PROFILE

Emma Fogarty

LIVING WITH EPIDERMOLYSIS BULLOSA (EB)

"The one thing that gets me up every day and keeps me positive is knowing that there is something being done to fight the battle against EB. "

My name is Emma Fogarty. I am 35 years of age and I live with Epidermolysis Bullosa (EB). Having EB means that my skin is as fragile and delicate as the wings of a butterfly and is just as easily damaged. The slightest knock or rub can cause my skin to blister and come off. 80% of my body is covered in bandages to protect open wounds and prevent further damage. It also affects me internally and externally and I have to take high levels of various medications throughout the day to try ease the pain.

But I never let it get me down. The one thing that gets me up every day and keeps me positive is knowing that there is something being done to fight the battle against EB. Research into better treatments and a possible cure for EB is happening worldwide and increasingly over the last few years there are more and more glimmers of hope.

This year I celebrated my 10th year as Patient Ambassador for DEBRA Ireland and I do everything I can to raise much needed awareness for the charity and the condition. I know that I am very lucky to support and have the support of such a well-established organisation. It is so important to have an organisation to fight on your behalf….otherwise there would be no hope and I would have no reason to get up in the morning. I am happy to see something is being done for people with other rare conditions because I can only imagine how hard it would be to fight a separate battle alone. Living with a rare disease is enough of a battle for any family.

A podcast of Emma talking about her life and EB is available:

https://podtail.com/en/podcast/the-other-side-of-perfect/emma-fogarty-talks-eb-life-outside-the-condition-d/

RARE DISEASE

About Epidermolysis Bullosa (EB/DEBRA)

Epidermolysis Bullosa (EB) is a distressing and painful genetic condition causing skin layers and internal body linings to separate and blister at the slightest touch. It affects approximately 1 in 18,000 babies born, equating to approximately 300 people in Ireland, and can range from mild to severe. Severe forms can be fatal in infancy or lead to dramatically reduced life expectancy, due to a range of complications from the disease.

Patients with severe EB need wound care and bandaging for several hours a day and the condition becomes increasingly debilitating and disfiguring over time. Adult patients with severe forms are extremely susceptible to an aggressive form of skin cancer. There is currently no treatment or cure for EB. In Ireland, children with EB are cared for at the multidisciplinary clinic in Children's Health Ireland, Crumlin and adult patients at a multi-disciplinary clinic in St. James's Hospital. Care requires the involvement of many different clinical specialists to extend life span and improve quality of life.