

All Wrapped Up

Cotton Wool Kids (Epidermolysis Bullosa)

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The first time I'd ever heard about a child with the rare skin condition Epidermolysis Bullosa (EB) was in a heart felt email from a friend. She told me about an amazing little boy she had met that day who, despite his obvious medical condition and being wrapped in bandages, smiled and laughed happily as she sat watching him play.

The young boy she was talking about is one of around 1000 Australian children living with this rare condition that are sometimes referred to as "Cotton-wool kids" or "Butterfly children" because their skin is as fragile as butterfly wings. These children have a tissue disease that causes blisters in their skin and mucosal membranes (e.g. nostrils, mouth, lips, and eyelids) that have been likened to second degree burns.

EB causes the skin to be extremely fragile and minor friction or trauma, such as touching or hugging can cause blisters to form. It varies widely in seriousness, from milder forms (which are still extremely difficult to live with) to severe forms that result in disfigurement, disability and early death. Often there is a family history of the condition but this is not always the case. EB is not contagious.

What it is like for children with a more severe form of EB:

- ▶ Painful wounds covering most of their body
- ▶ Having each and every finger wrapped to prevent their hand from scarring and fingers webbing together.
- ▶ Never being held tight by their parents because it may cause their skin to blister or shear off.
- ▶ Never running, skipping, jumping or playing games with other children because the slightest physical contact will injure their skin.
- ▶ A diet of liquids or soft foods only because other foods can cause blistering and scarring in the oesophagus.

Some children are diagnosed with EB as a newborn. Life can be difficult enough with the constant feeding, changing and sleeping routines of babies, but imagine the added complication of EB. Parents of babies with EB have to handle them gently, give them medical bathing and cleansing, drain their blisters, and constantly change their dressings, and at the same time learn the correct way to hold the baby to minimise blisters while still giving the baby the closeness it needs.

Most children with EB can go swimming in chlorine and/or salt water and many love going to the beach. However, this can be huge ordeal afterwards with reapplying all the dressings which can take up to four hours.

At present there is no specific treatment for EB. Current therapy is directed towards the prevention of skin trauma, prevention of infection and the treatment of complications.

Management of EB requires frequent application of specialised dressings and bandages to reduce skin damage and the risk of infection. The cost of dressings can be extremely high, reaching as much as \$5,000 per month for some.

As Mother's Day approaches I want to give a very special call out to all the mums of children with EB. You are

amazing! Special thanks also to Sue McKenna – Coordinator of DebRA Australia who assisted with this article.

Want more info?

Contact:

- ▶ **DebRA** - Dystrophic epidermolysis bullosa research association of Australia. www.debra.org.au
- ▶ **Australasian Blistering Diseases Foundation** – a non-profit organisation that fundraises for research into life threatening blistering diseases, and provides support for patients and their families. www.blisters.org.au
- ▶ EB Info World – www.ebinfo.com

Want to help?

- ▶ Buy a Butterfly item via the DebRA website. www.debra.org.au or get involved in Butterfly Day on 28th of October 2010 which is held in conjunction with International EB Awareness Week (Monday 25th October – Sunday 31st October)
- ▶ Add DebRA Australia to your Facebook page.

