



“This story is a prime example of a mother and father going above and beyond to help save their little boy. They will stop at nothing to make sure their child gets the best care and life that he deserves. I am honored to be a part of this amazing boy’s journey as one of his healthcare providers.”

- Kelsey Ortiz, Registered Nurse

“Life changing. Kristin’s story of hope helps you persevere through obstacles you face in life with a positive mental attitude. If you don’t believe in miracles, you will when you are done with this book!”

- Kristy Cikowski, Social Media Specialist

“There are no words to describe the strength, optimism, and inspiration surrounding Nixon’s journey. This little boy has defied all odds and only keeps fighting, while along his way, proving many in the healthcare field wrong. His mother and father are prime examples of pure love, positivity and persistence. I am humbled to be a part of Nixon’s healthcare team as his acupuncturist, and blessed to be able to see him on a regular basis. Inspiring is an understatement, as I have seen Nixon and his family go through many ups and downs. However, this beautiful little soul always rises above all expectations. The story of Nixon and his family, as described in this book, is a must read, hopeful, uplifting, and most of all, courageous.”

- Christina Guthrie, Licensed Acupuncturist
and Owner of Eastern Vitality
Acupuncture, Inc.

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“This is an inspirational, motivational, and touching story of an average American family. It will change your outlook on life and make you think twice before taking anything for granted. It will remind you to trust your instincts and emphasize to you that anything is possible with hard work, dedication and most importantly, hope. As a mother of three healthy children, I find myself, like most mothers, in denial that anything bad could ever happen to them. This story of Nixon’s journey has opened my eyes to reality, and the fact that no one, no matter who you are, is exempt from a devastating event that could turn your life upside down.”

- Jamie Coan,
Educator

“This journey is a moving account of love and strength. This story is courageous and inspiring, as it faces the most heartbreaking challenges that life offers when the Skenderi family learns of their infant son’s rare disease. This is a powerful testimony of one couple’s love, courage and determination to never give up. I’m honored to have the opportunity to share part of their journey with them and their beautiful son, Nixon, as they fight each day for his survival.”

- Linda Paller, Registered
Nurse

“An awe inspiring, up close and personal story of a young family as they navigate the world with an infant diagnosed with an extremely rare disease. Their courage and never-ending strength has forever changed my definition of hope and what it means to be humble.”

- Laura Durava, Retired Chief Operating
Officer

holding **hope** *in our hands*

A profound, true story to trust your instincts, push for more options, live for a smile and never, ever give up!

KRISTIN SKENDERI

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In memory of



Joseph Edilio DeFacci



Breighlin Olivia Isitt

Photos courtesy of the DeFacci and Isitt families.

Contents

Foreword	ix
Preface	xiii
Acknowledgements	xv
Introduction	xix
One	23
Two	39
Three	49
Four	59
Five	75
Six	85
Seven	95
Eight	105
Nine	113
Ten	125
Eleven	133
Twelve	143
Thirteen	155
Fourteen	171

Foreword

“A parent’s love knows no bounds,” but in my profession, I witness how frequently only parents can truly understand the depth of that commitment.

I have had the privilege of being Nixon Skenderi’s Pediatrician for the past two and a half years. His parents are an amazing couple, and I have come to regard them as friends. This book simply and emotionally outlines the struggles and sacrifices that the family endured through Nixon’s medical diagnosis, evaluations, testing and treatments. I believe that parents frequently make choices, emotionally, physically, and financially without regard for the long term consequences to themselves. As this book demonstrates, Nixon’s parents have literally sacrificed everything, including their home and financial stability. They firmly believe that Nixon is a significant individual and deserves so much more than was ordained for him. They refused to give up even when the odds and the Medical Community seemed against them. Through all the challenges, they maintained a close, loving, and mutually respectful relationship. When they completely disagreed, they never denigrated the other or their view point. This is a lesson for all those who want to maintain a healthy relationship.

Parents love their child unconditionally. They don't see the illness as a disability, but as something to face and conquer as much as possible, even if only through sheer will and persistence. They fully believe that their job is to protect their child and "fix" any problems that befall them. In reality, they frequently can't, and I wish they could relieve themselves of the guilt that they caused or could have prevented the issues. When significant issues arise, parents lose their innocence, as well as, their previous joys, hopes, and dreams. They become unwitting "experts" about medicine and medical procedures concerning their loved one.

Successful collaboration is the ultimate goal. The medical professional should accept the family as part of the team, instead of an inconvenience or an obstacle. Even if there is disagreement, be respectful and acknowledge their concerns, opinions, hopes, and dreams. The Skenderis formed alliances with many medical communities and professionals, which optimized Nixon's care and quality of life.

Each person who reads this book will develop their own perspective. The theme is easily recognizable to many who are dealing with a chronic or life altering illness. The story line is impactful, and I hope the reader will come to understand that the situations they face are not their fault. They did not cause it; they did not contribute to it; and they could not have prevented it.

Frank Roemisch, M.D., F.A.A.P.
Pediatrician

Preface

If you are a parent with a healthy child and consider yourself to have a “normal” life, please be grateful and do not take that for granted. Hug your kids. Appreciate good health always. A friend’s great-grandmother shared with me, “If you have your health, you have everything.” It is so very true. I started this journey without knowing anything different. I found myself to be very naïve. I knew there were sick children in this world, but I never knew to this extent. I never knew or acknowledged the astounding number of children that are suffering; nor could I have ever comprehended the level of illness some children endure. I certainly never thought it would or could ever happen to my child. It happened, out of the blue from nowhere, without a warning, without a manual, without anything. From the first second we discovered that our six-month-old baby boy was not healthy, everything changed. Every thought, every day, every evening, every plan, every part of our life changed. Permanently. Our life and our plans for the future were replaced with the new path that was laid ahead for us. My son, my husband and I stepped forward to endure this new life. The three of us together, holding hands, grabbing on for life. Literally. This was our new life absorbed with our worst possible fear, all of our love, and all of our hope.

Acknowledgements

Thank you, Ozzie, for going on this journey with me. Nixon was given to us for a reason, and that is because you and I make an incredible team. We have it harder than most, but somehow we make it all work. The cards were shuffled. In a million years, I would never had thought this would be the life we would be dealt. But I have to say that so far, I think we have played our cards right. I couldn't imagine going through this with anyone else. Look where we started, and look where we are now. We always knew what we wanted to do the minute that we decided to fight this. And that is what we will always continue to do; to never ever give up.

Thank you to my mom and dad who raised me right. The universe knew what it was doing when it put me in your arms. Anytime I have needed you, you have been there in a blink of an eye. You guided me through life and helped me learn to follow my heart. I have strength because of you. You have always believed in me and because of that I feel like I can do anything.

Thank you to my best girlfriends, the extra sisters that I chose for myself; my soul sisters. Good friends are hard to find, but once you find them, you have them for the rest of your life. Not

sure what I would do without you. I'm lucky to have you in my life. You helped me remember the important things when I felt I had lost them. My smile, my hope, and my courage.

Thank you to my family and friends for all of your support, love and generosity that you have bountifully shared throughout these challenging years. The power of a support system does wonders, and your support helped Ozzie and me more than you know. The fact that we have had so many people on our side means the world. We will never be able to thank you enough!

Thank you to Nixon's entire medical team: Dr. Maria Escolar, Dr. Mark Vanderlugt, Dr. Frank Roemisch, the NDRD clinic, the BMT staff, the Peds, PICU, and Respiratory teams that we visited at every hospital, all of the fabulous nurses that have taken amazing care of Nixon, his therapists, and to his Journey Care team. I'm thankful that you gave him a chance. You helped save his life and made him as comfortable as possible every day. You believed in us, and you gave us hope. We will never forget you and will be forever grateful.

Thank you to Cindy Tschosik, Carrie Keppner, and Jackie Camacho Ruiz. "The Dream Team." Nixon had a story to tell, and you helped bring it to life. Your talents are incredible, and I'm so happy that my path led me to all of you. You helped make this book what it is.

Last but certainly not least, thank you to Nixon Matthew. You have changed my life. This was all you; I was just your voice through the whole journey. You have done the impossible and have shown so many people that there is nothing in this world that you can't do. Do not ever let anyone tell you differently. You are my heart, you are my soul, and you are the love of my life.

Introduction

Everyone deserves a chance. My name is Nixon Matthew Skenderi, and I deserve a chance. That gloomy, rainy day in April of 2014 will be etched in Mommy and Daddy's minds for the rest of their lives. I was a normal six-month-old boy with a full head of dark brown hair and a smile that melted everyone's hearts. I had this little raspy cough that wouldn't go away. Concerned, my parents bundled me up and ventured to the doctor. As my pediatrician performed his usual exam, he noticed that I was not thriving as I should, and I was not meeting the usual growth chart milestones.

He immediately admitted us to the hospital for a barrage of tests that consisted of blood work, ultrasounds of my organs, visual and neurological reaction tests and a bone marrow biopsy. As we were playing with my toys, two doctors entered my hospital room. With one abstract sentence, Mommy and Daddy's world turned upside down. "Your six-month-old son has Gaucher's (gō'SHāz) disease." Mayo-Clinic defines it as "the result of a buildup of certain fatty substances in certain organs, particularly the spleen and liver. This causes these organs to become much larger than normal and can affect their function." The doctors explained it to Mommy, Daddy and me,

“This is a genetic, fast progressing lysosomal storage disease, which lacks an enzyme in the body that causes children to become disabled and not live past the age of three. It is extremely rare. It is fatal and has no cure.” No cure. No cure. No cure.

In three confusing sentences, we fell swirling into a black hole. In translation, Gaucher’s disease, enlarges many of my organs, affects my breathing, restricts my swallowing and limits my neurological development.

They say bad news happens in threes, and our small family has had our fair share. It started before I was born and before they were even married. In 2007, daddy was attacked while walking home from a night out in Chicago. He was hit over the head with a construction hammer and almost lost his life. He survived and lived to be the strong, loving, amazing daddy I know him to be today. In 2011, mommy turned her head the wrong way and tore her carotid artery. It caused her to have a mini stroke. The doctors said she should have been in a vegetative state, but she’s not. She is as energetic, brave and inspiring as any mommy I know. They were both given miraculous second chances. Then I was born, and it is the most joyous time in their lives. And now, this happens to me.

I may never be able to say “Mommy” or “Daddy.” I may never crawl or walk, go to school, have my first kiss, graduate, get married, nor see the world. It’s not fair. It’s not fair that I may not get a chance to live all of our dreams. Does good news happen in threes, too? Why is this happening? Why us? The truth is, why not us?

My mom and dad have taken this by storm, of course. They love me! They have spoken to almost every expert and doctor in the U.S. who knows of Gaucher’s disease. Each conversation ends with the doctor or expert saying, “there is no real hope.”

Doctors have been working on a treatment to help other babies like me, but any hope of a cure is still years away. Unfortunately, it doesn’t look like they will have a breakthrough in the next few months.

In an effort to slow the process down, we quickly started the most aggressive treatment available. It is only meant to help me feel comfortable. My treatment will become an all-day enzyme replacement therapy, which will be administered through an IV every two weeks. Physical therapy will help strengthen me, so I can hold my head up and roll over.

Regardless of the outcome, I don’t want mommy and daddy to be sad. I have this life with them, and they are the best mommy and daddy I could ever ask for. They show me and teach me as much of the world as they possibly can. I get to smile and laugh. I get to do things that, unfortunately, some other children don’t. I was given the chance to meet my family. Mommy and Daddy are going to make the best of this horrible situation. They are going to give me all the love that I can get. And they will truly enjoy the best of me.

Four

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“Great things are done by a small series of small things brought together.”

-Vincent Van Gogh

Week 1: Father’s Day, June 15, 2014

I have to say that the “Father of the Year Award” definitely goes to my husband on Father’s Day. In two weeks of flurry, he packed up our life and drove everything we owned to Pennsylvania on Father’s Day. As if that wasn’t enough, he didn’t even get to spend his first Father’s Day with his son. Amazing sacrifices made for a chance to save Nixon’s life. This is the true meaning of a great dad. Late last night, Ozzie made it to the housing complex provided by the hospital. He unpacked the car and began to make a comfortable home for us. This morning, my mom, Nixon and I arrive. As I walk in through the front doors, I marvel at my surroundings. I can’t believe how nice this place is for families to live while enduring such difficult experiences.

As I walk off the elevator, I notice a picture hanging on the wall. It reads,

“This is the house where families meet to continue their

lives, to eat and sleep, to find their strengths, and dry their tears, to look forward with hope to better years. This is the house that becomes their home. This is the house that love built."

I make a promise to myself to read that picture every day. I will draw strength from something so simple yet so touching. This “home away from home” has apartments for 60 families, and allows families to stay as long as we need. Prior to our arrival, in my mind, I pictured the space to be like a hotel room, but surprisingly, it is an actual one-bedroom apartment with a living room, bathroom, bedroom, and kitchen, which includes a refrigerator and microwave. It was quite cozy. Quite a gift.

If that wasn’t enough, almost every day there are families and organizations that volunteer to cook breakfast, lunch and dinner for the families in residence. Another gift. It will be nice to have a home cooked meal when possible. I’ve never been excited about hospital cafeteria food.

As we check in, I glance at some of the families walking in the halls, heading to the elevators. These people know what we are going through. Again, we are not alone. Yet, another gift.

During this first week while we are here, Nixon will begin the pre-transplant tests on Tuesday; luckily, these are all outpatient exams. With it being Monday, we take the day to organize our new apartment. We take a walk to familiarize ourselves with the surroundings. There are many shops, pizza places, and restaurants so close to each other that it reminds us of Chicago. The streets are so narrow and have many alleys, typical for an East Coast City. As I stand at the top of a hill, viewing the setting below me, I think about how this is going to be our new home, indefinitely.

Tuesday comes quickly and slowly at the same time. I have a feeling this will be our “new norm.” During the clinic appointment, we meet Dr. Mark and the transplant team that will be working with us. In addition to Dr. Mark, there are 4 nurse practitioners, and 4 other BMT (bone marrow transplant) doctors that will rotate every few weeks. It is apparent that this

group will be our family and friends for the coming months. They make us feel very comfortable and speak to us in terms that we understand. This is important and makes it easier for me to put my son’s life in their hands. Five months is the minimum length of stay, and of those five, three will be in-patient care for Nixon. That’s if everything goes okay. The following two months will be outpatient while residing at our new apartment connected to the hospital. I would rather be safe than sorry, and near instead of far, so this makes sense to me. Ozzie and I are good with it.

With long-term care, they want long-distance families to be as close as possible for as long as possible. They even asked us if we would be willing to move to Pennsylvania! Being that today was only our third day here, I needed more time to consider that idea.

Dr. Mark and his team covered the entire process and protocol with us, including what our days will most likely consist of. The part I am most scared about is the chemotherapy. He is going to get mouth sores. In addition, there will come a time period where we will have to bathe him five times a day because if he sweats; the chemo can burn his skin. He will also lose all of his beautiful dark brown hair and long luscious eyelashes. But I know they will eventually grow back.

They explain that the most difficult part will be a couple of days before the transplant and about a month after the transplant. Before is difficult because he will get the strongest boost of chemo along with the worst side effects. A month after is painful because the cells are starting to grow which causes bone pain and mucositis which feels like heartburn from your throat all the way to your gut. The month after is also the most critical because that determines if the transplant actually takes. My heart is just broken for him. He has been poked with needles so many times that three of his veins already popped. They are

running out of spots from where to draw blood. My poor little pin cushion! After meeting with Dr. Mark's team, Nixon heads down the hall for a brief evaluation, a blood draw, and has a nasal swab to test for infections. He also had a chest x-ray and an "ECHO" test to check his heart function. Luckily everything came back normal.

Wednesday is a much more involved day with many tests and evaluations. First is the GFR test for kidney function. Next, the CT scanned his head, chest, abdomen, and pelvis. He looks so cute sucking on his pacifier tucked all snug in the CT scanner. The scanner is even themed like a pirate ship. A little bit of amusement doesn't hurt. Once again, everything came back normal other than his spleen and liver were enlarged, which the disease caused. It wasn't a surprise, as we already knew it. Now that the testing is completed, we are full steam ahead with the transplant. They found three matches for him; two from the East coast and one from the West coast. A rating of 6/6 is the ideal match for a transplant. His matches were all 4/6. They are still able to perform a transplant with this ranking. They said it was harder to find a match for him than they expected.

The next step is to test which cord blood out of the three donors is the best match. It's interesting; I didn't realize that about every two weeks, they perform transplants on storage disorders at this hospital; which is more common than I thought. I'm starting to like the team here as well. I am definitely getting good vibes from the doctors who are taking care of him. As scary as all of this is, I just need to take things one day at a time.

Today is Thursday and marks Nixon's enzyme replacement therapy day. This will continue throughout the transplant process to help shrink his spleen and liver and will end the procedures for this week. Starting Monday, the real adventure begins. He will be admitted to the hospital to begin the transplant process. He will get catheters put into his heart, and

they will start him on a liquid version of chemotherapy. I am very concerned with the side effects, but the doctors assure me that they know how to treat all side effects. The real problem will be if he rejects the transplant because then his bone marrow will grow back, which means he will still have the disease. But that is not going to happen; I have to believe that it's not.

With some free time ahead of us, we want to enjoy the weekend. Tour Time! We head to the zoo; one of our favorite places back home. It actually reminds me of our favorite zoo back home as it has the aquarium, some historical sites, restaurants and shops. It's a beautiful summer day, but a little too hot for comfort. At the end of the day, we take Nixon for his first bar experience. Don't worry, alcohol wasn't served, but we watched the USA win their first world cup soccer game! As a seven-month-old, he was as ecstatic as he could be. Go USA!

As the weekend ends, a part of me can't help but think about how our life has come to this moment. How does it change in an instant? It's really surreal. To help calm my nerves, I talked myself into believing that we are on a vacation this week. The free weekend of fun definitely helps with that. However, I can't seem to escape it, and I feel so naïve. In the back of my mind, probably like most of us, I always knew about unfortunate circumstances in this world; that kids get sick; and hardships happen out of nowhere. But I guess I never truly realized how many people are enduring such serious circumstances. Here, at one hospital in the world, we are surrounded by so many sick children. Everywhere I look, every corner I turn, whether it is walking near the cafeteria or even going to do laundry, I see a child who is sick. It breaks my heart every day. I have no idea how I will stay strong through this.

Before I fall asleep at the end of our fun weekend, I hear a helicopter land on the roof; a helicopter that I hear frequently throughout the day. That helicopter carries organs and

transports sick children to this hospital, even from other states. We are at a hospital where transplants are a common everyday occurrence. The best doctors who are specialists in pediatric transplants, storage disorders and other illnesses are here, in this place, doing everything they can each and every day to save children. Hearing that helicopter gives me comfort in knowing that a child's life is about to be saved. That night, the sound of the helicopter and the meaning of its presence helps me drift off into a deep sleep thinking of how lucky we are to live in a place where things like this are possible.

Week 2: June 22, 2014

While other families are outside enjoying the June weather at parks, play dates and picnics, our Monday morning begins with Nixon's first surgery to place two broviac central lines into his heart. These lines will be used throughout the transplant process to administer medicine and draw blood very easily without him getting poked so much. The central lines are long, hollow tubes made of soft rubber-like material with an opening called a lumen. Each line will be inserted into the large vein leading directly into the heart.

My seven-month-old son is having surgery. Surgery! While in the waiting room for about 30 minutes, my nerves get the best of me. I want to vomit and cry, but instead I head to our temporary apartment and pour a glass of wine. I open and read one of the letters my friends sent, as I sip... gulp down my wine. It indeed helps me, and I feel a sense of calm, if only for a short time.

After I feel a little more composed, I walk back to meet Ozzie in the surgical waiting area filled with of many anxious and worried parents just like me. Parents whose legs can't stop shaking, who have the look of worry splattered all over their faces, and who keep pacing back and forth. I start a conversation with a lady who is waiting for her son to come out of his

surgery. We share our stories with each other, trying to make it lighthearted and help time pass. We even become friends on a popular social media site. Then my mind wanders, and I start thinking about how teeny Nixon is and how will they get everything in its proper place within Nixon's little body? Well... they didn't get everything in properly. His surgery finished after three hours. While in recovery, they snap a chest x-ray. They find the central line flipped where it shouldn't be in his chest. They head back to surgery and replace it. Two surgeries in one day. This is the longest seven hours of my life.

By the evening, we finally make it up to the transplant floor, 9B (9th Floor, B Wing). I look around at all of the nurses who are hard at work. They are all so pretty and appear very nice and friendly. Some remind me of my friends at home. Gosh, I do miss them. I miss having our girls' nights, seeing their kids, talking about what happens throughout the week, and having monthly dinners at our favorite wine restaurant. But then I snap back to my new reality; we will have those nights once again, when we get through this battle.

We arrive in his room, and Nixon starts to have trouble breathing. He is literally gasping for air. Suddenly, about 20 doctors and nurses flood into the room. Ozzie stays by Nixon, and I am paralyzed standing in the corner with tears in my eyes. Fear takes over my body, as I wonder if we made the right decision. One of the nurses walks over to give me a hug and hold my hand. A respiratory therapist is called to come to his room. She is responsible for keeping his lungs clean, infection free and the airway open. She gives him a few breathing treatments until he is stable and resting comfortably. It's hard to believe only 30 minutes have passed as it feels like a lifetime. Two surgeries in one day and being intubated two times can sometimes cause breathing issues. Other than that, central line placements are a piece of cake. If this is how our first day starts, then I have no idea what I'm in for.

Tuesday comes and marks his first blood transfusion because his red blood cell count is too low. This is not normal. When his hemoglobin gets too low, it causes him to feel sluggish and look pale. After receiving a rich, red colored bag of blood, the transfusion adjusted his levels where needed. Color flowed back into his cute little cheeks. Ahhhh. I can breathe again. Luckily that's all we had to deal with today. After Nixon's breathing trouble yesterday, I don't know how much more I can handle.

Chemotherapy begins. His first round is a low dose as a test run to make sure my baby boy can handle it. The chemo is administered through an IV bag for about 4 hours, and its job is to wipe out his white blood cells. At this point, our luck strikes again. Lo and behold, he has an allergic reaction to the chemotherapy. However, the doctors assure us that this is common. The antidote is to give acetaminophen and an antihistamine whenever he needs a transfusion.

As the day progresses and the chemo is completed, he spikes a 102-degree fever! Never a dull moment, I tell ya. By Thursday, they give him a higher dose of the same type of chemo, but this one requires a 7 hour drip. This experience brings on another fever and hives pop up all over his body. This is all starting to scare me. We have only been here for two weeks, and it's been one thing after another. I keep asking the doctors "If this was your child, would you be doing this?" They keep saying, "Yes." Everything that was not supposed to happen has happened so far. It is becoming a nightmare. I am starting to get apprehensive, but I know if I tell them to stop this whole thing, then Nixon will, for sure, die. It's just terrifying; I hate seeing him like this. I express my concerns to Dr. Mark, and he explains, "it will be like a roller coaster with the good and bad, but keep telling yourself that the end will be good. It has to get really bad before it gets really good." He said, "You will continue to feel like you want to stop this whole thing until everything starts to continue to go uphill." Words that I need to remember.

This Saturday and Sunday in the hospital are his "rest days." However, he is already experiencing the effects of the chemo and is feeling crappy. Luckily, we are having some moments throughout the day where he smiles and even laughs. This kid has the biggest smile that just makes you melt, and his laugh just gives you butterflies.

We are even able to leave his room with him for a few hours. His white blood cell count is now less than 300, which is what is supposed to happen within the first week. A normal range for white cells is between 5,000-10,000. The chemo worked! The goal is to get them to zero by transplant day.

Throughout the week, he is also taking a liquid version of chemo that he receives through a syringe. Each day, he still drinks his 30 ounces of formula. This makes his mama happy! Overall, for the first week as an in-patient, Nixon seems to be handling everything quite well, even with all the complications. He still seems strong and is ready to continue this fight.

By the end of Sunday, Ozzie and I were letting our nerves get the best of us. This is hard, a lot harder than I thought it would be, and it is just the beginning. We literally just sit in a room together with Nixon all day long, sleeping there, eating there and just watching him. We are helpless. There is nothing we can do except hold his hand through this. I ended up going to the store earlier in the day to just get out for a bit. I picked up some soft, comfy blankets that "feel like puppies," as Ozzie put it and other items to make the hospital room feel a little more like home. I needed to surround myself with happy things. Every night, much to Ozzie's dismay, I fell asleep to reruns of my favorite sitcoms about friends or happy, funny families. No drama, no scary TV, just plain old sitcoms. When Nix sleeps, I take breaks just to get out of the room. I walked up and down the transplant floor. I see the kids going through the same thing as Nixon and parents who feel the same as Ozzie and me. I am

scared to talk to them though; I don't want to know what to expect; not yet. I start to make small talk with some of the nurses. I can't imagine having a job where you see families go through this day in and day out. But they are someone for us to talk to, other than each other. Even though I have my brave face on, I know they can smell my fear from a mile away.

10 days till "Transplant Day" a.k.a. "T-Day" (July 9th)

Week 3: June 29, 2014

As June comes to a close, the hot days of summer are upon us. Nixon is now scheduled to have chemotherapy every single day this week. It is a mild chemo that stops cell growth and causes the cells to die. Fortunately, it is only about an hour each day through the IV bag. We thought he would be able to get a pass to leave his room on Monday, but his white cells were too low. They give patients passes so they get a chance to leave the room, take a walk through the hospital, go outside in the "healing garden," or even go back to their apartments. The good thing is that because his counts are low, it means the chemo is working. The bad news is since his last day to leave the room is today, he is stuck in there for a good three months now. Looking on the bright side, he is happy and loves when we make duck sounds! It's his new thing. We are trying to keep him as happy as possible because I keep hearing a little girl screaming in pain in the room down the hall from us. She recently had her transplant. When the cells start to attach onto your bone marrow, it's very painful. This is something that I'm not looking forward to. At all. My heart just aches every time I hear her. I don't know how I'm going to get through this, I really don't. So for now, I'm just going to keep quacking.

Tuesday and Wednesday came and went with few sessions of physical therapy, occupational therapy and speech therapy. He is sitting up better than he ever was, not quite on his own yet,

but he is getting there. As far as eating, he loves his bottle and he hates baby food with a passion. He hates carrots, bananas and any type of solids that we put in his mouth. I decide to hold off and try when he starts to feel better. He has been handling his chemo like a champ, and it doesn't seem to be as bad as we expected! The doctors are very pleased with how he is doing, and we are on track with his transplant for July 9th.

As our second weekend of in-patient care approaches, Nixon starts a stronger version of chemo. This is the chemo that will cause him to lose his hair. It will also make the space in the bone marrow for the new cells to grow, as well as fully knocking out his immune system. Side effects are hair loss (which is already starting to thin out) and getting mucositis. This is as bad as it sounds. It's a condition that will feel like he has sunburn from the top of his throat to his bottom area. He will get mouth sores and slimy mucus. His skin will change color, so that he will look like he has been at the beach! And he will be nauseous. We also have to bathe him 3-5 times a day because if he sweats, the chemo can burn him.

As we are settled in the hospital for the weekend, he starts to scream in pain. He is choking on the mucus, and it seems like the nausea is kicking in because he will not eat. I start to feel devastated, but he still has his moments throughout the day where he smiles and laughs from time to time.

We are at the beginning of the worst part, which will last about three weeks. A very scared feeling is starting to take over inside of me. My fear is that the transplant won't take, meaning his cells will start to grow back instead of the donor's, which can happen. However, Dr. Mark said that in the two years he has been at this hospital he has not seen that happen yet. I'm also worrying about graft versus host disease, which is when the regular blood cells start to fight the new cord blood cells. I know I shouldn't think this way, but I am his mom, and he is

the person who I love most in this world. I can't help it. I'm terrified, and I feel like I'm going to fall apart. I have to prepare for the worst and hope for the best. The sooner the hard part happens the closer we are to this being over. As I walk back to the apartment for my daily shower, I start thinking that it really isn't fair that this little human being has to go through something so horrific.

My parents visited this week, and it couldn't have been better timing. Having to watch my baby go through chemo is not easy. It is 4th of July this week, and we can take Nixon to the corner room of the floor and watch fireworks out the window. But Oz and I both need a break. The only time we ever leave his hospital room is to shower, to get food, or to take a walk. We went to pick up some groceries, had a drink together and just talked about how this was not the life that we mapped out for ourselves. But while we were gone, we couldn't get back there fast enough. I want to be with him every second. I want to switch places with him. I wish it was me and not him.

3 days till T-Day...

Week 4: July 6, 2014

This is it. Transplant week! It's Monday, and Nixon is receiving the heaviest dose of chemo, yet. This is the final dose of chemo he will ever need, and of course, he is handling it very well. Today he stopped eating because of the mucositis. He has sores and a bunch of buildup in his mouth that looks like slime. This is brutal. He also has started to throw up stomach lining, and he screams in pain to the point to where he turns blue and then chokes on his saliva.

They gave him some lorazepam last night to calm his stomach from nausea. I remember that the family in Florida told us that it would be our best friend through this whole process. I just

kept holding him and telling him how sorry I was. Tuesday is supposed to be a "rest day" before the transplant, but instead, he receives one medication after another to prepare him for the big day. He is still smiling and playing, but you can clearly tell that the days of chemo are really starting to take a toll on him. Tomorrow will be a new beginning. He will receive his new stem cells and will be starting over. I feel like it is the night I went into labor because the next day I brought a new life into this world.

Transplant Day. Wednesday, July 9, 2014

The day starts with Nixon getting pre-medicated. Then, his nurse brings in what looks like a bag of blood, but it isn't blood; it is the stem cells; these were the best match that they could find. That bag is the most important thing in my world at this moment. That bag is the possibility of my son's chance at this life. I can't keep my eyes off it.

In preparation, the nurses double and triple check Nixon's social security number, birthdate, blood type, blood type of the donor, etc. It seems really serious, and I am glad that they take it so seriously. The cord blood is run over about one-hour into his broviac central line. The nurse stays in the room the entire time to watch him, and Dr. Mark keeps peeking his head in every fifteen minutes to make sure all is okay. Ozzie takes out the video camera as we feel it is something that we need to remember. I know one thing that I will remember is creamed corn. The entire room smells like creamed corn, and we were told that every time a transplant happens that is the smell. Not sure why or how, but it is. Besides having a little fussiness, Nix breezes through the transplant process. No fever or high blood pressure. He did great! After it was over, he rests comfortably. I'm still completely baffled and in shock that my son just had a stem cell transplant today. It seems surreal, but that's it! All of this for one little bag that takes one hour!? What a breeze! This,

I can handle.

Ha! I spoke too soon. From that day on, the mucositis started kicking in hard core. Every time he has a bowel movement, he screams in excruciating pain. The slimy mucus causes him to choke pretty frequently, which requires us to suction it from his throat. We are learning to become nurses ourselves. So far, he needed two platelet transfusions and one blood transfusion. It can be dangerous for his platelets to get too low, as they help cause the blood to clot. It is normal to have transfusions after a transplant, but it usually doesn't happen until after day +6. We are only on day +4. Since he stopped eating, he gets his nutrition through an IV bag, and they put him on morphine every three hours to help with the pain that is caused from the transplant. It is an extremely agonizing process as the stem cells find their place in his body and start to grow. We start to deal with pain management, but the worst part of the mucositis is usually not until around day +10 which is July 14.

Saturday isn't seeming to be a very good day. Nix is in a lot of pain, and the mucositis is bad. He just looks so sad all of the time now, and I feel tormented. We are in the worst situation, and the worst of the worst is still to come. When he's not screaming in pain, he sleeps.

Sunday is the first day that Nixon seems somewhat back to his normal self. He is more alert, smiling and even playing with his toys. But now begins the waiting process to identify if he is engrafted. Engrafted means that the new stem cells have taken over his body and this usually happens around day +21, but it can sometimes happen sooner.

Some people think that a stem cell transplant is an actual surgery. I thought the same thing. I was baffled when I came to find out the actual process. Apparently, that is the easy part; it's all of the stuff before and after that is the hard part. Since

everybody is different, the doctors have a baseline on what to expect, but it's difficult to predict because each person reacts differently.

At this point, we continue to take everything one day at a time. But now we have to wait, and I have a very hard time being patient. I keep telling myself over and over, "good things come to those who wait."

So, while I'm waiting, I find distractions on social media and TV. I scroll through the posts, and I read everything that everyone else is doing. It sucks that we have to be here. It makes me sad, angry and jealous. But when I look at my son's face, I know that I would do this over a thousand more times if I had to, to make him better. I'm starting to get scared about what he may or may not be able to do when this is all over. I have a fear that he may not walk. I know that I won't know until everything is all said and done, but it's hard to not think about it all. I'm just hoping and praying that things turn out as best as they possibly can, and he can have the best life possible. But that fear just sits inside of me, waiting, haunting. However, I know that no matter what happens, as long as he smiles every day, that will be enough for me.

was put on the newborn screening test in the state of Illinois. If we had known prior to his birth that he had this

disease, and if I could do it all over again, then I would have chosen to transplant him right away.

180 | Kristin Skenderi

My whole life, whenever something was broken, I would always say, “Well, fix it.” I would always find a way, no matter what. I’m still that way. I’m still researching every single day, and I will always keep trying new things. I trust my heart and my gut more than anything in this world. My life motto is “Never, ever give up.” I will always have hope because without hope you have nothing. And I will continue to keep the faith. Because of that, you never know when miracles will happen. I will treasure the small things, as they are the things that keep me going.

I have learned a lesson from this entire experience. Live your life. Don’t worry about what could happen or what could kill you. Anything can happen to anyone for no apparent reason, whatsoever. And if an unfortunate circumstance happens, you find that inner strength and fight like hell.

The key to happiness is to let every situation be what it is, instead of what you think it should be. I never want to discredit any doctors, especially the ones that we spoke with, as they are only able to tell you what they know. But there is a reason why a parent is given such a thing as parental instinct. You need to follow that instinct, and always listen to what is in your heart. In the end, we live day by day. Sometimes hour by hour and sometimes minute by minute. We don’t know what the future will hold, and that’s okay. Sometimes it’s better to not know because it makes you appreciate every day so much more. What it all comes down to is – you must make sure that you always fight for what you believe in. This little guy has proven to me that anything is possible, that life is worth fighting for, and most importantly, to never, ever give up.

~

“Every great dream begins with a dreamer. Always remember, you have within you the strength, the patience, and the passion to reach for the stars to change the world.”

-Harriet Tubman



Kristin Skenderi, Author

Hearing a doctor say, “Your child is going to die,” was the worst moment in Kristin Skenderi’s life. Luckily, she is an eternal optimist and has never been one to take “no” for an answer.

“Every time a doctor tells me that my child is going to die, I reply, ‘I hear what you are saying, but that is not going to happen. Until I have exhausted every single option in this world, I will not give in.’ From that moment on, I keep it in the back of my mind. And every time I hear it, it just gives me the drive to fight harder.”

Wife and Author, Kristin Skenderi, is also Champion Mom for son, 3-year-old, Nixon Skenderi. “Even when I was younger with anyone who was sad or sick, my response was, ‘Okay, well, it

happened; how do you fix it? A lot of people get hung up on the ‘why or how did this happen?’ I say, ‘who cares? It happened. It doesn’t matter, let’s find a way to just fix it.’”

After growing up in Des Plaines, Illinois, Kristin graduated from Illinois State University driven to achieve great success in sales. She worked very hard at it and excelled among her colleagues. Her high school classmate, Ozzie Skenderi, graduated from Western Illinois, and the two married in 2012. Soon after, in 2013, Nixon was born, and Kristin planned to and wanted to return to work.

“When he was diagnosed, and I realized our lives were changing, my constant need to be busy, to work, to have job security, money and everything else went out the window. My sole focus was about him. I was and still am determined to do anything I can possibly do to save Nixon’s life.”

To find the ‘right solutions,’ Kristin asks questions and takes

copious notes. "I think we live in a world today that gives us so many options. We just have to keep looking. I always argue my way until I feel that I have found the right solutions."

"When the doctor is talking to us and giving us all types of information, we are not really listening to what he/she is saying. I use my notes later when I have time to read and digest the notes, research more and assess the following:

- Here's what they are saying.
- Here's what they are saying can be done.
- I think outside the box and ask, 'Is there another way? If we all worked together, maybe there is a better solution.'
- Then I ask, 'Am I well-informed; what is my instinct telling me; and does this 'feel like the right approach? "

There has never been a time when Kristin and Ozzie have felt they were going to throw in the towel and give up. They always wondered about how or if they would know. A good friend whose son had the same diagnosis shared, "You will just know. I can't even describe it to you. Nixon will tell you. He will tell you, 'It's time. I'm done. And you will know."

"Every time we try something new or we are going through a process, I look at Nixon's face, his eyes, his demeanor. For the more difficult decisions, I say, 'You have to guide me through this.' Never once has he told me to stop. His strength and will to live drives me every day. He is the strongest person I have ever known."



Now that you have read the book, keep updated with Nixon's journey!

Facebook – Search Nixon's Fight #NixonStrong

<https://www.facebook.com/Nixons-Fight-Holding-Hope-in-our-Hands-474937502650185/>

Update – July 21, 2018

Rest In Peace, Our Sweet Superhero, Nixon Skenderi.

November 1, 2014 – June 19, 2018.

I love you, Nix. Love, Cindy