

Jonathan Pitre, a fearless warrior from Russell Ontario, was born with Epidermolysis Bullosa, or EB for short, a rare and genetic skin disorder that causes blistering and shearing of the skin from the gentlest friction or minor trauma. The genetic defect results in the skin cells collapsing or skin layers not adhering properly to each other, causing areas of structural weakness. Along with the skin, EB affects all of the mucous membranes and internal organs, can result in skin cancer, severe infections, disability, and disfigurement as a result of the scarring and in the more severe forms death. Jonathan was 17 years old when he succumbed following a valiant battle with his disease.



Jonathan became involved with the Dystrophic Epidermolysis Bullosa Research Association (DEBRA) Canada (reg. #868336751RR0001) in 2012, following the DEBRA International Congress that was held in Toronto. Jonathan was invited to be a guest speaker on the patient/parent panel. This was the first time he had ever met other people with EB. DEBRA Canada is a non-profit registered charity dedicated to providing support for people affected by EB and their immediate families, and to increasing Canadians' awareness of this challenging condition. DEBRA Canada had helped him connect with others like him and had given him a sense of belonging in the EB community. Jonathan, like other butterfly children, touched the lives of so many people with his courage and positive attitude. Jonathan had become an EB Ambassador for DEBRA Canada. Through his own experiences and the loss of many friends to EB, he had become even more determined to help spread awareness in the hopes of one day finding a cure. He made himself vulnerable to the world exposing the open wounds that resembled third degree burns that covered more than 85% of his body and how it impacted his life. The thing that was the most staggering about Jonathan was his joie de vivre, his smiling face and seeing how he enjoyed life... he loved to live despite the challenges he faced and he did it so gracefully. He is remembered as a strong, determined advocate who worked to raise awareness and pushed for better understanding of EB.