Simple Acts of Kindness

A pivotal point in my life was the birth of my younger sister, Sophia. She was born on May 22, 2001 when I was a junior in high school. She appeared perfectly healthy, but by six months Sophia was neither able to eat solid foods nor crawl, and had an unending series of infections. In March 2002, Sophia was diagnosed with an extremely rare, metabolic genetic disease occurring primarily in children of Ashkenazi Jewish decent, called Neimann- Pick Disease, Type A. There is no known cure and the doctors only gave her two to three years to live. In spite of this dark prediction, our friends and neighbors have rallied around our family in surprising and inspiring ways. Along with exploring different treatments for Sophia, our family has started Sophia's Garden Foundation, which is dedicated to enabling families in similar situations to create holistic models of care in order to take charge of their health care and improve the quality of life.

My appreciation for my friends and family has exceeded any expectations I thought I could have previous to Sophia entering my life. I never realized how much love and support people are willing to give in a time of need. Due to the demands of caring for Sophia, strangers have come to our home with fully prepared meals, run errands and assisted with Sophia's care all to alleviate some of the added responsibility on my family's plate. Because of the rareness of her disease and the way my family has cared for her, our community has done medical research, written articles, case studies, produced a documentary film and photo essays, and started prayer groups all over the country to spread the word about Sophia's story. These simple acts of kindness have instilled in me a renewed belief in people's generosity. Watching the nurses, volunteers, and my dad and stepmother care for my sister, in addition to my helping to care for her, has made me feel more blessed then saddened. We are surrounded by people that care for us and who are willing to put their own issues aside in order to help others.

I have been taking care of my sister this past year and have become one of the main palliative caregivers along with my parents and a team of skilled nurses. Being able to work with such a culturally and age diverse team has given me a deep appreciation and respect for peoples differences and inherent commonalities. Having such significant responsibilities has helped me to mature and to expand my capabilities.

Also having a sister with special needs has given me a newfound respect for people with disabilities, along with the caregivers, educators and therapists that work with them. Caring for someone with special needs can be a very difficult and thankless job at times. It takes a very compassionate and dedicated person to succeed and feel rewarded by this unrecognized type of work. Their calm confidence and steady optimism has helped me to deal with adversity and stressful situations with ease and skillfulness.

My sister passed away on July 25, 2005 at the age of four. I have cherished every moment I have had with her. She has taught me more of life's lessons then anyone else I know. Having a family member with an unknown lifespan in your life makes you stop and think about your priorities. Little problems that may arise seem so trivial and insignificant now. My time with Sophia has given me the opportunity to take a step back from my life to evaluate my goals, aspirations and relationships. Sophia is the reason I am transferring colleges. I want to make an important contribution to my family and community with the talents I have and to make a difference. Life is too short to settle for less. I want to be excited about my choices and make the most out of them. By first going to Foothill College In fall of 2005 and ultimately attending the University of California at Davis in fall 2006, I will be able to follow my dreams and use the resources there to reach my fullest potential, and ultimately give back.