

H. Rosary student explains life with epidermolysis bullosa

Sophie Schulz is a sixth grader at Holy Rosary School in Evansville. She and her brother, Sam, have epidermolysis bullosa, a condition in which skin blisters develop in response to minor injury. She recently talked to her fellow students about the disease. Here are her comments.

Do you ever feel like someone is watching you? I do all the time. People stare and look away because they are shocked by my disease. My looks make people question if I have been burned, if I am a victim of a severe accident, or if I am contagious. None of these are true. I have epidermolysis bullosa, a severe disease that affects my skin inside and out.

It has been said that beauty is only skin deep, but our faith tells us otherwise. Oftentimes we glance at the surface and make a judgment based on what we see. We don't dig deep enough to see what is beyond the skin. Skin by definition means a thin layer of tissue forming the natural outer covering of the body of a person, but in my case, skin or lack of means something very different. I challenge you to look past the outer surface of someone and dig deeper and truly understand the person starting with me.

My name is Sophie Schulz and I am standing in front of you today on account of national EB Awareness Week. My brother Sam and I suffer from EB. EB is a genetic disease which means blistering of the skin. We are missing a protein called collagen 7. It is the glue that holds our skin together. Up to 80 percent of my body is an open wound. It is not contagious and cannot harm you in any way. It causes me to live my life in constant pain. It makes simple activities very challenging. My body can't do what my mind and heart want. This can be very frustrating. EB includes long bandage changes and frequent trips to the hospital which make me miss out on things.

I bet you are thinking to yourself that stinks. You are right. It's pretty awful. I constantly find myself praying my personal scripture Philippines verse 4-13: I can do all things through Christ who

strengthens me. As I get older I find myself asking my parents and God, 'Why me? Why Sam?' And then I think, 'Why not me? Am I any different or more deserving than Jesus he had to suffer?' Maybe I have been chosen to be here today to speak to you and make you aware of this disease. It only affects 1 in every 50,000 births and Sam and I are two of them.

My mom always taught me there is a gift in everything. Sure this disease causes me great suffering but I also see and feel compassion from my friends who carry my backpack, help me open a door or walk with me to class. Love from my family members, teachers and all staff at Holy Rosary. Faith from just being here gathered in prayer today. Hope that one day there will be a cure to end EB.

The bible tells in 1Corinthians chapter 13 verse 13: and now these three remain: faith hope and love. But the greatest of these is love. I have experienced all of these in my life. Please help me make a difference by being aware of EB, praying for Sam and me, hoping for a cure. I challenge you to remember the way you think makes you beautiful. Think about and pray for Sam and me and all others who suffer from EB.

Thank you.