

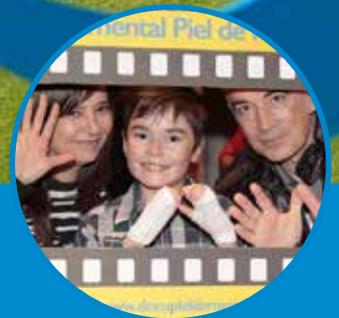
Butterfly Children Golf & Ball *Magazine*

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the Butterfly Children Charity DEBRA

TWO EVENTS, ONE GREAT CAUSE

Dos eventos por una gran causa



IN THIS PUBLICATION EN EL INTERIOR

- About the Butterfly Children Golf & Ball
Conoce el torneo de golf y cena Solidarios "Butterfly Children"
- Achievements of the Butterfly Children Charity in 2015
Logros Piel de Mariposa 2015

www.pieldemariposa.es
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TWO EVENTS, ONE GREAT CAUSE Supporting Butterfly Children and their families

DOS EVENTOS
POR UNA
GRAN CAUSA

The Butterfly Children Charity (DEBRA), has the pleasure of presenting this brochure, marking the 14th edition of the Butterfly Children Golf and Ball. We would like to share some special moments from last year's events and introduce you to the individuals and companies who make it all possible. Thanks to their support we are able to accomplish great things. **Please read about our main achievements** of 2015 in the article "Some wounds are worth it" **on page 6.**

Butterfly Children Golf & Ball, back for its 14th Edition

The beginning of June marks the time to swing for solidarity, birdie for the Butterfly Children and dance for their future. Fourteen years have gone by since a group of Aloha Golf Club members decided to organise a charity golf tournament within their club. We were so privileged that Don Fisher, Elizabeth Katz, Maggie Jackson and Carole Barnett chose us! Since then the Butterfly Children event has become one of the most prestigious, "not to be missed" charity events of Marbella's summer.

Celebrations start on the first Saturday of June with a Stableford Individual Golf Tournament at Aloha Golf Club. Players can enjoy this beautiful course with the opportunity to win €10,000 worth of prizes including prizes on every hole.

For those who like to be entertained, the Sunday evening hosts a 'Magical night under the stars' on the breath taking terrace of Aloha's Restaurant. After a delicious 3 course meal and wine, guests can enjoy live music from the sensational 'Ricky Lavazza' and 'Mr Maph and Simone Lisa' guaranteed to get everyone dancing.

All in all, two fantastic events for one great cause. Over the years these events have played a vital role in the growth of the charity allowing it to fulfil its mission of improving the quality of life for all those suffering from the devastating condition of Butterfly skin throughout Spain.

Hace 14 años un grupo de socios del Club de Golf Aloha quisieron organizar un torneo de golf y una cena de gala solidarios en su club, eligiendo nuestra Asociación como beneficiaria. Desde entonces el "Butterfly Children Golf & Ball" se ha consolidado como un **prestigioso evento social y deportivo** en el que cada año participan más colaboradores, acudiendo participantes incluso desde Reino Unido.

El evento cuenta además con un **padrino de excepción**, el golfista profesional **Miguel Ángel Jiménez**, quien siempre nos dona un exclusivo artículo de memoria para subastar en la cena de gala.

Son ya cerca de 600.000€ los que se han recaudado a raíz de estos eventos en los últimos trece años, los cuales han ayudado a la Asociación a desarrollar importantes proyectos de apoyo que mejoran la calidad de vida de las personas con Piel de Mariposa y sus familias en España.

Gracias a todos los que hacen posible que el "Butterfly Children Golf & Ball" vuelva cada año y además continúe con más fuerza.



Supported by Miguel Ángel Jiménez since 2009

The "Butterfly Children Golf and Ball" has been supported by professional golfer Miguel Angel Jiménez since 2009 when he became an official "ambassador" for the charity. Every year he donates a unique piece of golfing memorabilia to be auctioned at the gala dinner.

Keeping the tradition alive

The last thirteen editions of the "Butterfly Children Golf and Ball" have raised nearly €600,000 for the Charity. In 2015, 196 golfers participated in the tournament and 232 guests attended the gala ball. The weekend has become a real tradition, with supporters flying from the UK just to participate. Our dream is to keep this fundraiser growing in quality and numbers. Anyone who chooses to support it, can do so with the confidence of knowing that they are contributing to a better life for Butterfly Children and their families. Thank you all for giving us wings!!



2009 Miguel Ángel and Dunia 2016



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SOME WOUNDS ARE WORTH IT

Achievements of 2015

Butterfly Skin is a devastating and incurable rare disease causing continuous blistering of the skin. Butterfly Children Charity (DEBRA) works to improve the lives of the Butterfly Children Families in Spain. These are some of our main achievements from 2015:

First ever Spanish documentary about Butterfly Skin

"Some wounds are worth it" says Belen, the mother of 12 year old Lucia. Lucia enjoys playing and having a good time with her sisters even if this means that she will damage her fragile skin. She was born with the devastating condition of Butterfly Skin that, unknown to her family was to change their lives forever. Their story is one of five featured in the documentary created by the charity with the aim of raising awareness of the condition. It is the first ever Spanish documentary made about this devastating disorder. The production was publicly presented at a grand premiere in Madrid on the eve of the Butterfly Children International Day. In attendance was Princess Elena of the Spanish Royal Family, representatives of the Ministry of Health and other important public entities.



Watch the documentary with full English subtitles on www.docupieldemariposa.es



LOGROS PIEL DE MARIPOSA 2015

El 2015 fue un año de gran visibilidad para la Piel de Mariposa. **Produjimos el primer documental español sobre Piel de Mariposa** y lo estrenamos en una gran "première" a la que asistieron personalidades como la Infanta Dña. Elena y representantes políticos de sanidad y otros ámbitos. Con el estreno dábamos el pistoletazo de salida a una **campaña de sensibilización con motivo del Día Internacional Piel de Mariposa** el 25 octubre, que consiguió **gran cobertura mediática**, y llegó a ser **trending topic** en español en Twitter ese día. Además, **más de 15.000 personas vieron el documental** en www.docupieldemariposa.es, donde todavía está disponible.



Gracias a esta campaña y al trabajo realizado durante todo el año, la **Piel de Mariposa fue la segunda enfermedad rara más mencionada en prensa nacional en 2015** según un informe del Observatorio de Enfermedades Raras (OBSER).

En el campo de la acción política logramos, después de muchos años de reuniones con representantes políticos, que el Ministerio de Sanidad y todas las Comunidades Autónomas firmaran un **acuerdo para garantizar la dispensación gratuita de los materiales necesarios para el tratamiento de la Piel de Mariposa**, reconociendo por fin un derecho básico de todas las personas afectadas en España. Actualmente nos encontramos haciendo seguimiento con las Comunidades Autónomas para que el acuerdo se cumpla.

Butterfly Skin, second most spoken about rare disease

The presentation of the documentary in Spain was the catalyst for a **major campaign** called "Ponte Alas" ("Wear Wings") orchestrated by the charity **to raise awareness for Butterfly Children International Day** on the 25th October. The campaign successfully **reached trending topic status on Twitter in Spanish**, meaning that Butterfly Skin was one of the most commented on topics that day. We also managed to capture the attention of many important media platforms and over **15,000 people watched the documentary** during the campaign.

Thanks to the campaign and the public relations work carried out through the year, Butterfly Skin was the **second most discussed Rare Disease in Spanish press** in 2015, according to figures obtained from a study published by FEDER (Spanish Federation of Rare Diseases) in collaboration with the University Cardenal Herrera.

Raising awareness is essential for a small charity like ours, working with the rare and unknown condition of Butterfly Skin. **Awareness means less isolation** for the Butterfly Children Families **and more solidarity** from society. Additionally taking into consideration that 1 in every 227 people are carriers of this condition, any family could unexpectedly have a child or a grandchild with Butterfly Skin at anytime. Should this happen, they will know that they are not alone and that the charity is here to help.



Official agreement to guarantee free bandaging materials

One of the **basic rights that the Butterfly Children Charity has lobbied for**, for many years, is that patients should have access to all the bandaging materials needed for their daily wound care routine free of charge. On average a family could spend between €200 and €2000 a month on these materials. This is another discriminatory burden that the families have to deal with on top of the physical and emotional strains.

During the many meetings held with different authorities, it was always recognised that patients should have the right to access bandaging materials for free but an official commitment was never reached. Finally **in July 2015 we managed to achieve an official agreement** from the Ministry of Health and all the regional governments **to guarantee that all the Butterfly Children Families in Spain can access bandaging materials for free**. The next step for us is to follow up on the agreement to ensure that all hospitals, pharmacies and health centres abide by the agreement.

If you wish to now more about the work of the Butterfly Children Charity (DEBRA) please visit www.butterflychildrencharity.com or contact butterflychildren@debra.es Your help gives them wings.

OUR WORK IN NUMBERS NUESTRA LABOR EN CIFRAS



762

Enquiries addressed by our Health and Social care team

Demandas atendidas por nuestro equipo socio-sanitario



22

Families visiting the Respite Home

Familias que han visitado el Hogar de Respiro



7

Visits to new-borns

Visitas de nuevo nacimiento



2

Visits to families at home

Visitas a familias en casa



49

Families assessed by our team at Hospital La Paz

Familias atendidas por nuestro equipo en Hospital La Paz



51

Families attending the National Meeting

Familias que han asistido al Encuentro Nacional



2

Crisis management visits

Visitas de apoyo en situaciones de crisis

Supporters / Colaboradores

XIV Butterfly Children Golf & Ball - 2016



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Richard & Sue Fawcett
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