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Understanding the Hurting: A Look Into the Lives of Families Battling Ewing's Sarcoma

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SENIOR THESIS APPROVAL

This Honors thesis entitled

**“Understanding the Hurting: A Look Into the Lives of
Families Battling Ewing’s Sarcoma”**

written by

Abigail E. Dekle

and submitted in partial fulfillment of
the requirements for completion of
the Carl Goodson Honors Program
meets the criteria for acceptance
and has been approved by the undersigned readers.

Dr. Lori Hensley, thesis director

Dr. Nathan Reyna, second reader

Dr. David Ozmun, third reader

Dr. Barbara Pemberton, Honors Program director

April 16, 2012

This paper is dedicated to all children facing Ewing's sarcoma – you are my heroes.

A special thanks to Will and Renee, Jay and Judy, Brian, Dr. Lori Hensley, Amy Eubanks,

Dr. Nathan Reyna, Dr. Dave Ozmun, and Dr. Barbara Pemberton –

Thank you for investing in my life.

Above all, glory to God. Without Him, I am nothing.

Will's Story

A typical nine-year old who loved playing sports and being with his friends, Will has always found joy through the little things in life. With his positive attitude and winning smile, the slogan “Will to Win” coined by someone at his school became his reputation over the next two years. What was he trying to win? Will was in a battle for his life against a pediatric cancer known as Ewing’s sarcoma. Responsible for the death of over two hundred children and young adults in the United States, doctors discovered this Ewing’s tumor in Will’s right femur in October of 2009, which began his battle with cancer.



Picture 1 - Will with the support banner from his school friends

Will was playing football when he began having throbbing pain in his right leg and thought there might be a problem with his knee. He experienced this pain continually over the next few weeks and would wake up in the middle of the night in excruciating pain. He recalls that it felt like “something was grabbing [his] bone and then it would release and then it’d grab again”. Tylenol and other over-the-counter medication did not relieve his pain. Will woke up at his aunt’s house, his dad’s house, and his grandpa’s house and again while Will was playing football. Finally, it came to the point when Will woke up in the middle of the night crying and could not be consoled. That is when his parents knew something more serious was going on. Will also broke down at school, but everyone thought it was just growing pains. His mom, Renee, thought it was a good idea to call a well-known orthopedic surgeon in the area, Dr. Muller, who specialized in sports medicine. Renee recalled the whole appointment as being a “God-thing” from the timing of the appointment to the expertise and insight of Dr. Muller. Will

felt pain around his knee. Dr. Muller decided to take an x-ray and recommended physical therapy for a week, but Will did not feel any better after that week. Renee happened to mention that he was up at night for a four hour time span – a cue to the doctor that something more serious might be occurring.

Dr. Muller sent him for a bone scan as a precaution – not a typical move for a doctor but one that saved Will’s life. His mom has looked back on that moment and realized how blessed they were to have an insightful physician taking care of Will. The bone scan was on a Thursday. Dr. Muller, Renee, and Will saw the typical bright lights where growth plates were and all other features were symmetrical except on his right femur, where a bright light caught everyone’s attention. The light was so out of place that even young Will identified the tumor. Renee went to her office and called Dr. Muller. His nurse called back and said come in in the morning (Friday) and that she had made an appointment with an orthopedic oncologist for Monday just in case they needed it. No parent ever wants to hear the word “oncologist” or “cancer” when it comes to their child, but Renee remained hopeful and did not worry, trusting God that He knew what was best.



Picture 2 – X-rays similar to what Will would have seen at his doctor’s appointment. The red and blue circles indicate the location of the tumors.

At their Monday appointment, Dr. Muller recommended ordering a CT scan and possibly an MRI because all he could see at that time with the X-ray was either a tumor or a break. He sent Will and Renee to an oncologist. Renee’s

husband (Will’s stepdad) decided to go with them.

Renee remained strong for Will even though she

was emotionally hurting for her sweet son. She recalled a particularly touching moment at a Wendy's restaurant before their appointment with Dr. Gilbert, the oncologist. Renee said, "We were sitting on stools and Will jumped down to help this older lady and opened the door for her," – just one example of Will's sweet spirit and love for others, two of his stronger character traits. Like any mother, Renee did not want her sweet son to go through a battle with cancer. The threesome drove to the oncologist appointment. Dr. Gilbert immediately ordered a biopsy on Will's leg.

The family waited with anticipation in the waiting room of Dr. Gilbert's office. Will's dad had come in from out of town, and the foursome waited patiently for Dr. Gilbert's news. Finally the moment had arrived. Dr. Gilbert told them it was either a tumor or a viral infection he had never seen before. If it was indeed a tumor, Dr. Gilbert explained it would be either Ewing's sarcoma or lymphoma. The doctor immediately put Will on crutches as a precautionary measure. Sometimes bones become quite brittle and can break, which led to the decision to take Will out of school.

Will's dad researched the two cancers and ascertained that of the two cancers, Ewing's sarcoma was the better to have. From the Monday of the biopsy to Friday of that week, Will and his family waited patiently, prayerfully but not fearfully for a phone call from Dr. Gilbert's office. One of Renee's God-moments that got her through this time was God's timing with the phone call from the oncologist. Renee was thankful to have a dear friend and her friend's son over at the time they received the phone call, which kept them distracted until the moment the phone rang. She heard the words from Dr. Gilbert that confirmed the diagnosis – Ewing's sarcoma. For the first time, Renee heard the words, "Your child has cancer." Dr. Gilbert explained that Will needed to have a surgery for his chemotherapy port immediately to start

chemotherapy. There were no treatment options given, and Will was given two oncologists who would be his primary doctors over the course of his treatment – one medical and one orthopedic.

Chemotherapy was the only way to go at this point. The doctor later explained that there is a set treatment routine for anyone diagnosed with Ewing's sarcoma. The treatment routine is fourteen cycles of chemotherapy – once every two weeks. Will was hospitalized for each cycle. If there is a relapse then there is no protocol except to go at it again. In Will's case, no radiation was ever used because there was no metastasis with Will's tumor. (Metastasis always factors into whether or not they do radiation.) The oncologist and orthopedist decided for a surgery to be tentatively scheduled for the middle of his chemo treatments, hoping the tumor would be small enough by that point to be removed surgically. His treatment would finish up with a second set of chemotherapy treatments to insure complete annihilation of the tumor. There are slight modifications to the routine depending on the child's reaction to the treatment. Renee and her husband were given options for hospitals in the area which could administer the chemotherapy. Renee and her husband told Will the news that afternoon, and at that moment, Will was scared for the first time. Renee recalled, "That was the first time we used the "c" word. He had been in the meetings and knew something could've been up. Will cried. He was scared. I don't recall him saying "I don't want to die," but as we talked about it, it eased his mind. Since he's been free of cancer, he never believed he was going to die. I believe that was a God-thing that He gave him a peace that he wouldn't die. We know some kids who have died. He may have been nervous but never expressed it. His sister was very upset. "

Will rallied after he heard the news and remembered how he ironically had just met someone that had cancer – his youth minister, who had just shared his testimony in church. During the youth minister's senior year of high school, he was diagnosed with cancer and had to

quit playing football but then went on to play at Baylor. Renee told Will to remember the youth pastor's testimony. If he hadn't had that experience he may not have gone into preaching. This story gave Will hope. Monday port went in and Tuesday started chemo. Within a week from diagnosis they had started chemo for which Renee praises the Lord.

With the initiation of chemotherapy came the physical changes associated with the treatment, which, again, Will and his family handled with bravery. Renee called the first big change occurring before he was hospitalized for his second round of chemo. That morning Will woke up and hair was all over his pillow. Huge chunks of hair were falling out everywhere. Renee, wanting to keep the mood light, and Will began joking about hair falling into his cereal. At hospital, Renee looked at Will and said, "Let's just shave it off." So, off they went to the barber at the hospital. Another side effect of the chemo for Will was an altered sense of smell.

Smells really bothered him. The plastic lids on the food trays had to be taken out of the room. There were certain foods he would not eat, but the dieticians at the hospital ensured Will was receiving all the essential nutrients a growing boy needs. Many times cancer patients seem to gain weight, but the look of weight gain comes from the steroids they take. Will was on steroids, which did make him swell up a bit. He got mouthsores/throat sores from the chemo, and every time he had the sores, he had to go back to the hospital. Will could not eat at times. His family was on its toes making sure Will did not have a fever, especially if he began feeling ill. If a cancer patient has a fever, then they have to go to the hospital immediately due to their lowered immune system from the chemotherapy. In terms of behavioral changes, Will and his family became more conservative in all their choices. The whole family was very involved in his treatments and was very cautious about who was around and where they were going. As would

he expected, Will did not like going to hospitals very much. Unfortunately, there were very few places where Will could go.

Academically, Will tried his best, keeping up with his studies via his homebound teacher (i.e. homeschooling). Will's immune system was greatly compromised, leaving him susceptible to any pathogens present in the environment. The chemicals in chemotherapy target rapidly dividing cells, meaning the chemicals kill both healthy cells and the cancer cells. Because Will's immune system was destroyed and schools are well-known for spreading germs, attending school was simply not an option. "We were really really careful with him. Keeping him confined and keeping him away," recalled Renee. The homebound teacher was wonderful – an older lady. She had permission to go to the hospital. He did really well on his TAKS tests. His homebound teacher came in every Tuesday and Thursday. There was a lot of community support, which always rallied Will's spirit. His family would go to some games so he was outside a little bit, helping him cope with his inability to participate in sports. Renee recalled, "He had an adjustment going back into school because he hadn't had any tests or projects, and 7th grade is a huge project year at our school. Will was very overwhelmed at first and had a couple breakdowns saying he couldn't do it. But he's been very successful."

The support Will received during this difficult time was simply incredible. For example, before his treatment was completed, Will went to school to see his friends. The first year principal had shirts made that said "Will to Win" and bought them for all the 6th grade class and staff. Everyone wore their shirt when he went to the school. They embraced him. Will is a "very likable child" according to his mom, as evidenced by the love he was shown. Some boys shaved their heads for him. In Will's school system, they merge elementary schools as students move from elementary to junior high, and even though students didn't know him personally, they knew

of him and people bought t-shirts right-and-left. There was not a time when someone did not make him feel special even when Will was not physically present at school.

Will began physical therapy right after his surgery in January 2010. Because the tumor had eaten out a portion of his right femur, Will had a vascularized fibriolograph. The surgeons took his right fibula, placed the fibula in a cadaver bone, hooked up a blood supply, and reconnected the bone in the body. If a cadaver bone is used, the body will reject the bone or eat it away because the cells in the bone do not have the protein markers identifying the cells as "self". Without the protein markers, the body sees the bone as a foreign object and will attack. By using Will's fibula (i.e. his own bone), the body recognized the protein markers in his bone cells and did not attack the bone graph. Now, Will does not have a fibula in his right leg. The femur bone has grown completely back, showing no evidence of the bone graph. However, his right femur is now bigger and longer than his left femur bone because the blood supply to his right leg was increased above normal levels when the bone graph took place.

In March 2010 Will began walking again, which was no easy task, for he had to re-learn how to walk. His foot is still weak and he has a slight limp. His first task was balancing. He had surgery again in October 2010 because when the bones healed, the lack of a fibula affected the bones in his ankle and foot. The surgeons inserted a metal plate, stabilizing his ankle. However, the surgery put him back a few steps. Will was weaker due to the tightening of his bones, which put him back on crutches. In June 2011, Will began running again.

Rence's final comments were, "Cancer is lifelong which means lifelong changes. Will cannot play certain sports again for fear of breaking it (his femur). The doctors don't tell you all that. His surgery was so rare, so I don't know if the doctors know how much therapy he's been through. Will has to be very self-motivated because he has stretches everyday and exercises. No

team to support him. His motivation is that one day it'll be better. [It's] not an easy task. He's been doing the work, so he's probably better than 90% of physical therapy patients. He can become discouraged. Sometimes as a parent, you think did we do the right thing?"

In a conversation with Renee alone, she expressed her experiences that pertained to her role as a mom and a caretaker. During Will's battle with Ewing's sarcoma, the experience caused Renee to re-evaluate her time and priorities. "There were a lot of places I couldn't go emotionally. I was put into contact with someone who had lost someone from cancer, but I had to email him and say, "I just can't go there." Renee kept her job during this time, keeping her schedule as "normal" as possible and helping out with the extra expense of Will's medical bills. She recalled how hard it was to be at work and focus on the task at hand, but her boss was understanding. Since she worked for the school district, the nature of her job gave her some flexibility, which at times allowed her to take Will to his treatments in the morning and then go to work at night. As time went on, Renee's schedule became more routine, and her network of friends kept her emotionally strong during this time. Will's grandmother was also a main caregiver during Will's treatments. His grandmother would come for a few days, take care of Will, take him to the doctor/hospital, clean the house, etc. Along with Will's grandmother, close friends would take turns caring for Will. One particularly sweet friend even coordinated a schedule of when Will needed to be where and would take him to his treatments, etc.

Financially, the total cost for Will's treatments, surgery, and physical therapy added up to approximately one million dollars. Thankfully, Will's dad's insurance helped take care of Will. After a few months, Will qualified for Medicaid. Keeping track of the expenses was a very overwhelming task, but one of Will's aunts helped create spread sheets to keep track of insurance claims. Physical therapy is not covered typically by most insurance companies, and they as a

family still pay the co-pays. Many people are not aware of how draining taking care of the finances can be while trying to cope with the emotional stress and strain of having a loved one in pain.

There were many occasions when Renee and Will spent the night at the hospital. "Those nights were rough, but those experiences are just some of the many experiences along with God's grace that allow me to handle things today that I couldn't have handled three years ago. It's still hard for me to think about because he used to be such a good baseball player, and he can't play anymore. You just do it." The love and support Renee felt from her friends and family gave her strength to survive this season of life.

When asked what Renee's greatest fear was during this time, she replied, "That the cancer would have metastasized. Will still has to go get chest x-rays every three months for the next three years. They always take an x-ray of the lungs, and there was a lot of apprehension before each report [from the doctor]." Other fears during this time included losing Will and the long-term effects of chemotherapy. Renee dealt with her fears by remembering how much God had done in their lives during this time and that only He knows what tomorrow holds. She lived life one day and a time, and that is the message she shared with other families dealing with Ewing's sarcoma. She also emphasized, "Let your friends help you. You can't survive without their help without support."

After the cancer is gone, many families are not told what to expect by their physicians. Renee's post-cancer experience has entailed lots of doctor visits, physical therapy appointments, and sacrifice. Sometimes the doctor's appointments are early in the morning, but Renee's advice was, "It's really whatever you want to make it. If [Will] wanted to quit, he could have made that

decision, and he [would] pay for it. You can dwell on the fact that you have or had cancer and stop your life. Of you can say, 'Hey I'm going to get through this'."

As Renee finished sharing her experience, she shared her greatest moment of joy from the whole experience, which she remarked as being a difficult question since she had many joyous, "God-moments". She mentioned several experiences such as the stickers made for his friends' football helmets (over 700 were made and spread throughout the community) and the "Will Power" t-shirts sold by his middle school's cheerleaders to raise money for CureSearch, a cancer research program. She also mentioned visits Will received from local high school



Picture 3 - Will with some of his sports paraphernalia

football players and gifts from the University of Texas at Austin's football team, the Dallas Stars hockey team, a signed football from Roger Staubach along with several jerseys from Texas sports teams. Seeing Will run on the treadmill at physical therapy was also pure joy for Renee. However, the moment that outweighs all moments was the day Will was declared as having no evidence of disease (i.e. cancer-free).

Brian's Story

A sophomore at Bowling Green University, Brian was a normal college student who loved his friends and family and was involved in athletics, specifically soccer. He began feeling pain in his left groin area after playing baseball one day with friends. He and his girlfriend, Lori, thought it was probably a pulled groin muscle because he had tripped while playing. He probably just had an accident and it was no big deal. This first sign of pain occurred in the spring of 1991.

Brian continued living his life, participating in sports, and thinking his groin muscle never healed and was being pulled repeatedly over the course of months of playing baseball.

When the pain began to worsen and a mass began forming around his lower left pelvic bone. Lori and Brian thought maybe the muscle had balled up and was the reason a mass could be felt and seen in the area. In fact, the muscle had balled up, but it was not because he had pulled a muscle. The Ewing's sarcoma tumor had eaten away at the pelvic bone and consequently had removed the area where his groin muscle attached to the bone. In December, Brian and his dad decided to see a doctor. At this appointment, like Will's story, a doctor in Marion, Ohio, took X-rays to identify what was going on in the area. After identifying a tumor, the doctor told Brian's dad, Jay, it was cancer. At first, the doctors thought he had chondrosarcoma, a non-terminal, non-life-threatening cancer that could be removed by amputating Brian's left leg. Emotionally, Brian, Lori, and his family were relieved and tried to become used to the idea of Brian getting around without one leg.

Brian began practicing standing on one leg as he did everyday tasks. The surgery had been scheduled for the removal of the tumor. However, things took a turn for the worse right before Brian's surgery. He had his pre-operation appointment, and the doctors discovered his cancer was not chondrosarcoma. His lab tests came back showing Ewing's sarcoma. Compared to chondrosarcoma, Ewing's sarcoma was bad news. Instead of having an easily-removed cancer, Ewing's sarcoma was not as easy to fix. Emotionally, his family and friends had to re-



adjust their thinking. The surgery for amputating his leg was replaced with a surgery to insert a Broviac (aka a port) in his upper chest with two direct lines into large veins in his neck region. Jay and Judy,

Picture 4 - Jay and Judy, Brian's parents

Brian's parents, conveyed Brian's dislike for his port because it had to be cleaned constantly and watched for infection. Jay's thoughts at this time were, "It was very traumatic when they inserted the port. They're dumping chemicals in there! It's just overwhelming to think they're dumping chemicals into our boy. Very overwhelming!"

The doctors did not give Brian treatment options. As in Will's case, the oncologists followed a Ewing's protocol of one round of chemotherapy (five to six weeks of chemotherapy) to shrink the tumor followed by surgical excision of the tumor and a second round of chemotherapy and/or radiation. Ewing's sarcoma is an aggressive cancer and had already spread to Brian's lungs by this time. Once the cancer has spread to the lungs, there is a slim chance for survival. Brian went through one round of chemotherapy, being hospitalized for each treatment. Even though Brian was no longer a child (he was 20 years old), since Ewing's sarcoma is a pediatric cancer, he received chemotherapy at the nearby children's hospital in Columbus, Ohio, followed by a month of radiation treatment five days per week. His parents recalled many of the changes that took place in his life during this time period.

Brian's mom, Judy, recalled Brian craving fried bologna sandwiches along with anything from Taco Bell and Mighty Fine soda pop. The last time Brian came home from the hospital he asked Jay and Judy to stop by the carry out and pick up three Mighty Fine sodas. Brian only made it through the first two Mighty Fines. The third Mighty Fine still sits in Jay and Judy's refrigerator eighteen years later. When discussing this story, Judy made the comment, "I guess you could call us sentimental. Who would have a bottle of mighty fine unopened in the fridge for 18 years." Brian's feet were very sensitive during his treatments. Even the feeling of the sheets or anyone touching his feet inflicted great pain. Brian hated the doctors touching his feet to the point he would hide his feet when they came to check on him. As far as smells go, Brian was

utterly repulsed by the smell of hospital cafeteria food and the smell of his own urine, which was probably caused by the chemicals being flushed out of his system. Judy recalled those moments when they were returning to the hospital for another round of treatment. "He became so sick of that. It became hard for him to even go. We just said "You HAVE to go. You've gotta find some way to get yourself in there." They controlled the nausea pretty well. But he kept some stuff to himself because he didn't want us to worry. But we wanted him to be comfortable."

Brian was always a patient man who stayed strong and did not complain even at the hardest of moments. Brian always wanted to know the truth of the situation. There was no "sugar coating" the situation for him. Once when the doctor told them to wait before leaving the recovery room from his outpatient surgery, Judy told him everything was probably okay, and Brian responded with, "Mom, don't say that. I want the truth and nothing but the truth." Brian had the right perspective on his life. He knew that his time was precious and valued each moment with his friends and family, never wasting one moment arguing. Judy recalled a sweet story that exemplified his perspective during this time. "I remember once when Jay had been gone for a couple days, and Brian and I were really looking forward to him coming home. Jay was stressed and fussing at me for something, and Brian said, 'Dad, quit pickin' on mom. We've both been sitting here looking forward to you coming home. You're home now, so forget about everything else that's going on'."

Jay kept his job and was not able to be with Judy and Brian during Brian's treatments. When asked how Jay coped with this time, he replied, "The people that have a loved one who is really really ill, people kind of shy away from you like they don't know what to say. People really don't want to hear about it. You're kind of in a cocoon. You go about your daily activities and people may say, 'Hi. Good luck, Jay.' Most people don't want to hear a long drawn out

story. Maybe I was better off not having to face people about it. The whole summary of this was that it was overwhelming and consuming. It's all we thought about from when we woke up in the morning until we went to bed at night. Of course, Brian was consumed with it because he had it." Jay's job and health insurance helped the family during not just this emotionally difficult time but also a financially difficult time.

As in Will's story, the final bill for Brian's surgeries and treatments totaled in the hundreds of thousands of dollars in the early 1990's. Today, his bill would probably be close to one million dollars. Brian's qualification for Medicaid during his last few months assisted the family to an extent, supplementing their primary health insurance. Sadly, to qualify for Medicaid, Brian's primary care doctor had to write a letter to Medicaid explaining Brian's situation. "They basically said, 'This kid has no chance of getting through this'. In every situation, we were fortunate to meet the right people to help us so that Brian could get his last wishes," said Judy. Jay remembered just one bag of chemotherapy used during treatment cost \$6,100 dollars. Jay and Judy have had to pay off that financial debt for years, but asking them if it was worth paying all that money is not even worth voicing. Their answer would undoubtedly be yes. "Financially it was a hit. It was hard. You use up all your sick days, any days that are allotted to you," Jay said. Judy added, "People would come up to us because we lived in a close community where everyone knew us and would say they were sorry. We drew closer together because of this. Finances are not a big deal when you're faced with the fact that you'll lose part of your family."

After his first round of chemotherapy, Brian had his first surgery. The surgeons removed the tumor and part of his upper leg, resulting in his left leg being an inch shorter than his right leg. Brian had to use a cane to get around. Unfortunately the bone in his leg was rather sharp,

which meant he had to have yet another surgery in which his bone was shaved down. Brian was patient during this time, and according to Jay, Brian took the whole situation better than anyone else in his family. Brian did develop an infection in his left femur after the surgery.

At this point, Brian began his second round of chemotherapy, but the doctors knew he did not have a good chance of survival because the cancer had metastasized to his lungs, stomach, and other parts of his body. Judy recalled, "The nurse was blown away by how calm we were when she told us he didn't have much time left. We did it for Brian – not for us. I wanted to lie down and cover my head." By this point, Brian had been out of school for thirteen months. The last time Brian came home from the hospital was November 12, 1992. Judy reminisced about the car ride home from the hospital, "I don't think he gave up, but I think he was just tired. I think he just knew that it was past the point of even a transplant...or whatever. He knew it wasn't going to help him to go through any of that. You could feel the tumors in the back of his neck. Tumors in his stomach too. We were driving back from Marion [Ohio], and we were holding hands and both of us were crying. And we both just knew."

Knowing Brian would not be with them for much longer, his close friends and family members stayed by his side 24/7. He was on morphine constantly and in a coma, but still, he was never without someone by his side. At 6:56 am the morning of November 28, 1992, Brian passed away with his friend, Michelle, by his side. Michelle woke up Jay and Judy, told them he was gone, and everyone gathered in Brian's room to say their good-byes. "That was a blessing. Having your son with you and being able to say 'I love you, Brian' is more than any money there is," was Jay's comment from remembering this moment.

Brian had a large funeral, confirming his reputation as a likable, friendly guy. Knowing that Brian was no longer in any pain and believing he was in Heaven comforted Jay, Judy, and

Brian's sister, Lorrie, during this time of grieving. When asked about her grieving process, Judy responded, "It's different for every person how you grieve. You do it your way. Because you won't go through it once. You go through it over and over again. You try to go to the grief meetings afterwards, but I just couldn't. It was too personal. Jay and I have always been able to work through it. Like he vents, I vent, and then we talk about it. A few months later I told Jay, 'I don't think I can go on with these feelings.' 'What are you thinking?' Jay said, 'Well, if you can't go on, what am I gonna do?' And then I just realized how selfish my feelings were. Like just because Brian wasn't here, life didn't have meaning anymore, and that just wasn't true."

The state of one family member always affects the lives of the other members of that family. Many times people forget how cancer can affect the siblings of the one going through the cancer. Jay and Judy also described how Brian's battle with Ewing's sarcoma affected his older sister, Lorrie. Lorrie and Brian had a year together at Bowling Green University, which in retrospect was a huge blessing for both of them. When Lorrie found out about Brian's diagnoses, she put aside her emotions and decided as a psychologist to use what medical contacts she had to help Brian in any way possible. Lorrie felt guilty at times because she could not be in Columbus with Brian. She was one hundred miles away in Toledo, but Lorrie did what she could, coming home when she could to help out with Brian's week-long treatments. Jay stated, "I think Brian's illness made her stronger. She takes care of Judy and I; she's top-notch with keeping an eye on us. I think it has to do with her seeing Brian suffering through his illness." Judy closed by saying, "She won't always bring her emotions to the table, but she cares about our emotions. She's still tender about it."

The two stories of Brian and Will have many overlapping occurrences such as both young men being athletic and starting off with the same painful symptoms in their legs. Both of

their stories offer a glimpse of what actually goes on in the everyday life of a family dealing with Ewing's sarcoma. Though the majority of the world's citizens do not know what it is like to deal with a devastating disease, it is important that each person become aware of those individuals who are hurting around them. The closest anyone can come to understanding how cancer impacts a family besides going through the experience is through awareness. By listening, reading, and/or seeing the stories of children battling Ewing's sarcoma, empathy and compassion can be created in people's hearts and hopefully motivate them to support cancer research and reach out in whatever way they can.

Supporting cancer research is one way people who hear these stories can reach out to help those hurting families. The leading cancer research at this time is focused on developing tests that can detect cancer in its earliest stages and more specific drugs that can target the cancer cells without the harmful side effects seen in chemotherapy and radiation.

Chemotherapy is always the first option for oncologists to turn to because while it is not a perfect treatment, chemotherapy has had the most significant positive results and shrinks the tumor. Sometimes the goal of chemotherapy is completely destroying the tumor while at other times the goal is simply shrinking the tumor enough so it can be surgically removed. Systemic chemotherapy utilizes the port system mentioned earlier or pills taken orally. Regional chemotherapy places the chemicals directly into the cerebrospinal fluid, an organ, or a body cavity (e.g. the abdomen). The chemicals used in chemotherapy target rapidly dividing cells throughout the body and cannot differentiate between the healthy cells and the cancerous cells. This fact is what leads to hair loss, which is not limited to hair on one's head, and a suppressed immune system. Often chemotherapy patients will also receive steroids as part of their treatment. The steroids cause the bloating commonly seen in cancer patients. Dumping these chemicals into

a patient's body has strong repercussions, which is why scientists are testing drugs such as ajulemic acid. Researchers are searching for a more potent anti-cancer drug that eliminates the side effects of chemicals currently used in chemotherapy.

Radiation is also a viable treatment option but focuses on just one area of the body unlike chemotherapy. Radiation involves concentrating high energy x-rays onto the tumor's location. It can be administered externally via a machine, or radiation can be given internally via seeds, needles, catheters, or even wires. Again, while more concentrated to one area of the body, radiation cannot differentiate between healthy cells and cancer cells. Unfortunately both types of cells are mutated and destroyed in this process, leading to a weakened immune system and feeling flu-like during treatment. Radiation also has long-term effects. Researchers are also experimenting with stem cells for post-chemotherapy treatment to replace the healthy cells damaged by the process.¹

The greatest consequence to chemotherapy and radiation treatment options is the damage inflicted upon healthy cells also known as late effects. Late effects are post-treatment issues that arise months to years after the treatment has concluded and includes second cancers such as acute myeloid leukemia and other sarcomas, heart and lung damage, and problems with growth and development. Acute myeloid leukemia (AML) is common because it is caused by alkylating agents in the chemicals used in chemotherapy. Alkylating agents are good anti-cancer drugs because they attach to the cell's DNA and destroy its ability to perform mitosis (i.e. cell division). Not all late effects are physical. There can be psychological and mental disturbances such as moodiness, memory loss, troubled feelings, actions, and social disorders.² No one wants

¹ <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0032657/>

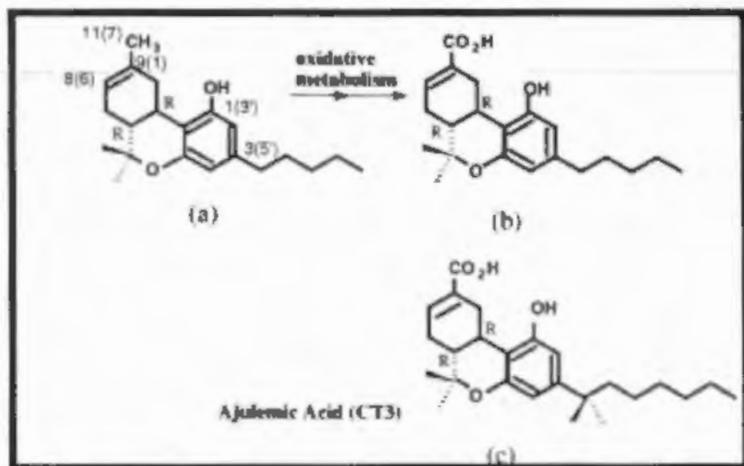
² <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0032657/>

to deal with the sickness and late effects that come as a result of chemotherapy, which motivates researchers to find a treatment option that does not have negative results on the body with all the

anti-cancer properties of other known effective drugs.

One of the premier anti-

cancer drugs being tested in laboratories today is ajulemic acid. Ajulemic acid is a synthetic derivative of tetrahydrocannabinol (THC), the active ingredient in marijuana plants. Ajulemic acid has been shown to possess anti-tumor effects without the psychotropic high associated with smoking marijuana. Dr. Lori Hensley, associate professor of biology at Ouachita Baptist University, has been studying the effects of ajulemic acid on pediatric tumors for the last few years. In the spring of 2011, I had the privilege of joining her team in exploring ajulemic acid's effects on Ewing's sarcoma. My specific task in her research has been treating Ewing's cells from the RD-ES cell line with ajulemic acid and determining the LD-50 for these cells. Cancer research can be quite tedious because each type of cancer has multiple cell lines. These cell lines come from different people, and each person gets their own cell line. Since there are millions of people in the world, it is impossible to treat every single cell line for a specific cancer. Therefore, the main task in cancer research is to find a drug that can bring about consistent results and allow us to tailor the dosage of that drug to fit the needs of various patients with that type of cancer. After treating my RD-ES cells for 12 weeks with different increments of ajulemic acid, we



Picture 5 – a) Tetrahydrocannabinol (THC) is oxidized by the body into b) THC-11-oic-acid. c) Ajulemic acid is the synthetic derivative. The pentyl side chain on THC-11-oic-acid has been replaced by a dimethylheptyl side chain.

discovered two important details: 1) the RD-ES cells grew in suspension and in adhesion; 2) our LD-50 was 53.7 μ M AJA.



Figure 3: MTS Assay in triplicate with of increments (from top L to R) untreated, 25 μ M, 50 μ M, 75 μ M, 100 μ M AJA

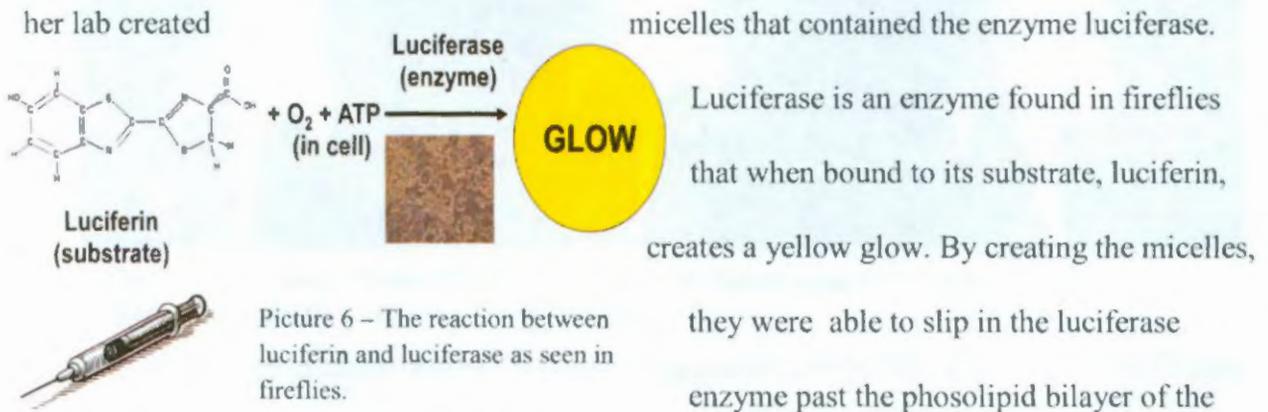
The first part of our discovery means that the cancer cells grow on surfaces and also grow when they are not on a surface. Knowing this fact gave us more insight into the nature of the RD-ES cells and also changed the way we analyzed how effective our doses of AJA were on destroying our cells. After plating our cells and treating them in triplicate with various increments of our drug, we used a special assay that gave us both qualitative and quantitative feedback on the

number of viable cells per increment of drug. The test we used to analyze our cells is called an MTT assay. An MTT assay uses an MTT chemical that is cleaved by actively respiring mitochondria in viable cells. When the MTT chemical is cleaved and DMSO (another chemical) is added to the cells, a purple precipitant is produced. The MTT assay measures the cell viability only of cell's growing in adhesion – not in suspension. The plate then is read by a plate reader, and we are able to measure how many cells are alive in that sample.

Knowing how many cells were alive in our samples led us to the second part of our discovery – calculating the LD-50. The LD-50 is the dosage at which 50% of our cells are not viable. Researchers seek to know the LD-50 for the following reasons: 1) Doctors do not want to give a patient more drug than is necessary; 2) the drugs being used are expensive; and 3) the LD-50 is the most common form of written notation in pharmaceutical literature to denote the dosage of a drug. For each set of data we received after reading our plate for that week, we created a bar graph comparing percent cell viability to micromolars of AJA. After three weeks of treating with

specific increments of AJA, we were able to mathematically calculate the approximate LD-50 for that set of data. Our next step was to treat our cells with a more narrow range of AJA closer in value to that of our calculated LD-50. After three more weeks of treating cells with these new increments, we again compiled the graphs and analyzed the data mathematically. Our first attempt at figuring out the LD-50 actually revealed the need to use the MTS assay instead of an MTT assay. The MTS assay analyzes cells growing in adhesion and in suspension, giving us a more accurate measurement of cell viability. The MTS assay produces the purple precipitant seen in the MTT assay and uses the solubilized form of the MTT chemical. Our second attempt at the LD-50 was correct at 53.7 μM AJA.

The findings in the initial *in vitro* studies led Dr. Hensley and her assistant, Amy Eubanks, to test their results on mice at the animal lab at the University of Arkansas for Medical Sciences in Little Rock, Arkansas. A set of mice were used for the *in vivo* study. The Ewing's sarcoma tumors were grown in the tibia of the mice. In order to track the size of the tumors, researchers in her lab created

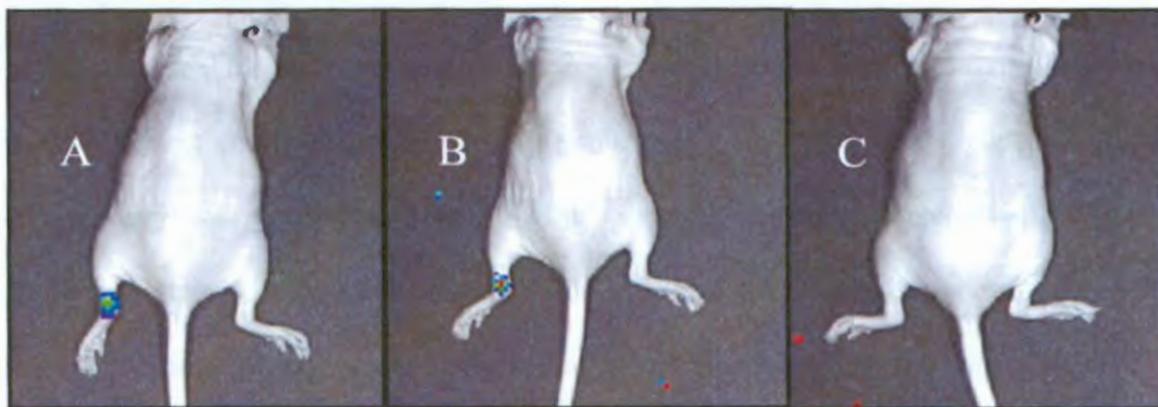


Picture 6 – The reaction between luciferin and luciferase as seen in fireflies.

Ewing's sarcoma cells. Then, when the researchers wanted to visualize the growth of the tumors, they injected luciferin into the mice's abdomen, simulating an intravenous injection. (The abdomen has a rich capillary network and therefore rapidly disperses the luciferin to the blood

stream and to the tumor site.) Once the luciferin and luciferase bind and create the glow, an imaging system was used to measure the intensity with which the tumors glowed.

The tumor was allowed to grow for ten days prior to the first treatment. AJA was given intraperitoneally twice/week at 0.0255mg/g body weight. This dosage was chosen for use because the 0.0255 mg/g dosage had been used in similar mice studies using ajulemic acid. They found this dosage as a starting point for their *in vivo* research. Mice were fed a steady, normal diet of food and water. After ten days, researchers injected the mice with luciferin to verify tumor growth. After only two treatments of AJA, the tumor had shrunk, and after four treatments of AJA, the tumor was no longer visible. Researchers continued treating the mice for two more weeks and then allowed the mice to live for six more weeks. The tumor never came back, and the mouse suffered no side effects from the treatment – the greatest discovery in our research.



Picture 7 – A) Tumor image after 10 days of growth B) Tumor image after two treatments (2 treatments/week) C) Tumor image after 4 treatments

With such positive results coming from research laboratories across the United States, the hope of all researchers is for this data to become published in literary journals and capture the attention of pharmaceutical companies and research hospitals that implement treatments still in the experimental stage. Knowing the background of Ewing’s sarcoma and the various techniques used to diagnose this cancer can shed light on the advances and limitations in the realm of diagnosing Ewing’s sarcoma.

Dr. James Ewing, an American pathologist, discovered the pediatric tumor that came to be known as Ewing's sarcoma in 1921.³ Among his list of accomplishments, Dr. Ewing was the first pathology professor at Cornell University and helped to found The American Cancer Society, and was a leading advocate for the utilization of radiation therapy in cancer treatment. Sadly, he succumbed to bladder cancer in 1943.⁴

There is a whole family of Ewing's tumors and among them are the typical hard bone Ewing's sarcoma that accounts for approximately 85% of Ewing's tumors, followed by extraosseous Ewing's tumors at 8% of EFT's, PNETs (primitive neuroectodermal tumors), and Askin's tumors (which affect the marrow cavities found in the chest wall).⁵ All of these tumors possess similar protein expression that is rarely found in other types of cancer and originate from the same type of stem cell.^{6,7}

This particular cancer has been known to primarily affect post-puberty Caucasian boys.⁸ The signs of Ewing's sarcoma can be as subtle as a slight fever, a little pain or tenderness at the tumor site, weight loss, or general illness.⁹ Ewing's sarcomas are usually detected after the affected bone fractures or the localized pain becomes unbearable. Normal diagnostic procedures can include a variety of tests, including the following options: X-ray, biopsy, bone scan, CT

³ <http://www.knowcancer.com/oncology/ewing's-sarcoma/>

⁴ [http://en.wikipedia.org/wiki/James_Ewing_\(pathologist\)](http://en.wikipedia.org/wiki/James_Ewing_(pathologist))

⁵ <http://www.mdanderson.org/patient-and-cancer-information/cancer-information/cancer-types/childhood-ewings-sarcoma/index.html>

⁶ <http://www.canceractive.com/cancer-active-page-link.aspx?n=585>

⁷ <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0032657/>

⁸ <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002279/>

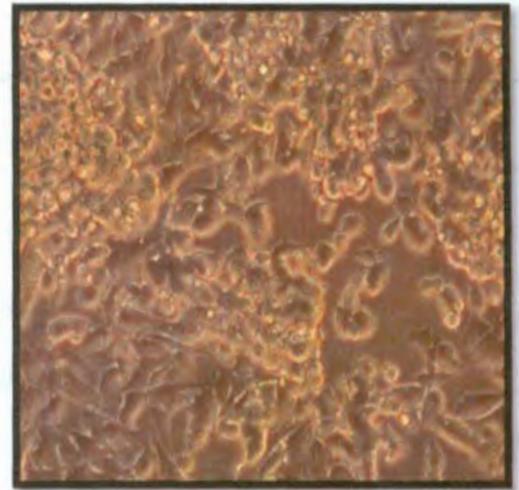
⁹ <http://www.childrensmn.org/web/cancer/199938.asp?gclid=CNi3wPfdqK4CFYuc7Qodr2ItSg>

scan, MRI, spinal tap (i.e. lumbar puncture), blood tests (e.g. CBC), and bone marrow aspiration and biopsy.

An X-ray is used to confirm the tumor's size. A computerized tomography scan (CT scan) will check for any tumor metastasis. A bone scan is used specifically for detecting metastasis to other bone¹⁰, and a complete blood count (CBC) is generally used for any patient presenting any type of symptom¹¹. CBCs are useful because they provide white blood cell, red blood cell, platelet, and hemoglobin levels.

Test results will place a tumor into one of two categories – “localized” or “metastatic” – meaning “the tumor is fixed in one area of the body” or “the tumor is spreading”.¹² If metastasis has occurred, the most typical locations for the cancer to establish another tumor are in the lungs or other bones. According to the NIH, approximately one-third of kids with Ewing's sarcoma will exhibit a metastatic tumor.¹³ There are three ways by which a tumor can metastasize – the circulatory system, tissue, and the lymphatic system. Multiple tests are used for confirmation of the tumor's existence before beginning any type of treatment plan.

Researchers cannot say with one hundred percent certainty what exactly causes these deadly tumors to develop, but it does not mean they are giving up finding ways to better understand their enemy (i.e. the cancer). Along with mapping the human genome, recent improvements in the understanding of genetics and the technology that goes with that knowledge



Picture 8 – Laboratory snapshot of Ewing's sarcoma cells demonstrating the lack of cell-to-cell communication that results in the formation of a tumor.

¹⁰ <http://www.childrensmn.org/web/cancer/199938.asp?gclid=CNi3wPfdqK4CFYuc7Qodr2ltSg>

¹¹ <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0032657/>

¹² <http://www.childrensmn.org/web/cancer/199938.asp?gclid=CNi3wPfdqK4CFYuc7Qodr2ltSg>

¹³ <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0032657/>

have led scientists down numerous untouched pathways in science including indentifying mutations in human DNA. The mystery of Ewing's sarcoma's pathology is beginning to unravel. A translocation has been found between chromosomes eleven and twenty-two. A translocation occurs when a piece of DNA from one chromosome changes places with a piece of DNA from a completely different chromosome, causing replication, transcription, and translation errors, which can lead to cancer. This translocation of genetic material brings about interactions that activate the Ewing's sarcoma gene.¹⁴

While there are still many questions about Ewing's sarcoma, the research being conducted is paving the way for more effective cancer treatment. This second most common malignant bone tumor in children and adolescents (second to osteosarcoma)¹⁵ has claimed many children's lives, but with the latest research using ajulemic acid, hopefully, the number of children who win against Ewing's sarcoma will greatly surpass the number of children who lose.

The real-life difficulties of dealing with Ewing's sarcoma can be seen in the lives of children and young adults every day somewhere around the United States and around the world. The difficulties these families face goes much deeper than the physical effects of chemotherapy and radiation, which is what most people think of when they hear the word *cancer*. Understanding what these families go through by increasing Ewing's sarcoma awareness through sharing their stories is how other people will develop compassion and empathy for those around them. Hopefully, this compassion will awaken the desire to do something about the cause of this

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http://medicalcenter.osu.edu/patientcare/healthcare_services/bone_disorders/bone_cancers/ewings_sarcoma/Pages/index.aspx

¹⁵ <http://test2.aaos.org/oko/description.cfm?topic=ONC008>

suffering by promoting Ewing's sarcoma awareness and financially supporting Ewing's sarcoma research.