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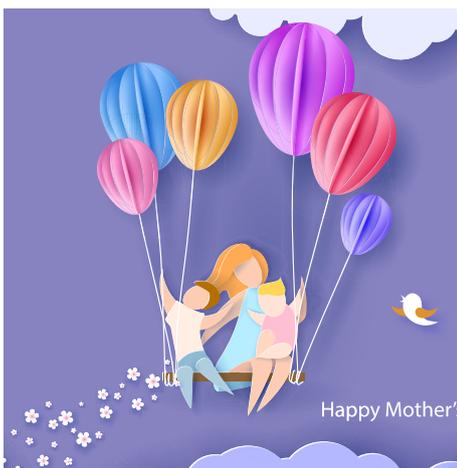
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DEBRA, Butterfly Children Charity

“ MY SKIN IS AS FRAGILE AS A BUTTERFLY’S WING. PLEASE HELP TO MAKE MY WORLD LESS PAINFUL. ”

Our skin is the largest organ of the human body, our protection and first defence against the outside world. We take it for granted that this is so, and that we only suffer pain when our skin is damaged and this line of defence of the body is breached, but for those who suffer from Epidermolysis bullosa, pain and suffering are a constant, lifelong companion.

Epidermolysis bullosa (EB) is a rare, debilitating and life-limiting skin condition, recognised to be one of the most overwhelming and painful conditions known to modern medicine. There is currently no cure. Having a child with EB dominates every aspect of life. Every decision has a consequence, and children

with EB suffer from unbearable pain every day of their lives. They are known as Butterfly Children because their skin is as fragile as a butterfly’s wings.

Your skin is your protector

The consequences of living without this protection are severe. People with EB suffer from lifelong disability, problems eating and drinking (patients are often fed through a tube), narrowing of the airways and muscular dystrophy. The internal linings and other organs are affected, fingers and toes fuse together making walking and simple every day actions difficult and painful. It can take up to four hours to bandage and dress the skin to protect it from damage and infection. The pain is so acute that powerful pain relief such as morphine is required to make daily treatment more bearable. Children and young adults will need multiple operations and interventions to deal with the complications associated with the disease. →



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Our mission

The DEBRA Butterfly Children's Charity is a non-profit organisation founded in Marbella to provide specialist support and care for children with EB and their families in Spain. A dedicated team of nurses, psychologists, community workers and researchers work to improve the quality of life for children with EB.

EB is a lifelong condition and DEBRA is available to help support families from the birth of a child with EB to end of life care. No family should have to make this journey alone.

- *We provide support and healthcare instruction to family members, carers and national health care professionals*
- *Our nurses travel to hospitals throughout Spain to visit newborn babies, to support and advise parents and medical professionals alike*
- *Our specialist team of nurses, community workers and psychologists provide essential home visits to families, offering advice and information on all aspects relating to the disease, including the best available treatment options, physiotherapy, nutrition, medical intervention, mental health, end of life care etc.*
- *We foster research projects and broadcast the results*
- *We promote the exchange of ideas and experiences between patients*
- *We focus on raising awareness and providing information on EB through our fundraising events, social media campaigns, information points, group events, our charity shops etc.*

Please help us to continue this work during these extremely challenging times. Keeping our support team working has been our main priority during the current crisis, so please let the care for the Butterfly Children not become another casualty of Covid.

Donate now to ensure our specialist healthcare team can continue to support children with this devastating and life-threatening condition, and help us to continue research into effective treatments and a cure. This is their lifeline!



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DEBRA gives wings to Butterfly children

There are many medical conditions that are well-publicised but also many that we are less familiar with. The Butterfly Condition, or Epidermolysis bullosa (EB) is one of these, but it is no less serious for being rare and the suffering it causes is such that it deserves our attention and support. In layman's terms, it comes from gene mutations that result in defective or absent attachment between or within the layers of the skin. This may seem a minor detail, given the overall complexity of the human body, but where you and I heal quickly when we scratch or chafe our skins, sufferers of EB lack the reconstructive, binding ability we're lucky enough to take for granted – and the result is wounds that won't close, cause extreme pain and discomfort, and ultimately can lead to life-threatening conditions.

It could happen to your child

We speak of Butterfly children because the condition starts at birth, or in milder cases once the little ones begin to crawl and move around. Even the slightest scratch, bump or friction produces wounds that almost never heal and are added to in intensity and number over time, in some cases leading to fatal cancers or narrowing of the oesophagus. It is horrible to think that a relatively small genetic mutation can cause so much pain and suffering, and it could happen to anyone as parents are unknowingly carriers of the condition. In fact, one in 227 people is a carrier, resulting in over half a million boys and girls having EB around the world.

The condition varies from case to case, with some having 20% of their body covered in sores while in some cases it is as much as 80%. Imagine how restrictive this is, when the kind of robust playing of children is out of the question and even walking, sleeping or getting dressed can be agonising. Butterfly children require constant care, as their wounds need dressing and the bandages have to be regularly changed. What's more, everything from the salves and bandages to the medical treatment and the training of nursing staff is specialised, making this a very labour-intensive and expensive condition for parents to cope with.

The truth is, they cannot cope with it all themselves and need the financial, medical, practical and emotional support of others. The level of help provided by state and private healthcare entities varies from country to country, but it usually falls well short of what is needed.



YOU MAY HAVE HEARD OF THE BUTTERFLY CHILDREN OR DEBRA WITHOUT KNOWING EXACTLY WHAT THEY'RE ABOUT, BUT THIS MARBELLA-BASED NATIONAL CHARITY THAT FORMS PART OF AN INTERNATIONAL COMMUNITY OF DOCTORS, NURSES, MEDICAL RESEARCHERS, PARENTS AND THE CHILDREN SUFFERING FROM THE RARE BUTTERFLY CONDITION, PROVIDES VITAL SUPPORT THAT GIVES HOPE TO THOSE IN PAIN.

It is to provide a community of support for Butterfly children and their parents that DEBRA was founded and has grown into a worldwide organisation dedicated to treatment and also medical research. By not fracturing but forming national parts of a single global organisation, DEBRA can pool its resources effectively into one research pot and lobby for more support and awareness.

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DEBRA's work in the local community

Working together with medical practitioners throughout the country but entirely dependent upon donations for its funding, DEBRA was founded in Spain by a couple whose child was I with EB. Though financially solvent themselves, they realised many other parents would not have the same resources and established the organisation in Spain some 27 years ago, with its headquarters in Marbella. Today, the team consists of dedicated professionals made up of four nurses, three community workers and two psychologists who help parents to deal with the situation and overcome their grief. Whenever a child is born in Spain with EB – which occurs some ten times per year – they will travel across the country to get to it within 24 hours, support parents and instruct them and the local medical practitioners on the specialised care required.

It doesn't end there, as DEBRA forms a vital support structure for the children and their relatives, which in addition to specialised medical care also provides practical and emotional assistance. "We form a community," says Evanina Morcillo Makow, who leads the DEBRA team in Spain. "Our fundraising goes to maintaining this system of help, spreading practical knowhow among doctors and nurses across the country, and very importantly into funding research that could lead to the effective treatment and perhaps even the eradication of what is one of the most heart-breaking conditions to affect children."

In doing so, DEBRA also raises awareness and lobbies, but above all works very hard to give the Butterfly children and their parents wings, the strength to deal with it and improve their quality of life as much as possible. Though times are hard in the current circumstances, having a charity that does such noble work in our midst deserves the support of us all!

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How can you help?

One of the hardest things for a parent with EB is to see their child in pain and distress from the simple process of protecting them, as daily treatments cause unbearable suffering and pain.

To hear your child cry is upsetting, but to hear your child cry and scream in agonising pain is emotional torture for a parent. They have to endure it every day.

In order for us to support and shield families from the daily reality of living with this condition we need your help now

All money raised will help 'The Butterfly Children's Charity' to continue to provide emotional, medical and practical support to families with EB. The team of specialist nurses, psychologists and community workers are there from the birth of a baby with EB to providing end of life support and care at a time when families need them most.

Please support the Butterfly Children's Charity and ensure that our specialist team of health care professionals can continue to provide this vital care.

At this difficult time your support is more crucial than ever before!

Regular donations:

Become a member and make a regular donation to the charity. Consistent donations that we can rely on make an enormous difference, helping us to plan ahead for the future.

A celebration with a difference:

Turn your special day into a fundraising event for DEBRA.

It could be a birthday, wedding or any other celebration. Use the occasion to share the spirit of kindness and helping others with your guests, as well as raising awareness for those in need. Ask family and friends to make a donation instead of giving presents. You may already have everything you need, so please think about a charitable gift list as the perfect way to make a difference on this magical day.

Or, thank guests for their love and friendship with our unique wedding favours: beautiful blue butterfly pins, key rings or butterfly necklaces.



Catherine McKeown & Family
Richard & Sue Fawcett
Peter & Ann Fawcett

Proud to support the **Butterfly Children Charity**



Lorraine Welford

wishing the charity all the best





Get active:

Organise a sporting challenge or event to raise awareness and funding. Our fundraising and events team are ready and available to help you with this.

A legacy changes lives:

Your support will continue long into the future with a charitable legacy. Make a difference and support families with EB by leaving a gift in your will.

Give the gift of time:

Volunteers play a central role in our organisation, providing vital resources to help with fundraising. Become a volunteer today and make a real difference. You will also make new friends, learn new skills, connect with others and have fun!

Think pre-loved:

Support the charity shops by donating quality clothing and other items, or recycle and reduce your carbon footprint by buying nearly new clothing and accessories.

Come to one of our golf events:

Take part in one of our golf tournaments, whether you are a serious golfer or just starting out, our golf events are held at exclusive clubs and promise an amazing day of sport and a fantastic way to contribute at the same time.

Join one of our fundraising challenges:

Run 5km, donate 5 euros and nominate 5 friends or sign up to climb to the top of La Concha Mountain with friends and family.



Visit our website for further information and ideas on how you can help us now.

The world has stopped because of the global pandemic, but babies with EB continue to be born and they need your help now more than ever before.





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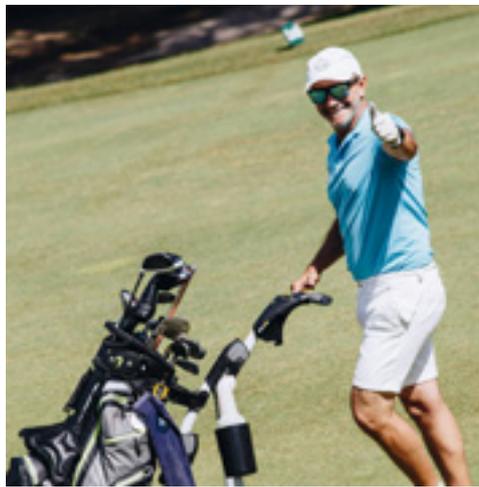
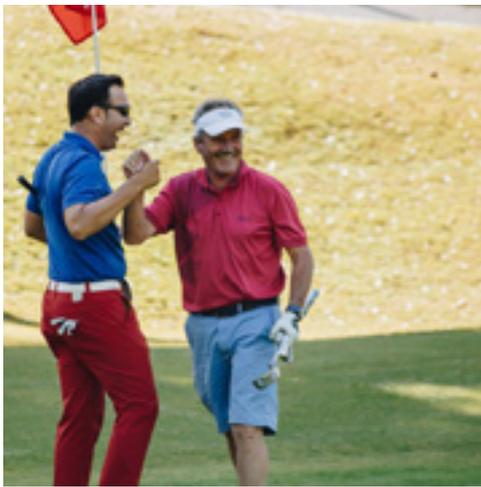
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XVIII Aloha Golf Tournament



After months of uncertainty, we were temporarily able to continue with our events calendar and to persevere with our mission to raise funding that improves the quality of life for children with EB, from the birth of a baby to end of life care.

The Aloha Golf Club tournament took place on the 12th of September. We were delighted to have 155 golfers and 78 collaborators participating in this amazing sporting event. All of the funds raised are used to support families with EB.

Professional golfers, José Luis Sánchez Barrero and John Roethling joined 'The Butterfly Children's Charity Golf Tournament' to help with the 27 competing teams throughout the day. There were trophies for the winners, with 16 prizes for the players with the highest scores in both the men's and women's categories being distributed individually along with prizes for all of the players who were able to complete the challenges set at each of the 18 holes.

We raised just over **17.000 euros** at this event, but sadly we are still struggling to cover our costs. The financial damage caused by this worldwide pandemic has been totally unprecedented and the charity is facing extremely challenging times: income has fallen by 80% and this all-important funding is key to continuing with our work to support families with a specialist team of nurses, community workers, psychologists and research. The charity is the only existing EB support organisation in Spain.

In order for the charity to support and shield families from the reality of living with this condition we need your help. Register now for upcoming events, become a member, a volunteer or visit the website for further information on how you can help.

www.butterflychildrencharity.com

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Golf Butterfly Children XVIII (2020)



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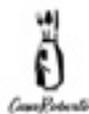
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La Opinión

La Pappardelle PASTICCERIA SPANISH



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Miraflores Golf Academy



Rio Real



SANTANA GOLF



Domarsa

Spanish BAILARINAS

THE STEAK 'N' RIB SHAK

SUR in English



TROFEOS RUZ





Research and DEBRA Butterfly Skin

DEBRA is first and foremost an organisation dedicated to the treatment of children with Epidermolysis bullosa (EB), and the support of their families, but internationally we pool our resources and strive to develop new, more effective treatments and commit ourselves to the research that will one day greatly ameliorate or even eradicate this suffering.

DEBRA International incorporates the different DEBRA charities from countries all over the world. The direct connection between each division means we can be in close contact and up to date on international research worldwide. The MSAP, a medical and scientific advisory panel, evaluates all of the research projects so that grants are continually assessed, ensuring funds are used in the most efficient way.

The initial reason for establishing the link between the different DEBRA offices was to optimally coordinate research work, yet we soon recognised that the importance of improving the quality of life of those families currently living with the disease is as important as trying to find a cure for the future.

Finances and resources from DEBRA Spain are limited, yet we contribute within our means as co-financiers on specific projects along with other the DEBRA charities from around the world.

DEBRA International priorities:

- *To improve genetic and biological understanding, encompassing all forms of Epidermolysis Bullosa, as greater understanding will lead to the development of improved diagnosis and treatments*
- *To work on the development of new therapies, including possible genetic, cellular, medical and protein therapies*
- *Better understanding of the nature of wound healing and the development of skin cancer in people with Epidermolysis Bullosa, and through this expand research into the development of ever more effective treatments and prevention*
- *To support research into medical care that improves treatment and symptom management*

DEBRA Spain has contributed over 200.000 euros to genetic testing and research for EB in the past three years – part of a committed drive to not only care for our Butterfly Children but also aim to greatly improve their lives. Our ultimate dream is to one day find a preventative cure for EB.

Help us to make it so!

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