weeks. Finally, they could interact
with Jimmy.
While Jimmy’s doctors and nurses
were just getting acquainted with
him, Jimmy surprised them with how
well he already knew them. As he
lie silent in his bed those two weeks,
3-year-old Jimmy was apparently
aware of the doctors and nurses who
came in and out of his room. “I know
you,” Jimmy told one young doctor.
“No, you couldn’t,” the doctor replied.
“You’ve been unconscious. You’ve
never met me.” But, Jimmy said,
“Yes, I have. I recognize your voice.”
After the doctors and nurses left,
family temporarily relocated to
Baltimore so the grandparents could
help with Jimmy’s sisters. Caring for
three toddlers was difficult enough,
but the added responsibilities of
managing Jimmy’s cancer made it
an impossible task to do alone.
The anticancer treatment was hard.
It made Jimmy feel sick. His skin
turned red. He suffered fevers and
chills. But, it was working.
As hard as the treatment
was, his parents remained
hopeful Jimmy would over-
come the cancer. When
other young patients died, it
was like a punch to the gut.
When the goal of each day is
to make it to the next day,
the death of any patient was
a harsh reminder of an
uncertain future. “Would we
lose Jimmy?” they wondered.
The worry was always there,
but Ginny and Ken, like most
parents of children with
brain cancer, focused on recovery—
any and every possibility of getting
better. The alternative was just too
painful. When one child died, other
parents mourned, held their breath,
worried, wondered, pleaded, and
prayed. They trembled ahead, a little
more broken but with even greater
resolve.
Finally, almost one year later to
the day, the treatment was over and a CT
scan showed Jimmy, now 4-years-old,
was cancer free. His parents believed
that cancer was in their past and they
were eager for Jimmy, who it seemed
had spent his entire young life fight-
ing one illness or another, to finally
look forward to the pleasures of just
being a little kid.
They were ready to close this
chapter and were preparing for a
party to thank all of the people who
had helped them during Jimmy’s
cancer treatment. Jimmy’s mother
was busy working in the kitchen
when he walked in and very casually
said to her, “Mom, I don’t feel good.
My cancer is back.” The words
stopped her in her tracks. “It’s in
my stomach,” Jimmy told her with
certainty. Ginny and Ken decided to
go forward with the party, trying to
distract themselves with the details
of the preparations and silently
reassuring themselves that it couldn’t
be the cancer. The next morning
they called Dr. Small.

A CHILD’S INTUITION

Hours later, Jimmy was back at Johns
Hopkins for a CT scan of his lungs,
the place his cancer had started
and so the most likely place it would be if
it had come back. The radiology tech-
nicians explained to Jimmy that they
were going to take a look at his lungs.
“But the cancer is in my stomach,”
the 4-year-old told them. He was
insistent that they look there. A technician
came out to the waiting room to
talk to Jimmy’s mother. “Your son
wants his stomach scanned, but our
instructions are to scan his lungs,”
the technician explained. Jimmy’s
mother asked the technician to check
with Dr. Small who then ordered a
scan of Jimmy’s abdomen. Just as
Jimmy said the night before, his cancer
was back, and it was in his stomach.
“How could this be?” Ginny and
Ken wondered. Just days before they
were celebrating Jimmy’s recovery.
They felt defeated, but a determined
Dr. Small assured them he still had
ways of fighting the cancer. This
time the treatment involved a bone
cell transplant using Jimmy’s own blood
stem cells. These are the cells from
which all other blood and immune
cells originate. His doctors collected
healthy blood stem cells from Jimmy’s
circulating blood, in a procedure
much like a blood donation. A tech-
nology developed by a team of cancer
experts at Johns Hopkins, including
Dr. Small, made it possible to extract
the rare but vital stem cells from the
blood. Jimmy received a four-day
regimen of total-body radiation therapy
to destroy his diseased bone marrow
and the cancer cells lurking within it,
followed days later by an intravenous
(IV) infusion of the blood stem cells
collected earlier. These cells would be
to Jimmy’s recovery and should
grow into a normal and cancer-free
bone marrow.
That’s what happened, and at last,
things were back to normal for the
Berents family. The years went by
without any serious health scares.
“It was wonderful,” recalled Ginny.

A TECHNOLOGY DEVELOPED BY A TEAM OF CANCER EXPERTS AT JOHN'S HOPKINS, INCLUDING DR. SMALL, MADE IT POSSIBLE TO EXTRACT THE RARE BUT VITAL STEM CELLS FROM THE BLOOD... THESE CELLS WOULD BE KEY TO JIMMY'S RECOVERY AND SHOULD GROW INTO A NORMAL AND CANCER-FREE BONE MARROW.

There were bumps in the road. Jimmy
injured one knee in seventh grade
playing lacrosse and suffered the
same injury to the other knee in
eighth grade. These types of things
they could handle. Anything but cancer
seemed manageable. Then Jimmy,
now 14, began experiencing excruciating
back pain. His parents again turned
to Dr. Small who ordered an MRI.

JIMMY IS COMFORTED BY SISTER MERRIED

THE SIDNEY KIMMEL COMPREHENSIVE CANCER CENTER AT JOHNS HOPKINS

JUST SUPPOSE
It revealed a tumor on his spine. Jimmy faced yet another surgery as Johns Hopkins neurosurgeons operated to painstakingly scrape the tumor, layer by layer, from his spine. His parents sat nervously and waited for Jimmy to come out of surgery, hoping for the best but well aware of the possibilities. It was a scene that had become all too familiar for Ginny and Ken. Would the procedure to remove the tumor leave Jimmy paralyzed? Was the cancer back? This time there was good news. The surgeons were able to completely remove the tumor without causing any paralysis, and the tumor was benign. Jimmy made a full recovery.

Dr. Small wondered if Jimmy’s knee injuries and spinal tumor were related to the cancer therapy he received. Health issues like these are not uncommon in pediatric cancer patients. Therapies that poison cancer cells also can be toxic to normal cells and developing bodies. This damage can manifest itself years after treatment has ended in muscular and skeletal weakness, heart and other organ toxicities, and even new cancers.

Dr. Small and his pediatric oncology team work diligently to unravel the causes and prevent late- occurring effects of cancer treatment. He put the Pediatric Oncology program at Johns Hopkins on the forefront of survivorship issues and established a dedicated program, led by nurse practitioner Dr. Kathryn Ruble, to monitor and manage the late effects of pediatric cancer therapy.

**CANCER ISN’T PERMANENT**

“We thought, at this point, we’re done,” recalls Ken. How could there be anything else, he wondered. Jimmy and his family had already overcome unimaginable hurdles.

Then, in his sophomore year of high school, Jimmy experienced blurred vision, was waking up at night thirsty, and was using the bathroom a lot. One morning after he left for school, his mother went to his room to make his bed and saw two large cups at his bedside. They were both empty. “No, this can’t be,” she thought. His mother recognized the signs. Jimmy’s father was diabetic, and now she suspected Jimmy was too. She called Jimmy’s school nurse, grabbed Ken’s blood glucose meter, and headed to the school. The nurse tested Jimmy’s blood sugar, and it was so high she directed them to go immediately to the emergency room. It looked like Jimmy had type 1 (juvenile) diabetes.

For nearly his entire life, Jimmy had been battling disease or injury. Yet, through it all, he remained optimistic and steadfast. He never complained. He never felt sorry for himself or broke down, but this time was different. The diabetes diagnosis challenged his resolve and broke his spirit. Jimmy sobbed. “None of the things I had been through before were permanent,” he says. “Dr. Small had been able to get rid of everything else, but you can’t get rid of this.” Jimmy lamented.

Just three months into his diabetes treatment, Jimmy was still coming to terms with the knowledge that he would need daily insulin injections for the rest of his life when he received a well-deserved reprieve. He didn’t have diabetes. Doctors believed his blood sugar could be controlled with diet and exercise. He no longer needed insulin.

The remainder of his high school years were uneventful. There were no more injuries or illnesses. His cancer appeared to be a thing of the past. It had been more than 14 cancer-free years since his stem cell transplant.

Jimmy looked forward to going off to college. His high school class was a small one of just 120 kids, and two of them were his sisters. He was anxious to meet new people. He applied and was accepted to Wake Forest University.

**THE REMAINDER OF HIS HIGH SCHOOL YEARS WERE UNEVENTFUL. THERE WERE NO MORE INJURIES OR ILLNESSES. HIS CANCER APPEARED TO BE A THING OF THE PAST. IT HAD BEEN MORE THAN 14 CANCER-FREE YEARS SINCE HIS STEM CELL TRANSPLANT.**

**UNTHINKABLE WORDS**

As a member of the graduating class of 2012, Jimmy had a few more rights of passage before heading off to Wake Forest. One of these, senior week at the beach and an ill-fated dunk in a garden hose-filled hot tub, left him
and several of his friends with skin infections and rashes. Jimmy had a harder time recovering, but that was not surprising given his medical history. He had a swollen lymph node in his leg that just wouldn’t go away. Antibiotics worked at first, but even with five rounds of treatment, the infection still returned. An ultrasound revealed nothing more than a swollen lymph node, so Jimmy began treatment with a stronger antibiotic. If that didn’t work, the next step was intravenous antibiotics. He cringed at the thought of going away to college with an IV.

The infection was taking its toll. Jimmy was tired and achy most of the time. All he wanted to do was sleep. He was packing and getting ready to head off to college in a few days, and with the infection still hanging on, his doctors decided to use a needle to extract some cells from the swollen lymph node. If they could determine exactly what kind of infection he had, they could identify the correct antibiotic to finally get rid of it.

It was a busy time in the Berents home. As parents of triplets, Ginny and Ken had three children heading off to three different colleges in three different states on three different days. It was hectic, chaotic, and stressful, but it was a good type of chaos, filled with excitement and promise.

Ginny was shopping for dorm supplies with one of Jimmy’s sisters when her cell phone rang. It was Jimmy’s pediatrician calling about the infection. “It’s lymphoma,” he said. She stood speechless and motionless as she heard those unthinkable words. It took her breath away. “How could this be?” she wondered to herself. Never once had she imagined the swollen lymph node was Jimmy’s cancer returning. He had been cancer-free for 14 years. She was so certain—everyone was—that it was related to the skin infection. She called Ken to give him the impossible news. Her next call was to Dr. Small. He had the cells taken from the lymph node sent to Johns Hopkins so expert pathologists there could confirm the diagnosis.

Ginny and Ken couldn’t imagine how they were going to tell Jimmy the news. He was worried about starting college on IV antibiotics. Now they had to tell him that the cancer he had fought off twice, the cancer that dominated most of his childhood, the cancer he thought was gone for good, was back.

In just a few days, he planned to celebrate his 19th birthday and then leave for college. It seemed too cruel to be true. “One day, I’m playing video games, thinking I’m going away to college. Then, I find out my cancer is back,” Jimmy recalled. “It was horrible. I was angry.”

THERE HAD BEEN MUCH PROGRESS SINCE JIMMY’S LAST RELAPSE 14 YEARS AGO. ADDED TO THE STANDARD CANCER TREATMENT WAS SOMETHING CALLED TARGETED THERAPIES.

A BETTER TREATMENT

Instead of heading off to Wake Forest University, he was going back to Johns Hopkins “I was devastated, but Dr. Small gave me hope,” says Jimmy. “It looks like anaplastic large cell lymphoma again,” Dr. Small told Jimmy and his parents. “But, don’t worry,” he said, “The treatment is much better now.”

There had been much progress since Jimmy’s last relapse 14 years ago. Added to the standard cancer treatment was something called targeted therapies. In the 14 years since Jimmy’s stem cell transplant, Johns Hopkins researchers had made significant advances in the laboratory that revealed alterations to genes and the chemical environment of genes that ignite the cancer process. Targeting and blocking these altered genes with drugs was among the newest and most promising breakthroughs in cancer treatment.

IN THE 14 YEARS SINCE JIMMY’S STEM CELL TRANSPLANT, JOHNS HOPKINS RESEARCHERS HAD MADE SIGNIFICANT ADVANCES IN THE LABORATORY THAT REVEALED ALTERATIONS TO GENES AND THE CHEMICAL ENVIRONMENT OF GENES THAT IGNITE THE CANCER PROGRESS. TARGETING AND BLOCKING THESE ALTERED GENES WITH DRUGS WAS AMONG THE NEWEST AND MOST PROMISING BREAKTHROUGHS IN CANCER TREATMENT.
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Ken understood the importance of research in finding better therapies for cancer. As chairman of the Johns Hopkins Pediatric Oncology Advisory Council, he had been working diligently to raise money for pediatric cancer research. When he began his work, he thought Jimmy’s battle was behind them. He was focused on raising funds that would help other children. Now, he was depending upon these advances to save his son’s life.

One of the advances was a shorter length of treatment. This time the treatment would take four months instead of a year. Jimmy received his final cancer treatment in August at Camp Sunrise, a Johns Hopkins owned and managed camp for children with cancer. Jimmy attended the camp for years and now is a camp counselor. He took his first college courses close to home at the University of Richmond, but with treatment behind him, he is preparing to leave for Wake Forest University this fall.

Despite a lifelong battle with cancer, Jimmy is grateful, not bitter. “I have found many more benefits than costs from having cancer,” he says. “I have met and become friends with other patients, who will be friends forever.

I got to know Dr. Small. He took me to a Ravens football game (a game where the Ravens beat the Raiders 55-20; the most points scored in franchise history). He let me fly his plane once. He came to many of my lacrosse games. Oh yeah, and he saved my life three times. I’m lucky to have him.”

The friends he has lost to cancer remind him that there are things worse than the fight. “I can’t complain,” he says. “Yes, I’ve had cancer three times, but more importantly, I’ve survived cancer three times.”

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**WORKING TOGETHER TO CLOSE THE BOOK ON CHILDHOOD CANCER**

The challenge of pediatric cancer is too great for any one of us to take on alone. Together, however, we can make a difference.

Jimmy’s story illustrates the power of research. The stem cell transplant he received and the targeted therapies he is getting today are the result of laboratory and clinical discoveries. Without these advances, his story could be very different. Improved treatments like the ones that helped Jimmy don’t just happen. They are the result of a partnership between philanthropy and science.

As Jimmy’s story illustrates, our team of pediatric oncologists do not give up. Patients, families, and doctors from all over the world turn to us for answers. Your contributions to Johns Hopkins Pediatric Oncology do not support the medical expenses of individual patients but rather fund the science that leads to better treatments and cures for all children.

In the battle against childhood cancer, every gift matters, just as every child matters. It doesn’t matter if it is $1, $100, $1000, or $1 million. Every donation makes a difference, and we are appreciative of each one. Together, we will rewrite the story of childhood cancer.

Thank you for joining us in our goal to ensure that the story of every child with cancer has a happy ending.
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