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SUFFER THE CHILDREN: A COLLECTION OF BIOGRAPHICAL
STORIES FROM PATIENTS, FAMILIES, AND PROFESSIONALS IN
THE WORLD OF PEDIATRIC CANCER

by

Samuel Taylor Farris

A thesis submitted to the faculty of The University of Mississippi in partial fulfillment of
the requirements of the Sally McDonnell Barksdale Honors College.

Oxford

May 2018

Approved by:

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With Special Dedication To:

This work was written in honor of all the brave children who have stared cancer directly in the eye and made it blink first. To all of those who valiantly fought, but ultimately fell victim to this awful disease, I personally salute your courage and resilience. Through stories like this, both written and spoken, the legacies will live on forever, ensuring that no child's sacrifice be in vain.

To the parents and families who lost their children, I express my deepest sympathies and sincerest prayers for recovery, closure, and peace.

Finally, to the professionals who fight everyday on behalf of the patients to find a cure to the disease we all fear, I wish to convey the utmost respect and gratitude for your service; for the light you all provide in the darkest times of our lives.

Last but not least, this work is published with special dedication to Nancy Roberson Wilkie and Stuart Wilkie. Though we never met, I wish you both much peace on the other side. Your husband and father is a great man who has helped me immensely on this project and in my profession moving forward.

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ABSTRACT

SAMUEL TAYLOR FARRIS:

“Suffer the Children: A Collection of Biographical Stories from Patients, Families, and Professionals in the World of Pediatric Cancer”

(Under the Direction of Curtis Wilkie)

One area of cancer diagnoses that has garnered much attention in recent years is pediatric oncology. Many adults, certainly not all, increase likelihood of cancer, both directly and indirectly, through usually habitual lifestyles (tobacco use, alcoholism, etc). Meanwhile, children are plagued by cancer through seemingly no fault of their own, provoking widespread curiosity. Researchers tend to analyze pediatric cancer with quantitative data, but this investigation is based on qualitative information, by compiling a list of thirty individuals who have, in some way, been affected by pediatric cancer, and examining their attitudes and reflections in various time stages, outcomes, and relations to disease.

In order to maintain strength in the analysis without belaboring on a generally melancholy subject, the list of thirty was narrowed to a dozen subjects, each of which provides a unique perspective. At least one interview was conducted with each subject, and a first-person narrative setting was created respectively, based solely off the individual’s daily routines, which would then channel into a period of reflection where the musings of the subject were incorporated. In essence, each section serves to paint a

picture of each subject to the reader, both in terms of a lifestyle and a mentality coping with cancer.

What I found time and again throughout the study was that, generally speaking, the subjects who had been patients were much more positive overall than non-afflicted individuals such as relatives and care providers. Moreover the healthcare professionals seemed much more affected by the patients than the patients were by the disease. Likewise, relatives of patients were much more emotional when discussing cancer than the sufferers themselves. Several interviewees admitted that in the most stressful moments, the children were the most stable beings, taking each blow in stride, regardless of severity.

After considering all of this, my conclusion is that though cancer levees children with a more substantial blow physically, the mental anguish and grief that it causes for witnesses is equally impactful. From a medical perspective, there seems to be very little correlation in backgrounds, demographics, or personalities when it comes to pediatric diagnosis or survival rates. Cancer appears to be a beast that, in regards to children, plays no favorites.

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Preface

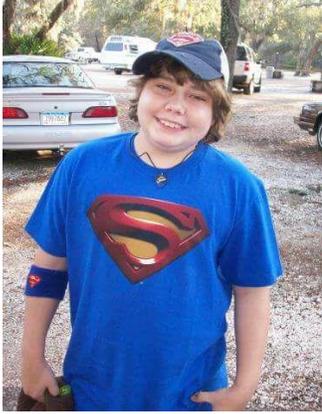
I was led to the topic of pediatric cancer through personal experience. In 2006, when I was ten-years-old, I was diagnosed with Stage IV Neuroblastoma, a rare and very aggressive form of childhood cancer that attacks the central nervous system. I was immediately enrolled as a patient at St. Jude Children’s Research Hospital, where I would spend a majority of the next two years. Over this time, I could not help but make connections and bonds with my cancer-ridden peers and their families. Not all of them made it, and that is something I will always carry guilt and questions over, never fully able to understand why I was one of the “lucky ones.”

In 2007, in the thick of my treatment regimen, I was visited by the Make-a-Wish Foundation, and after brief contemplation I wished for my own baseball field to be constructed in my backyard. The kind and unselfish representatives at Make-a-Wish made it happen through considerable hard work, and on June 9, 2007, “Farris Field” opened in Mantachie, Mississippi. Many volunteers helped bring my field of dreams to fruition, but one such institution was the very college I would enroll in just seven years later, Ole Miss. The university grounds crew laid the sod-work for the field’s grassy areas, creating a professional environment for America’s pastime.

After coming to the college years later, administrative changes had taken place, so I reached out to Ole Miss Athletic Director Ross Bjork, relaying my story and how the flagship had pitched in, no pun intended. Mr. Bjork was elated with the tale and expressed interest in having a mini-documentary made on campus. In October of 2015 the Video Productions Department released “Sam’s Story,” a sixteen-minute long recounting of my battle with cancer. Months later the video would be nominated for and win the 2016 Southeastern Regional Emmy for Best One-Time Sports Feature.

Upon receiving a replica of the award, I had an epiphany. It was not fair that my story was the only one to be told, out of all those I had encountered along the way, both survivors and those who passed, they all deserved to have their stories told. My tale was no better than any of theirs, but simply a perfect storm of location and connections. I originally had plans to exit the Honors College and forgo my thesis, but my obligation to my fellow warriors compelled me to stay.

These are the stories that deserve to be told; of triumph and tribulation, fear and strength, perseverance and sacrifice. The truth of the matter is, every story about a child battling cancer deserves any Emmy, if not something far greater.



“You are much stronger than you think that you are, trust me.”

-Superman

Amanda Kittrell

“Ladies and Gentlemen this one is starting to get ugly,” came Brent Musberger’s voice across the CBS broadcast of the Iron Bowl, yearly meeting between in-state rival colleges Alabama and Auburn. “Jalen Hurts has really rebounded from two early interceptions, and has the Tide leading big going into the fourth quarter.”

The commentator’s exclamation interrupted Amanda’s thoughts and brought her back to reality. She was a huge Auburn Tiger fan, but had long been bored with this game. Truth be told, she had not thoroughly enjoyed watching a game for ten years. She used to have the life that every small-town Alabama girl dreamed about. She held a stable job, was happily married, and had a wonderful son who always kept things exciting. It seemed liked so long ago now. Had it really been gone for a decade?

In August of 2006, Amanda’s 11-year-old son Stash, whose personality was as unique as his name, started suffering from excruciating headaches. After several trips to the doctor, Amanda received the news that still makes her weak to this day:

Stash had a brain tumor, Medullablastoma, one of the most aggressive types. The next few months passed as if they were mere minutes for the Phillips family; chemotherapy, radiation, surgery, repeat. The sicker Stash got, the more his mother's dream-life crumbled. Despite this, Stash's larger-than-life persona continued to shine.

Amanda smiled as she remembered her son rolling around the hospital in his prized pair of "heely" shoes that featured a wheel in the heel. Stash had become iconic around St. Jude Children's Hospital for his exuberant style. Amanda recalled that many people had commented that if it were not for Stash's slick scalp they would have never known he had cancer. His nurses called him Superman, and he embraced the tag with ease. After a year of devastating treatments, Stash defied the odds and conquered a rare pediatric brain cancer. Things were looking up, and it seemed as though Amanda might get her life back. Stash finished treatment and returned only for periodic check-ups.

It was November of 2007. It was cold and windy in Memphis, Tennessee. The Phillips family was eight hours from their home in Mobile, Alabama. They were in a familiar spot; anxiously awaiting the oncologist to give them Stash's latest scan results. He had been in remission for almost six months. Superman was on top of the world. Then the doctor walked in. The cancer had come back, except it was different and it was worse. In fact, it was the absolute worst possible recurrence; a brain tumor that was not only inoperable, but completely untreatable. Superman was reacquainted with his kryptonite, but this time it was there to stay. Stash Phillips had three months to live.

Looking back, Amanda knows she did what any parent would in that situation. She tried to be strong for her child, and she tried to make his remaining time as

comfortable and enjoyable as possible. What Stash never knew though, was that he was the one keeping his mother strong. His resolve to never show fear inspired his mother in a way that words could never express. When Superman Stash passed in January of 2008, Amanda lost her rock, her living source of strength in adversity. Shortly after the funeral, the cracks that started to show a year earlier began to grow larger with each passing day, eventually resulting in Amanda and her husband Clint, splitting. Ten years later they still have little-to-no correspondence, making the old life seem like an eternity away.

“TOUCHDOWN... A-LA-BAMA,” boomed Musberger’s voice through the television screen yet again. This score would ice the game. Amanda hated seeing Alabama win. She knew Stash would hate it too. She missed having him on the couch to help her yell “War Eagle” (the battle cry for Auburn-fans). She tries to find strength in knowing they will meet again, and she’s found love again in recent months, so things are starting to normalize as best they can. Sometimes she still misses Clint, and she does really like Robert, but Amanda knows that no other man will ever inspire her the way her Superman did.¹

¹ Amanda Kittrell, personal interview, June 2017, on life after losing a child to cancer and the effects it causes.



“Sometimes in the waves of change we find our true directions.”

Matt Hume

“C’mon Mom, one more wave,” he pleaded. “Alright, Matt, but be careful,” his mother responded. “The tide is coming in, not to mention a storm front later tonight.”

Matt Hume was trying to bask in the waning moments of a beautiful afternoon on the Santa Barbara coast line. It had not been too hot, and the light breeze created just enough wave action to test his finesse on the board he got last Christmas. Knowing better than to ignore his mother, he hollered, “Alright mom, I know. I’ll be careful. I just want one more good run to close the day.”

Matt was seventeen, but his mom worried about him like he was still seven. He was the oldest child in a family of four, and was soon to start his senior year of high school. He had been surfing practically since he started walking, yet every wave was like his first through his mother’s eyes. He understood why though. He knew he was different than most other seventeen-year-olds. He had very few memories of what happened, but he knew it set him apart from other kids; he knew, mainly because of how people treated him.

In 2002, September specifically, Matt was a normal two-year-old baby boy. By the end of the day, the entire framework of his life changed forever. After experiencing flu-like symptoms for some time, several doctor visits ultimately revealed that Matt had Stage IV Neuroblastoma, an aggressive and rare form of childhood cancer of the central nervous system. He would spend several months undergoing rigorous treatments and surgeries. Then it was time for the really hard part...waiting.

At that time, many pediatric protocols required a long period of “wait-and-see,” in order to gauge the effectiveness of treatments. For Matt and his family, the agonizing wait totaled ten whole years. An entire decade of not knowing if the disease that almost ended Matt’s shiny new life would return. Luckily for the Hume family, Matt’s treatments were successful. His cancer was dead. He had slain the beast that attacked him for seemingly no reason.

Since he was so young, he had very little recollection of the actual experience; however, he did clearly remember the years of waiting and the constant concern weighing on his parents. He never had been comfortable with the look of fear on their face as they lingered around the various doctor’s offices. A couple of scars and some fuzzy memories are all he carries with him today from his toddler-time trial. He’s a good bit shorter than most of his friends, a common side-effect of cancer treatment, and one that draws jokes with regularity. Matt knows the hecklers do not understand, so he plays down the cracks with the good-nature he has come to embody.

More recently he and his dad attended a seminar just for Neuroblastoma survivors. Who knew that there was a whole group of kids like Matt, and more

importantly to him, the existence of an outlet for his parents to vent, learn, and progress? At first he had been startled when he met the other survivors. Most of them were either disfigured or had an evident cognitive impairment. Of course, Matt was not judging them. He knew what they had been through, and he knew it was not their fault. It was the guilt that troubled Matt about seeing them. There they were, so horribly affected long-term by cancer, his cancer, and yet he had been pouting just days before over what, being just a little shorter than his friends? Immediately Matt formed an attachment with several of his fellow cancer-slayers, and soon he found that the conference was a good thing. He too now had companions and a venue that understood his feelings. He was so glad his dad had made him go, in hindsight.

As he paddled out for his last wave, he felt that sense of peace the ocean always gave him. Matt used to wonder why cancer happened to him, and the distorted memories made that worse, but he found relief in the water. In the vastness of the water, the “how comes?” of life seemed irrelevant. There was something tranquil about the sea, even on a wavy day like this one. The ocean made everyone seem small, so out here he was just a boy with a board. There was no cancer, no waiting, and no jokesters; just Matt and the water. He steadied himself upright to ride the day’s final rip through the dimming coastal sunset and he smiled. This was his solace. This was where he belonged. His days of cancer were behind him. He understood his mother’s concern, but the only thing he worried about these days was catching the next wave. ²

² Matt Hume personal interview on reflections from cancer and adapting to the changes disease caused. (30 June 2017, via online correspondence)

*“Heroes Get Remembered,
but Legends Never Die.”*

– Babe Ruth



Mia Norwood

She walked to the plate casually and calmly, just like she always did. It was the bottom of the sixth inning, and her team’s last chance to score. They were hours from home, playing in their biggest tournament of the summer. They breezed through the first three games, but now they were in a battle for the title, down to their last out with runners on second and third, trailing nine to eight. Luckily for the Titans, Mia was the one batting. When other players were nervous, she was always calm. In the biggest situations when the other girls feared failure, Mia transcended to another level. As she stepped into the box, dug her toes in the dirt, and eyed down the pitcher, she knew this at-bat was no different, even if there was a championship hanging in the balance.

Mia plopped down into the booth, completely famished after a long day on the diamond. She was completely oblivious to whatever her parents were discussing in the adjacent seats. All Mia cared about at this moment was the Big Mac she was ferociously

unwrapping. As she began to chow down and her hunger calmed, she refocused on her surroundings. Her whole team had packed in the Monroe McDonalds well after ten o'clock. They had just won the 12U softball championship and Mia had the winning hit; a line-drive over the shortstop's head with two outs and two strikes. She smiled as she reached for a fry, and looked around at her teammates. They were crowded into booths with their families, still beaming with the excitement that every new trophy brings. Before she could turn her attention to the last two bites of burger, Mia noticed something that brought back that dull ache in her chest.

One of her teammates was sitting in a nearby booth begging her mom for an ice cream cone as a reward for winning the game (despite the fact she hardly played). The unwarranted dessert is not what bothered Mia; it was what happened next. No sooner had the girl called-off her pleading, did her older brother return to his own seat at the table, carrying a freshly spun, white-and-creamy, vanilla ice cream cone, which he kindly presented to his little sister along with a thoughtful, "Good game, sis."

While it is true that Mia had two older brothers, neither one was there to give her a congratulatory treat. Granted, it was not about the ice cream; it was the not being there. Zach had a valid excuse. He was in college, he worked, and he had a girlfriend. Frankly, he did not have time to travel several hours to his twelve-year-old sister's softball game. She could not be mad at Zach. He was great. It was Bryce, her other big brother that she really wanted. He would have been there, and she knew it, but he just could not be. The truth was Mia had not seen Bryce in almost ten years. Actually, she doesn't even remember seeing him at all.

“It’s not fair,” Mia thought to herself. “All the other girls get to see their siblings all the time. I see Zach sometimes and never get to see Bryce. I always play well, one of the best on the team. I never get in trouble, and I do my best in school. Why am I the lonely one?”

Here’s the thing about Bryce: He was not at her game, because he had died. “Why did he have to do that?” In 2006, when Bryce was four, he was diagnosed with something called Wilms Tumor. All Mia knew was that it was some kind of cancer. When it came to Bryce personally, all she knew was what other people told her. Bryce died in 2008 after having beat cancer once, only to relapse a few months later. Mia was just a baby through the whole thing. She spent a little over two years with her brother Bryce but will never remember a single day from that time.

Based on what she could piece together, Bryce was amazing. She had seen hundreds of pictures and heard countless stories. One time Bryce got to hang out with Jennifer Anniston at a charity event for St. Jude Children’s Research Hospital in Memphis, Tennessee, where he was being treated. He was notorious for running the billiard table on fellow patients and their families at the Target House, where they lived. When he was feeling up to it, Bryce insisted on having pick-up baseball games on the Target House lawn, where everyone was invited to play, but very few were able to win. When his blood counts were too low for outdoor play, he organized board game groups in the facility commons. If all the stories were true, Bryce was champion in everything he did, and that just made Mia long for him even more.

Since she had taken up softball Mia had won countless trophies, medals, and rings. She had been called a champion, in her own right, more than once. As she turned her attention back to her remaining bites of Big Mac, she looked at her mom and dad. She knew it was not their fault that Bryce got sick, and she knew they missed him too. They were great parents and she loved them, and used their stories to develop a love and admiration for the brother she will never know.

Earlier that evening as she stood in the box awaiting the first pitch with the game on the line; she knew she was going to succeed. It was what Bryce would have done, because he was champion, and since he was her brother, she was a champion too. As she ran to first and watched the ball split the gap in left-centerfield, Mia looked up and smiled. Even though he wasn't there, Bryce had come through for her again. She played for him, and he helped her in the biggest moments. They were a great team, and she could not wait until they could play alongside each other for real one day.³

³ Based on conversations and interviews with the Norwood family, June 2017.

*“Health is a state of complete physical,
mental, and social well-being, and not merely
the absence of disease or infirmity.”*

~World Health Organization



Dr. Cheryl Stegbauer

She stepped off the elevator and strode down the hallway. She hit the button on the wall and entered the solid-tumor inpatient ward at St. Jude Children’s Hospital. Immediately as she rounded the corner and entered the view of the nurses’ station, those behind it shot up, making themselves look professional, prudent, and most of all preoccupied. Cheryl hardly noticed the reaction for two reasons. One, it came with the prominence of her position. Most of these nurses knew her as the head of the nursing program at the University of Tennessee. The second reason she failed to notice the shift in the nurses’ aura is because she was not there on business. She hated that cancer existed for anyone, but it was especially awful when the affliction fell upon her family. She quickly found room 1050 and headed inside to greet the ten-year-old cousin she had never met. As she did, there was a collective sigh of relief from the entire floor of nurses.

Dealing with cancer had been a professional norm for Cheryl. She knew that was not necessarily a good thing because it indicated the persistent volatility of the disease. Despite this, her familiarity with cancer made her especially helpful when it came to helping the suffering patients and families. Her experience with pediatric cancer had been somewhat limited, save a few cases of early-diagnosis finds during her days as a practitioner. In her eyes, though, cancer was cancer, and for the last several decades she had been charged as one of the leading educators at UT Medical for preparing future nurses for the professional and emotional strain that comes with treating cancer patients. The bedside manner of course was the same, but cancer was a disease unto its own simply because of the urgency that it places upon the patient. Cheryl trained her students to be fervent, meticulous, conscientious, and above all-else emotionally available.

From her perspective, “caring” was not just a general practice of treating a patient. When it came to being a good nurse in cancer care, one needed to care for his or her patients on a personal level, if nothing else for the subtle vibes that can pass from healer to sufferer. In her experience, it was quite obvious that patients were very perceptive of their nurses, and that often times the atmosphere created by the staff had a profound effect on the attitude of the afflicted. By her logic, a despondent nurse could endanger the future of a patient by negatively affecting the patient’s outlook; all because of the latter’s professional impression. Contrarily, an optimistic and buoyant nurse can improve a patient’s mind-set and subsequently their outlook on illness. One of Cheryl’s most prevalent teaching points was that “nurses are privileged to be with people in some of the most vulnerable times of their lives.” She believed this whole-heartedly and had echoed it for forty years to every student and colleague she encountered.

Cheryl had lived in Memphis most of her adult life, working at or around the city's medical facilities, and perhaps one of the reasons she loved the area so much was because their medical centers really seemed to embrace patient care concurrent with how she tried to teach it. As she made her journey through St. Jude earlier in search of her ailing cousin, Cheryl noted, as she did upon every visit, how welcoming and vibrant the atmosphere at St. Jude. Children and families filled the halls with varying degrees of the world's most dreaded disease, yet there was smiling, laughter, and radiance. Undoubtedly, at least for Cheryl, and apparently to the hospital's founder Danny Thomas, this cheerful environment contributed directly to patient response in treatment and disease.

Throughout her time as a practicing nurse, Cheryl applied many lessons to her professional and personal life, often times taught to her by some of her own patients. Most notably, one of them told her when she was a doctoral student that, "No human knows when another will die." In regards to treating cancer, her patients usually faced some lofty odds, but this particular lesson showed her that since there was no way to know when a patient would perish, it was best to treat them as if they would not. She related this back to maintaining a positive energy around the patient, acting oblivious to their possibility of death and creating the idea for them that survival was always not only possible but expected.

Another patient-led lesson for Cheryl went, "Be honest to the core in all that you do." Cheryl realized that this was a valuable lesson for all people, but she used it professionally, tying the musing to her own message about caring for patients personally. If a nurse's intentions are pure, and honest to the core, then they will always

subconsciously possess a genuine concern for those they treat, on a much deeper level than just that of nurse to patient. One thing Cheryl could say about herself was that her intentions had been pure, and she had been “honest to the core” for the last four decades. She had been with patients as they died, and she had been with them as they triumphed over their affliction. Four years ago, she retired from UT Medical and received professor emeritus status, after four decades of service during which her work was published over twenty times and she received dozens of awards and recognitions.

Disease, cancer especially, was always going to be difficult for people to handle, but Cheryl had long been aware of the vital role nurses could play in making those battles just a little bit easier, and that was not a duty that she would ever take lightly. It had been her mission for most of her professional life to emphasize that vitality to all of her students and peers. Nurses have a greater impact on treatment, attitudes, and survival than most people think; Cheryl was certain of that. All of her experiences had helped prove it, and educationally she strode each day to pass on the ideology, purely and honest to the core.⁴

⁴ Information obtained from personal interactions with Cheryl Stegbauer starting in 2014, culminating in a final interview in March 2018. Setting derived from a real event in 2007.

*“There are some family traditions
that I don’t want my kids
to carry on.” – Lorna Luft*



Lisa Redmond

Lisa Redmond watched as her two kids hopped off the school bus and scrambled down the driveway. Javon was battling a full load between his laboriously weighted backpack and his new trombone he received for making the high school band. Jakayla, on the other hand, toted just her lunchbox, and of course, her cell phone. As they clumsily approached the front door, Lisa could not help but admire how wonderful her kids were, and even more so, how strong they were after what she did to them.

Years had passed since it all happened, and to an extent Lisa knew she really could not blame herself for what happened. Still, though, she knew the risks of bringing kids into this world after the condition she had. She had Javon first, and for two years everything was perfect. He was a happy healthy baby boy, full of life and charisma. Lisa had been a single parent but she worked hard and made ends meet, never letting her child go without. Looking back, giving everything she had to her son nearly killed him.

In 2003, before Javon's third birthday, Lisa knew something was wrong. He was not his usual playful self. After several visits to the pediatrician, her worst fears came to fruition. Almost eighteen years before, to the day, Lisa had been diagnosed with Leukemia. She had been a five-year-old girl from the Mississippi Delta town of Clarksdale, with no way to afford adequate healthcare. At the time, it seemed like an assured death sentence. She did not really remember now how it all happened, but Lisa ended up at St. Jude Children's hospital an hour away in Memphis. There she received the care she needed that helped her reach a full recovery over cancer, or so she thought.

Fast-forward two decades and there she was, once again sitting in the Leukemia clinic room at St. Jude, waiting on Dr. Ching-Hon Pui, the same doctor she had years before. Sure enough, Javon had T-Cell Leukemia, a variation of the same cancer Lisa once fought. She had passed the world's most dreaded disease to her child, and it would take years before she would finally forgive herself. Javon fought with courage that his mother had never before seen, and despite relapsing in 2005, he never lost his smile. A year later, in mid-2006, Lisa welcomed her second child, JaKayla into the world after Javon had once again defeated cancer.

Some time passed and Lisa's family of three felt like the perfect life, and then right on cue, almost as if she were cursed by time, JaKayla was diagnosed with B-Cell Leukemia, days after her second birthday, once again sending the family back to the safety of St. Jude. This time around both Lisa and Javon were helpless, only able to watch JaKayla suffer with all-to-knowing eyes. When it seemed things could not get any worse for Lisa's once-immaculate little trio, the unthinkable happened. Javon relapsed a

second time in 2010, and this meant Lisa would now be charged with caring for two children with different forms of the same disease, at the same time.

She remembers now how the staff at St. Jude found her situation to be unfathomable, something they had never witnessed. Sure, parents had passed genes and diseases to their children before, but very rarely had affliction affected a family so often with such regularity. Two more years of treatment for Javon, before once again defying the odds by beating cancer a third time. Meanwhile, JaKayla reached remission in 2011, albeit only for a short time, relapsing less than year later. Javon remained stable and in good spirits, and he has aged enough to really understand the magnitude of his family's situation. He became his sister's biggest cheerleader, and his disease's loudest advocate.

When the dust settled, for what Lisa hoped to be the final time, JaKayla reached complete remission in 2013, and the family's grand total of cancer-bouts between three tallied seven distinct stints. While there was still a risk for it all to come unraveled and happen again, five more years have passed, a safety milestone, according to the doctor's at St. Jude. Lisa was not sure if she would ever completely let her guard down. In the back of her mind, after everything her family had been through, she just got the feeling that cancer was always lurking.

Despite the nervousness, she would probably always have, Lisa knew she could not let her kids see the anxiety, so as they clamored through the front door and into the kitchen, she turned her attention from the worrisome thoughts of wars past, to the peanut-butter and jelly afternoon snack she was preparing for her little warriors. Her last thought of that matter for today was that maybe it had not all been bad. Not only did it give them

all perspective into the suffering of the world, but cancer gave each member of the trio an identity. Lisa had become an advocate for single mothers with children that are sick or have disabilities. Javon used his experiences to become an honor roll student, and recently mentioned that one day he wants to work in communications for St. Jude's research department, ALSAC. Finally, there is JaKayla, who still only twelve, is full of life, and will without a doubt use her positive vibe and happy-go-lucky persona to help others. Lisa did not know if cancer had left her family for good, and she would always have a hidden fear, but for now she was focused once again on giving her all to her kids; only this time, she planning on just giving them the good things she had to offer.⁵

⁵ Information, Perspectives, and Concerns acquired through personal interviews with Lisa Redmond in August 2017 and February 2018

“It cannot cripple love. It cannot shatter hope. It cannot corrode faith. It cannot eat away peace... Cancer is so limited.” ~ Unknown Author



Calli Kalman-Calvert

The organ roared to life. The people rose to their feet. It was time. Her father looked down at her with his aged but ever-loving eyes, and with a smile he asked, “Well, kiddo, are you ready?”

Of course she was ready. She had been waiting for this exact moment for her entire life. This was the single isolated day she had dreamed about for twenty years. She took one more look at Frank and with her own smile responded, “Yes, daddy. I am definitely ready. Let’s do this.”

That had been Calli’s wedding day, almost six years ago. Every time she caught a glimpse of the picture on her desk, she could instantly recall every memory, every word, and every smile from that day. Every girl’s wedding day was special, and usually the happiest of her life, but for Calli the elation was multiplied exponentially.

Her marriage was not just a lifelong dream fulfilled, but it was a dream that seemed completely out of the question for so long. It was not supposed to have happened; not to Calli. There just was not any feasible way a man could love her after everything

that happened. Who was ever going to love the creature she saw every morning in the mirror? When Calli looked at her wedding picture she did not just see the memories from that day, but all the memories before it that made that day seem so impossible.

Eleven years before she married Vincent, she met another man, Dr. Dale Rowland. He was her pediatrician, and he had just told her that she had a tumor in her stomach of immense concern; so starts a fifteen year saga known as the life of Calli Kalman. After more tests in late 2001, it was determined that she had cancer, Stage IV Ganglion Neuroblastoma Nodules, a combination of two separate diseases that made her, at 12-years-old, the only kid in the country with this particular diagnosis.

She immediately underwent a surgery that removed 95% of her tumor, but they had not been able to get all of it because it was wrapped around her ureter. This instigated a year-long maintenance therapy with hopes of frying the remaining lump, and though initially successful, by December of 2002, her cancer had spread, so, back under the knife she went. Following the second surgery, that again had mixed results, Calli received eight rounds of chemotherapy, and subsequently her first stint of baldness, which she detested.

After some differences in opinion concerning Calli's case, her parents transferred her to Sloan Kettering Hospital in New York City, where she was scheduled to undergo yet another surgery. This time, all the results were favorable. The surgeon had gotten almost all of her tumor, which ended up being benign and harmless. If only Shakespeare had been wrong, and all things gold could in fact stay. Almost four years to the day, in 2007, Calli started having terrible pain in her upper-leg, and despite the extended period of remission, everyone knew it was back; this time with a vengeance.

Over the course of the next three years Calli had another surgery, twenty-eight rounds of chemotherapy, twenty-five rounds of radiation, and six different experimental treatments in four different states. In the midst of all the chaos in 2010, Calli very briefly reached remission before quickly relapsing, but it was this third recurrence that turned the tides of her life. There was one friend from high school that had insisted ever since her the beginning that Calli relay to him every test result, every update, and every feeling. He had always been there. So, when she relapsed for the third time, it was only natural that the next step was to call Vincent and break the bad news. It was during that phone call that he confessed his love for her, admitting to having kept it a secret for almost a decade.

Calli was completely astounded. She had been sick, deathly sick, for years. She vomited early and often. At times, she could barely walk. She was constantly circumventing the country to seek out new therapies that would undoubtedly further weaken her body. On top of all this, SHE HAD NO HAIR. What kind of guy falls in love with a girl that has no hair for him to play with? At first, she took it as pity, but the more she talked with Vincent, the more she felt his resolve. He was in love with her, and quickly she fell in love with him. He stayed every step of the way, for better or worse, and in 2012 following her graduation from Cal Poly and his honorable discharge from the Navy, the two were wed. Still, Calli worried.

She did not worry about her cancer coming back. She worried about not being able to give Vincent what he wanted. It has been six years since they tied the knot and she was still on various treatments, and she still had spots that concerned the doctors. Despite feeling fine, there were still so many things she could not do physically, and perhaps the most unnerving to her was that she would never be able to have children.

When Vincent came to her one day and told her that he wanted to look into the adoption process, she knew she had married the man of her dreams. She was so ill, so afflicted, and yet he loved her truly in spite of it all, “How remarkable,” she thought. “How is this even possible?”

Today, Calli still takes maintenance drugs to keep the cancer at bay, and she still struggles with everyday actions that many people take for granted. She has Vincent though, and that is a help greater than she could ever express. He makes her feel beautiful, comfortable, and most all, loved. In addition, she has the job of her dreams. She is a Wine Club and Event Manager in Paso Robles, California, in the heart of wine country. She and Vincent are in the process of adopting a child in time for Christmas, when she plans to become a stay-at-home mom and complete the last circuit of her life-long dream.⁶

⁶ Information obtained in interviews with Calli Kalman in June 2017



“And God shall wipe away all tears from their eyes; and there shall be no more death, neither sorrow, nor crying, and neither shall there be any more pain: for the former things have passed away.” – Revelation 21:4

Brent Powell

Brent hit the button activating the sliding door to the impatient room. He had been inside for over an hour, and as usual he was mentally drained from the melancholy atmosphere. It seemed that regardless of how valiantly he attempted to provide a positive twist to an otherwise dreadful set of circumstances, the hopelessness often prevailed for those inside. He knew in time that many would come around and embrace peace, but there were still equally as many who never would; a reality that frustrated Brent for three decades. As he made the last turn and approached the elevator to exit the ward, the battle-worn chaplain said one last silent prayer before turning his attention to a much more cheerful subject, lunch.

Brent Powell has been a chaplain at St. Jude Children’s Research Hospital for 31 years. For the past 28 he has served as the department head and director of Spiritual Care Services. His wife of 25 years, Jo Ann, also works at St. Jude, as a nurse in their Assessment Triage clinic. He has traveled all over the world, both learning and teaching

spiritual guidance, but this non-profit “place of miracles,” as he calls it, in Memphis, Tennessee, has always been his home and where he belongs. He has seen hundreds, if not thousands, of kids like the one he just left, who were on the brink of death, thanks to one part bad luck and one part cancer.

The Bible says plenty about pain, trials, and death, but it rarely does much to ease the immediate suffering of the children and families Brent saw each and every day. Though he had always maintained a strong foundation of faith, he would be lying if he said that he had never questioned his own convictions. The truth was, he never could understand or explain exactly why innocent children are chosen, seemingly at random, for affliction; and moreover why so many are never healed as a testament of God’s power, but rather die, causing families to doubt or downright discount the possibility of a “divine healer.”

Brent’s life was not all doom and gloom, though. For every patient and family who denied spiritual healing, there was one who would embrace it. Likewise, for each victim of childhood cancer, there was another spared. In fact, the survival numbers had as much as doubled in many areas since Brent’s arrival at St. Jude. When he started in the late 1980s many forms of cancer still had mortality rates exceeding 50%, but today those same diseases had seen those rates drop as low as 10%, thanks to the vision of St. Jude’s founder, Danny Thomas, who saw the need for an on-site and around-the-clock research center. Another addition of Thomas’, much more pertinent to Brent’s place in the hospital, was the diverse Chaplain Services department.

Many hospitals only employed a couple to three chaplains who work separately, just to ensure one is available to patients on death's door. Brent's department, contrarily, is an entire division of spiritual counselors and psychologists, from a variety of backgrounds, denominations, and affiliations, that cater not only to patients nearing the end of their battle, but also those who are relatively healthy, just in need of stimulating conversation or companionship. In fact, as Brent set his tray of lunch down on the cafeteria table, a prime example of the latter plopped down next to him, a regular occurrence that Brent welcomed, especially after the hard meetings like the one he just left.

At St. Jude, the cafeteria was one open common-area for patients, families, and employees alike to dine and interact. By doing this, Danny Thomas sent the message to his patients that the entire staff was with them and available the entire way. For Brent, it became an arena for him to converse with patients and their families in a far less formal setting. This is where he would learn backgrounds, interests, hobbies, goals, and the like, just in casual conversation over lunch. All of these personal interactions made him better at his job by creating a more relatable "friend" persona to his patients, which in turn allows him to learn about how his patients view pressing matters like disease, suffering, and death.

It is possible that throughout his three decades of lending spiritual advice, Brent has learned as much as he has taught. He has been inspired by how resilient the human spirit is, and how children with an otherwise limited worldview are able to not only cope but transcend a devastating illness. Brent learned that faith, hope, and courage cannot be impressed upon someone, but are actually inherit, waiting to be actualized; and these

suffering children usually have a better grasp on these traits than most adults Brent encounters. Cancer is a serial and unapologetic killer, but Brent admits that he has witnessed some beautiful products born from the suffering that cancer causes.

As he turns his attention from the morning musings to his veggie wrap and the young boy across the table eager for conversation about something besides cancer, Brent takes a relaxing breath, ready for an interaction that is nonchalant, but all the same educational. He knows he has helped lots of patients through the years, and he welcomes every opportunity to do so, but informal meetings like this one with his young chipper patient are perhaps more welcomed, if not necessary, because they help *him* become better at helping *them*.⁷

⁷ Ideas, Insights, and Information acquired through several conversations with Brent Powell via phone, e-mail, and in-person interaction starting in August of 2017.



“Come to me, all of you who are weak and heavy-laden, and I will give you rest...

For my yoke is easy and my burden is light.” ~Matthew 11:28, 30

Rachel Tyson

The alarm clock blaringly filled the room. It was only 5:00 am, but in this house the days could not start a minute later. Rachel flicked on the coffee pot and watched the strong dark miracle water slowly trickle into her eagerly waiting cup. After taking a small sip to arouse her senses, it was time for the first and most important step of the morning routine, prayer. It was something she and her husband Adam had always done, but now it was an absolute necessity. A day started with anything other than prayer, was a day doomed for chaos. Following the much needed “God-time,” Rachel was ready for the rest of the daily list.

The first step is getting Abel, thirteen, up-and-ready for school, a job easier said than done, since Abel was paralyzed. In addition, his mental function is also very stagnant, which makes communication minimally existent, requiring around-the-clock monitoring. In the mornings either Rachel or Adam, along with the night-shift nurse would wake Abel, turn off his feeding pump, give him his medications, including a nebulizer, conduct his percussion vest therapy, diaper him, and help place him comfortably in his wheelchair, all in time to catch the bus with his daytime nurse at 7:15. Most people would assume the routine lightens after seeing Abel off, but the Tyson's were not a family of three, but rather seven, meaning they have five other kids to tend to each morning, with four attending different Philadelphia-area schools.

Adam usually takes their ten-year-old son Will to school around 7:45, and then goes into work at a local medical center, where he is a doctor. Meanwhile Rachel delivers eight-year-old Benjamin to the bus stop for his school at 8:30. Later, she takes six-year-old Jonathan to his afternoon-only kindergarten bus at 12:30, before returning home to focus on housework and caring for her youngest child, two-year-old Emma. Busses start returning around four in the evening; supper was at six, family prayers at eight, and finally bed. It was organized chaos. Rachel had been an attorney by trade, but had not been able to work as much as she once could, given the obvious need for her around the house. Sometimes she missed her daily practice, but other times she enjoyed getting to focus most of her time on her family, and especially Abel.

Abel had been born a perfectly healthy baby and the first child to a young and in love Adam and Rachel. Around Thanksgiving of 2006, the Tyson's noticed a lump in Abel's stomach one night while tickling him. Several doctors opined that Abel had a

simple case of impaction that a laxative would solve. After two weeks though, the laxative had not affected the lump whatsoever, and Abel himself was acting much sicker, and this prompted another run to the pediatrician, suspecting the impaction required surgery. During an ultrasound to locate the obstruction, the doctor located the source of Abel's discomfort, and it was much worse than a bowel blockage. Abel had a tumor that had somehow grown to the size of a cantaloupe and engulfed one of his kidneys, all while causing minimal alarm.

Two months later, in January 2007, Abel underwent a surgery to remove as much of the tumor as possible. Up until that point, Rachel and Adam had thought, like many people, cancer was the worst of the worst, as bad as things can get, but on that fateful winter morning, the Tyson's learned a scary lesson; some things are worse than cancer. During the procedure, Abel slipped into an extended cardiac arrest. The doctors were able to revive him, but not without collateral damage. Abel's brain had gone without oxygen for thirty minutes, more than enough time to impair most mental functions.

He has been unable to walk, talk, or even crawl since that day. "He lived," Rachel remembered thinking, "But at what cost and with what quality to his life?" Adding to the tragedy of Abel's life being forever altered, he still had cancer. The surgeon had only been able to remove portions of the large tumor, meaning he would need treatment to subdue the remainder of the disease. Rachel and Adam decided that St. Jude Children's Hospital in Tennessee, would offer the best care for Abel, so the then-family of three moved two states south and started their new journey.

It took only five months for chemotherapy and radiation to eliminate what was left of Abel's cancer, later revealed to be Neuroblastoma, with a result much faster than most cases. After discussing it, Adam and Rachel elected to forgo the bone-marrow transplant, a capstone treatment of immune system rejuvenation present in almost all solid-tumor protocols. Instead, Abel took several more radiation treatments before returning home, and he has been cancer-free ever since. Although his brush with cancer had not been as extensive as many children the Tyson's met at St. Jude, it had still been cancer that ultimately caused the more damaging and lasting issues.

Eleven years have gone by with no recurrence of disease, making a relapse of cancer extremely unlikely. Despite numerous therapies and regular monitoring, Abel's brain function is not expected to improve much, if at all; however, his condition is not life-threatening moving forward. It took Rachel and Adam a long time to find peace amidst all the turmoil. Rachel initially fought bitterness, seeing her perfect family image shattered, but as more time passed and the pain eased, both young parents realized that perfection was relative in terms of family. Their group expanded from three, to four, and eventually to seven, and somewhere in all of the chaos, Rachel remembers the Lord showing her that her family was still perfect in its own way.⁸

⁸ Information gathered from personal interviews with both Adam and Rachel Tyson in March 2018.



“Friendship is born at that moment when one person says to another, ‘What? You Too? I thought I was the only one.’” – C.S. Lewis

Kayla McMillen

She sat down in the bright-pink rotating chair, slipped off her shoes, laid her head back, and relaxed. It was a much needed spa-day after a strenuously trying week at work. She loved her job and could never imagine doing anything else, but she had to admit, there were few careers she imagined being as stressful as teaching middle school math in Mississippi. As she started to soak in the comfort of the spa’s soothing atmosphere, she turned and looked at her best friend Jessie sitting in a similarly fashioned blue chair, preparing for a manicure.

“I really needed this, Kayla. It’s been a rough week,” Jessie said. “I know it has,” Kayla responded. “Just relax and enjoy it. This will be good for you.”

Jessie really was Kayla’s best friend, but their relationship was a little more complicated than “just friends.” The pair met a little over two years ago on Kayla’s first

day as a teacher at Center Hill Middle School in rural DeSoto County, Mississippi, almost two hours from her home in Pontotoc. From the moment she saw Jessie she knew they would be fast and lifelong friends. It was an unusual assessment, Kayla remembered, because after all, Jessie was not a fellow teacher she befriended on the first day. Strangely enough, her would-be best friend was one of her twelve-year-old students. Unknown to Jessie at the time, she and Kayla had one very striking similarity that transcended the decade wide age gap between them.

In 2009, roughly six years before Kayla and Jessie met, the former, who was sixteen at the time, was sitting in a colorful room in the middle of an otherwise dark situation. She had been rushed to St. Jude Children's Hospital in Memphis, Tennessee, after her mom had discovered a knot in the center of her back that had been causing Kayla much pain. After numerous tests and a nerve-racking wait to rival eternity, a doctor named John Furman shuffled through the clinic room door and delivered the bad news. Kayla had Stage IV Wilms Tumor, a rare and aggressive form of pediatric cancer. Worse was that a scan showed her tumor to be the size of a football, and according to Dr. Furman, she had, in all likelihood, only a week to live.

Kayla remembers now how devastated she was, and despite reassurances and encouragement from her family, she was resolved to death. When two weeks past and death still had not come, she began to wonder why she was still here. Death was said to be imminent for her, yet she had been spared for the time being. Was there a reason? As more days passed, and treatments provided Kayla with more time, her resolve began to waiver. By the time she agreed to her first surgery in November, three months to the day

after diagnosis, Kayla had decided she was going to fight, and she was going to prove everyone wrong.

As expected, the battle took a while, and it was by no means easy, but she held true to her charge. She beat cancer; on borrowed time nevertheless. It took 18 months of seven types of chemotherapy, 33 doses of concentrated radiation, and six invasive surgeries. She emerged battered and worn, but alive all the same, just in time to start her senior year of high school, where she graduated with honors. She went on to obtain two bachelor degrees from Blue Mountain College in education and will soon finish a Master's degree. After completing her undergraduate work she started applying for positions, and recalls how divine will seemed to lead her to Center Hill, and to Jessie.

The first day of class Jessie walked into Kayla's room, bald head beaming, donning a medical mask with a colorful band, a trademark of St. Jude. After introducing herself to the obviously cancer-ridden student and her parents, Kayla received the shock of a lifetime. Coincidentally, not only did Jessie have cancer, but she had the exact same type with an identical prognosis as Kayla received years before. Kayla immediately rooted a deep bond with Jessie and her family, and the two have been as thick as thieves ever since. She watched Jessie fight with inspiring strength for over a year, all while maintaining her school work at an impeccable level. At one point, Jessie reached remission status, but it was short-lived, as she soon relapsed with a new Wilms Tumor; this time in the same spot where Kayla's had been. The similarities were startling.

Another year has passed since the relapse. Kayla recently transferred to Potts Camp Middle School, much closer to her home, but further away from Jessie. Despite

this, the pair remains as close they ever were, and each allots regular time in their busy schedule to unite with the other, making spa-days like this one a common occurrence. Jessie continues fighting against the beast inside her, and her bravery inspires Kayla every single day. Recently, Kayla has noticed Jessie's strength fading, and she knows the doctors have already said that time is limited, yet Jessie continues to fight without relent. Kayla wondered for six, long, painstaking years, "Why? What was the reason for her affliction? Why was she led down a path of despair and suffering for so long?" Now, because of Jessie, Kayla knew why. She knew exactly why. Jessie was why.⁹

⁹ Based off of personal interview and stories from Kayla McMillen, February 2018



“The ones who are crazy enough to think they can change the world, are the ones who usually do...Innovation distinguishes leaders from followers.”

~Steve Jobs

Ken Aagaard

The crowd rose to its feet with a thunderous and moving applause as he stepped away from the microphone and down from the podium. One gentleman had just pledged one-hundred thousand dollars, bringing the night’s grand total to an even \$800k. It had been unbelievable for most people to see that much money fly through one room in two-hour’s time. Ken, on the other hand, had seen it countless times, and for the last four years he had been the spark that ignited the monetary firestorm.

He was a man of great success, possessing what seemed like limitless connections and influence. This particular evening, he had been in front of several hundred people at a charity event, of which he was in charge. This was his show. Ken Aagaard did not just know the man. He was the man. Fifteen times he had received an Emmy award. Twenty-five times he had produced the most watched annual television program in the world, the Super Bowl. Over the years, he has been charged with overseeing production of America’s most popular sporting events such as: the Masters PGA Golf Tournament, the NCAA Final Four, and the Olympics.

Currently, Ken serves as the Executive Vice President of CBS Sports and the Director of Innovation and Technology. All of the VIP events and outings of the rich-and-famous had become second nature to Ken, but recently his fire was renewed, and his focus was shifted, thanks to a personal tragedy that changed his life forever. In 2013, Ken's then eleven-year-old daughter, Ally, was a normal child. She was a Girl Scout, she played soccer, and she was becoming proficient on the clarinet. Her favorite activity, though, was swimming, and one day when she felt too bad for a dip in the pool, Ken knew something was wrong. Several doctor visits levied virus diagnoses, but this failed to satisfy Ken and his wife Emerald, as Ally only grew worse as the days passed. Finally, after nearly a week, Emerald rushed Ally to the emergency room, and that is when the walls of Ken's perfectly constructed world faltered.

Ally had cancer. There was no easy way to say it. It was even harder for Ken to look at it on the radiology screen. A tumor the size of a tennis ball, perfectly visible, sat firmly in the back of Ally's adolescent skull. Further testing revealed one of pediatric cancer's most volatile goons, Medulloblastoma, the most deadly and aggressive form of childhood brain tumors. At that very moment, Ken was struck with an unnervingly cruel reality. No matter how hard someone works, or how much wealth, fame, and notoriety they acquire, cancer is a merciless terrorist that wages war with any and all classes of victims; a savage of a most non-discriminatory nature. At once, Ken began putting his connections and his background in technology to good use, researching the newest and most innovated methods for treating Medulloblastoma.

All of Ken's research led the Aagaard family to Memphis, Tennessee, to the brain tumor clinic of St. Jude Children's Research Hospital and the watchful eye of Dr. Amar

Gajjar. Admittedly, at the time, Ken knew very little about St. Jude. He had seen commercials and various marketing campaigns, but outside of giving a few dollars each year during Christmas, his experience with the hospital was non-existent. That was soon to change during the Fall of 2014. Ken was instantly taken aback at how hopeful the atmosphere at St. Jude was, and how diverse the expansive population of patients. Then there was Dr. Gajjar, who from the onset was informative, collaborative, and calming. The wealthy and connected Ken Aagaard had visited the world's most breathtaking destinations, but never had he seen a place as remarkable as St. Jude.

Over the next several months Ken watched helplessly as Ally weathered thirty rounds worth of radiation and seven cycles of chemotherapy. There were days when he was not sure if she would ever get back up. He had a front-row seat to a vengeful war being fought inside the body of an eleven-year-old child, and not just any child, his child – his Ally. Luckily, Ally was not alone in her battle. Ken remembers how the employees at St. Jude were like an armed militia, waiting on a moment's notice to fight alongside Ally and help her gain the upper-hand. Finally, after almost a year of combat, the war was over. The fighting had ceased. Out of the rubble, from months of collateral damage inflicted upon her body, Ally was the sole survivor. Cancer was dead, and she was not. A disease that would have killed ten out of ten kids just a few decades ago had become almost ninety-percent curable today, and Ally was one of the victors.

It has been three years since Ally walked of St. Jude, triumphant over cancer. She still goes back twice a year to keep tabs on her remission, and so far she is doing great. Recently, she made her high school varsity golf team, and even competed on the ProAm for the FedEx-St. Jude PGA golf tournament, with Ken serving as her caddy. As he

looked out over the crowd of football fans and dignitaries alike, all still standing after the “Super Bowl fundraiser for St. Jude” total was announced, Ken saw Ally. She was standing next to Emerald, smiling from ear to ear, as beautiful as ever, forever a champion over cancer, and forever an inspiration to her father and many others.

Ally had redirected Ken’s focus and helped him to see how real suffering is in the world, and that time and disease are assailants that fear for no one. Thanks to this epiphany, Ken now uses his connections and resources to make him one of St. Jude’s most vocal crusaders. He even incorporated his advocacy efforts into his professional career, getting CBS on-board with several events benefitting the hospital and pediatric cancer research in general. There were other innocent children like Ally out there who need the help that St. Jude offers, and Ken was now living in line with the vision of the hospital’s founder, Danny Thomas, whose mission from the beginning was to ensure that “No child should die in the dawn of life.” Ken hated cancer. He saw what it did to Ally, and he was going to see to it that the wicked ailment one day be eradicated, never to harm another child. ¹⁰

¹⁰ Information obtained from a personal meeting with Ken Aagaard in June 2016, with a follow-up interview in February 2018



“When there is a love of the art of medicine there is also a love of humanity.” ~Hippocrates

Dr. Karen Wright

She turned her cart down the produce aisle in desperate need of replenishing her supply. She had always been conscious about her diet, but her meal management had intensified ever since a recent scare with Crohn’s Disease. She had never been a superb cook, but the various fruits and vegetables went well in shakes that she could down without being distracted from work. As she chose a few tomatoes and some kale, she saw it; a green that she used to detest, but had learn to love (when cooked a certain way). The only problem was, she did not possess the skills necessary in properly frying a piece of okra, so she always had to settle for the pre-battered kind she occasionally found in the frozen food section, which was nowhere near the same as the homemade batches she could acquire when she lived in the South.

Most of the time Karen was happy to be back in New England where she was from, but small memories like friend okra sometimes made her miss the life she made for

herself in Tennessee, and more than that, the people she left there. She really did love her jobs, splitting time between Boston Children's Hospital and the Harvard Medical School. She got to research and treat brain tumors while also teach the country's top medical students how to best diagnose, evaluate, and help cancer-ridden children. She never thought in a million years that this would be her life's work. She had been the first in her family to graduate from college, receiving triple-major degrees from Lehigh University in Biology, Mathematics, and Religion. The last of those initially won her over and led to a two month sabbatical in Israel studying the Dead Sea Scrolls. After she returned she made the decision to try her hand at medical school with the hopes of specializing in orthopedics, but during rotations in oncology Karen had a complete change of heart.

She remembered feeling so frustrated everyday of the adult oncology rotation, seeing patients who were often contributing to their own demise through various cancer-causing habits; meanwhile, in the pediatric ward kids just trying to be kids were struggling to live despite no wrong-doing of their own. From that point until she graduated from Temple Medical in 1999, she was hooked on the idea of treating children with cancer. It started with a residency in rural New Hampshire, at Ivy League Dartmouth, under a mentor who specialized in Neuroblastoma, one of the most deadly types of pediatric cancer, that ironically enough would be the disease in Karen's first case three years and thirteen-hundred miles later.

Upon finishing her residency, she had interviews set up with several prestigious cancer centers. Before she could see them all through, Karen was involved in a scary car accident during a snow storm that left her stranded over a hundred miles from home. The wreck totaled her Toyota and caused her to miss her last meeting, but otherwise she was

completely unharmed. Karen was set on accepting one of the positions she had been able to interview for, but after hearing of her incident, those presiding over the missed interview insisted on arranging a new travel plan, free of charge to Karen. She obliged their generosity out of respect, though she recalled having no desire in accepting their position, but the first time she stepped through the revolving door of the hospital named after the Patron Saint of Lost Causes, she knew that was where she belonged.

Karen spent two years as a clinical fellow trying to cure Neuroblastoma, while learning lessons almost daily about bedside manner, the human condition, and the resilience of children. For the second half of her fellowship she transitioned into the hematology lab, where she found what seemed like her fifth passion in as many years; brain tumors, and this area of pediatrics, much to her surprise, turned out to be her true calling as a physician. The next Fall, her exceptional work in the lab landed her a faculty position, which she gladly accepted and occupied for six more years.

It was during those six years Karen had a run-in with Crohn's Disease, an ordeal that came within minutes of killing her. Innumerable times she had entered a patient's room and asked how they were feeling, assuring them that things would be okay, but all of a sudden Karen inexplicably found herself the receiver of concern and reassurance, from her own patients oddly enough. Moreover, she had made countless attempts to enroll patients in experimental treatment plans without ever really understanding the fear of having to rely on a non-proven drug. Then one day, she was the patient sitting in the room, panicking internally as the doctor told her that experimental therapies were her only hope. She would have been lying if she said she did not feel any guilt about her previous lack of insight toward her patients.

Fortunately for Karen, the Phase I drugs had been a success in curing her Crohn's. It had not been a battle with cancer, but it had been close enough for her to gain a little perspective into what her patients suffer through daily. When she was cleared of her own ailment, she could not help but wonder how her remission day compared to those of her patients who had been fortunate enough to survive. Her only residual effects were a broken foot and puffiness from nine months of steroids, which she found herself pouting about regularly. Meanwhile she had seen children forced to live their remaining time with severe impairments and handicaps. The honest-to-God truth for Karen was that guilt was a side-effect of pediatric oncology.

After making a full recovery, Karen returned to the lab, but soon after, she was contacted by Harvard. As much as she loved St. Jude and all the patients and colleagues, it was not an offer she could turn down. She was thirty-three, never married and without children. Her parents were all she had, so moving back close to home as they entered their "golden years" was the best option; on top of the fact the nation's most prestigious university wanted to employ her. It's been two years since she accepted the offer from Harvard, and she has ascended all the way to Director of Neuro-Oncology Experimental Therapeutics. Karen had finally reached the top, but as she turned her attention away from the okra, back to her cart, she was sure that she never could have made it to this point without all the lessons she learned along the way, especially those from her patients.

Karen has finally come to terms with the fact that a majority of her patients will not survive. She has found peace in embracing each moment, realizing that time is not on everyone's side. She has been inspired hundreds of times by how bravely she has seen

children fight diseases that they statistically have no chance of defeating. She has witnessed countless parents beg for their child's life, and one of the most amazing recurring scenarios Karen observed time and again was when a child so near to death would hang-on against all odds for their loved ones. Then as soon as the family uttered that it was okay to let go, the child would peacefully and instantly surrender, as if they required permission to pass on, forcing themselves to suffer a little longer for those they love. At the end of life's rope, dozens of times, she had seen the roles of protector reverse, with fatally ill children sheltering the parents from the reality of impending death.

Not all of the lessons had been so sad though. Medically speaking, Karen had witnessed many positive progressions. No longer were children treated as if they were "mini-adults" with medications tested preliminarily on full-grown bodies. Now there were treatments and protocols created explicitly for pediatric patients, even tailored specifically for each one in some cases. The advancement of scanners and radiological machines have allowed for greater knowledge in targeting cancers.

Karen has been in this line of work for fifteen years now, and she realizes the sickening truth...most of medicine is a business, and unfortunately pediatric cancer would never be deemed profitable for "big pharma." This means that the best advocates in continuing to move pediatric oncology forward are, rather unfairly, the patients and families themselves. Karen's own work would be completely impossible without tissue and blood donations, private funding efforts, and grant support, spear-headed by those who most understand the need for a cure. From time to time she encounters one of the children she was able to help save, but she will never be able to forget the ones she has

lost, because they are daily reminders of why she does her job every single day and will never quit until cancer is dead.¹¹

¹¹ Information obtained from interview with Karen Wright in April 2018; Story based on interactions with Wright starting in August 2006.

“Brothers do not let each other wander in the dark alone.” ~Jolene Perry

“Because I have a brother, I will always have a friend.” ~Unknown

Carson Higgins



He eased into the parking space, put his car in park, and grabbed his backpack. He made a pit stop for a cup of coffee because he knew he would need it. This was not a day he wanted to be walking to class. He was a junior at Kent State University, majoring in Business Management. His grades were fine, so they were not his concern this morning. There was a far more heavy significance weighing on his heart. Eleven years ago to the day his life changed forever.

Garrett Higgins comes from a large but close-knit family of seven. His parents John and Debbie were high school sweethearts who started forming their brigade in Wildwood, Missouri, just outside of St. Louis, before moving to the town of Bath, Ohio. When expansion finally ceased, the Higgins' couple had five children, all boys; Brendon, Brett, Garrett, Carson, and Derek, with age gaps of three, two, seven, and one, respectively. Despite the thirteen-year span between oldest and youngest, the brothers were all incredibly close, and although each one possessed talents and traits that distinguished them from the pack, there was one Higgins brother who outshone rest.

This brother was the one Garrett ached over as he walked to class on an unusually frigid April morning.

In early 2007, the fourth Higgins child, Carson, who was three at the time, began seeing and talking to angels. John and Debbie led a family of faith so their concerns were limited, thinking maybe Carson had picked up a lesson from church and manifested some imaginary friends in divine form. Over the next two months Carson's angelic conversations morphed into a worsening illness, which all culminated in April, on Friday the 13th nevertheless, when he was diagnosed with Stage IV Neuroblastoma, an aggressive type of pediatric cancer that attacks the central nervous system. The Higgins family was rattled to the core. In the days that followed, Carson said goodbye to his brothers one at a time, as he and his mother traveled to St. Jude Children's Research Hospital in Memphis, Tennessee, where they would live for the next fifteen months.

Garrett had been in the fourth grade at the time and scarcely understood the gravity of the situation. As he looked back now, at 21, he remembers knowing that Carson was sick, but assumed that he would take some medicine for a while and then be good-as-new. He had been completely unaware that cancer covered his little brother's body from head to toe and polluted over 75% of his bone marrow, slating his survival chances at a measly 10%. One thing Garrett did remember well from this trying time, was how faithful the family stayed and how much stronger their bond grew. Garrett knew the pain he and his brothers felt at the time was nothing compared to Carson's struggle, but they longed for him to return home all the same. Then, miraculously, after a year and a half at St. Jude, Carson's body had been cleared of cancer and he was allowed to return home to a normal life. The Higgins "starting five" was back together.

Eight years went by and Carson's health scare had done nothing but strengthen the bonds between brothers, and Carson himself had become Garrett's hero and source of inspiration. Garrett, along with Brendan and Brett, all graduated high school and journeyed off for college. Meanwhile Carson and Derek were living it up in middle school, both on the honor roll. Soon after Garrett had moved away, Carson commandeered his older brother's bedroom, and symbolized the coup by placing his naked body on Garrett's pillow, covered only by a book, and sent a picture of the scene to Garrett as proof. Carson always was the jokester to get the last laugh. The brothers could never one-up him, no matter how hard they tried.

One night during Garrett's freshman year he was watching movies with a few of his friends in their dorm room when his phone rang. It was his dad, John, and something was evidently wrong. Garrett stepped out into the hall to continue the call, and after a few minutes, despite his comrades pleading, he darted off back to his own apartment where he remembers crying himself to sleep for the first, and only, time in his life. Carson's cancer had come back, and it was worse. For eight whole years Carson had been healthy and life had been great, and then just like that, it was all back again. A few days later the brothers were back in Memphis, once again parting ways with one of their own. After a few more days passed the news they all expected, but never wanted to hear, came to fruition. Carson's cancer had become terminal, and more than that, it was untreatable, completely incasing his spinal cord, quickly spreading throughout the body.

Garrett remembers how shattering the news was to him, knowing that his brother was going to die very soon, and he would spend the rest of his earthly life separated from Carson. Almost immediately following one of the hardest days the family had ever

experienced, they sprung into action, attempting to create a plan that would honor Carson and give him one last set of unbelievable memories. He listed all of the places and sights he wanted to see, and despite some fairly lofty hurdles, Carson's "farewell tour" was set. Before the family could leave, Carson required one more surgery that would make him comfortable enough for the journey. This procedure took place on a Saturday morning, and the family pulled out of their driveway, camper in-tow, on Wednesday, for the trip of a lifetime.

Over the next four weeks the Higgins family ventured through some of the country's most prized natural treasures. As news of Carson's trip spread, faster than the Higgins' could drive, there were many people along the way eager to help anyway they could. The sabbatical started in the Badlands, before making stops at Mt. Rushmore, Yellowstone, Grand Teton, and Glacier National Parks, with park rangers showering Carson in gifts and praise the entire way. Eventually the family entered Seattle, where they hopped a Norwegian Cruise-liner to Alaska, one of Carson's most sought-for destinations. Following the Alaskan voyage, the Higgins' turned south to San Francisco, where the family received a state trooper escort in route to a popular lighthouse along the Pacific Coast.

Garrett remembers how much fun the trip was, not just for him, but for Carson. He was not sure his little brother ever stopped smiling for the whole four weeks. The five boys were already close, but their experiences with Carson just kept making their bond stronger, as if they were five pieces of one puzzle. As the trip entered its fourth week the family knew Carson's remaining days were numbered, and it became more obvious with each moment, as his strength began to wane. They had made it to Las Vegas, with the

intention of eventually seeing the Hoover Dam, but on August 11, 2016, at 5:30 in the morning, the entire family awoke abruptly. A terrible gurgling noise that Garrett will never forget filled the camper. Carson was in respiratory distress and fading fast. For ninety minutes, the brothers, their father, and the paramedics performed CPR before arriving at the hospital. As the family joined hands in the ER trauma room, praying for their own strength and Carson's peace, he very briefly regained a pulse.

Garrett can close his eyes and instantly recall the very few moments he and his four brothers graciously received that morning; just long enough to tell the fourth piece of their puzzle farewell, and express their love one final time. Garrett's mother, Debbie, was the last one to say goodbye, and he watched as his mother told her twelve-year-old son "I love you," one more time, and quietly told him it was okay to go. Almost immediately after Debbie had given permission, as if he had been waiting for her decision, Carson was gone. His body was finally at peace. He had been the light and the laughter for the family. He was Garrett's pride and joy, and all of a sudden, just like that, after the best month of memories the family would ever make, Carson had passed into another life.

The band of brother may have lost a member, but Garrett finds comfort two years later knowing that the band will reform on the other side. For the present time, he stays as close as he can with the remaining three, keeping everyone together for Carson's sake. In another year he will graduate and venture into the world of business, and no matter where he ends up, everything Garrett Higgins does is for his brother. On sad days like this one,

as much as it hurts, Garrett focuses on the good times he had with his little brother, and uses Carson's legacy as his inspiration each day.¹²

¹² Information obtained from personal interviews with Garrett Higgins and his mother Debbie Higgins in April 2018

CONCLUSION

Cancer is a terrible disease. That was a widely accepted fact before this thesis. The takeaway from this though is that with every diagnosis of cancer, there is a unique story. In each and every case, there is a patient, a family, friends, and caregivers also afflicted. Comparable to war, in that, there is always a battlefield, which carries with it collateral damage, far-reaching reverberation, and emotional insecurity for more than just those on the frontline.

For pediatric cancer patients fortunate enough to survive, they provide a very unique platform in society that should never be understated, because with each cancer victor, researchers are afforded a successful blue print that can be used to help treat future children. In addition, these survivors gain keen insight from their battles at usually very young ages, and this can make them very positive influences on the population. They are living examples of the realness of both human suffering and resilience. As several of the subject-patients in this work portray, childhood cancer warriors can also become beacon of hope in circles of faith.

Contrary to the survivors are those who pass away, and for every time cancer wins, a family is left behind to grieve, never fully whole again. The reactions of these families are most worthy of marvel and respect. Those who eventually find peace after the loss of a child become valuable in counseling others through stressful circumstances, aiding in community growth. Even those who diverge into more negative realms after the

death of a beloved child have societal benefit. They help in fully depicting just how broadly damaging and toxic cancer can be, reiterating that is a disease that INfects one but AFfects many.

The final key to the war on cancer lies with the professionals who provide patient care. They are valuable in a couple of immensely important roles. First of all, it is widely assumed that the attitudes of doctors and nurses can have a direct effect on the ensuing attitudes from patients when faced with the decision to fight or concede. Without optimistic and involved caregivers, a child's chances at survival could seem even more dismal.

A sick child needs to know that they have a support team that believes in their ability to not only fight but succeed. Secondly, doctors are the key to eradication of the disease as a whole. They have been charged with specific duties to heal and research. The data is constantly being provided to them, albeit in real-world time with real-life children. It is their responsibility to use the data and resources at hand to not only try and heal the presently ill, but discover a future where cancer no longer exists.

Survival rates are steadily climbing, but there are still large numbers of children from various backgrounds diagnosed with cancer each year, proving that cancer can come for anyone. Suffering, despair, and death do not play favorites. Despite the thousands added each year, the pediatric cancer club is still exclusive, and every member has a completely unique story that abounds with substance. These stories absolutely deserve to be told. These stories are glances into the human condition, in its most innocent surrogates, providing the rawest paradigms for courage, resiliency, and love.

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