Jonathan's story: Living with epidermolysis bullosa

Meet Jonathan Pitre, a 13-year-old boy from Ontario who loves sports but can't play. This young man is living with epidermolysis bullosa, a genetic skin disorder that causes painful blisters on the body.

About Jonathan

Jonathan describes epidermolysis bullosa (EB) using the metaphor of grass and roots. "If there are no roots to connect the grass to the earth then you can peel it off," he says. "For us, it's like the roots of our skin are missing." In people with EB, the protein that connects the two layers of skin is missing, making the skin fragile. The slightest contact can cause painful sores.

Research into EB is not widespread, mainly because most people have no idea the disease exists. "When we go to a hospital, very rarely do we hear a doctor say 'Oh yes, I know this condition,'" says Jonathan. Luckily, he is treated by a multidisciplinary team at the Hospital for Sick Kids in Toronto, about five hours from his home.

The management of Jonathan's EB primarily involves keeping the condition under control. Most of Jonathan's body is covered in bandages, which must be changed daily. The condition affects almost all aspects of his life. "Walking or sitting down can hurt a lot," he tells us. "I have to be very cautious. A regular day, for me, is pretty complicated. When I wake up, brushing my teeth and getting dressed can be challenging. And I can't do it by myself so my parents help me."

After the morning rituals, Jonathan heads to school. "At school I do everything pretty normally. I'm in regular classes. The only difference is I have an aide who helps me with stuff like opening my plastic bags. I can't do gym. I stay back and watch. Then when we come home, we do dressings for two and a half hours."

Jonathan and his family have been **supported by DEBRA**, an organization that aims to help families affected by EB and raise awareness of the condition.

A warrior is born

Speaking to Jonathan, several things stand out: He is bright, confident and articulate. Calling himself an "EB warrior", he talks freely about his condition so that people might understand the disease. He has met others with EB on only three occasions, and none his age.

Jonathan and his family have been supported by DEBRA, an organization that aims to help families affected by EB and raise awareness of the condition. In 2012, Jonathan was chosen to attend the DEBRA conference—a life-changing experience. "When I went," he says, "it was the first time I'd met people who understand what's going on with me. That's when I became DEBRA Canada's young ambassador. I'm now really motivated and want to help the cause."

In closing, what does Jonathan wants people to know? "We're not that different from you," he says. "The only difference is physical. Up here [he points to his head] we are the same. EB is a very tough disease; it's very painful and requires a lot of patience. I'd like people to know that we are here and we would like some help." GS

Learn more about DEBRA
www.debracanada.org