Hello!

debra
Piel de Mariposa
Butterfly Children

Martina (Huelva)

Photograph Campaign: Osos Preciosos de Fundación Carrefour

Their skin is
as fragile as a butterfly's wing

Butterfly Skin is a **rare disease** causing **extreme fragility of the skin**.
The fault lies in a **genetic mutation** that fails to "glue" the layers of the skin together meaning that **the slightest touch can cause a blister**. Even a simple embrace can cause harm.

Sadly, to date there is **no cure.**

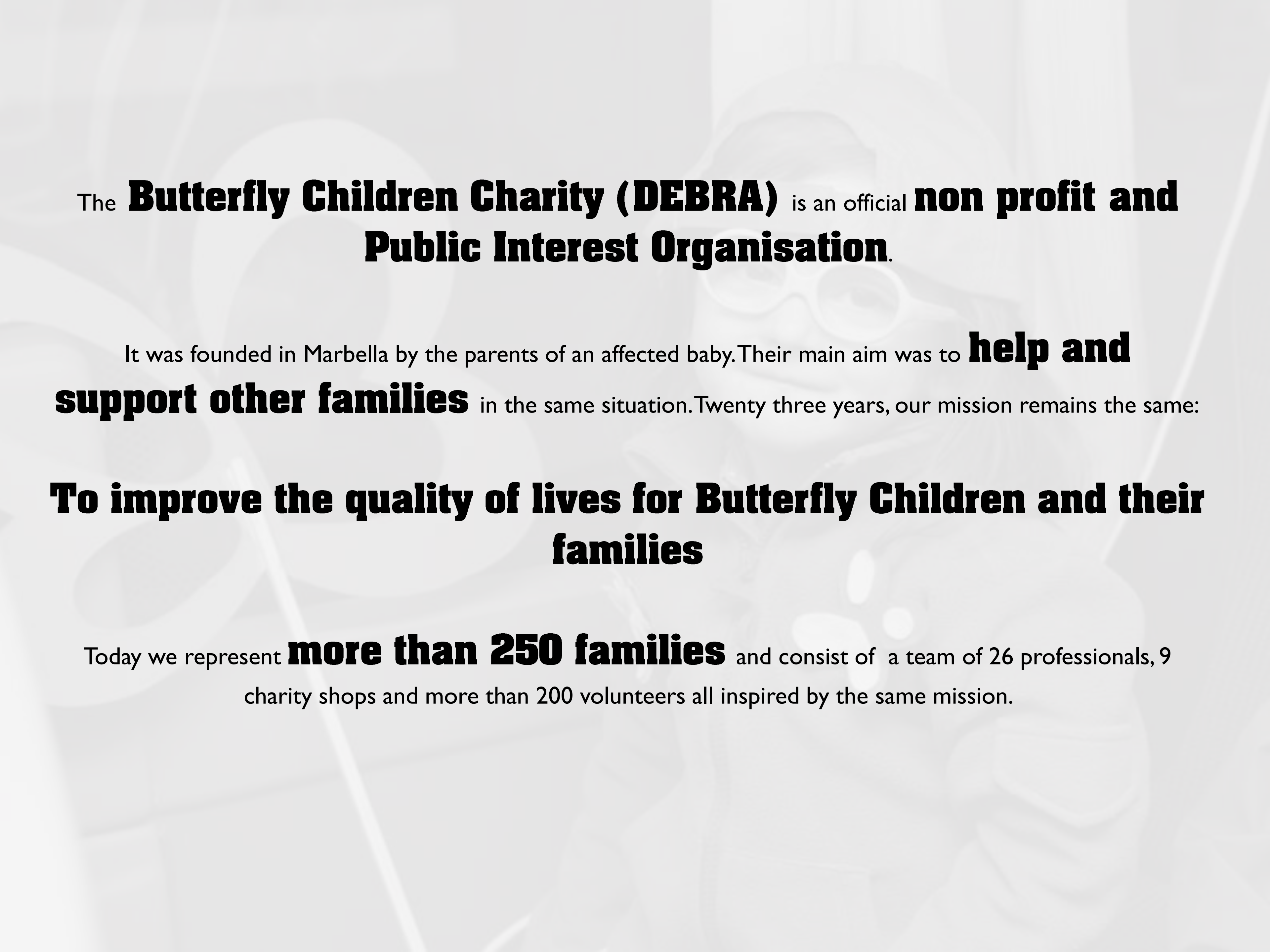
Take a moment to experience the life of a Butterfly Child

From birth **blisters and wounds continuously appear** all over their bodies. As part of the treatment and as a form of protection the children have to undergo **long and painful bandaging routines** every second day. In some cases management can be more complicated because the mucous membranes of the mouth, pharynx, oesophagus and eyelids can also be affected.

Everyday activities such as dressing, walking and eating can be challenging causing a high level of **disability and dependency.**

The psychological effects of Butterfly Skin impact on **the whole family**. Feelings of guilt, helplessness, anger and sadness can lead to depression, anxiety, fear and low self esteem.

Supporting families
since 1993



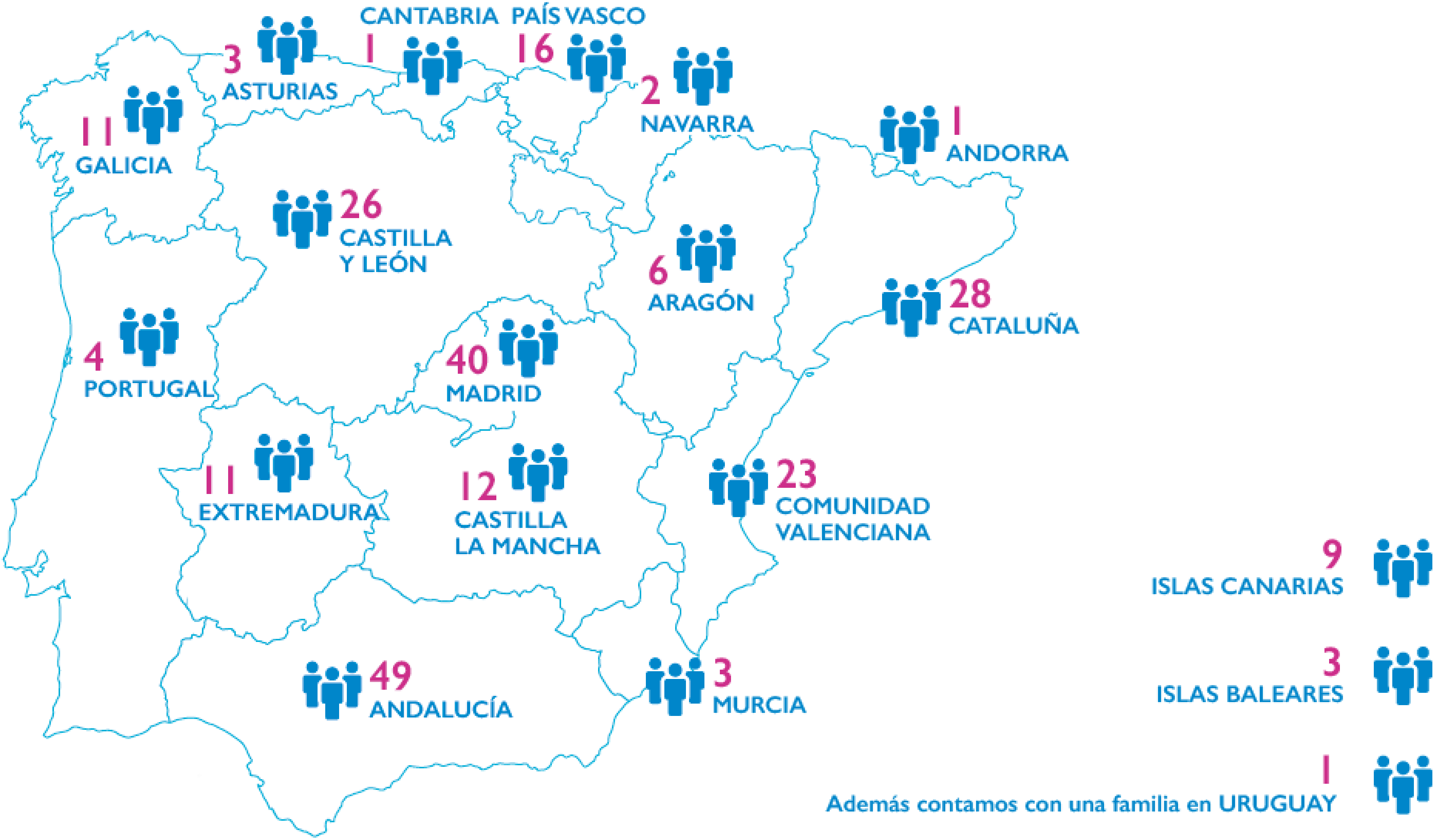
The **Butterfly Children Charity (DEBRA)** is an official **non profit and Public Interest Organisation**.

It was founded in Marbella by the parents of an affected baby. Their main aim was to **help and support other families** in the same situation. Twenty three years, our mission remains the same:

To improve the quality of lives for Butterfly Children and their families

Today we represent **more than 250 families** and consist of a team of 26 professionals, 9 charity shops and more than 200 volunteers all inspired by the same mission.

Number of associated families by region



Además contamos con una familia en URUGUAY

Our Team

DIRECTOR


Evanina

ADMINISTRATION

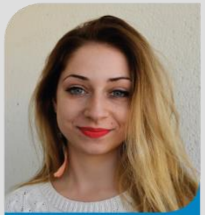

Silvia


Margit

COMMUNICATION AND FUNDRAISING


Minerva

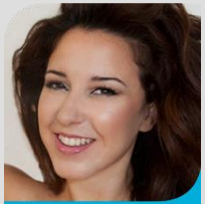

Ana María


Leticia

CHARITY SHOPS


María

Coordinator


Carmen

Málaga


Antonia

S. Pedro Alcántara


Belén


Jorge

Madrid


Anne


Mary

Alicante


Fina


Ana Lucía

Valencia


Eileen

Marbella

HEALTH PROFESSIONALS


Estrella


Aira

Social workers


Nora

psychologist


Nati


Esther


Álvaro

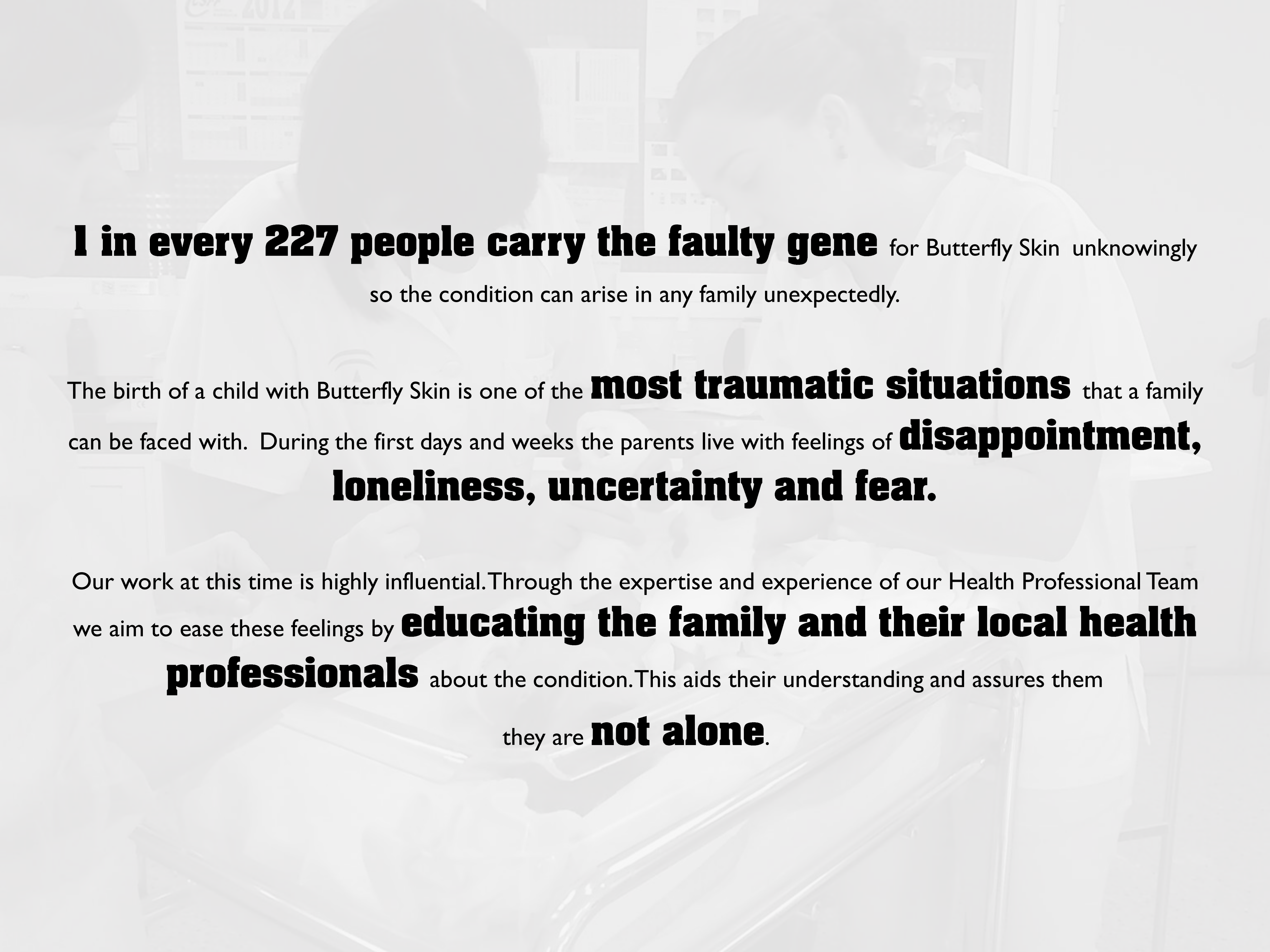
nurses


María


Miriam

nurses

New-born Visits

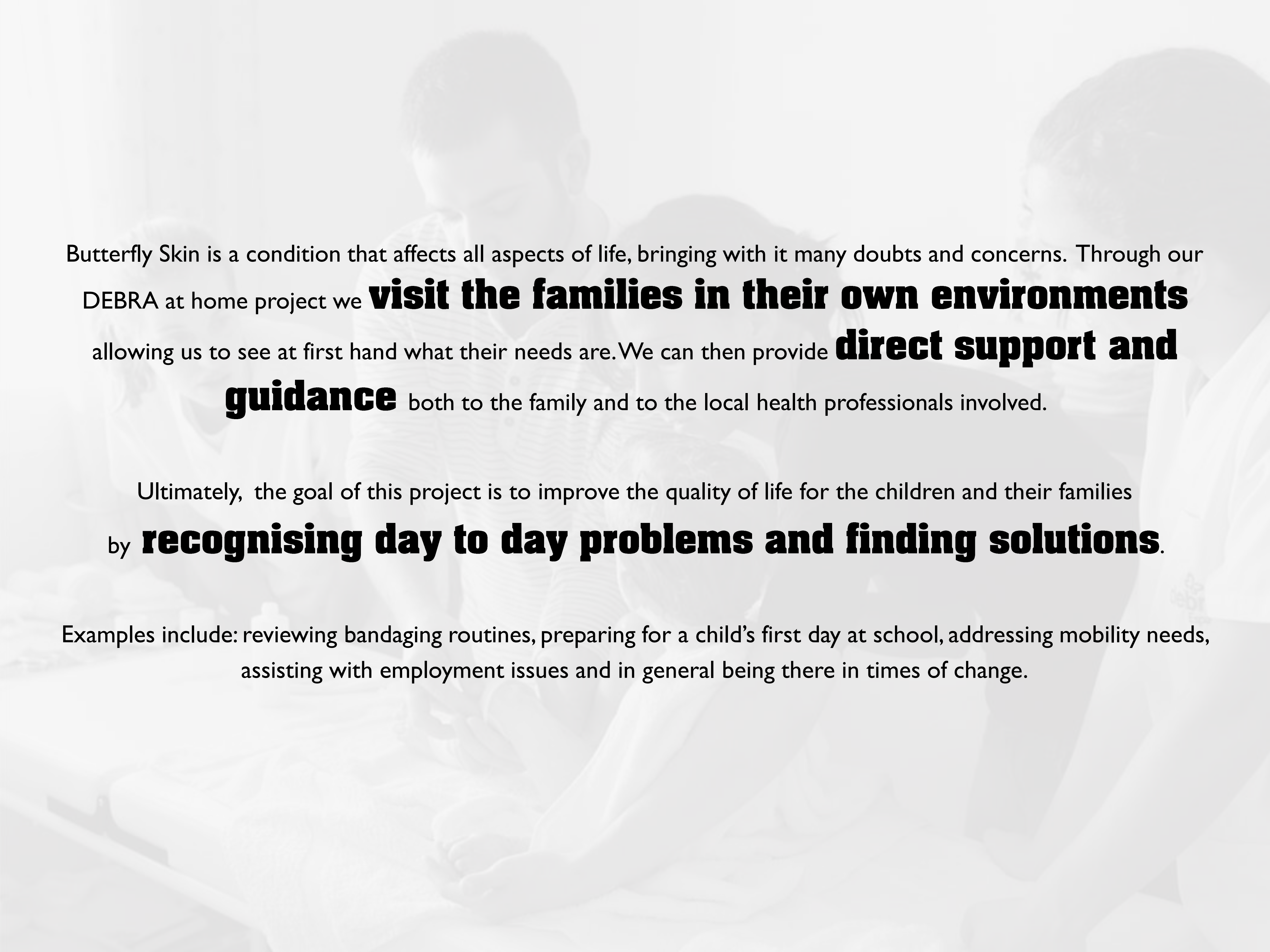


1 in every 227 people carry the faulty gene for Butterfly Skin unknowingly so the condition can arise in any family unexpectedly.

The birth of a child with Butterfly Skin is one of the **most traumatic situations** that a family can be faced with. During the first days and weeks the parents live with feelings of **disappointment, loneliness, uncertainty and fear.**

Our work at this time is highly influential. Through the expertise and experience of our Health Professional Team we aim to ease these feelings by **educating the family and their local health professionals** about the condition. This aids their understanding and assures them they are **not alone**.

DEBRA at home



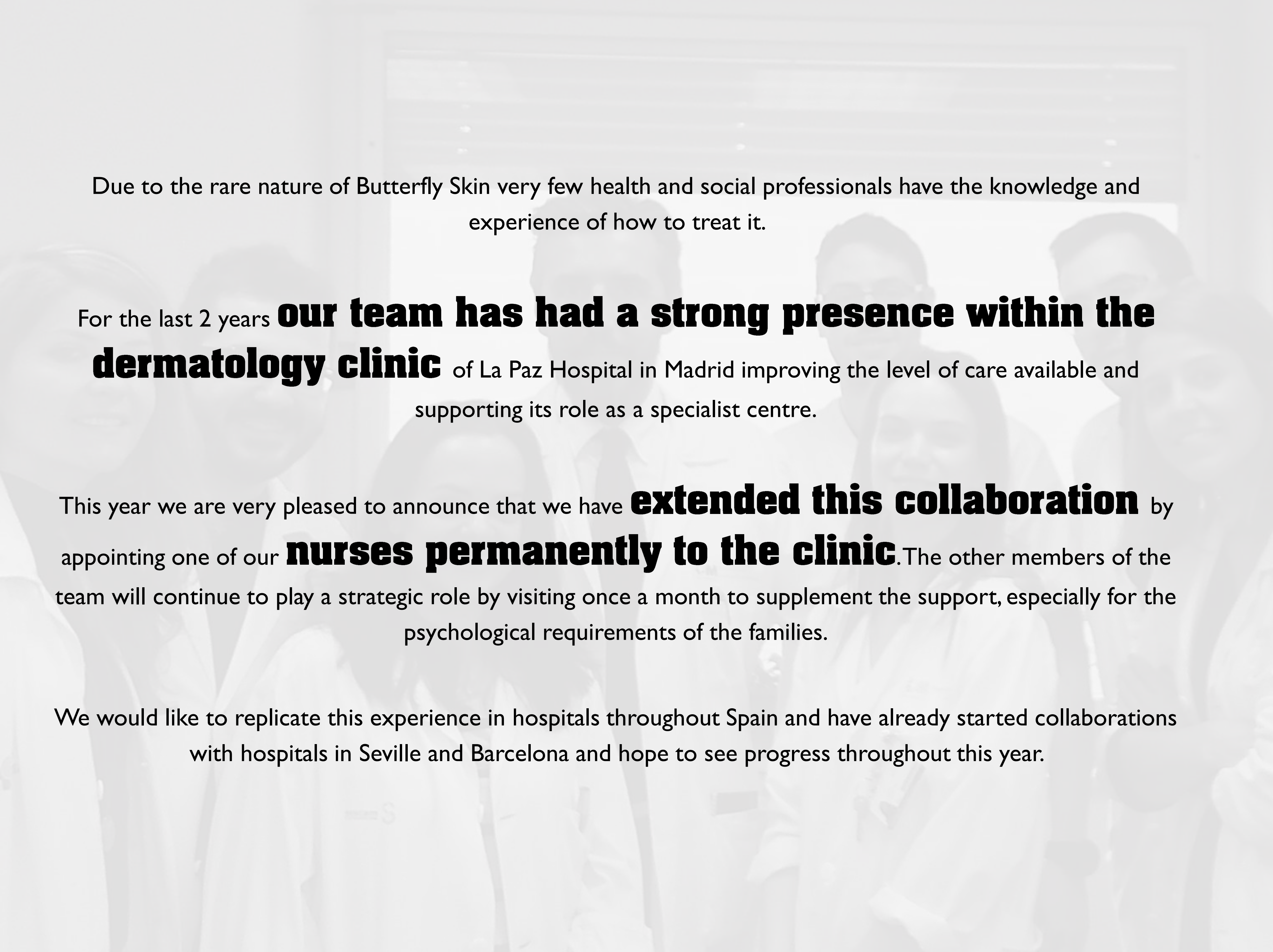
Butterfly Skin is a condition that affects all aspects of life, bringing with it many doubts and concerns. Through our DEBRA at home project we **visit the families in their own environments** allowing us to see at first hand what their needs are. We can then provide **direct support and guidance** both to the family and to the local health professionals involved.

Ultimately, the goal of this project is to improve the quality of life for the children and their families by **recognising day to day problems and finding solutions**.

Examples include: reviewing bandaging routines, preparing for a child's first day at school, addressing mobility needs, assisting with employment issues and in general being there in times of change.

Dr. Raúl de Lucas
Head of Paediatric Dermatology

La Paz Hospital



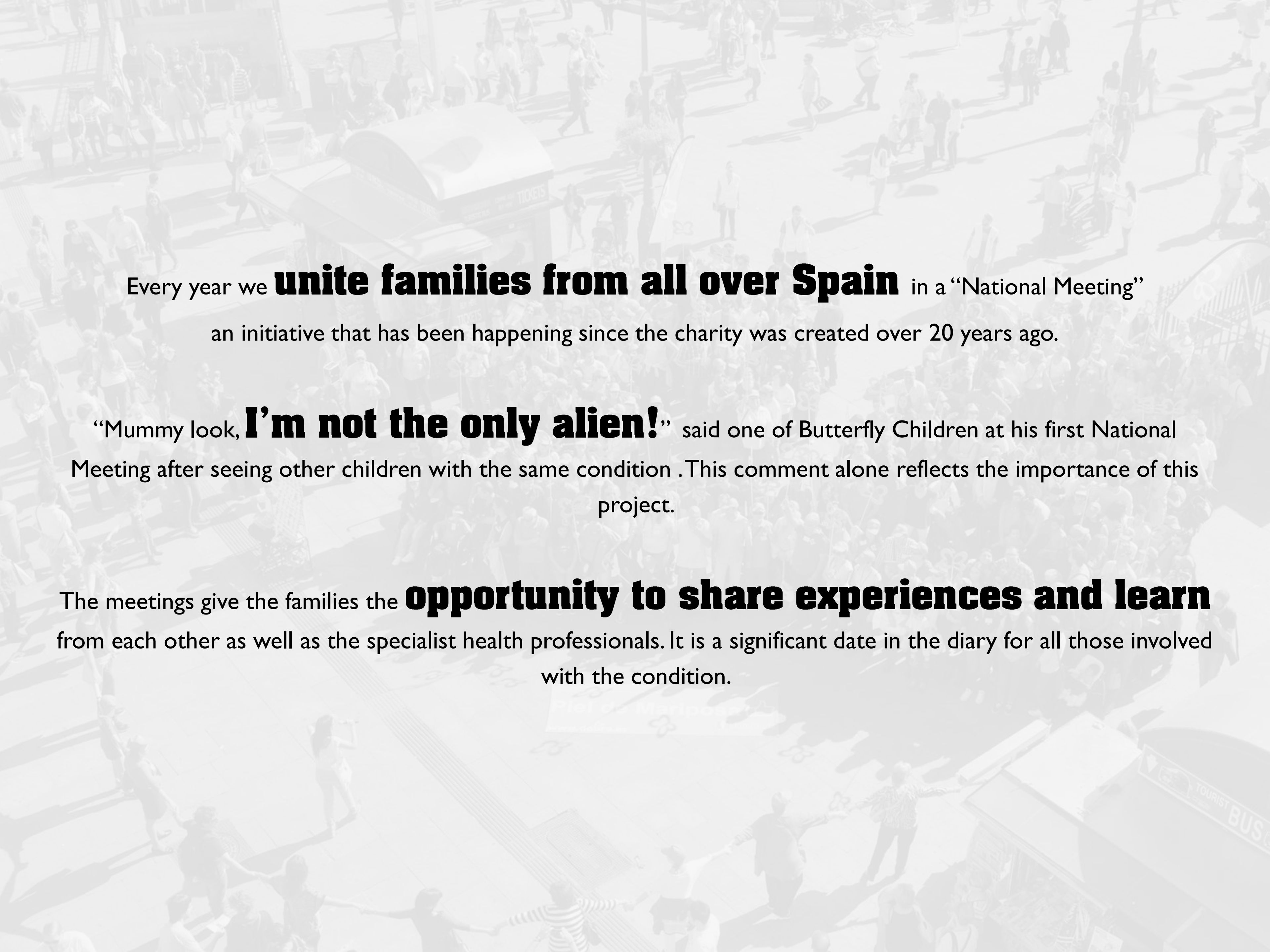
Due to the rare nature of Butterfly Skin very few health and social professionals have the knowledge and experience of how to treat it.

For the last 2 years **our team has had a strong presence within the dermatology clinic** of La Paz Hospital in Madrid improving the level of care available and supporting its role as a specialist centre.

This year we are very pleased to announce that we have **extended this collaboration** by appointing one of our **nurses permanently to the clinic**.The other members of the team will continue to play a strategic role by visiting once a month to supplement the support, especially for the psychological requirements of the families.

We would like to replicate this experience in hospitals throughout Spain and have already started collaborations with hospitals in Seville and Barcelona and hope to see progress throughout this year.

National Meeting of Families



Every year we **unite families from all over Spain** in a “National Meeting” an initiative that has been happening since the charity was created over 20 years ago.

“Mummy look, **I’m not the only alien!**” said one of Butterfly Children at his first National Meeting after seeing other children with the same condition .This comment alone reflects the importance of this project.

The meetings give the families the **opportunity to share experiences and learn** from each other as well as the specialist health professionals. It is a significant date in the diary for all those involved with the condition.

Estar Bien

Butterfly Skin is a **chronic condition** that affects the child for life. Our team of specialist health professionals are **always available** to the families and their local health professionals **to help them cope with the difficulties** that arise along the different stages of life.

Examples include:

HEALTH

- Advice on materials and **methods of bandaging.**
- Recommending local and regional professionals with experience.
- Supporting the genetic diagnostic process.

…

SOCIAL

- Assessing and assisting with **disability and dependency**.
- Advice and assistance with the financial benefits process.
- Addressing schooling and employment issues.

…

PSYCHOLOGICAL

- Help with the initial **impact of the diagnosis.**
- Coping mechanisms for the individual and the family.
- Support for the main carers.

…

Collaborations and synergies

We are **members of**

entidad de utilidad pública
feder
FEDERACIÓN ESPAÑOLA DE ENFERMEDADES RARAS

PLATAFORMA DE ORGANIZACIONES DE PACIENTES

and we **collaborate with**

er ciberer
CENTRO DE INVESTIGACIÓN BIOMÉDICA EN RED DE ENFERMEDADES RARAS

Instituto de Salud Carlos III

Internationally we are:

Members of the European Organisation of Rare Diseases **EURORDIS**.

Founders and members of the International network "**DEBRA International**".

Members of the International network for the Health Professionals of Butterfly Skin "**EB Clinet**".

In addition, we also work with other countries who do not have an association in place. We help them to create their own DEBRA especially the Latin American countries.

debra
International.

Our Claims

Our claims concentrate on **3 basic requirements** of life in the developed world:

①

Access to **specialised health care** through the designation of Reference Hospitals. Here, care from highly experienced professionals will be given regardless of their postcode.

②

For many years we have been campaigning for **free and easy access to bandaging materials**. Last year we achieved the first step towards this by receiving an agreement from the government and local health authorities to guarantee this right. However we know that not all the families are benefiting from it yet, so this claim remains open.

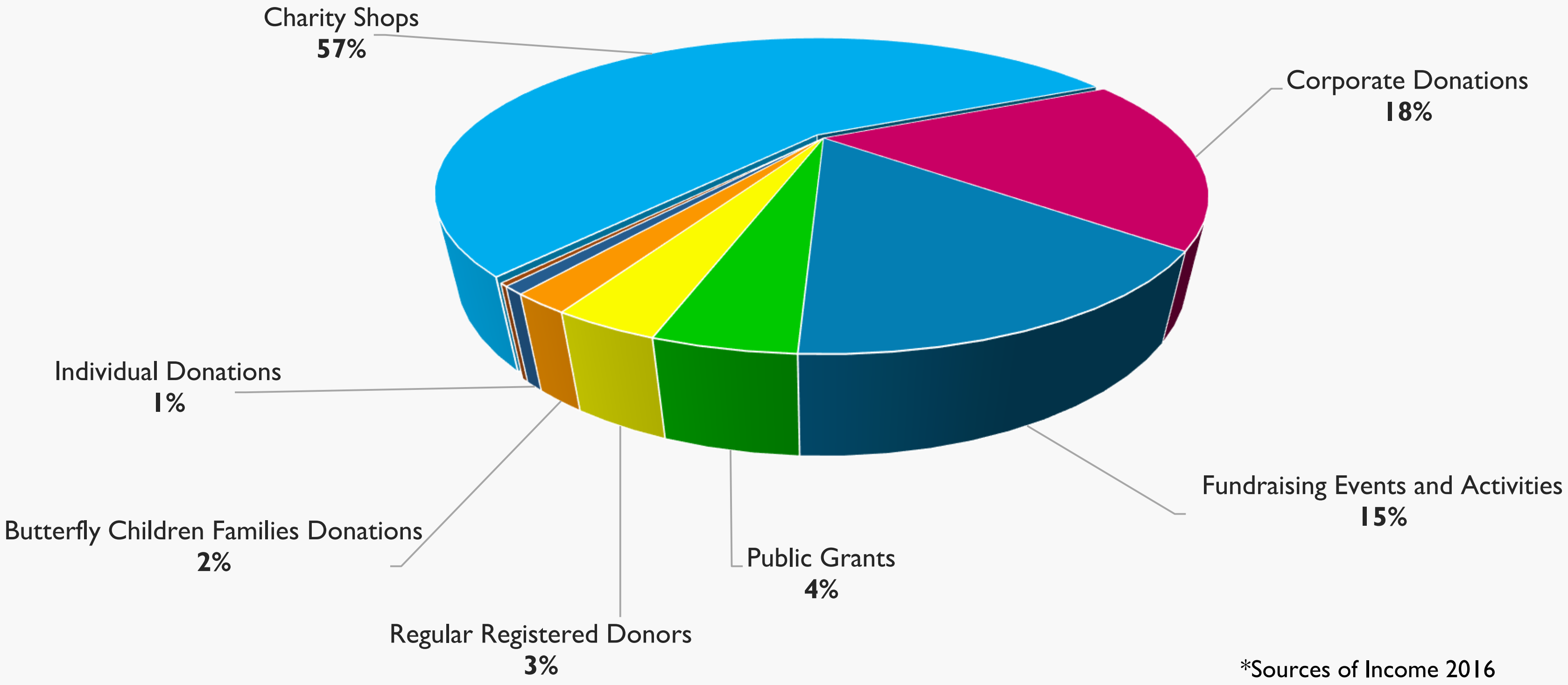
③

Families face problems such as disability, dependency, social exclusion and financial difficulties. These do not adhere to the social benefits criteria that exist today therefore the **social support and resources** available need to adapt accordingly.

Our projects are in place to compensate for the failings of the Public Health System. Once these have been resolved we can then dedicate more resources to areas such as research and awareness.

Your help gives us wings

To carry out our work comprehensively we rely on the **generosity of individuals and companies** as well as our own fundraising methods such as our **charity shops**.



*Sources of Income 2016

Less than 5% of our funds come from the government.

Whether you are a **company or** an **individual** there are many ways that **you can collaborate** to help build better lives for the Butterfly Children and their families.

Here are some examples…and we always welcome news ideas!

Become a Benefactor

Visit or donate to a charity shop

Take part in one of our events

Organise an event

Finance a project

Donate €1/month
Teaming.net

Advertise in our publications

Our shops give us wings

The **Butterfly Children Charity Shops** sell high quality items at incredible prices. All funds raised support the projects and services of the charity. You can **collaborate by donating, volunteering or shopping** in your local shop.

Donaciones

Tienda Solidaria

Asistencia
y sensibilización

Voluntariado

Venta
a precios asequibles

Supporting the Butterfly Children Charity Shops you are helping the families living with Butterfly Skin.

tiendas.pieldemariposa.es

Your help gives us Wings
Thank you!

debra

Piel de Mariposa
Butterfly Children

www.butterflychildrencharity.com

@butterflychildrencharity

@pieldemariposa

C/ Jacinto Benavente, 12 - 29601 Marbella (Málaga) 952 816 434 / 619 505 180 / pieldemariposa@debra.es