

Getting To Know Alyssa...



***So we do not lose heart. Though our outer self is wasting away,
our inner self is being renewed day by day. For this light momentary
affliction is preparing for us an eternal weight of glory
beyond all comparison.***

~ 2 Corinthians 4:16-17 ~

Alyssa Jane Sandmeier was born on April 17th, 2001, in Charlottesville, Virginia, to her parents Joe and Jill. She was a perfect baby: quiet, content, and adorably cute. From a very early age people were drawn to her because of her personality and presence. People always called her an "old soul." One example of this occurred when she was just nine weeks old. Joe and Jill decided Alyssa was ready to sleep through the night, so they conducted a brief family meeting wherein Alyssa was informed she was expected to sleep through the night. Upon waking the next morning, Joe and Jill found Alyssa peacefully sleeping in her crib - she hadn't woken all night - and the event repeated each night thereafter.

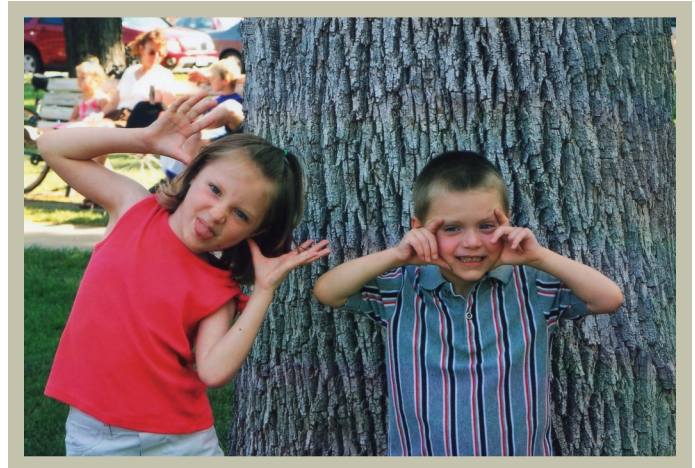
Just before Alyssa turned two, she helped Joe and Jill welcome her brother, Jacob, to the family. Immediately, she became a little mother to Jake and a huge help to Jill. Jacob and Alyssa were two puzzle pieces that fit together perfectly; they were best friends instantly, and as Jacob grew, Alyssa became his confidante, counselor, and constant companion.



When Alyssa was 3 and a half years old, she initiated a conversation with her daddy in which she confessed herself a sinner in need of a Savior and asked Jesus Christ to be Lord of her life. She was always passionate about spreading the Gospel and serving God. One of Alyssa's cutest playtime activities was playing "pastor." She would stand on a box and hold a Bible (or any book she could find) and preach the Gospel to her brother, parents, grandparents, or just stuffed animals.

Alyssa turned four in Nebraska, after her family had moved back in order to be close to relatives. In June that year, Joe became a student in the Clinical Laboratory Science program at the University of Nebraska Medical Center. Also in June that year, Alyssa began to have some minor health issues - tiring easily, experiencing fever and vomiting, and reduced appetite. Twice diagnosed with stomach flu, Alyssa returned for a third visit to her doctor, this time with her parents requesting lab work. The results of a simple CBC were life-changing. On June 30, 2005, Alyssa and her parents were sent straight to a pediatric hematology oncologist (children's blood cancer doctor) at the University of Nebraska Medical Center, whereupon they were informed that Alyssa had Acute Lymphocytic Leukemia.

During this first battle with leukemia, Alyssa was a champ! She took her meds (sometimes 25 per day) all in pill form so she didn't have to taste them, she kept attending school when she was feeling well enough, and she put up with frequent blood draws - so long as Daddy performed them - so the medical team could know if her chemotherapy was working. During this time, she also endured almost-weekly spinal taps and bone marrow biopsies, never once complaining. Joe and Jill often remarked how glad they were Alyssa was diagnosed at such a young age - she just thought people turned four years old and went to live at the hospital. She had no idea how different her life was from others. One fun way her life was different from others was when the family was sent to Disney World for Alyssa's Make-A-Wish trip. Her wish? To meet the "real" Cinderella. Mission accomplished!



One evening during this first course of treatment Alyssa joined her parents in the living room after having been tucked into bed an hour earlier. She informed them she was having trouble falling asleep, and when questioned about the cause, she told her parents, "I think God wants to talk to me." Her parents told her to get back to her room and talk to God! The next morning, when asked what God had told her, Alyssa matter-of-factly stated, "He wanted to tell me that I will meet Him at a young age." While her parents were stunned, she remained unfazed and went about her day. Days went on, and months went on, and many visits to the doctor were made, and never again was this conversation mentioned.



Alyssa's family encouraged her to live as normally as possible. She did well in school and participated in tae kwon do. Alyssa took out her "cancer aggression" in tae kwon do; she advanced rapidly and placed in the top three in every competition she entered. In September 2007, she began to experience back pain which progressed to the point that she had to discontinue tae kwon do. Her parents were told the pain was due to some inflammation in the area where the needles were inserted for her multiple spinal taps. When the pain became so great that Alyssa couldn't stand upright, her mother took her to the emergency room for better answers. As God would have it, Dad was working in the lab that evening and was the first person to see the cancer cells in her blood sample. Two years and three months after the initial diagnosis, with only eleven days of chemotherapy remaining, Alyssa had relapsed and her leukemia was back.

Mom and Alyssa "moved" back to Omaha, with Dad and Jake visiting as often as they could. Genetic testing proved that Mom was a match for the bone marrow transplant Alyssa



was to receive upon gaining remission. The leukemia was tougher on the whole family this time around, both physically and emotionally. After four months of high-dose chemotherapy, Alyssa was finally in remission and ready to move right into a difficult preparative therapy for the bone marrow transplant. This would consist of even higher-dose chemotherapy and total body irradiation. Alyssa chose to decorate her hospital room with a Hawaiian theme so she could pretend she was on vacation during the long recovery period - something she replicated during many trips to Omaha when she would throw her favorite blanket over her head and declare herself "on vacation," daydreaming about being anywhere other than traveling to the hospital once again. On February 7, 2008, Alyssa received a second chance at life as she was given a new bone marrow system from her mother - one that would start making good blood and grow for her a new, healthy immune system.

The transplant process went remarkably well, and by summer, Alyssa was back doing what she liked doing - riding a scooter, taking walks with her family, and playing with her cousins. She remained on several medications to keep her donor cells (the "graft") from being too powerful for her little body (the "host"), but looked forward to going to school again in the fall. Alyssa's family was in awe of the miracle of medicine, and they praised God for allowing her healing and her continued improvement. Alyssa then enjoyed second grade and looked forward to a "victory" trip back to Disney World with her family and grandparents. In May of 2009, just after Alyssa's eighth birthday, the group did return to the place where dreams really do come true. Of course the trip would not have been complete without the ambulance ride from Disney World to an Orlando ER. Poor Lissy, she just couldn't catch a brake. This trip to the ER would end in some more unpleasant news.

Upon returning from their family vacation, Alyssa's parents began noticing that she was having some issues with range of motion in her elbow and shoulder joints. When this concern was raised with the medical team, Alyssa and her family were informed that she was showing signs of chronic graft versus host disease (the new immune system was rejecting/attacking the cells of her body). In an attempt to stave off the progression of this disease, many therapeutic efforts were made. Alyssa endured months of extra-corporeal photopheresis (ECP) which required two days per week in Omaha hooked up to a monstrous "blood-cleaning" machine, stationary joint splints, dynamic (or stretching) joint splints, and physical/occupational therapy for up to 6 hours per week. As the disease progressed, Alyssa lost the ability to ride a bike, climb the stairs, hold a pencil, and hold a drinking glass. She experienced debilitating cramps in her bones and joints, making high-dose pain medication a staple in her twice-daily medication regimen. Quite often she was unable to fall asleep at night because of the intense pain and cramping. She spent many nights curled up in her parents' laps as they tried in vain to relieve her pain. Most nights she found very little rest even with prescription pain meds and a myriad of anti-cramp remedies. Other complications from her disease and its treatment included brittle bones which fractured frequently, growth cessation, appetite suppression, and fatigue.



One thing the diseases and medications never took away from Alyssa was her love for Jesus, family, animals, and life. Alyssa learned to adapt to different ways of doing things so she could continue to do the things she loved - writing, drawing, sewing, photography, and reading. At times she just accepted the pain and misery because she would rather deal with that than give up the things she loved. On August 31, 2009, in the midst of these new struggles, Alyssa made a conscious decision to publicly proclaim herself a follower of Jesus Christ as she obeyed His command to be baptized. What a joy it was for Alyssa's father to be the one to baptize his precious little girl.



Alyssa also loved her routines, especially at bedtime. She *had* to be tucked in with her five to seven different blankets all in a particular order. Prayers would be said and kisses would be given and received. Daddy would then bless with Numbers 6:24-26, and more kisses would follow. Numerous verbal expressions of love were always exchanged and more hugs and kisses were requested and given. Then, just before bedroom lights went out, "Dad, did you bless me?" "Yes honey, now go to sleep." As the last light was turned off in the basement, unfailingly, Alyssa would proclaim with a loud voice, "LOVE YOU," one last time before her parents would ascend the stairs. "We love you too, Lissy." People always knew where they stood with Alyssa.



During the course of the summer of 2011, Alyssa began suffering headaches from time to time. As the headaches increased in severity and frequency, her family made an appointment with an ophthalmologist to see if her vision needed correction. On August 9, 2011, Alyssa had an acute-onset headache accompanied by right-sided facial palsy. At the emergency room, a mass was found in Alyssa's sinus cavity, located behind her nose and under her brain, so it was off to Omaha for further investigation. The next day she underwent emergency surgery to remove as much of the mass as possible so it could be studied further. Two days later, on August 12, the diagnosis was delivered, and it couldn't have been

worse. Alyssa's leukemia was back for a third round; this time in a very rare form. She had what is called an extra-medullary relapse, meaning the leukemia (which was genetically identical to her other leukemias) had come back as a solid tumor located *outside* of her bone marrow and also in her cerebral spinal fluid. Subsequent scans showed there were many additional tumors throughout her little 45-pound body. Alyssa showed her maturity once more when she informed her parents that she would be the one to call Grandma, tell her teacher, and inform her friends.



Over the next two weeks, Alyssa and her family remained in Omaha while she received more powerful chemotherapy than she had ever received previously. As Alyssa's cancer now presented unlike anything her medical team had seen before, they conferred with other medical professionals around the country to develop a plan of action. On August 26th, Alyssa was discharged so she could spend some

time at home before returning to UNMC for more chemotherapy. She had cousins visit her, she was able to attend a school picnic (though by now Alyssa was only able to get around in a wheelchair), and, by God's sweet grace, the family was allowed time to get professional family photos taken.

On Tuesday, August 30th, Alyssa began having abdominal that was not being controlled with her home pain meds, so the family went to the emergency room for intravenous pain medication. While there, the physician discovered the source of Alyssa's mounting pain, she had suffered a perforated bowel. She was immediately life-flighted to Omaha for further evaluation and treatment. After Alyssa's medical team reviewed all of the findings, and just as Alyssa's father was arriving in the PICU at Children's, the fateful news was being delivered. They informed her family that no further treatment was available to make Alyssa better. Her stomach lining and intestinal wall had been devoured by disease and the ensuing infection would soon be overwhelming. Often surgery is an option for this condition, but not for Alyssa. She lacked the physical strength to endure it, and her intestinal lining was much too friable to be accepting of the patch material required to hold everything together. Alyssa would be going home.



When she was informed that surgery couldn't fix her and that she would soon be with Jesus, her first response was a very human one - "But I don't want to die, I'll never become an architect." Her second response was a spiritual one - "Daddy, I want to repent." What a joy it is to know Alyssa truly understood her need for forgiveness in Christ. She then asked her daddy to pray for God's will to be

done, and not her own. She also wanted to read about the new Heavens and the new Earth written about in Revelation 21, no doubt anticipating that day when her family would once again be reunited under the headship of Jesus Christ. Alyssa also asked to be the one to tell her little brother that she was on her way to live with Jesus.

After being transferred to UNMC where the majority of Alyssa's care had been for the past 6 years, that Wednesday was spent in Omaha making plans to go home and keeping Alyssa pain-free and peaceful. Nearly every grandparent, aunt, uncle, cousin, and special friend came to the bedside to say, "See you later," and with every visitor, at the count of 3, Alyssa would put a smile on her face for one last photo.

The next day, paperwork was finished allowing Alyssa's family to take her home so she could pass in the comfort of familiar surroundings. As they pulled into their neighborhood, Alyssa stirred from her medically-induced sleep and said with great contentment and as much joy as she could muster, "Home." Hospice workers met the family at their home and set them up with the agreed-upon comfort measures. And that evening, at 10:05 pm, on Thursday, September 1, 2011, with her parents at her side, Alyssa took her last labored breath, opened her eyes, and smiled at her Savior, finally healed from her six-year struggle with leukemia, and at home with her Lord.

Throughout her too-short life, Alyssa never once cursed God or asked, "Why me?" One evening over the Summer of 2011, Alyssa shared with her parents that though she knew in her head Jesus always loves her and wants the best for her, she was having trouble *feeling* that love in her heart. Her parents appreciated the opportunity the Lord provided for them to speak with Alyssa about trusting what we *know* to be true, what the Bible tells us is true, and realizing that our feelings are not always based in that truth. With her whole heart Alyssa unashamedly accepted the whole truth of the Bible and knew with unshakeable certainty (Hebrews 6:19) that her hope was in Heaven, and that her faith would undoubtedly become sight, all because of her Savior, who loves her very much. Alyssa's was a short life lived well; a life lived well for Jesus.



*This hope we have as an anchor of the soul, a hope both sure and steadfast and one which enters within the veil.
~ Hebrews 6:19 ~*

To learn more about The Alyssa Sandmeier Foundation and to read about Alyssa's hope in Jesus please visit us on the web at:

www.AlyssaSandmeierFoundation.com

