Media Release

Australians Urged to Dig Deep To Help Cure Devastating Epidermolysis Bullosa by 2030

Australia, Wednesday, 5 October 2022: EB Research Partnership Australia (EBRPA), the largest not-for-profit organisation funding research to cure Epidermolysis Bullosa (EB), is calling on Australians to help cure EB by 2030 this International EB Awareness Week (25 - 31 October 2022).

Epidermolysis Bullosa is a rare, life-threatening group of genetic diseases that affects the skin, causing it to blister, tear and peel - internally and externally. There is no treatment for the 1,000 people living with EB in Australia, and for those living with the more severe forms of EB, many do not live past childhood.

Sarah Thyssen, EB Research Partnership Australia, Executive General Manager, says:

“The biggest obstacle to curing EB isn’t science — it’s funding, and we believe that with funding, we can cure EB by 2030.

“Through tireless research, scientists have identified the mutation that leads to EB. They believe they know how to fix the problem. And they believe that this approach applies to many genetic diseases. But because most people have never heard of EB, a lack of funding holds back a cure for this devastating condition,” adds Sarah.

When Emma’s daughter, Blakey, was a few days old, Emma noticed a small blister on Blakey’s back. After medical staff had dressed it at the hospital, Blakey went home with her family only to return to the Emergency Department, presenting with a temperature. When doctors removed her dressing, all the skin on Blakey’s back came off. She was only four days old. Genetic testing found that Blakely had EB.

“Our first reaction was disbelief. We had to change everything we did with Blakey. When she is upset and wants a cuddle, we can’t touch her because her skin is too sore,” said Emma.

“A cure for us would mean relief; I panic a lot about school, family, having kids, travelling when she gets older. We see the kind of pain she goes through, and for us to be able to take that pain away – I’d give anything.”

For Melbournian, Lisa Brains, life has never been easy. Yet, through her work to help raise awareness for EB, Lisa has found strength and a sense of purpose.

"I was born with Recessive Dystrophic Epidermolysis Bullosa, a rare form of the disease. By the time I was 21, I had started to get weeping eczema all over my body which became 90% wound, and for more than a decade, I battled the most terrible time in my life and was close to death on a couple of occasions," says Lisa.

Determined not to let life get her down, Lisa has been part of various critical research trials to help cure EB and has experienced some of the genetic advances, discoveries and treatments, giving her light relief and hope.

Sarah concludes, "Our plan to defeat EB not only promises to change the lives of people fighting this devastating disease but also to change the way we treat other rare diseases.

You can donate and share a message of support by visiting: https://ebawarenessweek.raisely.com. For more information, visit: https://ebresearch.org.au/

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Notes to Editor:

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About EB Research

EB Research Partnership Australia aims to raise funds to invest in science and medical research that will lead to products and therapies for treating and ultimately curing Epidermolysis Bullosa, a group of life-threatening skin disorders that affect individuals from birth. https://ebresearch.org.au/