

My name is Miguel Garcia. I am a seventeen-year-old Native American attending San Marcos High School in Santa Barbara, California. I live with my mom and three younger brothers and I have three older sisters that no longer live at home. My interests are photography, playing the drums, doing magic tricks, listening to music and, like any other teenager, hanging out with my friends. I like to express my feelings through poetry and enjoy being by myself. I am very proud of who I am no matter what life has dealt me.

I was born with a rare skin disorder called Epidermolysis Bullosa, E.B. for short. E.B. is a genetic skin disease that causes severe blistering and sloughing of the skin from the slightest friction. This occurs both inside and outside of the body. The simplest things, such as swallowing food and wearing certain clothes can be extremely difficult and cause open wounds. When I explain it to my friends, I tell them that their skin is like that of an apple, tough and pretty sturdy, where as my skin is like a ripe peach, fragile and easily torn. As of now, there is no cure for E.B. just daily wound care and bandaging.

There are two types of days in my life. The first is where I get up and get ready for school. Before I head out for my school day, I have to take my daily regiment of medications, which can consist of up to 7 different ones. I

then head out to school on my scooter. The reason I use the scooter is to help me get around school and be more independent because without it I get blisters on my feet from walking. Yes, something as simple as walking can cause me pain. Don't get me wrong, I do walk, but I need to be careful on how much walking I do. At school, I have a full time aide who helps me take down notes, carry my books and other things that are a bit more difficult for me, you see due to my E.B. I have lost my fingers due to scar tissue and my aide helps me throughout the day with what most people would consider a normal or routine things. After school I come home to relax. At the end of my day, I have to hook up a tube that is connected directly to my stomach to a machine that slowly pumps a high calorie supplement directly into my stomach. Throughout the day I cannot eat the necessary amount of calories required for my body to remain energized and to heal any lesions or wounds I may have.

My second type of day is similar to the first except that on this day I have to take a bath. Baths may be simple and pleasurable, but to me it is much work and very time intensive. A bath consists of unwrapping all of the bandages that are covering open sores and then soaking in a tub full of bleach water solution. The bleach helps keep the lesions clean of bacteria because they are highly susceptible to

secondary infections. After soaking I get out and wrap all open sores with clean bandages. Remember, I have no fingers and being very self-reliant, I like to do things on my own so this whole process can take anywhere from 3-5 hours depending on how many lesions my body has on that particular day.

I enjoy doing what every other typical teenager likes to do, but many times I cannot, due to these daily routines or just because it could cause serious damage to my skin. I would love to be able to skateboard, take jumps on my bike, go to the beach or even play sports but, I have to be very cautious of many activities. I have to be careful in crowds not to bump into people or even at home I cannot horse around with my brothers because I can easily get hurt.

Every summer I look forward to attending a week long camp called Camp Wonder, which is a camp for kids that have various skin diseases. At this camp there are doctors and nurses at all times taking care of all our needs. This is a place where I can actually do things that I could not normally do, such as swim in a pool. I love that feeling of being in the water because I can exercise my joints and muscles without a big strain on them. Normally, I cannot find a pool here in Santa Barbara that will allow me to swim because of my open lesions.

This is just a little taste of what I go through on a regular basis. The reason I tell you a little bit about myself is not for pity or for you to feel sorry for me because that is the last thing that I would want. I want people to be aware of E.B. and to tell people that you cannot catch it from contact or that you shouldn't be scared of people with it. We may look a little different and do things a little differently, but we are just like you with feelings and sensitivity. In life many people have obstacles thrown in their path, but with a little perseverance and faith, those obstacles can and will be overcome.