

I Am Still ME.®



Forward



I never thought my children would be affected by cancer. Yet, at age 10, my son Matt was diagnosed with Hodgkin's Lymphoma Stage 3A. While Matt was thrown into treatment, our entire family was affected by the trauma of his diagnosis and the horrific side effects he experienced, including his hair loss.

Matt was devastated when he found out he would lose his hair. Even though he liked to keep his hair short, Matt felt that losing his hair was a concrete identifier that further separated him from his peers. He didn't want to have to worry about his outside appearance changing when he had already felt so much worse internally. Matt's hair loss instantly showed he was a cancer patient.

I remember talking to the hospital staff about his illness and the timing of his hair loss, looking for control in the chaos around us. I wanted to know when he would lose his hair and how I could prepare my husband, my children, and myself for our emotional response and the public's reaction to seeing my son bald.

Working in partnership with the hospital, The Dragonfly Foundation created its "I Am Still Me" Program to provide patients and their families with a greater sense of self and community during treatment.

We are grateful to the patients and family members that provided input to this booklet and our Hair Loss Care Package Program. We appreciate the David R. Clare and Margaret C. Clare Foundation for the opportunity to make our programs a reality.

We hope these words will encourage patients and families to be strong in the face of adversity.

Wishing you comfort and joy,



Christine Neitzke
Founder of The Dragonfly Foundation
Dragonfly.org

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“Our wish is to help **ease** your **anxiety** about **hair loss**...”

Serena's Story

Before

Life before the hair loss was hectic. Serena was always too busy to get her hair combed. Ponytails, three to be exact, were my specialty for her. Serena is a fun, adventurous girl who loves pink and all things sparkly. If and when I found pink sparkly things for her, I had her won over. I dreamed of this little girl with dark straight hair like her dad's. She is my princess, and I dress her as such every chance I can. Bows, ribbons, beads, barrettes, you name it, she had that accessory.

During

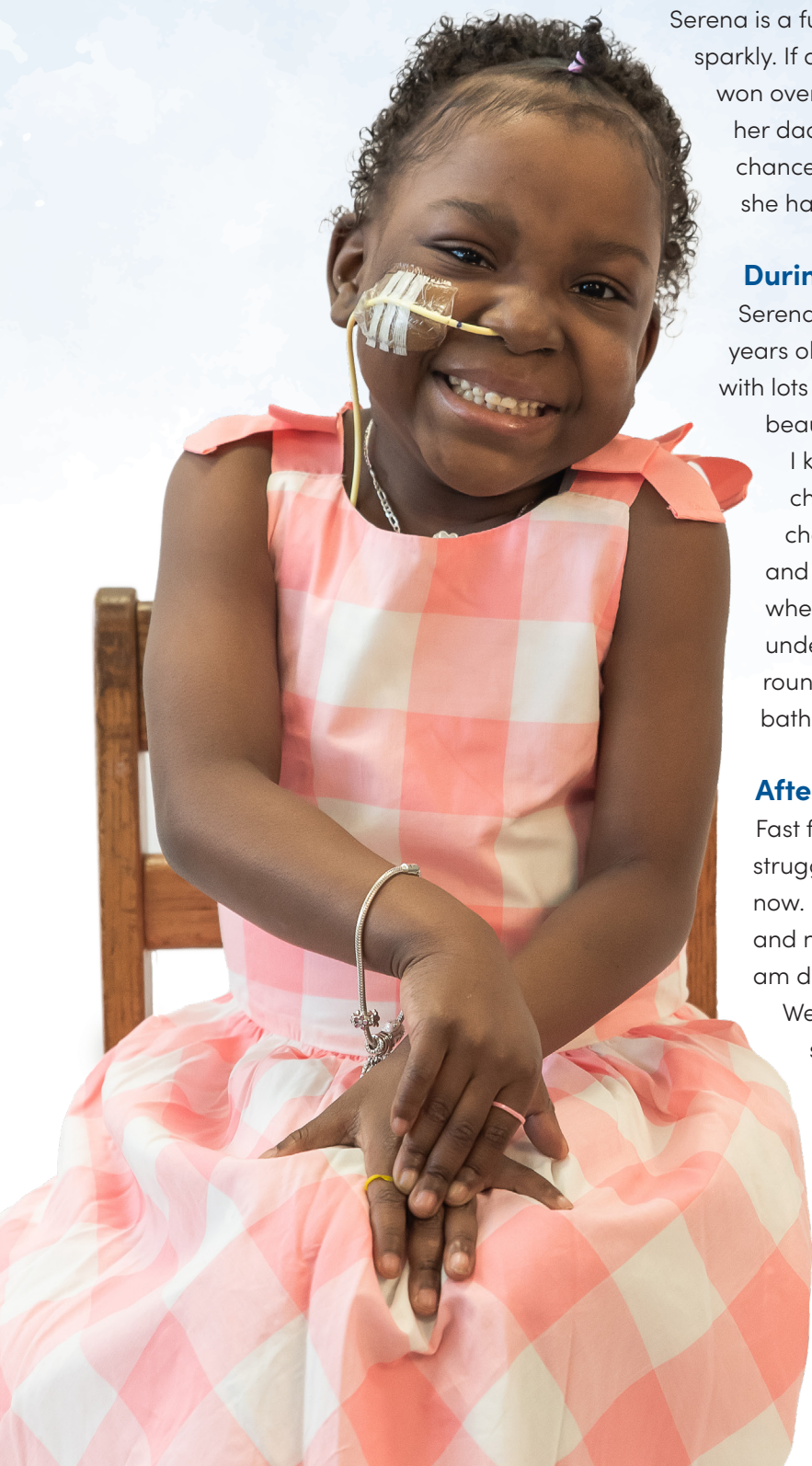
Serena was diagnosed on August 20, 2020. Serena was five years old. It was life-changing hearing these foreign words with lots of letters. Serena sat on my lap, and I rubbed her beautiful dark straight hair. I wanted to scream because I knew it would not be there much longer. A nurse and child life attempted to prepare Serena for this drastic change. Like always, her response was unexpected and quick. "It's OK. I am going to let Mommy braid it when it grows back." I thought to myself, "She does not understand." Serena lost her first ponytail after the first round of chemo on our first day home. I cried in the bathroom. She played with her dolls.

After

Fast forward two years later, her hair is back, and so is the struggle to comb it. She is different now. Her hair is different now. It was straight, and now it is curly. It was dark black, and now it is dark brown. It was thick, and now it is thin. I am different from her brothers, her sisters, and her dad.

We are all different. Different, how you may ask? We are stronger, and it is all because of her. This makes me think of the song by India Arie "I Am Not My Hair."

"I am not my hair
I am not this skin
I am not your expectations, no (hey)
I am not my hair
I am not this skin
I am the soul that lives within."





“We are stronger, and it is all because of her.”



“I knew at some point **my treatment would get rough, and my hair would fall out,** so I had to be tough.”

Ariyana's Story

Before

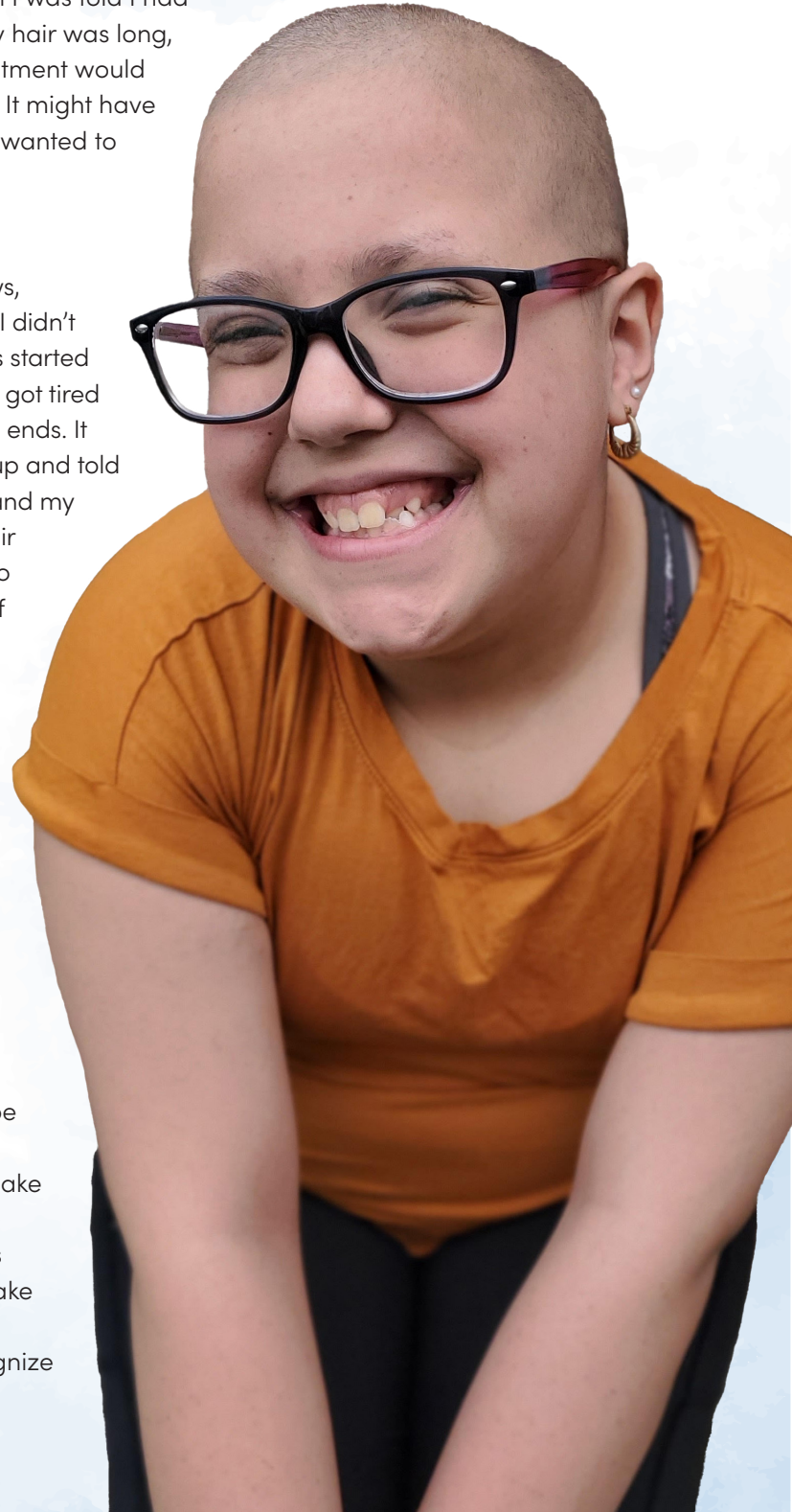
My name is Ariyana. I was first diagnosed with leukemia on October 3rd, 2019. I was only nine at the time and was told I had cancer?! I was terrified and scared. I didn't know what to do. My first thought when I was told I had cancer was, "What about my hair? I don't wanna lose it! My hair was long, light brown, and it was curly!" I knew at some point my treatment would get rough, and my hair would fall out, so I had to be tough. It might have looked like I was tough, but deep down, I was terrified and wanted to get it all over with and just cry in my parents' arms.

During

Six months into treatment, I started seeing hairs on my pillows, clothes, shoes, etc. I knew it was coming, and I was terrified. I didn't wanna lose my hair, but again I knew it would be soon. Days started to pass by, and it kept on falling out. One day, I woke up and got tired of that, so I thought maybe it would stop if I got a trim on the ends. It worked for a while, so we kept doing it. But one day, I woke up and told my mom, "I wanna cut it all off." So that night me, my mom and my dad went to the bathroom, and my dad started to get his hair clippers. I kept wanting to take it back and not cut it, but I also knew that it would just keep falling out, so we shaved it all off (my dad also shaved his head, and my mom got hers cut). When we were done, I looked in the mirror and wanted to cry. It wasn't me... I didn't recognize myself. But we thought of wearing wigs and scarves and hats, so that's exactly what I did - I wore them all for a few months. I started getting tired of wearing those, so I told my mom one day, "I don't wanna wear any wigs or scarves or hats. I don't care what people think anymore. It's not like I'll see them ever again... plus the wigs itch."

After

I started to put headbands in my hair when my hair started to grow back. It felt weird, all the tiny hairs would kinda itch, and it was coming back really light. I thought I would be blonde, and my neck wasn't getting cold anymore! Once it started to grow back, I would have to cut a few inches to make sure it would be the same length. But I was excited to see it grow back. It definitely came back a darker brown and less curly, but I still love it! And I recently got highlights in it to make it stick out more. It still feels weird to this day, but it's ok and definitely a little bit harder to style. I'm also starting to recognize myself when I look in the mirror.



Noah's Story

Before

I was diagnosed with adrenoleukodystrophy at birth through newborn screening. My parents found the human genetics, neurology, and endocrinology teams at Cincinnati Children's Hospital, who have been monitoring me since birth. I have been having regular MRIs of my brain and checks of my adrenal function since birth. When my MRI came back showing cerebral development of my genetic disorder, everything moved really fast! My parents got us in to see the bone marrow transplant team at Cincinnati Children's, and we learned a week after diagnosis that my twin brother was a match to be a donor. We also learned I would lose my hair as a result of the chemotherapy and related treatments. My parents told me how I was getting all of this done to be able to protect my brain and that losing my hair would help the doctors get an even better look at my perfect head to make sure I got better. My dad and I shaved my head right before I went into the hospital for my transplant so that I controlled when I lost my hair. I looked like a minion, and my dad looked like Gru!! In the hospital, some of my hair grew back before my treatment, so I did lose my hair again after the chemo. Child life came in and set up a barbershop just for me and made it fun to get my second shave to remove the rest of the regrown hair. The morning after, the HAIR FAIRY came and left me gifts to open while I was sleeping for being so brave!!

During

After getting my head shaved, it was fun to have a new "hairdo," and I made sure to show all my family and friends the new look every chance I got. My doctors said I was one of the bravest boys they had met and that I showed chemo who was boss and refused to let it get me sick or tired. I had to check in and make sure my dad and my papaw kept their hair shaved, so they looked like me, and they did a pretty good job of keeping up! While I was bald, I really liked to wear hats, especially anything with minions on it (since I looked like one, you know!). My mommy and daddy did an awesome job making sure I had plenty of fun things to do after I got my chemo so that I could stay active, happy, and engaged. The doctors can't prove it, but they said that having so much fun stuff in my hospital room was a big reason I stayed so active and playful and feeling good when going through my treatment.

After

I was in the hospital initially for 42 days. The day I "escaped" and rang the bell was one of the happiest days for my family and me to get to go back home. Going home still meant coming up to the hospital a lot to see my doctors and make sure I was recovering the way I needed to. It also meant there was a good chance I would probably end up back in the hospital for monitoring, even for minor things. So far, I have had three trips back into the hospital for another 13 "sleeps," as I call them, and my nurses, doctors, and child life friends remembered everything about me when I came back and made the really hard days of being back in the hospital as good as they could. My hair started growing back about 3-4 months after my treatment, and it's darker and thicker than it was before. Some of my medicine also made me grow hair all over my body! I call it my "fur," and some of it got so long that my mommy and daddy had my sideburns and ear lobes shaved because they looked so funny! I still have short hair and wear a lot of hats, but hair or no hair, I am still me!



“I still have short hair and wear a lot of hats, **but hair or no hair, I am still me!**”



“Hair does grow back, and I am enjoying watching mine do so.”

Sydney's Story

Before

I was diagnosed with a rare form of Leukemia on February 19, 2021, right after my tenth birthday. We caught the cancer very early before it started to show any signs. I had a lot of support when I was diagnosed. People sent lots of gifts, love, and prayers. It made me feel good to know many people were on my side, even people I didn't know. My hair was long, thick, straight, and dark brown, which is why I chose to donate it to the "Wigs for Kids" organization. Helping someone else made me feel a little better with the idea of losing my hair.

During

After a few weeks of intense treatment, my hair started to fall out. I would wake up to see that there had been hair all over my pillow. I had a hard time watching my hair fall out, so my parents and I decided it would be best to just shave it all off instead of letting it all fall out on its own. I shaved my head myself and made some crazy hairstyles during the process. The mohawk was my favorite. After I shaved my head, I wore lots of hats instead of wigs because the wigs were very itchy, and everyone already knew I lost my hair, so I decided to just embrace it.

After

My hair started to grow back a lighter color and curly. It felt weird not being able to feel my smooth, shiny head anymore. I was just getting used to it. My head was so itchy as it grew back. I'm still deciding whether I should keep my hair really short or grow it out long like before. When I look at old photos of myself without any hair, eyebrows, or eyelashes, I don't even recognize myself. I looked like a whole different person. Even though I was completely bald less than a year ago, it still feels like forever ago, like a distant memory. Hair does grow back, and I am enjoying watching mine do so.



Matt's Story

Before

My name is Matt. I was ten years old when I was diagnosed with cancer. Not only was I afraid of chemotherapy, but I was also afraid of losing my hair. I knew that once I lost my hair, people would stare at me and see that I had cancer.

I was scared.

The chemotherapy made me sick. I felt terrible all the time. I kept dreading losing my hair. After my second round of chemo, my hair started to fall out, but I refused to shave my head. My mom thought it would be a good idea to shave my hair into a buzz cut to make it easier to transition to a bald head. She arranged for a hairdresser to come to the hospital and cut my hair.

After losing part of my hair, it felt good to have it short after all the stress.

A few weeks later, my short hair continued to fall out, and we constantly had to change my pillowcase. I knew we had to do something at that point. My best friend, Vinay, came to see me at the hospital and shaved his head with me. It was great to have a friend there – it made me feel better. My friend was by my side, and I was not alone.

During

While I was bald, my head got cold a lot. I would wear ski hats to keep my head warm. When the weather got warmer, I always wore a baseball hat.

After

Looking back on everything, losing my hair was not as bad as I expected it to be. My family liked to rub my head and make wishes on it. I am a survivor and have voluntarily shaved my head twice to raise awareness about pediatric cancer and The Dragonfly Foundation.





**“Looking back on everything,
losing my hair was not as bad
as I expected it to be.”**



“I chose to donate the hair I cut off so other kids could get a wig, just like I would need a wig.”

Chloe's Story

Before

My name is Chloe. I had long, light brown hair, and it was so silky. I loved my hair so much. I never even wanted to ever trim it. When I got sick, I found out I'd lose my hair. I was crushed.

During

First, I decided to cut my hair to my shoulders because the doctors/nurses said it would feel like a lot more with my super long hair falling out if I didn't cut it. I chose to donate the hair I cut off so other kids could get a wig, just like I would need a wig. When my hair started falling out, I'd notice it mostly when I put my hands through my hair, when I showered, and on my clothes after I took them off. We made a game by making giant hairballs out of the hair I lost at different times and named them different "Hairy" names (Hairy, Hairy Jr, Hairy Sr, Salon Dimitri Hairy, Never Ending Hairy, Hoodie Hairy, etc.) before we threw them away. When a lot of my hair was gone, it stopped falling out as much, but I was missing tons of hair. I decided to shave it then and went to a salon.

After

My head was fuzzy after I shaved it. I loved how it felt all fuzzy! I ended up more okay with being bald than I thought I would be. My family, friends, and teachers were super supportive of me and helped me. I wore a ton of hats that my mom picked out for me (I loved them - they were so cozy and warm!) and even got to wear them to school even though the rule is no hats. After it warmed up outside, I decided to just rock my bald head!

Now it's growing back and it's a full pixie length now. It's almost exactly the same texture and color as before, just a little lighter.



Ethan's Story

Before

Our three year boy was diagnosed with B-cell Acute Lymphoblastic Leukemia in 2021. When our family learned of Ethan's diagnosis, our world broke apart. Ethan was too young at the time to understand what was happening fully. He was still the happy, giddy boy that he had always been. As he was going through treatment, he took each day with a great smile. There were definitely things in treatment that made him scared such as port access, intramuscular chemotherapy injections, and hair loss. Ethan's first hair loss experience was a bit traumatic for him. At the time, he couldn't understand much but was able to understand when we talked about hair loss. He did not want to lose his hair. Ethan couldn't comprehend or imagine what he would look like without his hair. Our family read many books about hair loss together to calm Ethan's anxiety. My husband and I even offered to shave our heads with him so that he would not feel left out. To our surprise, Ethan did not want us to shave. He said, "I like you with your hair."

During

When Ethan's hair started to fall out, it made him very itchy. Hair was everywhere except where it was supposed to be, on his head! Hair was in his bowl while eating. It was falling onto his toys. He'd wake up from sleep with hair covering his pillow and bedding. To Ethan, it didn't bother him. To us, it was heartbreaking. We managed to convince him to shave his head so the hair wouldn't make him itchy anymore. It was his first shave ever. He was nervous during the process. When he took a look at himself for the first time after the shave, he smiled and said, "Look at me! I look so silly without hair!" The weather was turning cold during Ethan's first hair loss, so it was a great way for him to show off his beanies.

After

Ethan lost his hair two times during the intense phase of treatment. The first one was harder, as it was a new experience for all of us. However, when he lost his hair the second time, we were not greatly bothered by it. Yes, the process was still annoying nonetheless, because the hair was everywhere. However, now that we look back at it, it was not as scary as we thought. It may have made Ethan look different; he is still the same happy, giddy boy that we know and love.





“...now that we look back at it, it was **not as scary as we thought.**”



**“...my scars don’t define me,
but they are proof of how strong
and beautiful I really am.”**

Izzy's Story

Before

I was diagnosed with brain cancer just three weeks after my 2nd birthday. I was too young to really remember what happened, but I do remember having to spend a lot of time away from my best friend, my twin sister Joey.

We are identical twins, and it had always been really hard for people to tell us apart with our jet-black hair and bangs. Friends would always comment on how beautiful, thick, and shiny our hair was, and I loved wearing all sorts of crowns & tiaras.

During

In order to save my life, I underwent three major brain surgeries. For each of the three surgeries, the doctors had to shave all the hair from the right side of my head and add a shunt to help drain blood.

Each of these shunts left a visible scar on my head. My mom had to ask the doctors to please also shave the other side of my head too so my hair would look even. As I healed from the surgeries, my hair started to grow back, which was exciting, but then I had to undergo chemo for a year, and I lost not only my hair, but my eyebrows too.

It started to become very easy for people to tell me and my twin sister apart. People also started to assume that I was younger than my sister because I was bald and because while my sister grew taller, my growth halted for a while.

I always loved playing outside and riding my bike, but my mom was very afraid of my head getting sunburned, so I wore a lot of really fun hats. My favorite was a hat that someone crocheted and donated to me, which looked just like Queen Elsa's hair. When I wore that hat, I felt just like a Disney princess.

After

Once my treatment was complete, my hair finally started to grow back for good. However, the hair never grew back over the many scars left on my head from my numerous brain surgeries. In the beginning, I was able to cover the bald spots on my head with my hair, but as I grew older and my head grew, the bald spots got bigger and more apparent. I also started to notice the indentation on the back of my skull from my surgeries more. However, my mom reassures me that I'm perfect just the way I am and that my scars don't define me, but that they are proof of how strong and beautiful I really am.



**“You have to stay strong, fight,
learn, and stay positive.”**



I Am Still Me

