

This is what life feels like to Butterfly Children



LOWE GGG


debra
Piel de Mariposa
Butterfly Children



As fragile as a butterfly wing

Butterfly children suffer from **Epidermolysis bullosa**, a **rare, chronic and incurable disease**. It is characterized by **extreme fragility of the skin**. The lightest touch causes **blisters and painful open wounds**. These can also occur spontaneously.

Butterfly skin is diagnosed at birth. In its severest form, children suffer from:

- **Long and painful daily treatments.**
- They lose the use of both hands and feet causing **serious disability and total dependency** on parents and carers.
- **Constant health issues** including: malnutrition, anemia, narrowing of the esophagus, infections, dental problems and malignant skin conditions are predominant.



Social and administrative inequality

Along with the daily physical suffering from living with the disease, Butterfly children in Spain are also subjected to the consequences of medical negligence and lack of support from social services.

- Generally **doctors know very little about the disease**, diagnosis is often late and **the treatment options are very limited**.
- Unfortunately **there is currently no Spanish National Reference Centre** where patients can be treated by specialist doctors and physicians.
- Bandages and daily treatments are essential to the well being and comfort of Butterfly children. **Social services do not always cover the cost of treatments and care.**

For a better quality of life

DEBRA Spain is a **non profit organization** founded in 1993 with the aim of **improving the lives of Butterfly children**. The charity offers the following support and services to patients:

- Specialist nursing assistance.
- Counseling.
- Advice on support and social services.
- Advice and mentoring for health professionals in both the public and private sector.
- Funding for research.
- Campaigning for patients rights.
- Collaboration with both national and international entities.





Your help gives us wings

Less than 5% of our funding comes from public entities. Therefore, **the help we receive from individuals and businesses is vital** to our survival.



Become a member. With a small monthly, quarterly or yearly donation, you will not only be contributing to our economic stability, but will also help make our campaign stronger.



Become an ambassador. Instead of making a monetary donation you can donate your time, knowledge, ideas, bring us your contacts and help us to reach out. Our cause can become yours.



Help us in the DEBRA charity shops. We need volunteers, quality articles to sell and of course customers!



Follow us. Be aware of our projects, events and news through our social networks, web page and our online news bulletins.



[butterflychildrencharity](https://www.facebook.com/butterflychildrencharity)



www.youtube.com/pieldemariposa

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