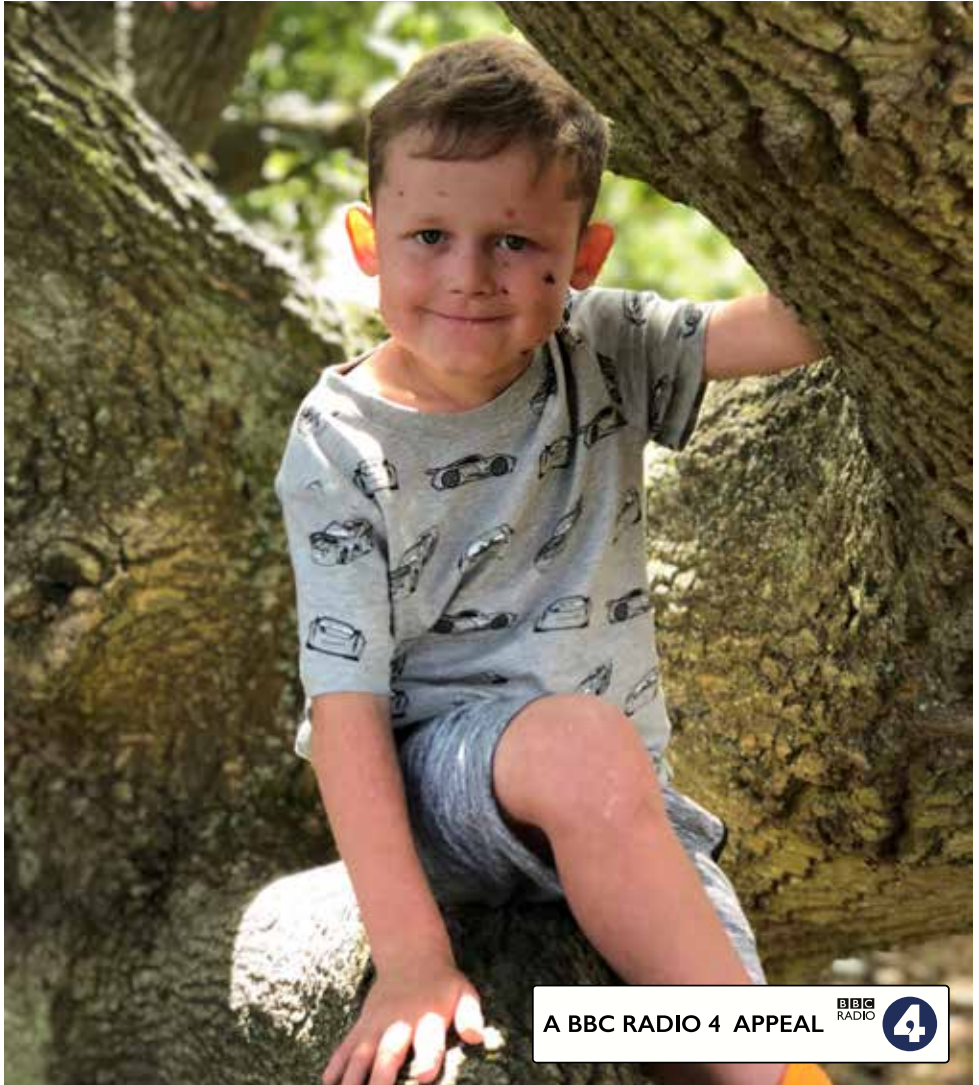



The logo for 'debra news' features a stylized purple butterfly icon above the text. 'debra' is written in green and 'news' in purple, both in a bold, lowercase sans-serif font.

Supporting those suffering from EB

Edition 2 2018



A BBC RADIO 4 APPEAL 

Please listen to Freddie's story on BBC Radio 4

Welcome to the Winter edition of DEBRA News

As we celebrate our 40th anniversary this year, it's my pleasure to begin this issue of DEBRA News by announcing that DEBRA has been selected for the BBC Radio 4 Charity Appeal on Sunday, 4 November.

Sports personality and long-time DEBRA supporter Steve Rider will be presenting the appeal on our behalf. Jenna and Nick struggled to cope when their son Freddie was born with EB. Tune in to hear their story and how practical and emotional support from DEBRA's EB Community Support Team is helping the family now.

With an audience of 1.82 million people, we hope the appeal will raise awareness of EB across the UK and funds too, as we rely wholly on donations to carry out our work.

Please listen in on Sunday, 4 November at 07:54 to hear what a difference your support makes. You can catch it again at 21:25 on Sunday evening or 15.27 on Thursday, 8 November. It will also be available to listen to online immediately after broadcast, just search for 'BBC Radio 4 Appeal'.



Ben Merrett, DEBRA CEO

This adds to what has already been such a fantastic year for DEBRA. A real highlight being the official opening of the Rare Diseases Centre at St Thomas' Hospital by the Countess of Wessex which took place on 25 September (read more on page 14). I would personally like to thank you all for celebrating our 40th anniversary year with us, for making it so special and for your continued loyalty and hard work to #FightEB.

I wish you all a very happy and warm festive season! Don't forget to purchase your Christmas cards from DEBRA (catalogue enclosed) and to visit your local DEBRA shop for some great stocking fillers.

Thank you. Together we #FightEB, together, we will beat EB.

A handwritten signature in black ink, appearing to read "Ben Merrett".

Ben Merrett – CEO of DEBRA

Thank you!



Welcome to DEBRA News

Winter 2018

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About EB & DEBRA

Epidermolysis Bullosa (EB) is a potentially fatal skin condition that causes constant pain due to unstoppable internal and external blistering. Excessive blistering creates scar tissue that can cause fingers and toes to fuse together, and can lead to an aggressive form of skin cancer.

DEBRA is the national charity supporting those directly affected by, and working with, EB.

- We fund pioneering research for symptom alleviation and, ultimately, a cure
- We provide care and support to the entire EB Community

Trustee spotlight



Andy Grist with his daughter, Isla

Andy Grist, Vice Chair of DEBRA's Board of Trustees lives near Inverness with his wife Rachael and his two daughters, Isla (10), who has EB and Emily (12).

"I became aware of DEBRA shortly after Isla was born. It was quite obvious there was something wrong as there was no skin on her hands or feet.

When Isla was diagnosed with EB, we were guided and supported by a team of specialist EB nurses and consultants, which DEBRA helps to fund. DEBRA's support has continued as Isla has grown up. DEBRA brings us a lot of things including expert nursing care and the opportunity to get some respite in one of their holiday homes, somewhere we feel safe.

Being part of DEBRA has also made us part of the wider EB Community. Life with EB can feel quite isolating at times.

But that ends when we meet other families through DEBRA, where we can share experiences with others facing similar challenges.

I became a Trustee of DEBRA to do what I could to make sure Isla and everyone who has EB has a good quality of life and that to ultimately find a cure. Fundraising is so important to achieve this – it's your support that means DEBRA can continue to provide care and support to the EB Community and fund vital research. I am always humbled by the amount of effort DEBRA puts in on behalf of EB sufferers. As a Trustee and as a parent, I am extremely grateful."

Find out more!

To find out more about our trustees, visit our website at www.debra.org.uk/about-us/our-trustees

Why I'm leaving a legacy to DEBRA

Supporter Philip Evans has been involved with DEBRA since the charity was founded in 1978, including 23 years as Chairman of Trustees. Philip shares with us why he has decided to include a gift to DEBRA in his Will.

"I decided to leave a gift to DEBRA in my Will because my daughter Francesca was born with Recessive Dystrophic EB. She suffered terribly during her short life and I would like to do what I can to spare other children the dreadful pain that Francesca went through.

Having been involved with DEBRA over many years, I have no doubt that a cure will be found. The progress of research into EB has been gathering pace in the last 20 years. The speed of change is increasing all the time, and major breakthroughs are in sight. It is no longer a question of "if" a cure will be found but "when" a cure is found.

The present is dreadful for those people suffering from EB. A cure cannot come quick enough. In the meantime, there is so much that DEBRA can do to help people living with EB now in terms of healthcare, information and support.



Phillip Evans

I would encourage others to please give DEBRA their support. A gift in your will could help end the pain of thousands of children who carry the EB gene in the future. Thank you."

DEBRA's promise to you

- ✓ We recognise your loved ones come first in your Will
- ✓ We will never ask you about the size or type of bequest, because every gift makes a difference
- ✓ We understand that you may need to update your Will if your circumstances change
- ✓ We promise to use your gift wisely, in line with your wishes

Please contact Frances Greaney on **01344 467782** or e-mail frances.greaney@debra.org.uk to find out more information about how your bequest could help.

Government moves to legalise some forms of medicinal cannabis

Could medicinal cannabis be used to treat pain and itch caused by EB?



We welcome Home Secretary Sajid Javid's decision to legalise some forms of medicinal cannabis following a clinical review earlier this year.

Members of the EB Community in many countries around the world have reported that cannabis can reduce the impact of pain and itch caused by EB, so we're funding research to collect the evidence needed to help make a safe and effective form of cannabis-based pain relief for people with EB widely available.

In terms of treatment, cannabis-based medicines may be more effective than the opioids and anti-inflammatories which are currently often prescribed to EB patients to reduce the impact of pain and itch.

The clinical review, which took place in June 2018, concluded that there is evidence that some forms of medicinal cannabis have therapeutic benefits for some conditions.

Following this, and after receiving advice from two sets of independent advisers, the Home Secretary has made the decision to reclassify some cannabis derived products, making it easier to prescribe some cannabis based medicine for those with an "exceptional clinical need".

Our CEO, Ben Merrett, said: "Existing treatments for pain and itch in the condition are limited so we hope this new ruling will make it easier for some people with EB to access more effective pain relief."

Read our Q&A on this research on the next page.

Why we're funding research into cannabis-based medicines

We're funding an international clinical trial to evaluate the impact of cannabinoids (a component of the cannabis plant) as a potential treatment for the constant pain and chronic itch caused by EB – two symptoms which have a severe impact on the quality of life for people suffering from the condition.

This clinical trial is a first step towards collecting the scientific evidence needed to prove the safety and efficacy of cannabis-based medicines (CBMs) in EB, as well as determining optimum dosage and possible side effects for people with EB.

This research will help find the safest and healthiest way to deliver medicinal cannabinoids to people with EB, with the maximum alleviation of symptoms and the minimum of side effects.

If successful, the trial could ultimately lead to an effective form of cannabis-based pain and itch relief being made available to the EB Community, significantly improving quality of life.

What is the treatment being investigated in this trial?

During the trial, a group of adults living with EB will pipette a cannabis-based oil under their tongues four times daily.

The oil contains naturally derived compounds, cannabinoids, from the cannabis plant. The measured cannabinoids are tetrahydrocannabinol

(THC) and cannabidiol (CBD) at 1.3% and 2% respectively.

Participants in this study will report changes in levels of pain and itch and changes in their quality of life through a number of surveys.

How does this treatment work?

Research into THC and CBD shows they can modify signals that transmit messages for pain and itch. It is hoped that they can be used to control and reduce the itch and pain experienced in EB.

Where could this research lead?

Ultimately, we hope this research will lead to a much more effective treatment for the pain and itch caused by EB. This trial will formalise the anecdotal evidence that suggests that CBMs could be an effective treatment for pain and itch in EB and pave the way for future research.

This study also could lead to changes to clinical practice for the treatment of pain and itch in EB and the creation of a treatment protocol, helping clinicians determine when it is appropriate to prescribe CBMs to people suffering from EB.

Read our full Q&A on the research at www.debra.org.uk/CBM

Your donations make this research possible. Thank you.

Steve Rider Fights EB on Radio 4 Appeal



Steve Rider, Sports Presenter

We asked sports presenter Steve Rider to give the Radio 4 Appeal on our behalf. Here's why he volunteered to fight EB:

"I was brought to DEBRA through my good colleague Peter Aliss, who was the BBC golf commentator. 15 years ago, we did a fundraiser for DEBRA where I met a charismatic young man called Jonny Kennedy, who suffered from EB.

Although we didn't appreciate it then, he was in the last weeks of his life. He was very compelling company, because of his humour and positive outlook – we knew then we had to be involved with DEBRA on a long-term basis. We started by working with the charity to set up the DEBRA Golf Society, which I am still Vice President of today.

It's second-hand involvement – I'm not on the frontline of EB care but I want to do what I can to fight EB. The DEBRA Golf Society brought me into contact with many people affected by EB, including Jenna, Nick and their son Freddie, whose story you will hear in the appeal.

Meeting people with EB like Freddie has made me realise the condition can take over every part of life, both practically and emotionally. Every individual is profoundly affected, whether they are a family member or a sufferer.

This makes it a very easy decision for me to give up my time to raise money for DEBRA.

EB is a condition that can be beaten. EB makes huge demands on the individual and the family, but those can be counteracted with the practical and emotional support DEBRA provides, and the research DEBRA funds. It's a charity that has a very positive effect on every level. You can see the benefits that it generates.

That's why I support DEBRA – I'm delighted to present the appeal on their behalf and raise awareness of EB and funds for DEBRA so they can carry on helping people affected by EB like Freddie and his family."

Listen to the appeal on Sunday, 4 November at 7.54am or search online for 'BBC Radio 4 Appeal'.



Jenna, Freddie and his sister Sophie

Where does your money go?

Freddie, whose story you'll hear in the BBC Radio 4 Appeal, has EB and he needs constant care. His parents, Jenna and Nick struggled with his diagnosis and worried about how they would cope financially. Because of you, DEBRA was able to help.

Life with EB is so hard for Freddie, for his family and for the 5000 people in the UK who suffer from the condition.

With your help, DEBRA can make sure no one has to face EB without support.



£32 could give a family like Freddie's one month of life changing practical and emotional support



£50 could help fund two hours of specialist nursing, helping people with EB minimise damage to their skin



£75 could help a person with EB attend a social event, such as DEBRA's Members' Day, and meet other people with the condition



£100 could help a person with EB and their family enjoy a week of respite in one of our holiday homes



£200 could pay for a soft carpet and help a child like Freddie learn to crawl in a safe environment

Thank you

Where do you work? Does your company offer match funding?

Match funding makes a massive difference to our work each year, helping to raise thousands of pounds to #FightEB. Many companies will 'match' the funds that an employee raises, doubling the impact of their fundraising.

We have a wide range of events and we always need volunteers to come and support them and help raise money. We also have many challenge events available throughout the year such as London Landmarks, Great North Run or Ride London. All of these things are opportunities for match funding. If you are not sure if your employer has a match funding scheme, please ask them.

Barclays offer match funding and several of their members of staff volunteer at DEBRA events.

Here is what one of their volunteers has to say...






'DEBRA is such a worthwhile cause. The days spent out of the office with the DEBRA team highlights the commitment they have to make life better for the children and adults with EB. If I can support the team with my time and raise funds for DEBRA I know it will be appreciated and used to full effect. I would encourage others to come along and do the same.' Barbara Barker from Barclays.

Find out more!

Get in touch with jenny.jackson@debra.org.uk if you would like to discuss opportunities to volunteer to help raise funds and secure your match funding, or if you would like more information about challenge events you could take part in.

Butterfly Walk coming in 2019!

Join us at Greenham Common in Berkshire on Saturday 6 July 2019 for DEBRA's very first Butterfly Walk to #FightEB

-  Family friendly event
-  Short and long distance for all abilities
-  Achievable fundraising targets
-  Idyllic surroundings in the South of England
-  Meet with other DEBRA supporters and help us create a sea of purple, together we will #FightEB

To book, please go to www.debra.org.uk/butterflywalk



Remarkable fundraising stories

We have some remarkable fundraisers who have overcome incredible challenges in the last few months. Here are just two examples of how our fundraisers decided to #FightEB.

Without our fundraisers' hard work and determination, we would not be able to provide care and support to the EB Community or fund research into effective treatments and, ultimately, a cure.



Miles Crossley

This year DEBRA supporter Miles Crossley completed three amazing cycle challenges to #FightEB. Miles devised the three challenges himself to increase awareness of the condition and raise vital funds for DEBRA. It is a cause extremely close to Miles and his family's heart as his son Mason has EB.

He says: "I'm doing this to raise money to help DEBRA find a cure and end this horrific condition and ultimately create life-changing results for those affected. DEBRA has also supported us, and I'm doing these challenges to help DEBRA care for other people suffering from EB and their families."

Allan McGrath

Dedicated supporter Allan McGrath decided to embark on a running challenge to celebrate DEBRA's 40th year. Allan's good friend and DEBRA Trustee Andy Grist's daughter Isla has EB. Allan decided to run 5k every day for 40 days after seeing the devastating effects EB can have on family life. He wanted to raise funds so DEBRA can carry on with vital research and provide essential care and support to those suffering from EB.



Thank you to our remarkable fundraisers for all their hard work!



40th Anniversary Tea Party

This year marks 40 years since DEBRA was founded. During October, our charity shops held their own Tea Party events to celebrate. Join us in celebrating by hosting your own Tea Party in aid of DEBRA!

Hold your own Tea Party in aid of DEBRA!

Get together with your friends, family, colleagues or school mates and enjoy some tasty treats while raising money to help people suffering from EB across the UK.

Your free fundraising pack has everything you would need for a morning or afternoon filled with fun! Starting from posters and flyers to help you spread the word, to cupcake toppers and bunting to make your Tea Party a success!

Download your free Tea Party pack from:

debra.org.uk/teaparty

You can also find some inspirational

recipes at debra.org.uk/teaparty

Don't worry if baking is not your thing, just pop to the shops, we won't tell!

Drink tea, #FightEB

A charity registered in England and Wales (1084958) and Scotland (SC039654).
Company limited by guarantee registered in England and Wales (4118259).


for people whose
skin doesn't work
we do

Volunteering

Meet our new Volunteer Manager

We would like to welcome Wendy Bridge to the DEBRA team. Wendy started working as Volunteer Manager as part of the HR team at DEBRA at the beginning of August.



Wendy Bridge

About Wendy

Wendy brings a wealth of experience to the role, previously working as a Volunteer Manager recruiting and supporting volunteers in the Hospice and Retail Sector. Prior to this, Wendy worked for over 20 years as a Senior Marketing and Operations Manager.

Retail opportunities for you

Our 130 nationwide charity shops are heavily reliant on volunteers. From offering customer support to sorting our stock, they #FightEB. Our retail volunteers are greatly valued and essential to helping the shops run efficiently. Being a volunteer is rewarding and is a great way to develop your skills and experience. Our wide range of volunteering opportunities and flexible approach mean that you decide exactly how and where you give your time.

Fundraising Volunteers

We have an exciting calendar of DEBRA fundraising events, from charity golf days to sponsored runs, dining and cycling. Have a sneak peek at some events we have planned for 2019 on page 16. We're always on the hunt for new volunteers to join our growing team and help out at our events!

Get in touch!

For more information on volunteering for DEBRA contact Wendy Bridge at Wendy.Bridge@debra.org.uk or visit your local DEBRA charity shop and ask to speak to the manager about current volunteering opportunities.

DEBRA's Royal Patron opens Rare Diseases Centre



DEBRA's Royal Patron, The Countess of Wessex, officially opened the Rare Diseases Centre at St Thomas's Hospital, London, on Wednesday, 25 September.

DEBRA contributed £250,000 to the construction of the new centre at St Thomas's Hospital, which is specifically designed for people with genetic conditions, including EB.

Her Royal Highness met people who have benefitted from the state-of-the-art facility as well as the doctors and nurses who work there, including DEBRA Member Henry George, who has EB, and Consultant Dermatologist Professor Jemma Mellerio, who specialises in EB.

The Countess of Wessex heard how the centre has transformed the patient experience for EB sufferers visiting the hospital.

Before the facility opened, patients were seen in separate clinics around both the Guy's and St Thomas' sites, and had nowhere comfortable to rest between appointments, which could take several hours.

Using feedback directly from patients, the centre has been designed to meet their needs. For example, it has soft chairs and furniture with curved edges so that it does not catch on the fragile skin caused by EB.

Speaking at the opening ceremony, The Countess said: "It is a huge pleasure for me to open the Rare Diseases Centre. The testimonies we've heard from the patients with different rare conditions make it clear why this was so necessary."

DEBRA CEO, Ben Merrett, added: "At a time when the NHS is struggling financially it is wonderful that a charity partnership with St Thomas' Hospital has enabled the construction and development of the centre. St Thomas' Hospital is a Centre of Excellence in EB and now the facilities match the truly exceptional standard set by the clinicians working there."

Thank you to all our supporters who made this project possible. You #FightEB

Find out more about the Rare Diseases Centre at www.debra.org.uk/RDCOpening

2018 highlights


As DEBRA's 40th anniversary year comes to a close we want to thank everyone for helping us make it such a memorable and special year. Some fantastic achievements has been made and we wouldn't be able to carry on providing care and support to people suffering from EB or funding vital research into effective treatments and, ultimately, a cure, without you!

Here are a few of our memories from 2018!



2019 dates for your diary

We have an exciting schedule of events and fundraising opportunities coming in 2019. Book the dates in your diary now and don't miss out!

January 

12th - DEBRA Business Network, Twitter Head Offices, London

Do a sponsored Dry January

March 

24th - London Landmarks Half Marathon 2019

May

1st - Blackwell golf day

8th - DEBRA Sporting Challenge, Buckinghamshire (shooting)

18th & 19th - Members' Weekend and AGM

February

4th - DEBRA Great Chefs Dinner, Roux at The Landau

Hold your own Pancake Day fundraising event 

April

9th - Hankley Common golf day

26th - St George's Hill golf day

28th - Virgin Money London Marathon 2019

28th - DEBRA Business Network, Riverbank Plaza, London

June

13th - Archerfield golf day

14th - Celebrity Chefs event





July

6th - Butterfly Walk,
Greenham Common,
Berkshire

Hold your own
Wimbledon
Sweepstake



September

5th - DEBRA Business
Network (venue TBC)

8th- Great North Run

November

21st - DEBRA
Business Network
(venue TBC)

August

4th - Prudential
RideLondon-Surrey
100 miles



Hold your own
Summer BBQ



October

Hold your own
Tea Party



Fight Night (date TBC)

December

Hold your own
Christmas concert,
Christmas jumper day
or wrapping session



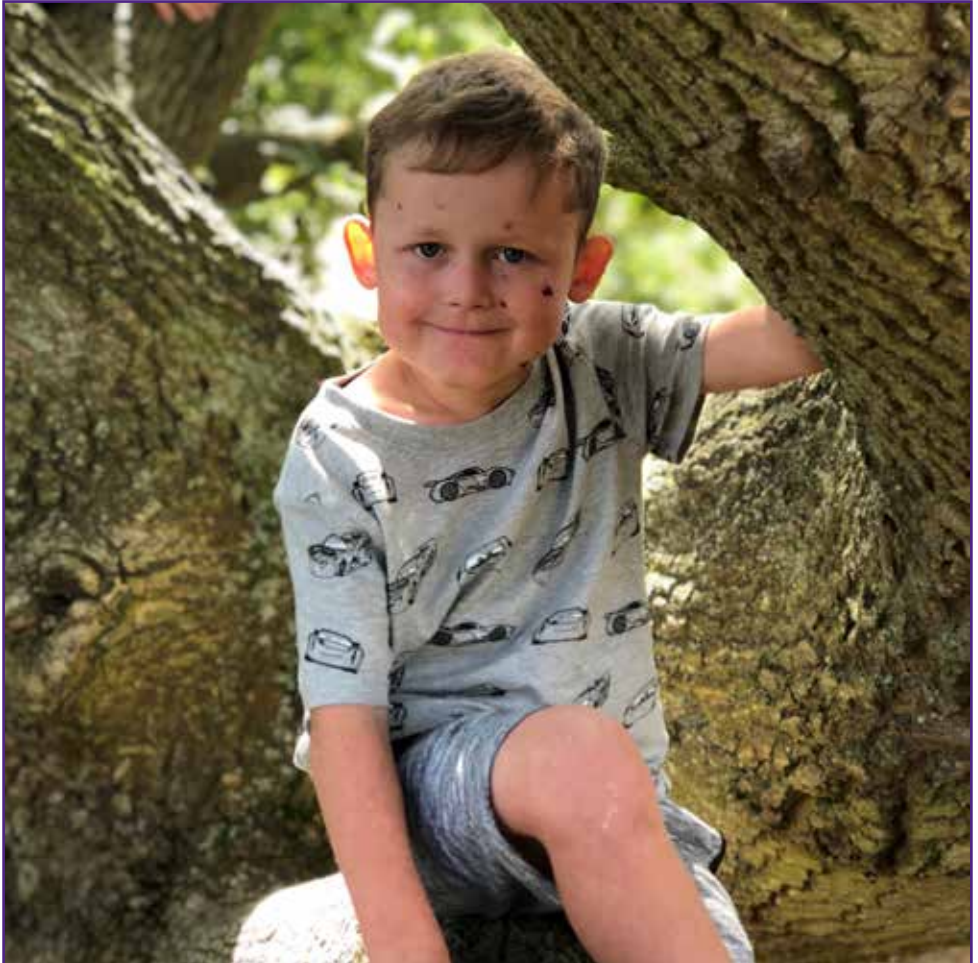
Plus, lots more to be announced! Keep a look out on our website at www.debra.org.uk/events where you can book onto any of our events or contact the Fundraising Team on **01344 771961** or email fundraising@debra.org.uk

Help people like Freddie #FightEB

Regular donations help us plan ahead and make long-term commitments to help people impacted by EB, like Freddie and his family.

By giving a monthly gift, you could help fund life-changing practical and emotional support, specialist EB nursing services or give hope for the future by funding pioneering research projects to find effective treatments and, ultimately, a cure.

Please complete and return the regular donation form overleaf.



I want to help people suffering from EB

1. Give a regular donation

I would like to give:

£100 £50 £25 £10 Other _____ Monthly Quarterly Annually

Please fill out instructions to your Bank or Building Society overleaf.

Or give a one off donation

I would like to give a one off donation of: _____

I enclose a cheque made payable to DEBRA

I'd prefer to donate by credit card, debit card or CAF charity card

Card Number: Start date Expiry date

Issue Number Security Number Date

Signature

2. Your details

(Only complete this section if your contact details are not on the back of the magazine, they are incorrect or you'd like to update your communication preferences.)

Full name

Address

Postcode Tel. number

Record number (if known) Appeal Code

We would like to contact you about how your gift could make a difference to people suffering from EB, and about other ways in which you can get involved and support DEBRA.

Yes, I'm happy to be contacted by Post Phone Email

Email address

Please select the areas you would like to hear about:

- | | |
|---|--|
| <input type="checkbox"/> News, campaigns and fundraising activities | <input type="checkbox"/> DEBRA Golf Society |
| <input type="checkbox"/> Cycling events | <input type="checkbox"/> Running events |
| <input type="checkbox"/> Wining and dining events | <input type="checkbox"/> Walking/trekking events |
| <input type="checkbox"/> Clay pigeon shooting events | <input type="checkbox"/> DEBRA Fight Night |

We respect your privacy and will not pass your details on to any third party without your permission. Full details of DEBRA's Privacy Policy can be found at www.debra.org.uk/privacy. If you do not wish to receive DEBRA News in the future please contact DEBRA on **01344 771961**.

3. Instructions to your Bank or Building Society

Please pay DEBRA Direct Debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with DEBRA and, if so, details will be passed electronically to my Bank/Building Society.

Name(s) of Account Holder(s)	<input type="text"/>	Service User Number	<input type="text" value="5"/>	<input type="text" value="9"/>	<input type="text" value="9"/>	<input type="text" value="9"/>	<input type="text" value="9"/>	<input type="text" value="4"/>
Bank Building Society Number	<input type="text"/>	Sort Code	<input type="text"/>	<input type="text"/>	<input type="text"/>	Reference (to be completed by DEBRA)	<input type="text"/>	
Commencing on (Direct Debits are taken on 15 th of the month)	Month	<input type="text"/>	Year	<input type="text"/>				
Name and full address of your Bank or Building Society:								
To the Manager: Bank/Building Society Name		<input type="text"/>						
Address	<input type="text"/>	Postcode	<input type="text"/>					
Signature	<input type="text"/>	Date	<input type="text"/>					

- This Guarantee is offered by all banks and building societies that accept instructions to pay Direct Debits. If there are any changes to the amount, date or frequency of your Direct Debit DEBRA will notify you 10 working days in advance of your account being debited or as otherwise agreed. If you request DEBRA to collect a payment, confirmation of the amount and date will be given to you at the time of the request.
- If an error is made in the payment of your Direct Debit, by DEBRA or your bank or building society you are entitled to a full and immediate refund of the amount paid from your bank or building society.
- You can cancel a Direct Debit at any time by simply contacting your bank or building society. Written confirmation may be required. Please also notify us.



4. Gift Aid – don't forget to tick here

If you are a UK taxpayer please tick the box below so we can claim back 25p for every £1 you give at no extra cost to you.

Yes, I want to Gift Aid my donation and any donations I make in the future or have made in the past 4 years to DEBRA. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Please contact our Gift Aid Team on **01344 771961** if you wish to cancel this declaration, no longer pay sufficient income or capital gains tax, or change your name or home address (Gift Aid may only be claimed against a home address).

Please fill out and return this form to: DEBRA, 13 Wellington Business Park, Dukes Ride, Crowthorne RG45 6LS

giftaid it

Thank you for making a difference



**Help us
make a lasting
difference and
#FightEB**





Delivered by



Name

Address 1

Address 2

Address 3

Address 4

Postcode

Record number

A charity registered in England and Wales (1084958) and Scotland (SC039654).

Company limited by guarantee registered in England and Wales (4118259).

DEBRA is the national charity supporting those directly affected by, and working with, Epidermolysis Bullosa (EB) - a potentially fatal skin condition that causes constant pain due to unstoppable internal and external blistering. DEBRA provides lifelong care and support to the entire EB community.

