Butterfly Children Golf & Ball *Magazine*

May 2018
Published by
DEBRA - BUTTERFLY CHILDREN CHARITY

*GIVING WINGS TO PEOPLE WITH BUTTERFLY SKIN**

Dando alas a las personas con Piel de Mariposa

* Butterfly Skin is a rare and incurable condition that causes extreme fragility of the skin · *La Piel de Mariposa es una enfermedad rara y sin cura que provoca una extrema fragilidad en la piel.*

IN THIS PUBLICATION ***EN EL INTERIOR***

· Don Fisher; life and soul of the "Butterfly Children Golf & Ball"
Don Fisher, el alma del evento solidario Butterfly Children

· Pain is Eased with Good Company
El dolor se pasa con la mejor compañía

www.pieldemariposa.es
www.butterflychildrencharity.com

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Butterfly Children

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DON FISHER; LIFE AND SOUL OF THE "Butterfly Children Golf and Ball"

DON FISHER, ALMA DEL EVENTO "BUTTERFLY CHILDREN"

Each and every June, an event takes place that solidifies not only the support, but the special relationship held between the "Butterfly Children" and the Aloha Golf Club. Don Fisher is a much needed and valued piece of the puzzle. A true gentleman that shares a huge heart and a huge smile with everyone he meets, who has never failed to support the cause over the last 16 years.

Why did you choose to support DEBRA-The Butterfly Children Charity?

My relationship with the charity began when the Founder, Inigo Ibarrondo built my home in 1996. That's when I first met his family and his son, who, affected by "Butterfly Skin" always had his limbs bandaged. Despite having worked with many charities by that time, the distinct and instant connection I felt from the moment I came across this cause, was unlike any other, perhaps it was because I also knew Inigo personally.

How did the idea to organize a charity event come about?

Three of our members, Elisabeth, Maggie and Carole, approached me with an idea to organize an event in support of a cause and asked for my help. I then reached out to Iñigo for more details of the mysterious condition which his child suffered from and I instantly became aware of how difficult life with this disease must be, and in that moment, I agreed to help however I could.

How do you remember the first years?

I was a member of the Executive Committee of the Club and as a result I was able to ensure we could obtain the course free of charge. We held the first tournament that year and I'll never forget the moment we announced the amount we had been able to raise as a result of our efforts, a grand total of €35,000 It was an incredible result; there's no doubting the generosity of the Aloha Golf Club and its members.

How has the event progressed over the past 16 years?

The most concerning times we faced were in 2008, when the unforeseen arrival of the financial crisis hit us hard. That was a very difficult time for us. It was the year that we were most challenged to raise funds, in comparison to previous years.

What encourages you to keep supporting the cause?

These children are, quite frankly, the bravest children that I have ever known in my life. One year, the charity invited me to their annual National Families Meeting, and to my surprise when I was introduced as the person responsible for enabling the employment of the first full-time nurse, the entire room took to their feet and applauded. It was a deeply emotional moment.

What are you proudest of?

I am most proud of what the charity has been able to achieve and how they have grown in this short time. When I first came on the scene it was just Iñigo and his wife Nieves, the organization's President. There are many charities that I don´t trust, but this particular organization has never failed to fill me with confidence in both their ethics and the management of its funds. The manner in which the organization has rolled out their projects over the years is admirable and I couldn't be prouder that the Aloha Golf Club plays a part in their journey.

Since the inauguration of the event over €650,000 have been raised. None of this would have been possible without the unwavering support and trust of people such as Don Fisher, Elizabeth, Maggie, Carole, the Aloha Golf Club and of course the companies and individuals who collectively help us to create a wonderful event.

Cada junio tiene lugar un evento solidario para ayudar a las personas con Piel de Mariposa en el Club de Golf Aloha. Don Fisher es una de las piezas clave ya que lleva 16 años haciendo posible el Torneo de Golf y la Gala Butterfly Children.

¿Por qué decidiste ayudar a la Asociación?

Mi relación con la Asociación comenzó cuando el fundador, Íñigo Ibarrondo, me construyó una casa. Así le conocí a él y a su familia, incluido su hijo con Piel de Mariposa. La conexión que sentí desde el primer momento fue única.

¿Cómo surgió la idea del evento?

Tres socias del club, Elizabeth, Maggie y Carole, me pidieron ayuda para un torneo de golf solidario. A través de un folleto sobre la enfermedad pude ver lo dura que era la Piel de Mariposa. Y pensé, ¡haremos algo por estos niños!

¿Qué evolución has podido percibir?

Los mayores problemas que tuvimos fueron en el año 2008 con la llegada de la crisis económica. Fue muy duro. Fue el año que menos recaudamos en comparación con el resto.

¿Qué te da fuerzas para seguir ayudando?

Estos niños son los más valientes que he conocido en toda mi vida. Un año, la Asociación me invitó al Encuentro de Familias Piel de Mariposa. Y cuando me presentaron como la persona que había ayudado a poder contratar a las primeras enfermeras todos se levantaron y comenzaron a aplaudir. Fue tan emocionante…

¿De qué te sientes más orgulloso?

Estoy orgulloso de todo lo que ha crecido la Asociación. Existen muchas ONGs en las que no confío, pero la Asociación nunca ha mostrado el más mínimo defecto en sus cuentas ni en su ética. Amo la ONG y a los niños para los que trabajan.

Desde 2003, hemos recaudado cerca de 650.000€. Nada de esto habría sido posible sin el compromiso de personas como Don Fisher, Elizabeth, Maggie y Carole, el Club de Golf Aloha y todas las empresas y personas colaboradoras.

Butterfly Children Golf & Ball 2017

Torneo de Golf y Gala "Butterfly Children" 2017

XVI Butterfly Children

Charity Golf · Golf Solidario

2nd June
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www.butterflychildrengolf.org

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In collaboration with: essential marbella magazine

Funds raised to support the Butterfly Children.
Fondos recaudados para apoyar a las personas con Piel de Mariposa.

XVI Butterfly Children

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SHORT BUT POWERFUL STORIES

PEQUEÑAS-GRANDES HISTORIAS

ANA *Mía's mother / Madre de Mía*

"When my daughter Mia was born, we found ourselves alone and vulnerable. The charity visited us in hospital as soon as they found out about Mia. Thanks to their support, my daughter now has everything she needs and we have access to the necessary supplies of dressings, free of charge. On top of that, the organization were able to assist the training of the nursing staff on how best to treat the condition as they had no previous experience handling the needs of one of these patients. Without the organization, we would have been completely lost."

"Cuando nació nuestra hija Mía, nos encontramos solos y desprotegidos. La Asociación no tardó ni dos días en presentarse en el hospital. Gracias a su apoyo, mi hija tiene ahora todo lo que necesita y podemos adquirir gratis el material de cura. Además, los profesionales de la ONG se encargaron de formar al personal del hospital que no conocía cómo tratar su enfermedad. Sin la Asociación estaríamos huérfanos."

ANELIYA *Martín's mother / Madre de Martín*

"It was my dermatologist that introduced me to the charity. When I called them, their team explained everything I needed to know about the condition, the treatment it requires and they connected me to all the specialists I would soon come to rely on. They helped me to fully understand my son Martin' condition and how to best care for him. I am so immensely grateful that the charity exists."

"Mi dermatóloga me habló de la Asociación. Cuando les llamé, sus trabajadores me informaron sobre la enfermedad, su tratamiento y me conectaron con todos los profesionales especializados que he necesitado. Me ayudaron mucho a asimilar la enfermedad de mi hijo Martín. Me explicaron cómo cuidar bien de él. Agradezco muchísimo que exista la Asociación."

IRENE *Lady with Butterfly Skin / Afectada de Piel de Mariposa*

"I have 'Butterfly Skin' and on the day I gave birth to my children one of the nurses from the charity stayed by my bedside throughout labour. From the moment I was admitted until I reached the theatre, the nurse was involved in everything the hospital staff were doing. The peace of mind that it gave me to know someone was watching over me made a big difference"

"Yo tengo Piel de Mariposa, y el día que dí a luz a mis hijos una de las enfermeras de la Asociación me acompañó en todo momento: desde el ingreso hasta la llegada al quirófano, interviniendo en lo que iban haciendo el resto de los profesionales. La tranquilidad que te da el saber que hay unos ojos que lo ven todo por ti hace mucho."

PILAR *Pedro's mother / Madre de Pedro*

"I contacted the charity to ask for their help because I needed them to explain my son's condition to the school staff as I wanted to avoid the teachers from feeling the inevitable fear associated with dealing with someone with Butterfly Skin. As well as visiting the school, the charity lobbied the local council to help secure a dedicated carer to help Pedro in his daily activities whilst at school, which has made everything so much easier."

"Contacté con la Asociación para que pudieran explicarle al colegio de mi hijo su enfermedad. Quería que los profesores no tuvieran miedo de tratar con él. A partir de la visita de la Asociación conseguí una monitora para Pedro que le ayuda en su día a día en la escuela. Desde entonces todo es mucho más fácil."

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PAIN IS EASED WITH GOOD COMPANY

EL DOLOR SE PASA MEJOR EN BUENA COMPAÑÍA

Fernando is 16 years old and although he enjoys learning all about the field of Information Technology, he says he would like to be a Doctor. He dreams of finding a cure for Butterfly Skin, but until that time he enjoys the peace he finds in music, conversations with friends and a hearty meal. Without doubt our member and friend, knows how to make the most of his situation. Despite his age he has a lot to teach us about life.

Describe your day to day life…

On a school day, I wake up, get myself ready and prepare to go to class. Whilst in class, I do everything I possibly can without risking hurting myself. In the afternoons I do homework and spend the rest of the day focusing on being happy with who I am. There are moments of extreme discomfort but I have learned to put that aside and concentrate on my friends, my family and my duties.

How is life with the condition?

The truth is that you never get used to it, but you can learn to tolerate it. Even after so long I still don't understand everything about the condition, but I do know how to protect myself now.

What does having Butterfly Skin involve for you?

I don't consider it something from a different world, and it might well be that I have difficulty doing certain things but that doesn't mean it's a bad thing. It means there is always going to be pain, but having the company of family and friends helps alleviate it.

What would you like to do when you grow up?

Ideally I would like to be a Doctor because I think it would be nice to help other people, just how I have been helped myself. But I would also like to explore opportunities in the Information Technology field because that is one of my strengths.

How important is it for this charity to exist?

The charity is extremely important in my point of view because without their support we wouldn't have been able to access many of the things that I need, and that is an enormous help to my family.

What have you learned about Butterfly Skin?

Whilst it's true that most of what we know about Butterfly Skin is negative, there is a silver lining; the incredible people you meet who are prepared to help you however they can. If it wasn't for Butterfly Skin I would have most likely made different choices in life and that would mean I wouldn't have met the people who are so kind to me. Despite everything, I wouldn't change this part for the world.

I have also learned that we must never give up or give in. It might be hard but we only get one life and each and every one of us are dealt the cards we are dealt. We must live our lives to the fullest in spite of any and all difficulties!

Fernando tiene 16 años y sueña con que se descubra la cura a la Piel de Mariposa. A pesar de su juventud, nos da toda una lección de vida.

¿Cómo es un día en tu vida?

Pues un día lectivo me despierto, me aseo y voy a clase. Hago todo lo que puedo permitirme sin hacerme daño. Por la tarde hago alguna tarea y el resto del día lo paso feliz de ser yo mismo. Existen dolores, pero he aprendido a darles de lado y centrarme en mis amigos, familiares y obligaciones.

¿Cómo es la convivencia con la enfermedad?

Pues sinceramente uno nunca se acostumbra, pero la soporto. Después de tanto tiempo aún no sé algunas cosas, pero ahora me sé proteger a mí mismo.

¿Qué supone para ti tener Piel de Mariposa?

Puede que tenga dificultades para algunas cosas, pero eso no implica nada malo. Claro que siempre supone dolor, pero eso se pasa con la mejor compañía que son los amigos y la familia.

¿A qué te gustaría dedicarte cuando seas adulto?

Me gustaría ser médico porque para mí sería bonito dar a los demás algo que en algún momento dieron por mí para ayudarme. También me gustaría hacer algo que tenga que ver con la informática, se me da bien.

¿Es importante que exista esta Asociación?

La Asociación tiene una gran importancia porque desde mi punto de vista sin ellos no podríamos acceder a muchas cosas que ahora nos facilitan, y eso es una gran ayuda que merece la pena.

¿Qué has aprendido de la Piel de Mariposa?

Yo he aprendido que nunca hay que rendirse. Puede que sea difícil, pero vida solo hay una y a cada uno le toca lo suyo. La vida hay que vivirla al cien por cien a pesar de todas y cada una de las dificultades.

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How many dimples are there on a standard golf ball?

How many people in Spain have epidermolysis bullosa (Butterfly Skin disease)?

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