

*I am Still Me*TM



THE
DRAGONFLY
FOUNDATION®

*Bringing Comfort and Joy
To Kids & Young Adults
Enduring Cancer and
Bone Marrow Transplants*

Special thanks to Cincinnati Children's Hospital Medical Center for helping make this book possible.

forward



I never thought my children would be affected by cancer. Yet, at age 10, my son Matt was diagnosed with Hodgkin's Lymphoma. 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, something that further separated him from his peers. He didn't want to have to worry about his outside appearance changing when he already felt so much worse internally. For us all, Matt's hair loss was an instant, visual sign that 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 Cincinnati Children's Hospital Medical Center, 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 more than 100 patients and family members that provided input into this booklet and our Hair Loss Care Package Program. We hope their words will encourage patients and families to be strong in the face of adversity.

Wishing you comfort and joy,



Christine Neitzke
Co-Founder of The Dragonfly Foundation
www.Dragonfly.org

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

Matt's Story

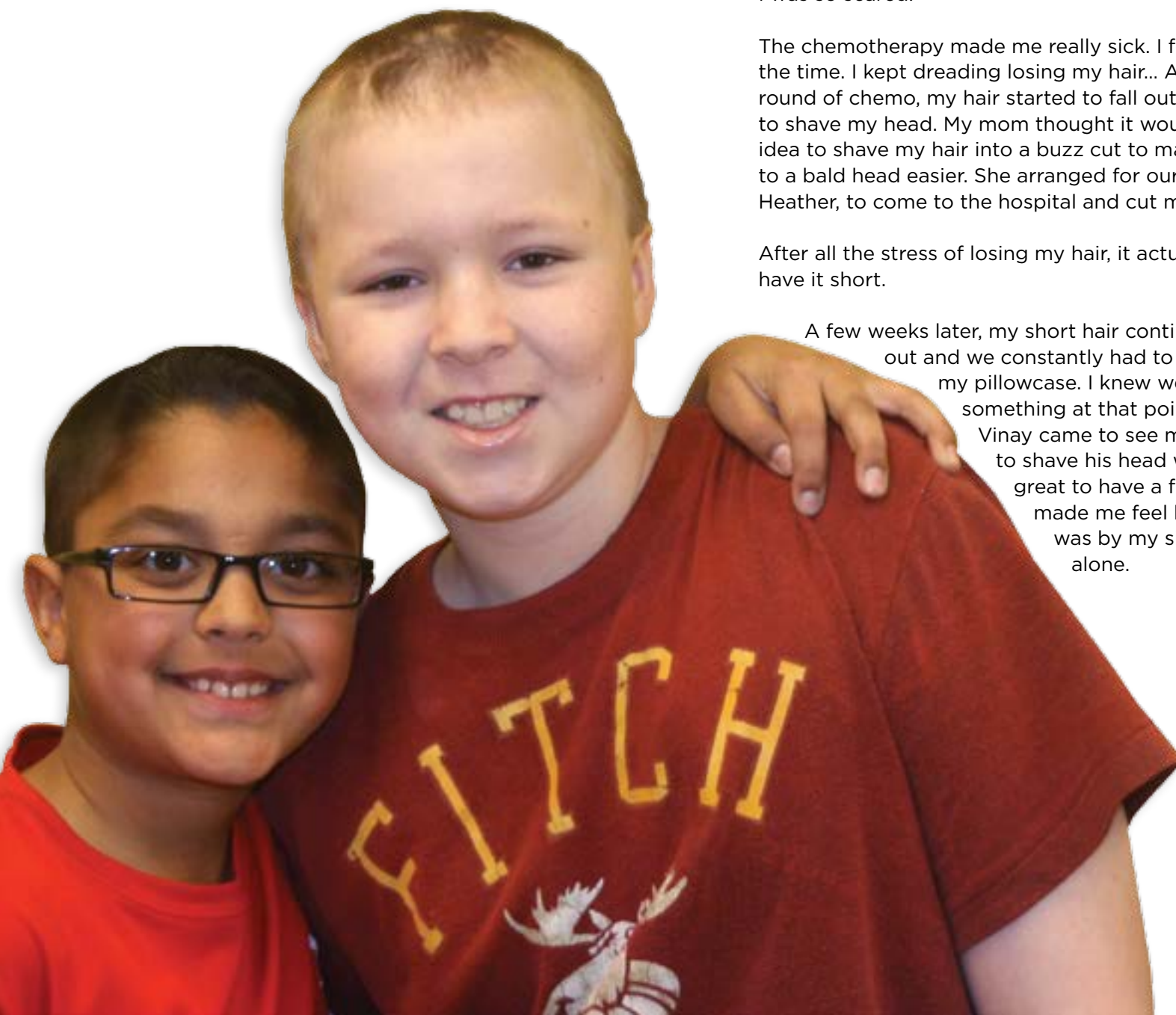
Before: My name is Matt. I was 10 years old when I was diagnosed with cancer. Not only was I afraid of chemotherapy, I was afraid to lose my hair. I knew that once I lost my hair, people would stare at me and know that I had cancer.

I was so scared.

The chemotherapy made me really 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 didn't want to shave my head. My mom thought it would be a good idea to shave my hair into a buzz cut to make the transition to a bald head easier. She arranged for our hairdresser Heather, to come to the hospital and cut my hair.

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

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 to shave 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 wasn't as bad as I expected it to be. My family liked to rub my head for good luck and make wishes on it. I am currently in remission, and have voluntarily shaved my head twice to raise awareness about pediatric cancer and The Dragonfly Foundation.



Matt's Tip: 

Shave your head with a family member or friend.

“My family liked to **rub my head for good luck** and **make wishes on it.**”

Anne's Story

Before: My name is Anne. I was first diagnosed with Stage 4 Metastatic Melanoma in June 2011 when I was 23 years old. Not only was I feeling extremely lost and terrified, but one of the first things that came to my mind was “how am I going to be without my long hair I’ve had my entire life? Will I lose my identity completely?” Luckily with Melanoma, even though it is a deadly cancer, there are quite a few options that didn’t require me to lose my hair. So the first treatment I tried was actually a type of immunotherapy, where I didn’t lose my hair.

The therapy worked for a while, but I had to switch treatments when the doctors found a large tumor in my upper intestine. Once I met with the doctors to discuss the next phase of treatment, I realized I couldn’t escape the chemotherapy that went with my certain protocol. I knew it was then I would have to accept that my long blonde locks were going to be gone for a while.

I decided it would be an easier transition to cut my hair shorter before I started my new treatment. I cut about 14 inches off and dyed my hair purple. My hair was still past my shoulders— that was short for me! I figured I might as well have fun with my hair while I had it!



Overall my advice would be:

1. Take things day by day. Trying to look far into the future will only overwhelm you, and you can’t obsess over what might be. You don’t know what might happen!
2. Don’t ever think that something external or tangible, like your hair, defines who you are. It’s how you present yourself and yes, even how you present your baldness that makes you unique; embrace it!
3. Make sure you talk with your doctors. About 10% of patients going through chemo don’t lose their hair. You might be one of the lucky ones who don’t lose it at all! Be patient, but be prepared for any outcome.
4. If you do end up losing your hair in colder months like I did, wear hats! You lose a lot of body heat from your head. On my downtime during treatment I would go online and look at different hats. There are so many options that are functional and can help you express yourself.
5. If you can’t cope with losing your hair, there are countless wig options. Most of them are super affordable, or even better, free!
6. Listen to the members of your support system and try to make the best out of the situation!



During: Once I began my treatment I didn't really have any idea of how long it would take for my hair to fall out. Even though the chemotherapies I was taking were rough, my hair wasn't falling out. Every day I would randomly pull on my hair to see if it was firmly attached, and for a time, it was! I remained hopeful that hair loss wouldn't happen to me. Then, about 18 days after my last chemotherapy treatment, I woke up one morning, pulled on my hair, and saw that it came out in clumps.

Luckily, I had my extremely supportive boyfriend with me and I asked him to shave my head in my hospital room. Once he started, that's when the waterworks began. I couldn't stop crying until he let me shave his head. That's when my tears of sadness turned into tears of laughter; I never realized how bad someone could be with clippers! I was so new at shaving heads that his hair—or what was left of it—ended up looking like he had a lawn mower ride all over his head! Once I looked in the mirror it dawned on me that I looked a lot more like my dad than I thought. I thought my hair was what defined me, but once I looked in the mirror, I realized I was a lot more than that. After that moment, I knew I was strong.

After: Before I lost my hair, I always thought “will I want a wig? I will want a wig.” Honestly, everywhere I went with my bald head I got compliments; people loved it! I was shocked. I worried that when anyone saw me, they would jump to the conclusion of thinking I was sick. Really a lot of people just ended up being more intrigued by my baldness than anything else. Don't get me wrong—there are definitely days where I miss my long hair, but you learn to love who you are inside and appreciate what you have. It's a sign of progress.

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“I knew then this really was going to be the **first day of the rest of my life.**”





Kila's Story

Before: As a teenage girl, hair was always important to me. I had long, wavy brown hair that people always complimented me on. To me, at least, I thought that without my hair I wouldn't be me. The minute I heard Leukemia and my name in the same sentence, I immediately thought about my long thick hair that would soon diminish to peach fuzz. Most importantly, I was nervous about what people would think. Would my friends still be there for me when I was bald? Luckily, I was quickly reassured by my best friend and her mom—they weren't going anywhere.

During: Once I had reconciled that I was losing my hair, I wanted to control the loss, not Leukemia. Right away I had my mom shave it off and boy, did it feel good. My first shower post hair felt like a deep tissue head massage. I walked the halls of the hospital with pride, showing my new style. Prior to the shaving, I had forced my mom to buy me a real hair wig; I wasn't going to let anybody know I was bald. That changed quickly. I only wore the wig once! It itched, and it didn't feel like a part of me. I switched to unique looking scarves that were more ME. In fact, my mom and I made the most of them, and people started complimenting me on my scarves. I was bald with pride, and still me.

After: Looking back over this year, as I am still bald and still in treatment, I'm glad I had the confidence to take on the stares people would give me and remain true to myself. My confidence today is a lot greater than when I had my hair. I truly believe that what doesn't kill you, makes you stronger!



Kila's Tip:

- ▶ Don't shy away from going bald because you may be worried about what other people think.
- ▶ Embrace your temporary look... even by wearing scarves. I got a lot of complements about my scarves!
- ▶ Wear sunscreen!



“My confidence today is a lot greater than when I had my hair.”

Sunder's Story

Before: I had turned 23 when tests came back diagnosing me with XIAP, a very rare primary immunodeficiency. I was informed that I needed to have a bone marrow transplant. I didn't know everything the transplant entailed at the time, so I was hesitant to go through with it. I did know that I'd have to go through chemotherapy and a bunch of other treatments. I knew nothing would be the same.

When I started my treatments, it was in the early summer. They were terrible. Along with feeling sick and tired, I was waiting for the inevitable: losing my hair. So many questions ran through my head. Would it grow back? What color would it be? Would I be one of the lucky ones—would my hair not fall out? The child life specialists came and offered me some clippers to shave off all my hair if I wanted, but I couldn't do it. I put it off and put it off. Then it started — the hair on my pillowcase, coming out slowly. I decided to go ahead and shave it all off. It was a really weird feeling to have hair one moment, then gone the next. What I didn't expect was the relief I felt when I took control of the situation and took care of it.

“All my concerns about losing my hair turned out to have been **unnecessary.”**

During: The first night after shaving my head, I was surprised by how hot my head was when I was trying to sleep. I had to keep flipping my pillow! I had expected the complete opposite; I thought I'd be cold all the time. I had never been big on wearing hats before my hair loss. That changed. Hats concealed my bald head and protected it from the sun. Hats were security for me in multiple ways.

After: My family and I tried to make light of my bald head. I tried my best to have a sense of humor about losing my hair because there was no going back. My hair has almost fully grown back to the thickness it had been before the transplant, but it grew back darker than my original hair color. I'm happy to see that it is slowly lightening back up. All my concerns about losing my hair turned out to be unnecessary.

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Sunder's Tip: 

Do something fun with your hair before you shave it that you never would have otherwise. Dye it a crazy color. Cut it really funky. Have fun with it!

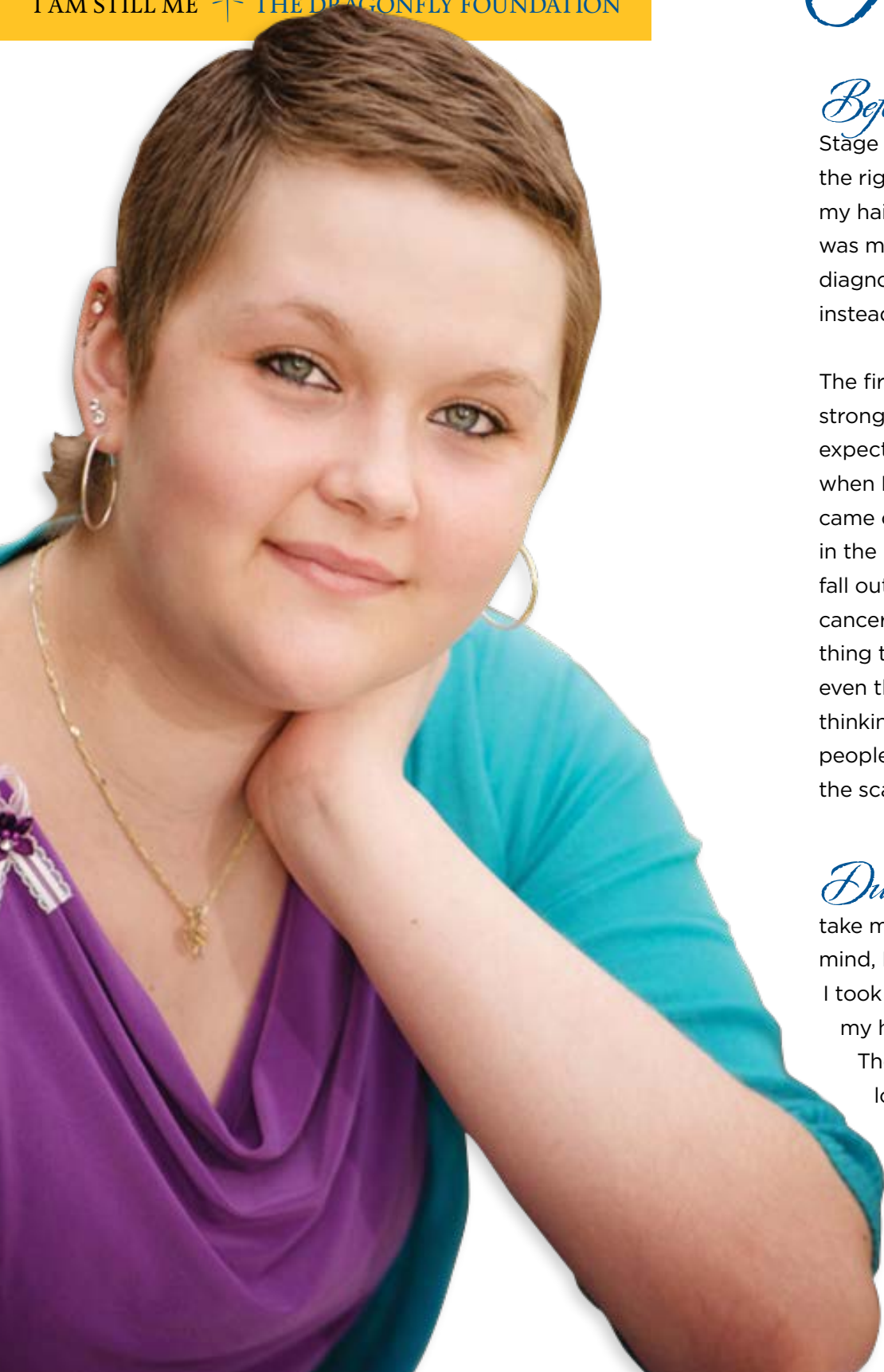


Mary's Story

Before: I was diagnosed with Hodgkin's Lymphoma Stage 4 when I was 19. I thought I had everything going the right way for me. I liked to express myself and getting my hair done was one of the ways I did that. My hair was my "everything." When I was told cancer was my diagnosis, all I really thought about was losing my hair instead of my life.

The first chemotherapy treatment I was given was so strong, that I started losing my hair right away. I didn't expect to see it go so fast. My plan was to cut it short when I left the hospital so it wouldn't be so bad when it came out. That didn't happen. I ended up having to stay in the hospital the whole month. I had to watch my hair fall out in large clumps. One of my nurses went through cancer when she was my age, and she told me the best thing to do was just to shave it all off. At first I couldn't even think about doing that. Once I was alone and thinking about what I would look like, worrying what other people would think and say, I had a panic attack. It was the scariest thing I've gone through so far.

During: Once the panic attack passed, I decided to take my nurse's advice and shave off all my hair. In my mind, I saw it as beating cancer and chemo to the punch. I took my hair away before the treatment could. Once my hair was gone, I couldn't look in the mirror for days. The day I finally looked in the mirror I stared for a long time. I just didn't see myself as the bald girl in the mirror. I started wearing hats all the time and getting used to the bald me. Everyone told me I was still beautiful and should stay with short hair or even bald once my hair grew back. I didn't like the idea at first, but I realized that short hair was a reflection of a new, stronger Mary.



After: Once I got used to not having my hair, I realized that hair is not what makes a person who they are. It's not what makes a person beautiful. After a while, I learned to leave my head bare and not care what people thought. I am now done with treatment and my hair is coming back. I'm happy it's coming back, but I think I'm going to keep it really short or close to bald. After my struggle, I know my hair is nothing and my life is everything.

Looking back, I can see that I didn't know much about myself before treatment started. I think this experience has made me a better person; I see things differently and more clearly now. When you have cancer you can't just think of the bad; you have to stay strong, stay positive, learn, and always fight. I am now enrolled in classes to become an oncology nurse to help other adolescents fight through cancer, like my nurse did for me. Before cancer, I would always look first at the bad, but now after my battle, I have learned to look at the good and what things can be. I believe I'm a lot stronger and I want to go on in life and be the inspiration some people say I am. I am completely different now and I believe that my hair is what made me who I am now. I love my hair short.

When people ask me about my short hair now, I tell them I would rather have it short over not having a life.

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Mary's Tip:

When your hair is about to come out, beat the chemo to it! Shave it off so you can say you made the decision for yourself instead of having it made for you. Don't let anything keep you down. Learn everything you can from your battle instead of just suffering through it. Let it build you up, not break you down. Always say I'm beating this, no matter what!



“I know **my hair is nothing** and **my life is everything.**”

Maya's Story

Before: My name is Maya. I have always had bright blonde hair, and I loved it. But then I got sick and I had to go to the hospital. My mom said that I would lose my hair from the medicine. I told my mom that before I lost my hair, I wanted to dye it my favorite colors!

During: We got my mom's hairdresser to come to my room at the hospital. She dyed my hair bright pink, blue, and green. I also remember that it started to fall out, and every morning we had to change my pillowcase. My hair was falling out bit by bit. One day, all my hair came out. I'm glad we had fun with it when I still had my hair.

After: Losing my hair wasn't as bad as I thought. We really had fun making my hair different colors. Now my hair is coming back red. Maybe I will be a red head!





Maya's Tip: 

Dye your hair in bright colors
before it falls out!

“We really had fun with **making my hair different colors.** Now, my hair is coming back red.”

Kyle's Story

Before: I was diagnosed with Hodgkin's Lymphoma in June of 2010, when I was 14 years old. I began my treatment in July, right before I started high school. Growing up, I always had thick, curly hair, but the doctors told me in all likelihood I would likely lose it from a side effect of chemotherapy.

During: My friend and hairdresser, Mary, has cut my hair since I was little. She came to our house and gave me a buzz cut on the back porch of our house. My dad and brother also had their hair buzzed really short too. The buzz cut helped when my hair started falling out; there wasn't as much of it.

With no hair, I was stressed about going to high school. I went to the freshman orientation and the first day of school before I had to go back to the hospital for more treatment. I hadn't decided if I wanted anyone to even know that I had cancer. I just didn't want all the pity looks and questions. I also didn't want to stand out by wearing a hat or anything. Those days were really uncomfortable for me because some kids stared, whispered, or asked me where my hair had gone.

After: While I was in the hospital, I talked with my parents and they convinced me to let the teachers tell everyone. The school made an announcement the next day and everyone prayed for me. After school, the freshman football team asked the administration if they could shave their heads so that I wouldn't feel so out of place. Then the varsity football team asked, as well as other kids. Two days later during lunch, the school sponsored a "buzz-a-thon" and 90 people, including students, teachers, even 4 girls, shaved their heads and donated to the Leukemia and Lymphoma Society. It felt really good to have everyone's support.





Kyle's Tip:

Don't be afraid to share your story with friends at school, they can be a great support system for your journey.



“My dad and brother also had their hair buzzed really short too.”

Jessica's Story

Before: I'm 18 years old, but have been dealing with CANCER since I was 7 years old. The journey with this disease has been long, hard, frustrating, challenging, but also very rewarding.

HAIR.....there's long, short, curly, straight, blonde, red, brown, etc. We don't realize that hair is really important to us until it's gone. In a way, hair is a security blanket and WE can control what we do with it.

During: I was nine years old the FIRST time I lost my hair. Before losing my hair, my Aunt Megan cut a piece of it to save so that we could compare it to the new hair that would come in later. I was determined NOT to shave my head with whatever hair I had left. That was still MY hair that didn't want to leave me, plus it drove my mother nuts. (She told me that I looked like I had an old man's ring of hair around the bald top of my head.)

I have lost my hair 3 more times after that. Two of those times, I still didn't shave my head because I believed this is "ME." The third time I did shave the rest of my hair to help raise money for cancer research. I was very excited to help make a difference for not only myself, but for others who are also facing this journey.

From the time I was told that I was going to lose my hair until I was done with chemo, I was given a bunch of hats and bandannas. My favorite was one that someone actually made just for me. It was pink baseball cap with my name sewed on it. It was the most comfortable hat and so easy to throw on. I liked that it matched almost everything I wore. The funny thing is that I even wore this hat even after I got my hair back. The hat has continued with me on my journey.

I have been bald during every season. Being bald during the winter was the worst, even if I did have a hat and ear muffs on. It was cold and my head was sensitive to cold breezes. It was great having no hair in the summer, when it was warm, except I had to remember to put sunscreen on my head and ears.

After: When giving advice and guidance to someone to losing their hair, I would tell them about some of the good things that I have encountered during the process. I didn't have to wash, brush, or fix my hair every day. I actually got to sleep in before school.

Before the hair loss starts, go out and try on different hats, bandannas, scarfs, headbands, and even try some wigs. It is so much fun to dress all these up and bedazzle them. Start a new trend and even get your friends involved. The last time I lost my hair, I finally got 2 wigs. One is short and one long. This has been so much fun! The best part is that I can do my hair the night before, put the wig on "my fake head" so that it is ready to go in morning. This gives me more time in the morning! I am able to put on my make-up, throw on my wig, and head to school.

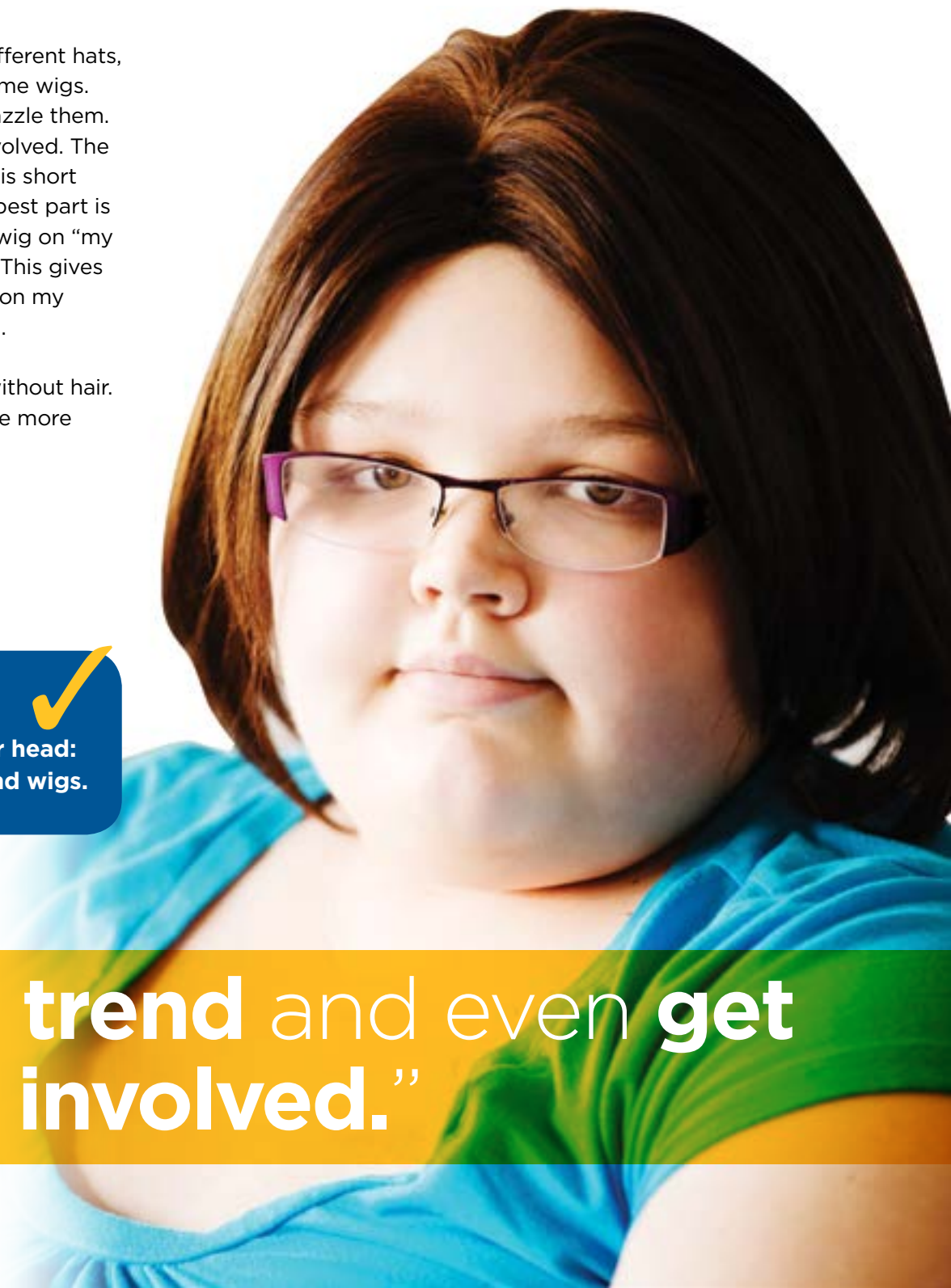
I have learned a lot about being ME with and without hair. Remember YOU ARE still YOU - just with a little more SPUNK!!

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Jessica's Tip:

Think of fun creative ways to cover your head: hats, headbands, bandannas, scarves and wigs. 

"Start a new trend and even get your friends involved."



Evan's Story

Before: As Evan's mom, I can tell you that his hair loss impacted our family, too.

As with most aspects of this horrible experience, it's imperative to remember we all see and feel a little bit differently about every aspect of this journey — AND no two perspectives are exactly the same. That said, here are my thoughts and my hope is that they help someone else in some minor way with an extremely difficult journey.

As we embarked on this journey, I worried much more and still do about the toxic impact of the chemotherapy than the hair loss. That said, I did have "feelings" about it. Namely, that this would be a visible, tangible impact on my child that I would see and feel. Before the actual hair loss, I also thought about how I felt every time I saw a bald child and thought about what they must be going through. Each and every time, I felt sad. But when they smiled, I thought about how strong they were and how ADMIRABLE. And NOW this would be my child.

Evan thought he would be among the 10% that do not lose their hair as a result of chemotherapy. When we talked about hair loss, he said, "Some people don't lose their hair, right Mom?" I said, yes that is true but most do. He planned on being in the 10%. That's the thing about kids.

It's their natural instinct to think bad things don't happen to them — even when they do. That outlook inspires me every single day. If my 6-year-old son can do this, so can I.



During: As the hair started falling out, my husband and I were sad. Sad to see it happening but mostly we were happy for every step of this journey that we didn't want to make. We could now cross this off "the list" of things we had to do to get through to "get to the other side" and to move on. We are still "check boxing," ready for the final result: a healthy, happy child. That's our end goal, and that is where we focus our energy... most of the time.

Evan's hair fell out gradually, but then there was hair everywhere! Even with bald patches all over, our son didn't want to shave his head. He didn't want to be a bald 6-year-old. He had patches all over, but we waited for him to be ready to shave his hair. We did encourage it because we thought getting it over quickly would be best. That day came, when he couldn't stand sleeping in a bed covered in hair.

When I shaved his head, I looked at him and I felt sad but proud. He had endured so much and was now handling this as well. It was just hair after all. I think if he was a girl, and more connected to his hair, it would have been different.

When we shaved his head, we used an electric shaver. It was uncomfortable for him when we touched his head. We kept showering him and using a washcloth to eliminate the remaining stubble. But eventually, my husband used his razor, very carefully to eliminate the rest. Fully bald was MUCH more comfortable. And yes he was beautiful and he was still him!

After: Hats are a personal issue. Evan did not think baseball caps were necessary or comfortable. He likes the chemo-type caps when he is chilly, but that it isn't often. I thought he would be cold without his hair, but he isn't. He does not feel the need to cover his beautiful bald head. We took his lead and encouraged his comfort first.

Today, as his hair starts to grow back and we await his full recovery I dwell more. I do this especially as he sleeps. I often think about the ramifications of his treatment. I know his recovery is the most important thing in the world. But I do cry often as I look at my bald, sleeping child. And tonight when I kissed his fuzzy head, I thought deeply about how it felt, and about how grateful I was that I could still kiss him...hair or no hair.

Lisa Percelli
Evan's Mom

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Evan's Tip:

In the beginning, I didn't want to shave my head because I didn't want to be bald. I finally did because the hair was all over my bed all the time. It hurt a little when there was prickly hair left on my head. Then that fell out and it was smooth. Once my head was smooth, it felt good. My head felt better.

If my 6-year-old son can do this, so can I.

Tiara's Story

Before: I was diagnosed with AML (Acute Myeloid Leukemia) at the age of 23. There was very little time between my diagnosis and treatment. Since I was aware that I would lose my hair due to the chemotherapy, I asked my hair stylist to come to the hospital and give me a new cut the minute I saw signs of major shedding. I opted for the G.I. Jane look. [This was before Amber Rose (a model and recording artist) made it cool to rock a bald head.] Making this choice made me feel empowered at a time when I was losing not only my beautiful curls, but a part of my independence. I was not going to allow cancer to change my life. Whenever possible, I was going to be the one to say when and how changes would occur. Deciding to shave my hair allowed me to do exactly that: to have some control on when and how I would depart from my tresses.

During: I looked at this time as an opportunity to explore myself. I had fun wearing scarves, hats, and wigs of various lengths, styles, and colors that I would not ordinarily have tried otherwise. Also, I listened to music that uplifted me and reminded me of my beauty and strength, such as "I Am Not My Hair" by India Arie. In addition, I surrounded myself with photos of beautiful people with bald heads, like Shane O'Connor, Michael Jordan. Most importantly, I began to view my bald head as a badge of honor, a statement, that shouted "I am strong, a survivor, and still here."

After: My hair grew back relatively quickly, and it was still the same color and texture. Although, during one round of chemo it grew in blonde but eventually turned black. Over the years, I lost my hair two more times due to chemotherapy. Each time I continued to look at it as a learning experience and a chance to try new things. My family and friends shaved their heads with me the second time, which really helped.

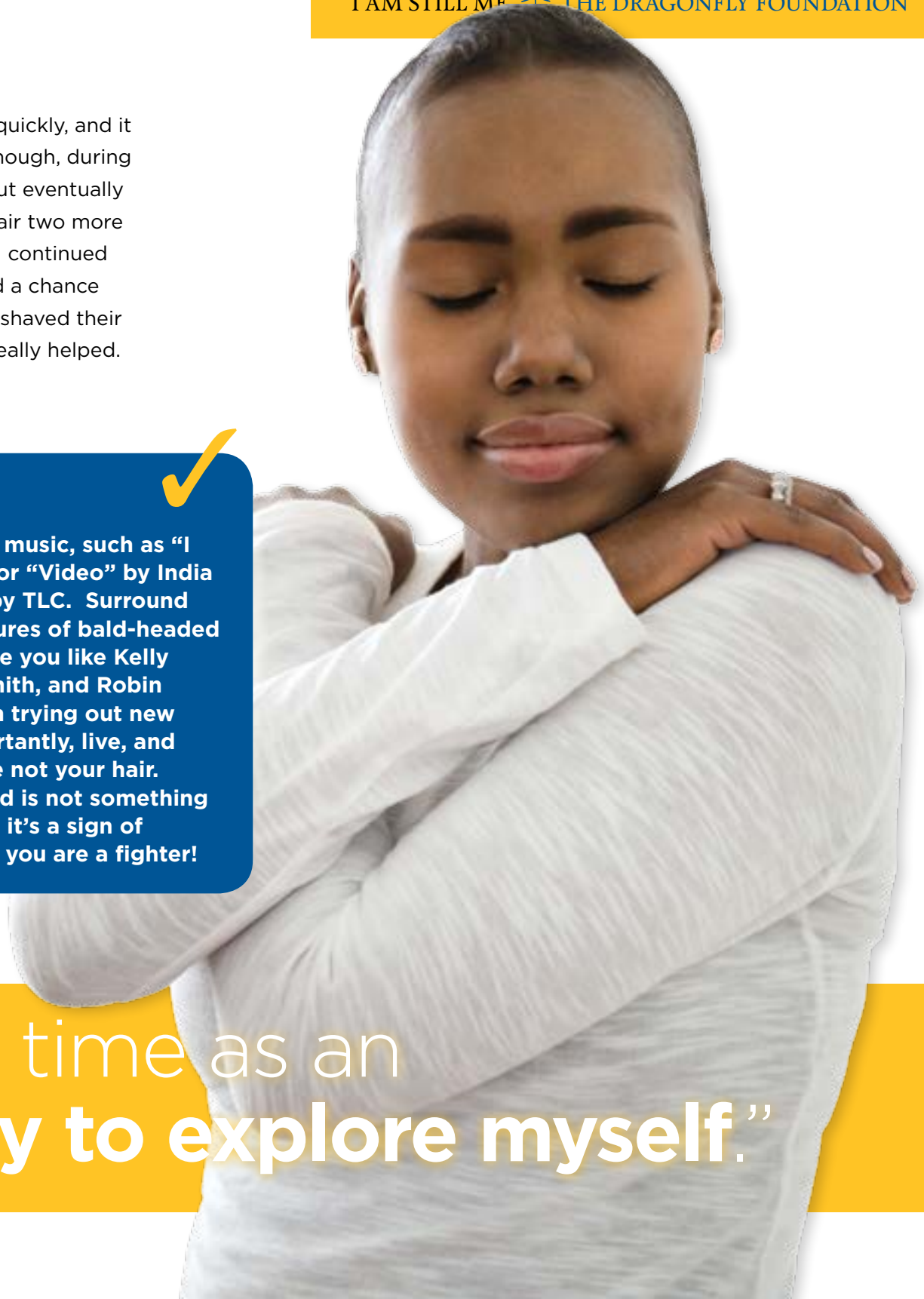


Tiara's Tip:



Listen to uplifting music, such as “I Am Not My Hair” or “Video” by India Arie, “Unpretty” by TLC. Surround yourself with pictures of bald-headed people who inspire you like Kelly Pickler, Willow Smith, and Robin Roberts. Have fun trying out new looks. Most importantly, live, and remember you are not your hair. Having a bald head is not something to be ashamed of; it’s a sign of strength, and that you are a fighter!

“I looked at time as an
opportunity to explore myself.”



McKenzie's Story

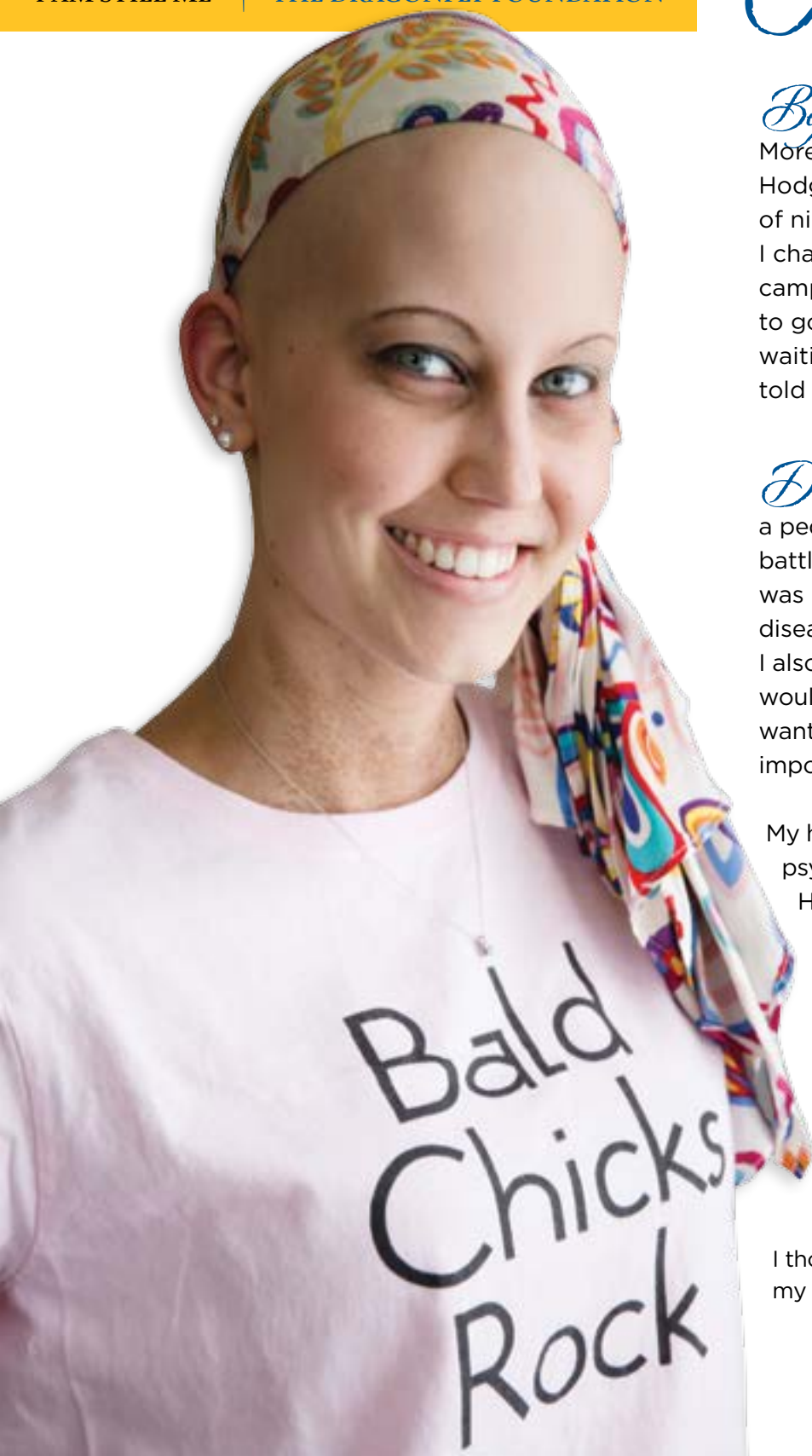
Before: In 2011, I was 19 years old and a student at Morehead State University when I was diagnosed with Hodgkin's Lymphoma Stage 3. I had experienced symptoms of night sweats, severe back pain, and weight loss, but I chalked it up to having a bug that was floating around campus. After soccer, however, I was feeling bad enough to go the emergency room. I had been there for 6 hours, waiting with my twin sister, when the doctor came in and told me I either had lymphoma or leukemia.

During: After treatment, I became determined to become a pediatric oncology nurse; I want help other soldiers in their battle against cancer. However, in July 2013, I relapsed. This was heartbreaking news, not just because I had to fight the disease again, but because I had to put my dream on hold. I also would have to delay graduation, which meant that I would not be able to graduate with my sister, something we wanted to do together. However, I know that my life is more important than school.

My hair has always been important to me; so losing it was hard psychologically. Watching it come out was the most difficult. However, hair does grow back, sometimes in a completely different way than before. It is always fun to see what your hair will be like.

After: I never would have thought that I would have to fight cancer, not once, but twice, by the time I was 22 years old. The struggle has made me a stronger person. I have been fortunate to have great support and wonderful doctors and nurses.

My hair has always been important to me, especially because I thought it defined me as a female. However, the seriousness of my disease made me realize that hair is overrated.





McKenzie's Tip ✓

ALWAYS REMEMBER: hair grows back! It might take weeks; it might take months; but it always grows back!! Having your life is worth enduring chemotherapy and losing your hair.

- ▶ Having your life is worth enduring treatment and losing your hair
- ▶ As soon as your hair falls out in clumps, shave it!!
- ▶ If you are afraid (like I was!), sometimes it is easier to have someone else shave your head
- ▶ Pick out fun headscarves, hats and wigs

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“...the seriousness of my disease **made me realize that hair is overrated.**”

Allison's Story

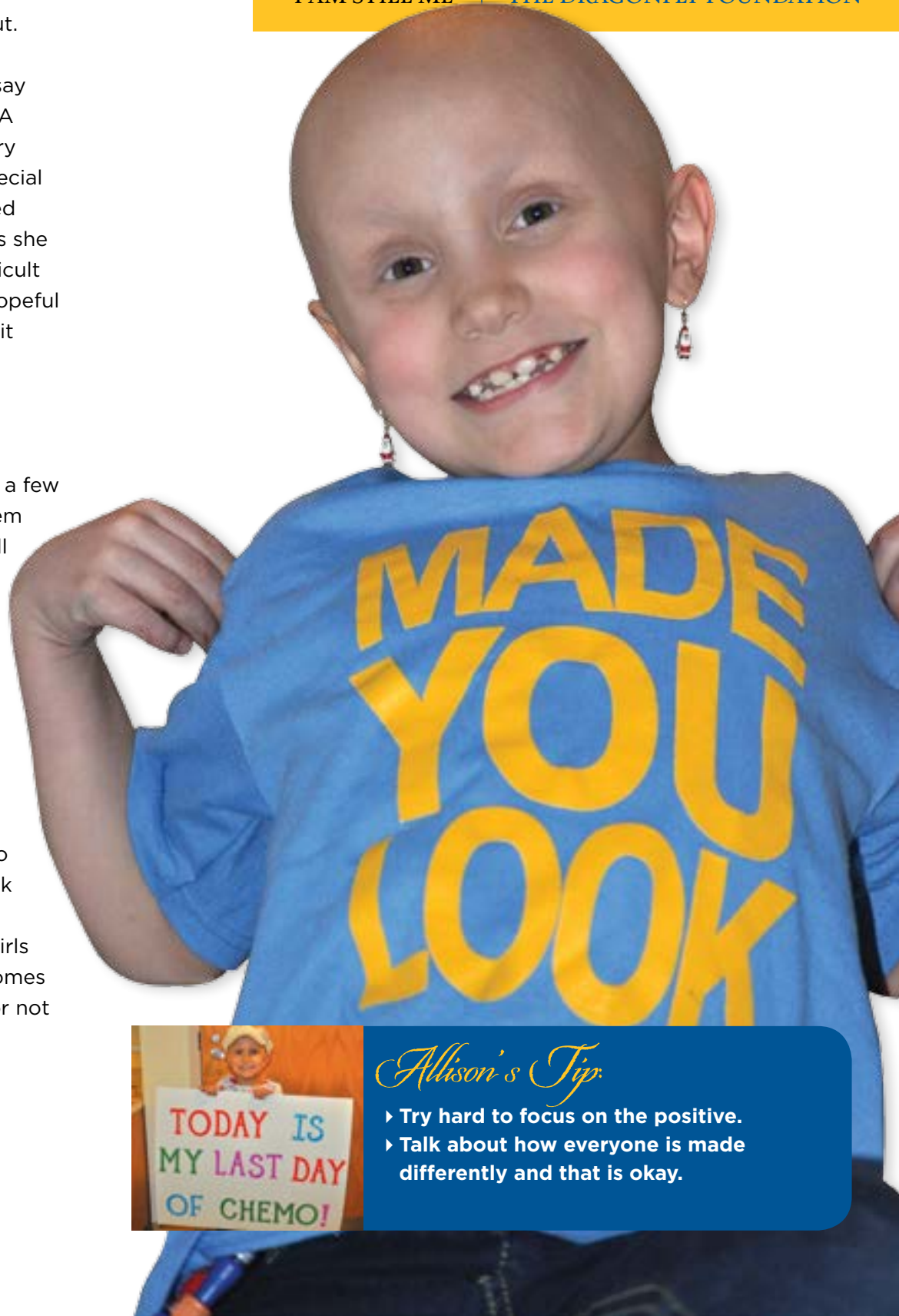
Before: Before Allison was diagnosed with cancer at the age of 7, she was a healthy little girl with beautiful long hair who enjoyed playing soccer and spending time with her friends and family. When Allison was diagnosed with Ewing's Sarcoma, one of the first things I worried about was how to tell her that her hair was going to fall out. I hadn't exactly figured out how to tell her the news, so I just didn't bring up the topic with her. Allison's 4-year-old brother came to visit at the hospital and had heard from his Sunday School teacher that Allison's hair would probably fall out because of the medicine. Unprompted, Jay said: "Allison, I will still love you even if you don't have any hair." Allison said: "Jay, why would you say that?" One thing led to another and we told Allison the medicine would make her hair fall out, but it would eventually grow back. Allison seemed unphased and just kept playing with her little brother. Over the next couple of days, Allison asked a few questions about her hair falling out, but didn't seem too worried about it.

"I truly learned that beauty comes from the inside out and whether she has hair or not doesn't matter to me at all."

During: During Allison's second round of chemotherapy, Allison's hair started coming out. She would stand by the trashcan and pull out clumps of it. Instead of being sad, she would say "Wow, look at how much hair I got this time." A child life specialist told Allison that the hair fairy would come to the hospital and leave her a special gift in exchange for her hair. Allison was thrilled and worked all night to get out as much hair as she could for the hair fairy. As a parent, it was difficult to watch my little girl lose her hair, but I was hopeful that if the chemo was making her hair fall out, it must also be working to kill the cancer and we definitely wanted that cancer gone.

After: For several months, Allison still had a few hairs holding on and she didn't want to cut them or shave them off. Eventually, all of her hair fell out and she had a perfect bald head. In the beginning, she was self-conscious and would always want to wear a hat when we went anywhere. However, she quickly became self-confident and walks around school, goes to the park, and even attends church with no hat. She decided early on that wigs weren't for her (after trying on a couple of silly ones), she said they were too itchy. Allison has finished treatment and is starting to sprout some hair. It is amazing to see how dark her hair looks against her head. Even with no hair, Allison is one of the most beautiful little girls I have ever seen. I truly learned that beauty comes from the inside out and whether she has hair or not doesn't matter to me at all.

Theresea
Allison's Mom



Allison's Tip:

- ▶ Try hard to focus on the positive.
- ▶ Talk about how everyone is made differently and that is okay.

From Other Dragonflies

“When I lost my hair, **100 kids supported me by shaving their heads too.**”

“I **dyed my hair red** and **shaved the Reds’ logo into my hair** to **support the Cincinnati Reds** going into the Playoffs.”



“A lint roller is a must in the beginning! Nick was very itchy when it was on his pillow and collar.”

“Hair loss does matter to boys. **Most people think it only matters for girls, but does it matter for boys.**”

“We collected Eli’s hair and saved it in a baggie to **sprinkle outside for birds to use for their nests.** The thought of Eli’s little curls being used to **keep baby birds warm was comforting.**”

“I felt embraced by my community.
Many people sent me support cards.”

“To make me feel better, I decorated my head. My friends would make it into different characters, **which made hair loss more fun.”**



“I liked choosing to cut my hair and shave my head when I wanted to. It gave me more control to decide.”

“I wore a wig at first, but it was hot and itchy. I ended up wearing bandannas a lot more than my wig.”

Parents' Thoughts

“Stef was 13 when she lost her hair. A week or so before that happened, she had her long hair cut much shorter, so the impact wouldn’t be as great (in theory). She was not a ball cap wearer, and really, really wanted a wig. We really wanted to do whatever would make her feel more comfortable given this delicate age, so we bought a very nice wig with little knowledge about less expensive ways to go. The reality, however, was that she never wore the wig in public and just wore hats (she received many very fun and warm ones) or went without... she ended up very comfortable just as is...amazing! I would truly recommend waiting a couple weeks after hair loss to see what feels best. Wigs cannot be returned, and I think a lot of kids really adjust once the horrible shock of losing their hair passes. We, too, saved some of her hair after it started falling out. The rest was shaved, which was very traumatic for her, but much better than the slow process of losing hair in sections over days.”

“Child Life let us read the Hair Fairy book (where the fairy gives the hair to bunnies for their homes) to Natalie so after we shaved her head we kept it in a baggie for them to collect while she slept that night and it was replaced with a few little toys. She loved it and to this day when she sees a bunny she says she hopes the bunnies love her hair! Also her daddy and brother kept their heads shaved all through chemo and didn’t let theirs start growing back until Natalie’s started to. She also still talks about how her daddy let her paint his bald head. Natalie also liked to go pick out the soft headbands to wear as well as a lot of hats. She loves having a lot of hair again but also whenever she sees someone with no hair she wants to go up and tell them it’s okay because it will grow back.”

Parents' Thoughts

I AM STILL ME 7|5 THE DRAGONFLY FOUNDATION

“Gracie was 5 when hers came out... We shaved her head and her daddy’s head that night, and her brother Lucas got his done shortly after. We made it a fun family event, so much so that her sister JoJo had a fit because her head was not shaved too! We also made a HUGE deal out of the Hair Fairy, who left a lot of cool stuff in her bedroom that same night. Gracie still says she heard the hair fairy talking to the tooth fairy in the family room.... Agree to give it some time to let the child get used to it, I would bet parents are often amazed at how gracefully and quickly the kids adapt. Attitude goes a long way in



“My husband and I were going to **shave our heads in honor of our 23 year old.**”



I AM STILL ME  THE DRAGONFLY FOUNDATION

A Note from Social Work



Dear families,

We, as social workers, would like to take this opportunity to describe our role and how it serves you during this difficult time. As social workers, we love our jobs because it is all about forming relationships and providing support to you. We are here with you from initial diagnosis throughout treatment and beyond (yes, beyond does come even though it seems so far away right now.) We provide supportive counseling, assistance with resources and hospital services, as well as help you to address and overcome the unique challenges that are a part of a diagnosis. One of these unique challenges that face both the patient and the family is dealing with hair loss. Hair loss elicits so many feelings from patients, parents, siblings, and friends. You may be sad, angry, shocked, dismayed, or you may not even give it a second thought. It is important to know that everyone experiences it differently. Social workers, along with your medical team, can help you manage these changes and feelings, connect you with others who may have had a similar experience, help find resources related to hair loss, and help you come up with a way to talk with others about this hard situation. Whether it be visiting you in your hospital room, checking in outpatient, or a simple phone call, we are here to offer a constant supportive presence throughout your entire journey.

Sincerely,

CBDI Social Workers

Bridget, Carrie, Elizabeth, Mandy, Maureen, Nancy, Nicole, Sharon, Surani, Susan, and Wanda

A Note from Child Life

I AM STILL ME 7/7 THE DRAGONFLY FOUNDATION



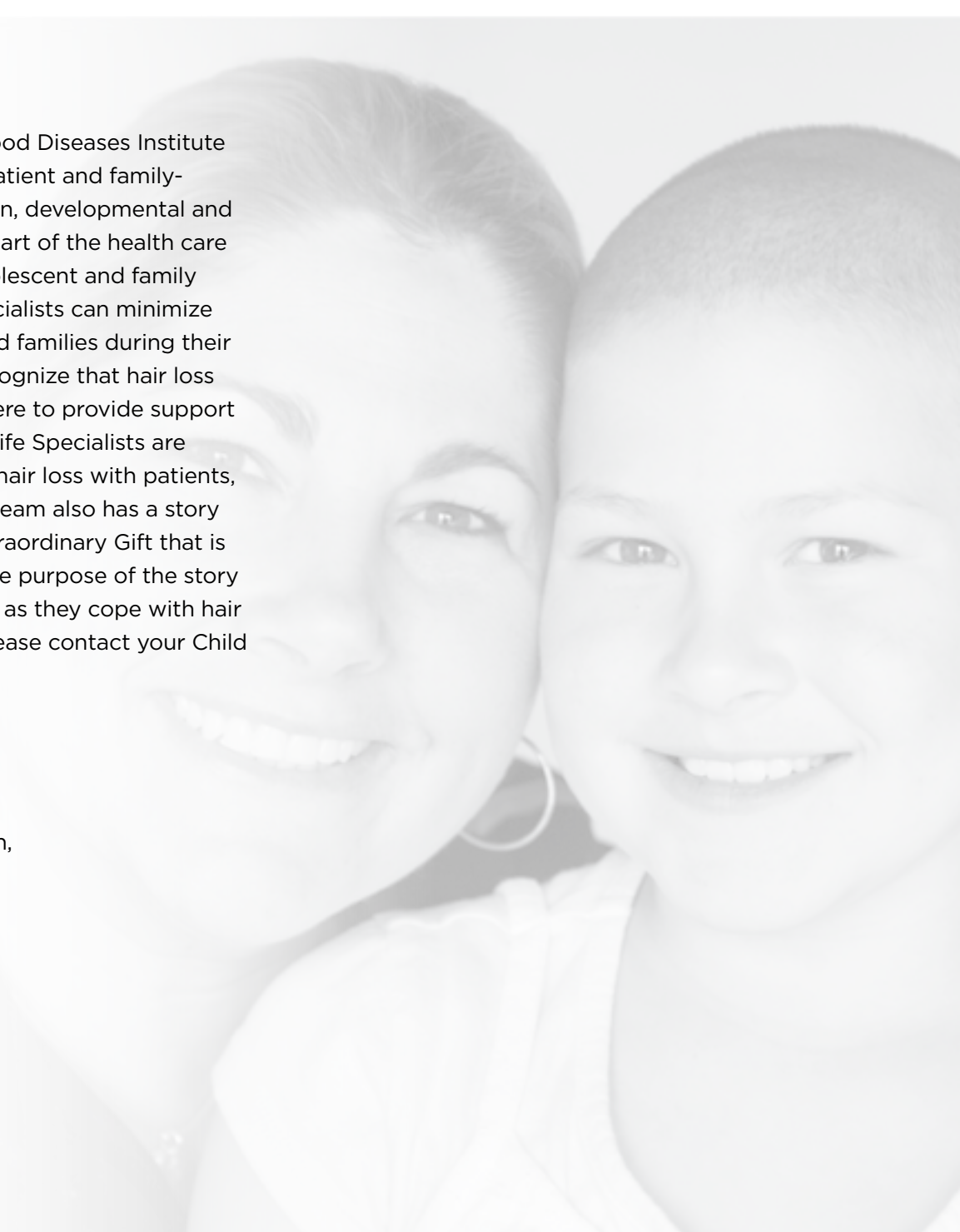
Dear families,

Child Life Specialists in the Cancer and Blood Diseases Institute (CBDI) are committed to the practice of patient and family-centered care by promoting play, education, developmental and psychosocial support. We are an integral part of the health care team who can support you, your child/adolescent and family during your hospitalization. Child Life Specialists can minimize stress and maximize coping of patients and families during their health care experience. In the CBDI we recognize that hair loss is a reality for many patients and we are here to provide support during this challenging experience. Child Life Specialists are available to facilitate conversations about hair loss with patients, siblings, and families. The CBDI Child Life team also has a story called The Beautiful Hair Fairy and the Extraordinary Gift that is often shared with patients and families. The purpose of the story is to provide patients and families comfort as they cope with hair loss. For further support and resources, please contact your Child Life Specialist.

Sincerely,

CBDI Child Life Specialists

Amy, Ashleigh, Bekah, Brandi, Jenna, Karen,
Meg, Michelle, Noelle, and Rhonna





I AM STILL ME >|< THE DRAGONFLY FOUNDATION

Resource List

Hair Donation Resources

www.locksoflove.org

www.pantene.com - Beautiful Lengths Program

Wig Retail Resources

Beau Belle
56 6th Street
Bellevue, KY 41073
859-291-8552
By Appointment Only

Hair Max Beauty Supply (Tri-County Mall)
11700 Princeton Pike #A260
Cincinnati, OH 45246
513-671-0502

Jag's Wigs
630 Nilles Rd
Fairfield, OH 45014
513-829-8988
NKY Location: 859-261-3118

Star Wigs and Beauty Supply
11475 Springfield Pike
Cincinnati, OH 45246
513-771-5773

Wig Resources

Hair for Kids Fund
Contact: Becka Sampson
www.beccas3700.com
937-298-9222

Children With Hairloss
www.childrenwithhairloss.us
888-4KIDS HAIR

Wigs For Kids
www.wigsforkids.org
440-333-4433

“My friend was by my side and
I was not alone.”

Thank You!

I AM STILL ME >|< THE DRAGONFLY FOUNDATION

**A special thanks to all of the patients and families who shared
their stories to inspire others along this journey.**

This booklet could not have been possible without you!



T2DESIGN
PRINT + WEB



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



I am Still Me

