

A KID WITH CANCER
And Life Beyond

A Kid With Cancer
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Nikki Ruddis
and
Mary Anne Ruddis

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Authors Note

NIKKI WROTE THIS BOOK just a few short weeks before she died. I promised her that I would publish it and after 22 years, I am now finally doing that. She told me that I could add to it and I have written and rewritten it many times. I have also struggled with other challenges in the intervening years, most notably, the subsequent death of one of her two brothers, also from cancer. However, that is another story for another time.

Nikki intended this book for other kids with cancer to bring them hope. Even though she died, she left a legacy of optimism, determination, and hope by letting us know that death is not the end.

I have left her story in her own words. The acronyms she used are explained below. Following her words, I have added a true

account of the gift she left behind that left no doubt that life continues after death and that we all have a time and purpose to our individual lives.

Abbreviations, acronyms, and definitions

Chemo — chemotherapy

EMLA — topical local anesthesia

IV — intravenous

ALL — acute lymphoblastic leukemia

ANLL — acute non-lymphocytic leukemia

broviac — venous access chest catheter

OICU — oncology intensive care unit

Regular floor — pediatric oncology unit

PICU — pediatric intensive care unit

pic line — peripherally inserted central
catheter

CHOCO — Children's Hospital of Orange
County

mask isolation — when out of the room, a
mask needed to be worn or a mask needed
to be worn by anyone entering the hospital
room

tubes — lines from the broviac catheter
PT — physical therapy
BMT — bone marrow transplant
BMA — bone marrow aspiration
LAF — laminar airflow room
ileus — a blockage of the intestines
GCSF — Granulocyte-colony stimulating
factor (to boost white count)
GVH — graft vs. host

Mary Anne Ruddis

A Kid With Cancer



MY NAME IS NIKKI and I'm nine years old. I've had cancer twice in my whole life. When I was little I had a different kind of cancer and I went through chemo for two years and then I was better until last year on April 26.

I was diagnosed with leukemia. They found out when they drew my labs that day. I had a lot of bruises on my legs. The nurse said, "Wow, where did you get all those bruises?"

I laughed and told her I was playing with my two brothers sliding down the hill at my grandma's house. So they drew my labs and my mom took me home. Later on that night my mommy got a phone call from the doctor and I walked into the kitchen and mommy was crying and I asked her what was wrong and she said, "They want to you to go into the hospital overnight."

And I was scared. My aunt came over to help my mom take me to the hospital. I went in and was admitted to the hospital. It was 10:30 at night when I got there. They gave me a really nice nurse, her name was Crystal. About 1 a.m., they put an IV tube in my hand. And I cried really hard when they put it in. They didn't have any numbing stuff to put on it. But now they have something called EMLA which numbs your skin and that way you don't feel it as much.

They put me on a bunch of fluids and so I went to bed that night. My mom stayed overnight with me. The next day they did something called an aspiration—it's a shot in the back that helps them find out what's in your bone marrow. When the results came back it said I had leukemia. And, I had one of the rarest kinds of leukemia. Most kids get ALL but I had ANLL.

My mom told me that I had cancer again. And I got really mad and scared. I stayed out on the floor for about three days. And I got something called a broviac—it's a special tube that's in your chest and that way you don't

have to get poked. And you can get the IV out of your hand. After surgery they put me in a unit called OICU and I wasn't allowed to go out of that unit. And I got REALLY bored sometimes.

Everybody had to wear a mask when they came in my room. After they gave me chemo, my counts got really low and I wasn't allowed to go out of my room anymore. It stayed that way for a long time and then finally they let me go out of my room even though my counts were really low. And that's when I was exposed to chicken pox and they had to give me two shots in my legs. And they used the EMLA cream this time and it helped. I had to move out on the regular floor which really upset me because I didn't know any of the nurses out there except Crystal. And then I met a nurse named Stacy out there.

When I first went into the hospital, I was allowed to go out of my room on the unit, but I wasn't allowed to this time because I was exposed to chicken pox. When I first went to the hospital, I met some really nice people. There was Mrs. Lewis, the schoolteacher, and the recreation therapists, Jill and Doug. My

birthday was June 10 and I was kind of upset that I had to spend it on the unit because I really didn't know anyone out there.

But I still got presents from CHOCO Bear. And in the afternoon my mom got off work and came to see me. She gave me a piece of paper that looked like a card, I opened it and it said I was allowed to go on a pass for an hour. A pass is when you get to go out of the hospital for a few hours. My counts were still really low, but I ended up having a really good birthday!

At the time, my grandpa came down to help us because my dad had cancer too. I couldn't go home though because one of my brothers had chicken pox and my dad couldn't come see me because he would get exposed to chicken pox. But I drove by my house and waved out of the window of my car. My other brother already had chicken pox and he came with mom and me to my friend's house to have a birthday party there.

A few days later I got a fever and they did cultures from my tubes and it said I had an infection in my broviac and I got really sick. I would have gone back to OICU, I think, but

I couldn't because I was exposed to chicken pox so I had to go to PICU where a lot of really sick kids were. Right then they had to pull my broviac.

I was really mad and scared. They put me to sleep and they pulled it. Jill and Kathy (another rec therapist) gave me a teddy bear when I woke up. And Gary DiSarcina (my friend from the California Angels) came down there to visit me too. And he gave me an autographed baseball.

At first I was really, really, really sick in PICU and I had a pic line in my arm—it's kind of like a broviac but it's in your arm. I started to get better after two weeks. They had to pull my pic line because it was getting infected and they put in a groin line. But then I started wetting the bed because I was too sick to get out of bed and I had to wear a diaper and they thought I had ileus—that means you stop pooping, so I would have to go a lot in the diaper and I was glad because it meant I didn't have ileus. They gave me something called GCSF and that made my counts go up really high.

There were also physical therapists named Susan and Guy—they made me do exercises

but I was too sick to do them when I was in PICU. After a while in PICU the doctor came in and he wasn't wearing a mask and I said, "Hey—you have to wear a mask in here!" He said, "Not anymore!" I was very happy because I got to go back up to OICU that day. I was so happy to see all the nurses. All the nurses were happy to see me. I still had the groin line in.

The next day they ordered PT for me again because I was really weak but I did my exercises and I got stronger. But I got into a habit of wetting the bed. On Thursday they were going to put a new broviac in. I was really scared and I wet my bed on Wednesday morning and the nurse got mad at me and she said in a strict voice, "Why did you do that?" And I said, "because I'm scared to get my broviac in." And she said in the same voice, "That's no excuse!" Her name is Diane. I started to cry. Then she said she was upset because I needed to get up and go to the bathroom and not just wet the bed. They had to switch the surgery to Friday. Diane said, "Don't be scared because you won't feel anything." Diane became my favorite nurse and she was my best friend.

And Friday they put my new broviac in. I was really sore so they put me on pain meds. Everything went okay and I was fine. And I didn't have the groin line anymore. I was able to walk, but I was still kind of weak but I kept getting stronger. After I came back from PICU, I didn't have to go back into mask isolation. They let me answer the phones at the nurses' station. I had fun doing that. I was always really bored though. When I did PT, I did exercises and ran around the unit. They said I might be able to go down to the gym and I was excited because they said I could.

I had to go in the afternoon because the outpatients came in the morning and I couldn't be around them. There were two other kids in OICU, Cleavon & Gino, and they went to PT together and I went by myself. But then Gino had to be in mask isolation and he couldn't come out of his room. So Susan (PT) introduced me to Cleavon and we went down to PT together. Cleavon and I became friends. We had fun together—we played ball in OICU if we got bored and I wasn't bored anymore. That's what made it easier to be in the hospital,

plus when my mom came to visit me. She had to take care of my dad and two brothers plus work. Then Gino was able to come out of his room, so the three of us would go down to the gym together.

I still had to get bone marrow aspirations though. I would always get really scared, even though they would give me meds to sleep. I would be afraid that I would wake up and it would hurt really bad. I would always cry before them and get all worked up. And there was nothing I could do about it. My mom ended up having to go on leave from her work. In August I was able to go home before my transplant. My counts were still kind of low. I went swimming at home and had lots of fun.

My mom and dad wanted to wait until after the holidays for my BMT. I would need platelets almost every other day. They wanted to do a BMA and they did it in the outpatient clinic in a place called short stay. I got really worked up. When the results came back they said I had leukemia again and they had to do my BMT right away. They still couldn't find a match for my BMT, so they had to use my mom

for a donor. They gave me lots of chemo. They gave me something called an LP—that's when they give you chemo in your back. Like a shot.

I had to go into a room called LAF—where everything is sterile. I also have a favorite blanket, it was very old—in two pieces, but they lost one of the pieces here at the hospital. They had to get my blanket sterilized. When I first went into LAF, I didn't have any clothes or any of my stuff. I have a spare blanket, it's a green one so I put that in to be sterilized. It came in my room the next day, but my white one was still down being sterilized. It finally ended up coming up to my room. Also, before my BMT, I had to get radiation—they had to wrap me up in sterile blankets to keep me sterile and clean. After all of that, they did my BMT.

Everything was going good. Eighty-something days later, I got to get out of the LAF room. I lost a lot of my strength. I had to spend Christmas in the hospital but I was out of the LAF room, so I had a good Christmas. Christmas Eve my mommy and daddy and brothers came up to see me but they left around 6 p.m. Santa came to my hospital room in the night and when

I woke up, not only did I have tons of presents, my mom and dad and brothers were there. My brothers had their presents from Santa Claus too and we opened them together. I got extra presents from the nurses. I had a really good Christmas.

And I got to go home about two weeks later. When I came back in with an infection, they did a BMA—I had relapsed. That made me scared, because they couldn't give me any more chemo and it just kept on getting worse. I kept getting scared, but they tried a new thing called GVH. Which is a reaction to the new bone marrow. That was supposed to fight the leukemia, so they took me off some of my meds and let my GVH flare up and it helped for awhile but the GVH itched too much and they had to go back to the old meds and the leukemia kept getting worse.

They want to try Taxol—it's a new kind of chemo. They did a lot of aspirations and I got used to them. So I wouldn't be scared, I thought about how I would be asleep and wouldn't feel anything and they could give me Benadryl beforehand to help me relax. That

way everything goes much easier if I'm relaxed and won't feel anything but if I'm all worked up, I won't relax and it could hurt more and you could wake up during it. If you have to get a new broviac—tell them “put me to sleep and I won't feel anything.” That way it's much easier on you.

I've still got leukemia right now. My dad died of his cancer on Easter of 94. I was diagnosed with leukemia in April 93 and I don't know if I'm going to live or not. That's the reason I wrote this book because I might not be able to become a social worker because I want to help you and other kids. Cleavon and Gino both did die which made me sad. But just because my friends died doesn't mean I will.

Never give up hope! Even when things look the worst. And if this happens to you—you want to do a lot of things after your BMT with your family. If you just get an infection, you can probably make it through it—just be confident and tell yourself you can make it. Look what I've been through and I'm still alive!

The End

And Life Beyond



NIKKI'S SECONDARY CANCER, ANLL was caused by the two years of chemotherapy she received when she was diagnosed with rhabdomyosarcoma at 16 months old. She received high doses of toxic drugs designed to cure her and although medically she was considered cured of the initial cancer, that cure came with a high cost. Nikki is not alone. Childhood cancer remains the number one disease killer of children and the treatments are brutally toxic and can have long-lasting and devastating side effects.

When told that we were out of options medically to cure Nikki, she had already endured lifetime doses of radiation and some medications, we chose to do whatever she wanted to do in the time she had left. My husband died in April, only two months after we learned that Nikki relapsed. I often say that

Nikki taught me how to live. When overcome with grief, I reminded myself that my daughter deserved to live fully for whatever days she had left—whether days, weeks, months, or years. Even in the face of a terminal diagnosis, we held on to hope.

Nikki loved Chinese food and decided that she wanted to go to Chinatown in San Francisco and eat real Chinese food. That was our first trip. While there, we also hiked the Redwoods, visited my husband's family, and toured the city. While hiking the Redwoods, I carried Nikki on my shoulders for much of the way. A photo was taken of us as we walked up the path. Later, when the photo was developed, there appeared a child-size figure of light behind us on the path. It was a comfort to see that photo and know that none of us walk alone. While in the city, Nikki picked out a post card to send to her favorite nurse and friend, Diane. She carefully selected the perfect card of a baby seal.

Our next trip was to Youngstown, Ohio to visit my family. Nikki wanted to visit her cousins. During that trip, Nikki met my childhood friend Valarie and they quickly

formed a bond and friendship. When Nikki died, Valarie came to California for the funeral and brought two medicine bags that her brother, a Native American medicine man, made for me after having a dream of Nikki being helped on her journey to the afterlife by a man in a boat with a white beard. He had never met Nikki.

While in Youngstown, Nikki became very ill and was admitted to the hospital. She was already very weak and needed to use a wheelchair if she was going to be walking for any extended amount of time. She wanted to go home to California but the doctors wouldn't release her from the hospital. We took her out of the hospital against medical advice but we were unsure how to get her home. She was unable to fly on a commercial airline because she needed to be on oxygen. Her home health care nurse arranged with The DeBartolo Group, a local company with the means, to fly her home on their private jet. The nurse accompanied us on the flight. It was one of many fortuitous events that carried us through those final days. We are eternally grateful for the kind hearts of so many who made that happen.

After returning to California, Nikki was admitted to the hospital once again. By that time, her legs began to give out on her even more and she needed to be in a wheelchair more of the time. They sent us home, knowing that there wasn't much time left.

Nikki's last request was that she wanted to swim one last time. She loved swimming but with her compromised immune system and receiving continuous intravenous drip pain medication, we needed careful planning and she needed a private pool. I coordinated with her doctor to give her extra pain medication and unhook her continuous drip. Then I contacted a friend with a backyard pool and asked if we could come and swim. Unfortunately, the pool was being repaired and would not be filled again for another three days. This was on a Friday afternoon and we made plans to go the following Monday. Unfortunately, Nikki ended up in the hospital that night for the final time.

Around 2:00 a.m., Nikki began to experience excruciating pain. I rushed her to the hospital after unsuccessfully trying to get her pain under control. The nurses quickly administered more

pain medications and Nikki fell into a drug-induced coma. The next morning around 10 a.m., my sister and I sat on either side of her bed, holding her hand, and noticed that her bed was wet. We checked her IV lines and they were not leaking, her clothing was dry, she did not wet the bed. We couldn't find any source for the wetness. We called her nurse to have her check and she could not find any source either. We slid waterproof pads underneath her to shield her from the wet sheets and keep her dry rather than disturb her with a full bed change. The nurse left and after about ten minutes, we noticed that the pads were wet. Going through the same process, we checked everything and found no reason for the pads to be wet. We called the nurse back and we went through the same checks and again, found nothing, and she assured us that the pads were indeed waterproof. We layered another set of waterproofing under Nikki and didn't think of it again that day.

That evening, August 6, 1994, Nikki passed away after waiting for her brothers to come to the hospital to visit. She previously had

requested that I let the doctors do an autopsy so that they could learn from what she went through. After she died, I wasn't sure I wanted to let them have her body. While my sister stayed with her, I walked outside to clear my head as I wrestled with honoring her wishes and selfishly not wanting another procedure done on her ravaged body. As I sat on a bench in the cool evening air, I heard her voice as clear as if she was sitting next to me, "It's okay mom. They can have my body, I'm not there anymore." I went back in to her room and signed the papers to allow them to learn medically what they could from what she went through.

After Nikki's funeral, we were gathered at our house. Various elements of her final weeks came together. Her doctor came into the house and saw a picture of Nikki's grandfather on the mantle. In the photo, he had a full white beard. My father in-law had passed previously. She said, "That looks like the man I saw in a boat trying to help a baby seal out to the ocean. It was the morning that Nikki died. I was at the boat docks and saw a single baby seal in the

water by the boats that was obviously lost. The man was trying to guide it out to the sea.” Diane commented that Nikki had sent her a postcard of a baby seal from San Francisco just a few weeks before. Valarie reminded us of her brother’s dream of a white bearded man in a boat helping Nikki to crossover. When I asked her doctor what time she was at the docks, she said it was around 10 a.m.—the same time that Nikki’s hospital sheets were mysteriously getting wet.

What I, and many others learned spiritually, was that Nikki did get her last swim and that she truly is still alive—even after all that she went through.



The End ... or not.