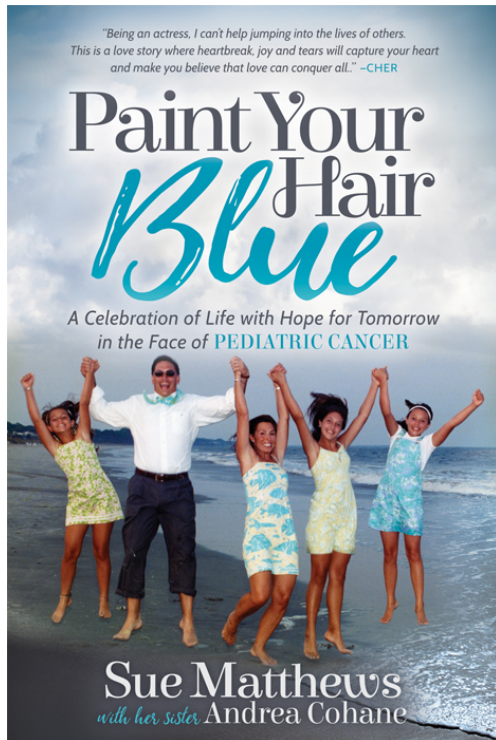


# Paint Your Hair Blue



**An empowering human interest love-story about a mother who lost her daughter at age 16 to cancer.**

**A memoir that provides support and specific advice for other parents confronting cancer as well as anyone going through a cancer diagnosis, or caring for someone who is.**

**A legacy in Taylor's memory through the Taylor Matthews Foundation which has raised \$1.4 million to battle pediatric cancer.**

**An inspirational tale about living life to the fullest despite a daunting cancer diagnosis.**

Sue Matthews, a CPA, wife, and mother of three, was living a normal life fifteen years ago until the day came when her middle child, daughter Taylor, was shockingly diagnosed with cancer at the age of eleven.

The family was thrust into turmoil, confusion, angst, and deep sadness. But as Taylor fought courageously, a life mission developed that continues today, a decade after Taylor's passing at age sixteen.

Sue, with the help of her sister, Andrea, wrote a book, *Paint Your Hair Blue* (Morgan James, June 2018, [www.paintyourhairblue.com](http://www.paintyourhairblue.com)), that takes the reader through the heartwarming tale of heroic courage and, devastating blows that characterized Taylor's odyssey through the underfunded world of pediatric cancer. This book is an inspiring tale of the power of love and determination. It will empower the reader, no matter the circumstance, to embrace life and take control of their own destiny and face fears with strength, fortitude and confidence while living

life to the fullest. Taylor will make you a better warrior in the war on cancer with this story of survival, where love transcends all and where every moment is a celebration of life.

**Sue and Andrea are available to discuss:**

- Life lessons gleaned from Taylor's battle with cancer.
- Advice for parents and family members who are navigating the world of pediatric oncology.
- What can be done to fund pediatric cancer and greatly improve access to adult treatments for children.
- Taylor's "beat-the-odds" five-year battle with cancer,
- How a family, despite a cancer diagnosis, continued to *experience* life and have fun, sometimes thumbing their noses at the medical world, so that their daughter could live as a kid with cancer, rather than a "cancer kid."
- How a mother and father were able to divide and conquer responsibilities, creating a synergistic team to help their daughter beat the odds.
- How a mom was able to stay strong while her daughter remained in the hospital for five weeks following a 14-hour surgery to save her life.
- Winks from heaven and how Taylor continues to show her love.
- How Taylor even found romantic love amidst a cancer diagnosis.

Whether you are facing a life-threatening disease, have a loved one who is, or are just going through the ups and downs of life, I hope Taylor's story will give you hope, inspiration, and courage.

The Taylor Matthews Foundation (TMF), founded by then eleven year old, Taylor, when she was diagnosed with cancer, is now run by her mom, and her aunt serves on the board. The shock of diagnosis soon gave way to the alarming reality that treatments for Taylor's disease had not changed in decades. Even though cancer is the number one cause of death by disease in children, only 4% of the National Cancer Institute's budget is allocated to childhood cancer research.

TMF has raised \$1.4 million and funded research at several leading institutions, including Memorial Sloan Kettering, The National Institute of Health, Children's Hospital at Columbia University Medical Center and MD Anderson Cancer Center. TMF is dedicated to raising awareness and funding pediatric cancer research and is actively lobbying Congress for legislation to improve access to cancer treatments for children. Sue, a former senior manager at Deloitte and a CPA, has teamed with Andrea, a business litigation lawyer to keep the memory of Taylor alive and to help children and parents in need as they battle for life.

Sue, in a stunning tribute to her daughter, recounts on the foundation's website just what she means to her: "Taylor, your life was not only about what you accomplished, but also about what you left behind. Your boundless optimism at the bleakest moment, your concern for others even when you were at your worst, and your zest for life even as death neared, taught me more about love than I thought there was to know."

2018 marks the ten-year anniversary of Taylor's death. "I have learned to live life without Taylor because I have no choice," says Sue. "And while the shock and intense anxiety has

diminished as every year passes, the depth of my grief has increased. Every anniversary marks another year she missed of a beautiful life. What would she look like at twenty-six years old? What would she be doing? What would our family be like?"

We are taken on a mother's journey with her daughter in *Paint Your Hair Blue*, into the world of childhood cancer treatments, pediatric oncologists, pediatric surgeons, and hospital systems around the globe, providing invaluable insight into a world that is foreign to most.

This book serves in equal portions as an inspiring tale of the strength of love and determination and a cautionary tale of the state of pediatric oncology and the need for parents and all caregivers to be their own advocates.

Readers will be guided through Taylor's medical crisis and learn dozens of tips and pointers, gleaned by painstaking trial and error about navigating the maze of oncology through the lens of a lay person.

The reader will learn how Taylor and her family learned to balance the necessity of her continuous medical treatment with the need for her to be a kid and to live as normally as possible. Taylor taught even the most jaded oncologists that she was a kid with cancer rather than a "cancer kid."

Perhaps above all, this is a love, story between mother and daughter, and as you embark on the journey with Sue and Taylor from page one to the end, you will laugh and cry, sometimes simultaneously, and learn to love a little deeper.

**Contact Information:** MEDIA CONNECT

Adrienne Fontaine 646-307-6309 [adrienne.fontaine@finnpartners.com](mailto:adrienne.fontaine@finnpartners.com)

Brian Feinblum 212-583-2718, [brian.feinblum@finnpartners.com](mailto:brian.feinblum@finnpartners.com)

# **Sue Matthews**

## **Q&A**

### ***Paint Your Hair Blue***

#### **1. What happened to your eleven year old daughter fifteen years ago?**

Taylor was diagnosed with cancer in 2003 when she was eleven years old. We were completely and entirely blindsided. She was in sixth grade, extremely energetic, with chubby cheeks, often rosy from exertion on the playground, and big sparkly brown eyes, full of wonder. We hadn't even the slightest inkling that she was sick. However, at travel soccer practice she was out of breath. I took her to her pediatrician who diagnosed her with exercise-induced asthma. With an inhaler she went back to full sports. As is my cautionary way, I took her to a pulmonologist just to be sure her asthma medicine was correct. That's when the unimaginable happened. The doctor took a routine chest x-ray and found a large tumor in her rib cage and a multitude of metastases in both lungs. It was cancer.

#### **2. How did you respond to this crisis that you and your family were thrust into?**

We didn't have time to respond. Taylor was in school that morning and by nightfall in our local hospital after being diagnosed with cancer. My husband and I were a team from day one. I went home to tell my family and my other daughters and Bob had the heartbreaking task of telling Taylor. We were told the following day the biopsy could be life threatening. We decided to transfer Taylor to Memorial Sloan Kettering, which ended up being a mistake. We went to Sloan for its reputation without interviewing the doctors. However, I don't know how any parent can choose options when they are in a state of total shock and denial.

#### **3. How would you describe lessons learned from how Taylor fought cancer?**

Taylor taught us:

- To never be a victim, never pity yourself no matter what your circumstances are.
- To live life in the moment.
- Have fun wherever you can find it.
- Live life on the edge.
- That LOVE is all you need.
- That every day is a gift. Enjoy it! Cancer is not a death sentence. In many ways, it provides an eye-opening opportunity to live your life to the fullest.

#### **4. How did you, your husband and two other children find the courage, strength and resources to fight alongside Taylor?**

First and foremost, my husband, Bob, and I became a synergistic team. Bob was in charge of speaking with the doctors and researching next steps, while I took care of Taylor's day-to-day care and making life with cancer as much fun as possible. We leaned on family members who were willing and able, as well as close friends, and found a wonderful nanny to help with our other girls. We never stopped looking for answers, especially when the ones we were getting

weren't what we wanted to hear. When one hospital ran out of solutions we searched for other doctors and hospitals that were willing to think outside the box and ultimately Taylor went into remission. We trusted our gut instincts and advocated for Taylor at all costs. Perhaps most importantly, we made Taylor believe that she could win!

**5. What did you think when your daughter, riddled with cancer at such a young age, wanted to form what would become the Taylor Matthews Foundation?**

We were astounded and so proud of her. There are no words that can possibly explain our happiness. She seemed to always make lemonade out of lemons. Her choice to help other children with cancer by funding pediatric cancer research was something any parent would be overjoyed about. Our exuberance shined through and she loved making us so happy. Additionally, we were thrilled that Taylor's foundation helped her through her own cancer journey. In an interview on CBS, she said, "When I was sad, sick, missing my sisters and my friends, I knew I should go and design (the foundation initially raised funds by selling accessories) because I would be helping the people after me who didn't feel well. Knowing they may be getting treatments that I funded research for is really great." To this day, her legacy gives my life tremendous meaning. By continuing her work I am living the life she would want for me. It gives me unexplainable joy to hear that we have helped to save lives.

**6. What exactly does the foundation do?**

TMF is dedicated to raising awareness and funding pediatric cancer research. We fund cutting edge, innovative research that reaches sick children now. It is our mission that children with cancer will live long, healthy, and productive lives.

TMF has funded pediatric cancer research at: Memorial Sloan Kettering, Columbia University Medical Center, MD Anderson Cancer Center and The National Institute of Health. Currently, TMF is funding comprehensive genetic sequencing at Columbia University Medical Center that enables personalized treatments for individual patients and individual tumors. Research has found that sequencing impacts clinical decision-making in nearly 70% of cases, which is a huge breakthrough in the treatment of childhood cancers. TMF has covered the cost of genetic profiling for approximately seventy-five sick children – both newly diagnosed and relapsed cases.

**7. What will it take to prevent, treat or cure childhood cancer?**

A critical step in treating any cancer starts with early diagnosis. In this regard, childhood cancer poses a unique problem because when children complain of pain, doctors and families do not initially think of cancer and thus it can take longer to diagnose. In 80% of kids, the cancer has already spread to other areas of the body by the time it is found. Other than doctors routinely testing a child's blood count during an annual physical (which can identify leukemia) there is no screening for children at this time. Ultimately, more philanthropic dollars and government funding for research is needed for better screening and treatment of childhood cancer, hopefully resulting in a cure and long-term survivorship.

**8. You supported the recent passing by Congress of the RACE for Children Act. What does this legislation promise to do?**

We are proud to be a part of the childhood cancer community that lobbied for the Research to

Accelerate Cures and Equity Act (RACE) for children with cancer signed into law in August 2017. The RACE Act requires that every new drug developed for an adult cancer be considered for treating a pediatric cancer if a similar biological underpinning is found. We celebrate this hard-fought achievement and continue fighting for all opportunities to secure a healthy future for all our children.

**9. 2018 marks a decade since you lost your daughter, tragically, at age sixteen, after her five-year battle with cancer. How is she still very much with you?**

Every day, Taylor's absence is evident but her presence is felt. We could write an entire book about all the "signs" she has sent us from heaven. Taylor was born on 11/1 and passed on 2/22 and I can't count the number of times those numbers have shown up unexpectedly or in strange ways. I have kept a journal of all the times Taylor has "shown" herself to me, or to others, and I would be happy to share those stories in the future. Some of it is in the book, but we had to take a lot of it out in order to keep the book concise and focused.

**10. What are you hoping to accomplish with the publication of *Paint Your Hair Blue*?**

From the time Taylor first started her foundation, her constant mantra was: if I could save the life of one child, it would all be worth it. In writing this book, our goal is to help other families going through a difficult diagnosis by affording them knowledge that took us painstaking years to obtain, from day-to-day care, to tactics that could help save someone's life. In addition, our goal was to keep Taylor alive through her stories of love, laughter and endless adventure. It is my way of not letting her voice go silent.

**11. What does the title derive from?**

When Taylor first found out she was going to lose her hair, she didn't take it as hard as I expected. Taylor always seemed able to find the fun in literally any situation, from taking a rubber chicken into the operating room during her first surgery, to wearing a "Bad Hair Day" t-shirt when she was bald. Over the course of her diagnosis, we were asked several times by other parents about how to handle it when their child loses his or her hair. Taylor's advice epitomized how she lived her life. She said to tell the child that beforehand she should dye her hair pink, or a combination of all her favorite colors, or tell boys to cut a Mohawk. Have "fun" with it! In retrospect, before shaving it off, we should have dyed Taylor's hair blue, her favorite color.

**12. Your younger sister and book co-author, Andrea Cohane, has helped you immensely to get through all of this. What was her support like during the most trying and challenging times of your life?**

My sister has been my best friend and soul mate from the day she was born, ten years after me. She was always a call or plane ride away. Her support for me, my family and Taylor never ceased for a moment. During Taylor's illness she was living in Charlotte, NC and then London. Even while living in London if we needed her she hopped on a flight at a moments notice even leaving her young children at home. During the last week of Taylor's life she was with us in Germany where Taylor was receiving an experimental treatment. When Andrea arrived in Germany, Taylor said, as she did many times during her illness, "When Aunt Annie comes I always get better." She gave Taylor a great deal of hope and comfort. Andrea was with us when Taylor passed. I believe Taylor knew it. After we lost Taylor Andrea has helped me to survive life without my daughter. She keeps Taylor alive by talking about her, she is a board member of TMF and in the afterlife Taylor sends her more signs than anyone else in the family.

**13. What advice do you have for parents learning their child is battling a deadly disease?**

There's no way for any parent to completely avoid the fear and pain that comes with a cancer diagnosis, but you do have some control. First, your most important job is to make your child feel safe, and believe he or she will survive. You don't have to hide your sorrow, but try to hide your fear. Second, you must understand that your family has to go on *living* and *experiencing* life to its fullest. Lastly, you cannot ever stop advocating for your child. Even if you have the very best doctors, you still have to question them and your child's protocol at every turn, making sure he or she is getting the most effective and creative treatments available in the world.

**14. Medications for teens can be hard to keep up with. What should parents and children do in this regard?**

When Taylor was ill I kept a strict journal of the dose and time I administered medications to her. Today apps exist to keep track of medications that will alert you when a medication is due. I suggest that both the teenager and the parent maintain the app so no confusion exists and they are both alerted. Additionally, check every prescription when you receive it from the pharmacy. Human error is always a possibility.

**15. What about when surgery is needed-what should parents be asking, doing or saying to ensure the best medical treatment for their child?**

1. Seek second opinions and different surgical options.
2. Speak to your personal anesthesiologist on the day of your surgery. Don't count on your pre-op anesthesiologist to pass along information.
3. If you have an allergy, make sure you are wearing a red wristband and discuss the allergy with the anesthesiologist.
4. Many people become nauseated after general anesthesia. Ask for an intravenous infusion of anti-nausea drugs before you wake up.
5. Insist on going into the operating room until he or she receives anesthesia.
6. Ask for updates during surgery to alleviate stress, especially if surgery exceeds the amount of time you expected (which often happens).
7. Insist on being in the recovery room when your child or loved one wakes up. It is very frightening for your child to wake up without a loved one nearby.

**16. Mother's Day. February 22 – Taylor's birthday. How do you contain your grief on such days?**

My grief ebbs and flows, much like the tide. When Taylor first passed, the waves of pain were constant and wiped me out without warning; any day, any time. As time passes, the pain is just as deep, if not deeper, but it's more predictable. Holidays and anniversaries are the worst, no doubt. I can't help but re-live years passed before we lost her. However, I prepare myself for the onslaught and do things to honor her memory. I surround myself with my family and friends and allow myself to grieve. The reality is I will grieve forever, and I will never be the same without her. Nor would I want to be.

**17. Are we winning the war on cancer?**

That's a difficult question to answer. We are making great strides in cancer research but we still have a long way to go. Each year, the parents of approximately 15,700 kids will hear the words "your child has cancer." Across all ages, ethnic groups and socio-economic classes, this disease remains the number one cause of death by disease in children. There have been major advances –

fifty years ago there was an overall survival rate of 10 percent and today it is nearly 80 percent. However, for many rare cancers, the survival rate is much lower, sometimes 0-20 percent. Furthermore, the number of diagnosed cases annually has not declined in nearly twenty years.

**18. Early on she had to under-go a risky, life saving surgery that kept her in the hospital for five weeks. Where did you find the inner strength to meet the daily challenges of your daughter's health?**

Keeping Taylor as comfortable as possible, by pushing the pain management team, while living life to the fullest even when she in the hospital and on chemo was the only possible solution for us. My inner strength came from a determination to keep Taylor alive and happy and by the pure unconditional love shared by mother and daughter. Hearing Taylor laugh or seeing her smile made all the difference. Taylor made it easy for me. She always found fun at every corner. A day of pure fun while in the midst of chemotherapy was a godsend. We couldn't control her chemo, but we could control having fun.

**19. How did she live way beyond what the doctors expected?**

Taylor lived beyond her prognosis because my husband worked by day and researched by night every possible treatment available for Taylor's cancer. Many doctors will warn you that much of the information on the web is inaccurate, contradictory, generalized, and overwhelming. If you can put the fear factor aside, the Internet can be very helpful in explaining different treatment options, identifying current research, and citing the names of doctors and institutions where valuable support can be found. Bob got over seven "second" opinions. When treatment failed we looked to another doctor, or another hospital for solutions both nationally and internationally. We asked Taylor's doctors to collaborate with the doctors at other institutions, which gave us the best treatment options available nationally and globally. We trusted our gut instincts. Doctors can sometimes make one feel like your questions are insignificant, stupid, or a waste of time. We did not blindly trust anyone. That is not to say we distrusted our physicians; on the contrary, in many ways, they were our lifelines. However, they are just as human as anyone else, and we felt we had the right to advocate for Taylor at all costs. We never gave up hope.

**20. What are some of the most amazing moments during her battle?**

One might think Taylor's best moments were her most momentous ones such as her Sweet Sixteen party, a family trip to Hawaii, biking in Normandy, France, or when she fell in love; however, I would say her most amazing moments were every day, when she lay in my arms and together we loved each other deeply. Or when she belly laughed with her sisters or friends-which happened on a regular basis. Taylor received love from so many because she gave so much love. Although the situation was dire, because we were together almost every day, we shared so much more quality time together than a normal mother and daughter. I cherish every moment we shared together.

**21. How did losing your mom a year before Taylor died help you handle loss?**

Losing my mother a year before Taylor died did not help me handle my loss. There's nothing that can prepare you for the loss of your child. As painful as it is to lose a parent, it is in the natural order of life, and something you always expect to occur one day. When you lose a child it is a wholly different experience. The one thing that does give me some solace today, however, is knowing that my mother is with Taylor in heaven and that one day we will all meet again.



# **Treatment Tips**

by Sue Matthews and Andrea Cohane  
Co-Authors, *Paint Your Hair Blue*

In the course of Taylor's cancer journey, we gathered many "nuggets of gold," or anecdotal lessons through the trial and error of treatment. If you or a loved one is going through a long illness, you may find some of these tips helpful. Naturally, I am writing from the perspective of a parent of a cancer patient; however, many of these tips can be applied to a variety of situations and illnesses.

## **Diagnosis**

- Send your pathology to other hospitals to confirm diagnosis and to analyze the tumor. Your hospital will send the slides for you for a nominal fee.
- Get a second, third, and even fourth opinion! Bring copies of your scans to the doctor providing the second opinion or mail in advance if a second opinion is discussed over the phone. Do not count on your hospital to send it.
- Research your disease. Many doctors will warn you that much of the information on the web is inaccurate, contradictory, generalized, and overwhelming. If you can put the fear factor aside, the Internet can be very helpful in explaining different treatment options identifying current research, and citing the names of doctors and institutions where valuable support can be found.
- Have your tumor analyzed as soon as possible by Precision Medicine. Precision Medicine uses genomic profiling to make personalized, genetically informed treatment recommendations and assist with clinical decision making, culminating in better outcomes for patients. When the biopsy is performed, a sample can be taken for this purpose.

## **Scans**

- Insist on getting results from scans immediately. Some hospitals will tell you results may take days. Don't accept that answer. Every moment waiting for test results is grueling.
- Get a copy of every radiology report and read it in depth. Don't let your doctors summarize it. Sometimes they tell you only what they want you to hear.

## **Medications**

- Check all medications and chemotherapy you receive. Anyone can dispense wrong medications by accident. Trust your doctors, but check them every step of the way – it can only help!
- If anything seems wrong, call your nurse and/or your doctor immediately. Trust your gut!

- Whether in the ICU or inpatient, pain management doctors will decide what pain medications to administer. Do not accept what they say if your pain is not manageable. You will quickly know what works best for you.
- Get an Insuflon, which is a small access point put into your leg that needs to be changed about once a week. This way, you can give yourself a shot at home, and it won't be painful. When inserting an Insuflon or accessing a port, ask for Emla cream (numbing cream).

### **Surgery**

- Speak to your personal anesthesiologist on the day of your surgery. Don't count on your pre-op anesthesiologist to pass along information.
- Many people became nauseated after general anesthesia. Ask for an intravenous infusion of anti-nausea drugs before you wake up.
- If your child is the one receiving surgery, insist on going into the operating room until he or she receives anesthesia.
- Insist on being in the recovery room when your child or loved one wakes up.

### **Family and Friends**

- Family and friends want to help, but often do not know what to do except send gifts and meals. Let them know these are helpful! A great gift you can ask for is for them to give blood and platelets and reserve them for your child. Never accept "pooled platelets" (platelets from several donors), which can cause an allergic reaction. You want platelets from a single donor.
- Family and friends can be apprehensive to pry but often want an update. A popular and unobtrusive way to provide this is for you to write a blog. Not only is it cathartic to do so, it is also a relatively easy way for you to control the information available about your situation. It also removes the pressure of having to return calls and emails. You can easily create a blog through the website [caringbridge.org](http://caringbridge.org).
- The most important thing you can do in this journey is to trust your gut instincts. Doctors can sometimes make you feel like your questions are insignificant, stupid, or a waste of time. Do not blindly trust anyone. That is not to say you should distrust your physicians; on the contrary, in many ways, they are your lifelines. However, they are just as human as anyone else, and you have a right to advocate for yourself or your loved one at all costs.
- Do what is right for your family and remember every day is a gift. Enjoy it! Cancer is not a death sentence. In many ways, it provides an eye-opening opportunity to live your life to the fullest. That's what Taylor did. That's what she taught me, and that is what she would want you to know.

# The Taylor Matthews Foundation

[www.taylormatthewsfoundation.org](http://www.taylormatthewsfoundation.org)

A portion of the proceeds from the sale of the book, *Paint Your Hair Blue*, will be donated to TAY-BANDZ INC. doing business as the Taylor Matthews Foundation.

The Taylor Matthews Foundation, a tay-bandz organization is a 501(c)(3) nonprofit organization founded by Sue's then eleven-year daughter, Taylor, when she was diagnosed with cancer. Taylor was horrified that thousands of children could be suffering from cancer, yet their cries for help were being ignored. Taylor was determined to make a difference. Taylor aptly named her foundation, what is now called The Taylor Matthews Foundation, "tay-bandz," for her nickname Tay and for headbands, the first product made. She dreamed that "someday, no child would ever have to face cancer," and repeatedly told me, "Mommy, if I could save the life of one child, it would all be worth it."

Taylor being only eleven years old thought the best way to fundraise was to sell goods, but she decided she did not want tay-bandz to simply be an arts-and-crafts project. She wanted to sell products that were professionally made. Big dreams aside, when she first started tay-bandz, none of us had any idea the money raised would ever become something other than the equivalent of a large school bake sale.

TMF is dedicated to raising awareness and funding pediatric cancer research. TMF funds cutting-edge innovative research and treatments that can reach sick children today, not months or years from now to improve outcomes and reduce the long-term survivorship side effects associated with pediatric cancer. We are embarking on a new day in pediatric cancer: a day of less toxic and more successful treatments, greater hope for sick children, their families, and easier access to therapies of all kinds. We are a few steps closer to achieving Taylor Matthews' mission that all children with cancer will live long, healthy, productive lives. Our research is saving lives today.

## Research Funded by TMF:

Children's Hospital at Columbia University Medical Center: TMF has funded Precision Medicine which involves comprehensive genetic sequencing of an individual child's tumor to identify mutations in their DNA enabling personalized treatments for individual patients and individual tumors. Precision Medicine brings the best technologies to newly diagnosed, relapsed, and high-risk patients as well as those who have failed standard therapies. Of the patients sequenced, 67% had clinically impactful findings resulting in diagnostic confirmation and treatment protocols that would not otherwise have been identified.

Memorial Sloan Kettering: The anti-body study funded by TMF has reached completion. The antibody was used for a specific cancer that typically hits 15-18 years old and has a very poor prognosis.

The National Institute of Health: TMF has funded the completion of a clinical grade master cell bank to support development of a new immunotherapy based vaccine for patients with pediatric sarcomas.

MD Anderson Cancer Center: TMF has funded research focused on pediatric osteosarcoma, a soft tissue sarcoma that can occur in adolescents and young adults.

“Our goal has been and always will be to help children with cancer by funding cutting edge research that can impact their lives now, not years and miles of bureaucratic red tape from now,” says Andrea Cohane.

“We will never stop pushing the boundaries of conventional therapies, dated public policy, and the logjams that keep good drugs in the lab and out of the clinic,” says Sue Matthews. “All our children deserve a bright and healthy future.”

## **Pediatric Cancer Facts**

- Cancer is the number one cause of death by disease among children in the United States.
- The average five year survival rate when considered as a whole is 83 percent. Therefore approximately one in five children diagnosed with cancer will die in the first five years.
- One in 285 children will be diagnosed with cancer before the age of twenty.
- Approximately 35 percent of children diagnosed with cancer will die within thirty years of diagnosis.
- Those who survive the five years have an eight times greater mortality rate.
- More than 95 percent of childhood cancer survivors will have a significant health-related issue by the time they are forty-five years old; these health-related issues are side effects of either the cancer or, more commonly, the result of its treatment. One-third will suffer chronic side effects; one-third will suffer moderate to severe health problems, and one-third will have severe or life-threatening conditions.

Despite these facts, the issues surrounding childhood cancer are consistently misunderstood.

## Select Excerpts

### As Long As We Had Each Other

No one would wish cancer on his or her worst enemy, but there can be some good that comes out of it. If you let it, cancer slows life down just long enough to afford you opportunities to hold close the ones you love, breathe in their scent, feel their skin upon yours and unwaveringly thank God for bringing them into your life. As long as we had each other, nothing else mattered.

### My Heart Will Go On

In August 2003, Taylor was scheduled for a herculean surgery to remove her primary tumor and the metastases in her right lung. During the pre-surgical conference, again only attended by my husband, Bob, in an effort to shield and protect me, we both expected to hear the worst. Shockingly, Taylor's first oncologist, Dr. Redmond Sparrow, whose passive-aggressive personality was confusing and irritating, and our surgeon, Dr. Michael La Quaglia (also known as our hero), didn't agree on whether she should have surgery. The risks were enormous, and the surgery itself was life threatening. However, if the surgery wasn't performed, they told us, "Taylor's prognosis would likely be only a matter of months." What choice did we have? We thought the answer would be black and white and were stunned that the doctors presented Bob with their disagreements. Were they really asking Bob, a financier with no medical experience, to decide what to do with his daughter's life?

Ultimately, the doctor's warnings about the risks of surgery fell on deaf ears. When we deciphered the medical jargon, it came down to this: If we did the surgery as planned, Taylor could possibly die on the table. If we didn't, we would buy time to keep trying. This was not, in the end, a hard decision but it was agonizing.

### Mischief on 68<sup>th</sup> Street

It was still August; the weather was warm, and the city was quiet. Sun washed the floor in her hospital room at the end of the day. Taylor was exhausted and irritable about being cooped up. Every twenty minutes or so, the nurses would pop in, saying, "Remember, Taylor; you owe us one more walk." Taylor would listen, wave them off, and turn her head.

Bob very gently put his hand on Taylor's head, and as she turned toward him, he said, "Tales, you know this is part of getting back on your feet and getting home. You promised one more walk. I know you have had it with the pain and the pushy people. But I think you're missing an opportunity." Her eyes searched his for a hint.

"Tales," he said, "they want a walk? Let's give them a walk they'll never forget." She was intrigued. He had her attention now and could see her impish grin. "They think we should go outside? Let's go outside!" Taylor began giggling, knowing she was part of a scheme created by Bob. "Tales," he said, "let's go get some ice cream!" Tales was as energized and as upbeat as she had been in a while.

When the elevator opened on the ground floor, Tales headed for the main entrance onto York Avenue. Bob remembers the smell of cigarette smoke filling his nose as they passed a pack of hospital patients getting some air—most of them, unbelievably, smoking. Taylor never noticed or flinched. She skillfully kept walking, turning left at the corner of 68th Street and heading uphill toward First Avenue. This was one heck of a walk!

Tales was still in her hospital gown, a thin gray smock with the back wide open, exposing blood seeping through the bandages. Her underwear was like a flag waving in the back as she pushed her IV pole laden with three bags. She looked to any passersby like an escapee from a mental institution, and Bob remembers thinking that they wouldn't have been completely wrong. But this was New York City, home of the good, the bad, and the ugly, and a half-naked insane person strutting down the street wasn't that shocking.

She should have been afraid of the uphill walk and the physical effort, but instead she was delighted at calling the shots and once more poking her finger in the eye of the giant. People on the street stopped, stared, and then applauded. Cabs tooted their horns, maybe thinking she was a nut or maybe congratulating her. Passengers opened windows to cheer her. They all laughed like it was a publicity stunt. She walked all the way up that hill, huffing and puffing, turned right onto First Avenue, and kept walking. First Avenue is far busier than York Avenue, so there was even more commotion. Taylor was clearly tired but elated and felt in control.

### **Driving Outside the Lines**

We had been in cancer hell for only a few months, but it already felt like an eternity. “This is a jail sentence, Mommy! How can they make me stay home?” whined Taylor. Thanks to chemotherapy, Taylor had a low immune system, a condition called neutropenia, which made it incredibly difficult to fight off infections. Staying away from all germs meant public places were forbidden and visitors were limited. Try explaining that to a twelve-year-old with ants in her pants.

Demoralized, Taylor slumped into her chair, grabbed the remote, and put on *ER* reruns. It beggared my heart to see Taylor watch television, something she rarely did before she got sick. Chemotherapy had taken over; her energy was low, and she appeared to be giving in to her situation.

I grabbed her books from the car, thinking that getting some schoolwork done would be distracting and productive. Taylor gave me one of her “are you serious, and now I might stab you” looks. Suddenly, it came to me. I turned around, threw her books right back into the car, and ran into the house with excitement. “Taylor, do you want me to teach you how to drive?” I smiled and laughed, waiting for her to process what I had just said. She looked up, confused at first, and then her face could have illuminated the entire block.

Taylor screamed with pure delight, “Let's go!” She threw a coat over her pajamas and sprinted to the car as if she were an exceptionally trained racehorse. My veins were pulsing, my heart throbbing. I was breaking into a cold sweat as both anxiety and excitement crept up my spine. I knew Taylor would be fearless, gutsy, and cocky behind the wheel. Yet my trepidation was

overshadowed by my elation at being able to give Taylor a gift, a gift I had control over at a time when we had no control.

Taylor's expression of pure jubilation filled me with a surreal feeling. She was back again, wild as ever, ready for the next adventure.

### **Poise In the Face of Adversity**

The biopsy came back positive. Cancer had bulldozed its way back into our lives. Bob and I sunk deeply into our chairs, our eyes misty and glazed over. Reality had not yet fully hit. Taylor was outside with her friends in the hot tub. We felt she should know right away. Were we insane to interrupt her time with her friends? Maybe we were the ones who needed her support and courage. When we called her inside to tell her the news, she looked at us blankly, said, "Okay," and left.

An avalanche of hot tears streamed down my face as we watched her jump right back in with her friends as if nothing had happened. We wondered, *How does she compartmentalize like that?* Cancer, like a hurricane with one-hundred-mile winds, was about to wreak havoc and knock us down again and we knew it. We kept telling ourselves we were lucky because she relapsed to a single site, a tumor on her adrenal gland, when many times cancer comes raging back more aggressively. We were determined to look at the glass as half full.

When Tales was first diagnosed, we knew very little about her disease, the ordeals to follow the treatments she would endure, and what surgery really meant. By now we knew exactly what was coming, and the prospect of entering the war zone and doing battle again felt inconceivable. True to form, the first person to snap back into battle mode and resign herself to round two of this title fight was Taylor. Taylor just looked her disease in the eye and kept fighting. She was a force of nature. Others couldn't comprehend how she could look past the hurdles and concentrate on the next item on her life's agenda while being subjected to so much suffering – and to do it while giving you a good slap in the face, occasionally.

### **Knowledge Is Power**

Fighting cancer means asking questions and questioning the answers. Questioning should never cease, no matter how comfortable you are with your doctors and your treatment plan. Parents desperately want to believe their doctors are gods who can cure everything. We learned to ask detailed questions, putting the doctors on the spot, so they couldn't wiggle their way out.

We were finding quickly that opinions on treatment varied enormously. Had we sat blindly and refrained from forcibly asking questions, getting second opinions, and sometimes breaking the rules, no one would have done it for us. We were Taylor's only true advocates. With certainty, I can say that Bob's tenacious ability to never stop researching, and speaking to doctors across the world extended Taylor's life dramatically. Knowledge is power!

### **Final Moments**

Like a shadow in the night, I stood up and purposefully walked across the dimly lit, unforgiving hospital room toward my beautiful baby girl lying motionless in her bed, very close to death. With bulging eyes, tangled hair, tattered clothes, and that red hat, I got into bed with Taylor

pulled my baby's warm body close to me, and with tears drenching both of us, I stroked Taylor's hair, took in her scent, and studied her beautiful hands and toes for the last time.

I desperately tried to commit to memory, for all eternity, every unique and exquisite facet of Taylor's face and body. I tried to summon the strength to speak to her one last time as the cacophony of the various machines and monitors clanged and clattered, taunting me with every startling beep. My lips and body quivered uncontrollably as I finally spoke: "I love you; I love you –don't leave me here alone. You are all things great in this world. I need you. Please, please don't leave me, my perfect angel. How will I ever live without you? Why can't you live the life you love so much? I am so sorry, my baby."

Our love story continued almost immediately after Taylor's passing. Sobbing, I held my beautiful angel for the last time and stroked her hair. As I glided my hand over her soft cotton pillowcase, a little heart soldered to the charm bracelet I was wearing broke off. I stared at the shiny, silver heart against the backdrop of the white pillowcase in utter disbelief. At the time, I thought of it as a symbol of my forever broken heart, but now I believe that she was telling me that although we were physically separated on this earth, we would never be separated spiritually. She was taking my heart with her.

### **What Do I Have to Be Angry About?**

Three weeks prior to her passing, I asked, Taylor, again, "Why are you not angry that you are tied to an oxygen tank, missing school and your friends?" She replied, "Mommy, what do I have to be angry about? Everyone loves me."

### **One Year Anniversary**

Many times, Taylor was not willing to accept help, but you managed to give it to her through your acts of pure love. Whenever you face any kind of challenge in your life, remember what she would tell you: LIFE SUCKS; WEAR A HELMET!

We can never prepare ourselves for the loss of a friend and a sister. We all miss her terribly, but I truly believe she would want all of you to hold her in your hearts and, at the same time, to move forward, be happy, go to college, enjoy life to the fullest, do things for her that she never got to do, and live to your heart's passion. Do whatever excites you. Live with purpose and excitement. Believe in yourself; believe you can do anything because, if you try you can. Shower others with the love you showered Taylor with and truly make your daily life an adventure. And lastly, cherish your friends and your family as if your life depended on it. Because always remember in life: if you have love, you have everything.

### **Life Lessons**

Taylor taught us that during every dark moment, there's a brighter day in the future, and for every black day, there's a rainbow. So, in the meantime:

Paint your hair blue.

Go on that midnight ice cream run.

Break the rules.

Dance in the rain.



And never forget to say I love you.

## **The World Is Just Not Black and White**

**by Taylor Matthews**

*Red, orange, yellow, green, blue, purple, or pink, colors of my life, colors of me  
A color to celebrate with, one to cry with and a color for everything in between.*

*White, white for everything pure and whole.*

*Black. For when there is no other color to feel*

*Black. Its called darkness for a reason*

*Black. The color of the inside of my eyelids as I fall asleep wishing I won't wake up*

*Black. Covering everything else, one shade one true color*

*Black. As the paint covers the rainbow of my life, trickling slowly like blood.*

*Black. Cold metal, cold water, cold hands*

*Black. As the room blinks in front of my eyes*

*Black. As voices fade and everything leaves*

*Black. As I forget, as I take a deep breath*

*But then it's not so black, because there is always tomorrow*

*Red, orange, yellow, green, blue, purple, or pink, colors of my life, colors of me  
A color to celebrate with, one to cry with and a color for everything in between.*

*White, white for everything pure and whole.*

*White. The first thing I see as I wake up.*

*White. The color of making it through.*

*White. Remembering, recognizing,*

*White. Knowing where you've been and where you're going*

*White. The peace of a blank canvas.*

*White. Faces, faces and voices coming back to me*

*White. The last minute for me to grab only me*

*White. The Last color before the colors of life start to come back*

*Red, orange, yellow, green, blue, purple, or pink, colors of my life, colors of me  
A color to celebrate with, one to cry with and a color for everything in between*