Still cycling!
DEBRA member Keith shares his story – see page 10

#ShowYourSeams – see page 7

PIP and Motability – see page 9

Plus
- Get together
- Drug repurposing
- Dental care and more...

www.debra.org.uk

This edition sponsored by Clinidirect.
Welcome to the Autumn edition of In Touch

In response to feedback from members, I’m delighted to confirm that a number of regional events for people living with EB will take place around the country in 2017. Further details to be announced in the next edition of In Touch. For details of DEBRA’s national Members’ Weekend to be held at Drayton Manor Park and Zoo in 2017, please see page 3.

Many people call EB ‘The Worst Condition You’ve Never Heard Of’. This EB Awareness Week (25 – 31 October), please help us change that by joining in DEBRA’s 2016 #ShowYourSeams campaign and raising awareness of EB in your local community – find out more on page 7.

In Touch is the magazine for DEBRA members – thank you to everyone who reads it, sends in suggestions for articles or shares their own news with DEBRA. Keith is one of the many people who have been inspired to share their experiences of life with EB after hearing from other DEBRA members in these pages – read his story on page 10. Please keep making your voice heard – email debranews@debra.org.uk or call 01344 771961 with your stories now.

Lastly, I’d like to thank the clinical EB teams and the DEBRA EB Community Support team. From the recent launch of EB: My Story at Birmingham Children’s Hospital and the Brilliant Butterflies’ willingness to run the extra mile for EB awareness (see page 18) to dentist Chris Dickinson’s marathon challenge (see page 4), I am constantly impressed by their dedication to providing the best possible support to people living with EB. Remember DEBRA is here to support all people affected by EB – please call 01344 771961 to find out how we can help you and give us your suggestions on how we can offer more support.

Best wishes,

Claire Mather
Director of Healthcare, Membership and EB Community Support

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Christmas cards are now available to buy online at www.debra.org.uk/onlineshop, in your local DEBRA shop or using the order form enclosed with this magazine. There’s a range of affordable, cheery designs to choose from. The best bit is that every card helps to fight EB and support DEBRA. Order now and get them in plenty of time for the festive season!

Disclaimer:
Articles in this publication have been written by people living with EB who have found certain products or services useful. DEBRA does not endorse any products or services mentioned in this publication, and will not be held responsible for any consequences arising from the use thereof. DEBRA is not responsible for the content of any external websites.

Last chance to book Get Together: Birmingham!

Don’t miss out on a fantastic opportunity to meet other people living with EB, chat and share experiences in a relaxed setting.

When: 12 November 2016

Where: Thinktank, Birmingham Science Museum, Millennium Point, Curzon Street, Birmingham, B4 7XG

Call Hazel Ewens, Membership Manager, on 01344 771961 to book your place now or find out more at www.debra.org.uk/get-together-birmingham. Hurry – booking is essential and places are limited!
Save the date now:  
DEBRA Members’ Weekend and AGM 2017! 
Saturday 13 – Sunday 14 May 2017  
at Drayton Manor Hotel, Theme Park and Zoo, Staffordshire

This annual event for DEBRA members is a great opportunity for people of all ages and backgrounds to meet other individuals living with any type of EB:

• Meet other people living with EB and share experiences
• Chat to your DEBRA EB Community Support Manager, EB researchers and healthcare specialists
• Hear EB research updates from around the world
• See new products designed for people living with EB
• Browse stands from a range of companies and healthcare professionals
• Get to know the team at DEBRA
• Enjoy a three-course evening buffet and disco
• Make a weekend of it and stay overnight – spend Sunday enjoying Drayton Manor Theme Park and Zoo

The presentations explained EB and research in a very clear way

Watch out for further details coming to you soon by post and email.

Keep an eye on: 
www.debra.org.uk
/DEBRACharity
@CharityDEBRA
Taking on the challenge for DEBRA

In 2016 I set myself the challenge of running three marathons on three consecutive Sundays: the Manchester Marathon, the Brighton Marathon and the Virgin Money London Marathon. I first heard about EB and DEBRA from colleagues over 15 years ago, while working in domiciliary dentistry providing dental care to clients with medical conditions in their own homes.

Working as a special care dentist, I’ve met many people living with EB since then – the blistering caused by EB can also affect the mouth and teeth. The courage that people with EB and their families show, every day of their lives, is phenomenal. Fundraising for DEBRA seemed the obvious choice – the blisters I got while training for and running these marathons were nothing when compared with the blisters people with EB endure every day of their lives.

Although I only got back into it a few years ago, I really enjoy the challenge of running! The Brighton Marathon was my first in ten years and it went far better than I’d hoped – I finished in less than four hours, even though I got cramp in the middle. I’ve been bowled over by the generosity of people too, who have given so readily on my JustGiving page (http://uk.virginmoneygiving.com/ChrisDickinson1). Thank you for your donations – I really appreciate all your support. Roll on the next challenge!

Chis Dickinson – Special Care Dentist, Guy’s Hospital (London)

News for you

Go to page 14 to read Chris’ advice on looking after your teeth.

Welcome – Kiri Irani

As the Senior Occupational Therapist at Birmingham Children’s Hospital, working in the Hands and Upper Limb Service, I work full time, specialising in EB one day a week.

Joining the service at Birmingham Children’s Hospital, which provides such excellent care for children with EB and their families, is very exciting and rewarding. I support patients that are struggling to participate in daily living activities as a result of their condition. This can be anything from holding a pen to doing up buttons on a shirt. I also liaise with community occupational therapy teams to make sure patients can get local support and equipment to make it easier and safer to carry out day-to-day tasks at home. I work with children after hand surgery to help them optimize their hand function as much as possible. This can include making bespoke splints and/or working through home exercise programmes. Hand therapy is fundamental to the role. Seeing a child who can be that little bit more independent after they have had surgery is definitely one of the benefits of the job. I look forward to working more with children who have EB and learning from them, and working with colleagues at DEBRA and in the wider EB community.

Kiri Irani – Senior Occupational Therapist, Birmingham Children’s Hospital
Volunteers needed

DEBRA is looking for volunteers to help out at The Oracle Shopping Centre in Reading this November and December. If you or someone you know would be able to give a few hours of their time please email Shumena Begum, Volunteering Manager, shumena.begum@debra.org.uk to find out more or visit www.debra.org.uk/volunteer.

DEBRA is proud to be one of The Oracle’s charitable partners in 2016. So far the partnership has raised over £3,250 for DEBRA though a range of activities including bucket collections, a #ShowYourSeams cycle ride and choir performances. There’s something for everyone!

Regional Get Together: York

When: 26 November 2016
Where: The National Railway Museum, York
What: Meet other people living with the condition and share experiences. There will be two programmes to choose from.

Programme one: this year’s meeting for people living with EB Simplex, led by Prof. Irwin McLean and the team from the University of Dundee.

Programme two: enjoy the opportunity to chill and chat with other DEBRA members living with all types of EB and make new friends in a relaxed setting.

Please note: this is one of the regional events that we are introducing to our programme of member events each year. Invitations will be posted or emailed to DEBRA members in the region. DEBRA members from across the country are welcome, but places are limited and priority will be given to people in the region.

The get together is free and includes entry into the museum after the event. Refreshments and a light lunch will be provided. Check out DEBRA’s website (www.debra.org.uk/get-together-york) or Facebook and Twitter for further details. Alternatively, please call Hazel Ewens on 01344 771961 or email hazel.ewens@debra.org.uk for more information.

Could your workplace fight EB?

Help fight EB, raise EB awareness in your community AND have fun by supporting DEBRA at work.

Excellian Luxoft Financial Services chose DEBRA as their Charity of the Year for the second time in 2016, participating in a variety of fundraising and volunteering events, from running and cycling activities, to more unusual events such as dragon boat racing, bake-offs and wine tasting.

Could your workplace support DEBRA as Charity of the Year? We’d love to hear from you. Email lorraine.rudge@debra.org.uk or call 07884 078504 to find out more about how charitable partnerships fight EB and how they can work for you.

Congratulations

Very best wishes to DEBRA members Elaine and Neil, who recently got married! The happy couple tied the knot on board Concorde at Brooklands Museum in Surrey. Elaine, who has EB Simplex, sent in this beautiful photo from their special day. Thanks for sharing!
Spotlight on governance

The role of trustees

The role of DEBRA’s Board of Trustees is to govern the charity, ensure its objectives are adhered to, set the strategy for achieving these objectives, and assist the Senior Management Team by providing guidance and scrutiny.

Being a trustee can be a most rewarding role within DEBRA, but it also requires a significant commitment of time and effort, something which is often underestimated. The role of trustee comes with a high level of personal responsibility, particularly in DEBRA’s case. DEBRA is registered as a limited company and trustees also become directors of the company. DEBRA trustees are volunteers – the time and the skills they bring to the charity are very valuable and much appreciated.

Who can be a trustee?

Our Articles of Association require that all trustees are members of DEBRA. The majority of trustees must either have EB or have a close family relative or partner with EB – it is very important that people living with EB are represented on the board.

It is equally important that DEBRA has a trustee board which includes skills such as accountancy, research or clinical expertise and retail and fundraising experience. These skills may come from outside the EB community and some trustees may not have EB or a direct connection to someone with the condition.

What happens next?

Each year, before the Annual General Meeting (AGM), DEBRA members are invited to apply to become DEBRA trustees. Applications are reviewed by the Nominations and Governance Committee and a trustee from this committee will meet potential candidates.

When there are vacancies for elected trustees, candidates will be put forward for election at the AGM. Vacancies for appointed trustees will be recommended by the Nominations and Governance Committee and a final decision on approval will be made by the Board according to the skills required on the board at the time.

The induction process

New trustees will meet with the Chief Executive and the Senior Management Team and discuss the role to ensure they fully understand the significant commitment and responsibilities involved. They can team up with another member of the board, a ‘buddy’, who will be happy to assist them while they familiarise themselves with the role. New trustees will also receive information to help prepare them for their duties. Appropriate training courses will be offered and new trustees will be invited to join a DEBRA committee which fits their skills and experience.

How can I get involved now?

If you are thinking of becoming a DEBRA trustee in the future, joining a DEBRA committee can be a good way of gaining an understanding of how DEBRA works and how the committees work with the board. This can be an excellent first step towards becoming a trustee in the future. If you would like more information on DEBRA’s Articles of Association, committees or trusteeship please contact Dawn Jarvis, Company Secretary, at dawn.jarvis@debra.org.uk or call 01344 771961.

The 2017 AGM

The 2017 AGM is free to attend. It will be on Saturday 13 May during the DEBRA Members’ Weekend at Drayton Manor Theme Park and Zoo (see page 3). Keep an eye out for further information in the post or, if you’ve given us permission, we’ll send information about the AGM to you by email to keep costs down.
#ShowYourSeams

for EB Awareness Week

(25 – 31 October)

This EB Awareness Week (25 – 31 October), we’re asking everyone to help raise awareness of EB in their local community by joining in DEBRA’s 2016 #ShowYourSeams campaign.

As we know, even clothing labels and seams can damage the skin when you have EB. But the effects of EB are not always visible.

That’s why we’re asking you to #ShowYourSeams to raise awareness of the condition and what it’s really like to live with. It’s simple:

- Turn your clothes inside out and post a photo to Facebook (at www.facebook.com/DEBRACharity) or Twitter (remember to tweet @CharityDEBRA) with the hashtag #ShowYourSeams.
- Do you cut out rough labels or remove itchy collars? Share a picture of your own customised clothes and shoes with the hashtag #ShowYourSeams, showing the adaptations you’ve made.
- Hold a #ShowYourSeams dress down day and ask colleagues or classmates to wear their t-shirt inside out for a suggested £1 donation to DEBRA.

By taking part and encouraging your local school or workplace to join in too, you’ll help raise awareness of EB in your community and improve understanding of EB more widely.

Please download your #ShowYourSeams pack at www.debra.org.uk/showyourseams to get involved now. If you would prefer to receive your pack by post please call 01344 771961 or write to DEBRA, 13 Wellington Business Park, Dukes Ride, Crowthorne, Berkshire, RG45 6LS.

Thank you

Thank you to everyone who came to the opening of DEBRA’s new shops in Ashford, Clarkston, Dalgety Bay, Mlingavie and Winstanley. Every time you shop with DEBRA, you support research to find effective treatments for EB and help to fund care and support services here and now. If you would like more information on any of the DEBRA shops please visit www.debra.org.uk/shop/intro or contact DEBRA’s retail office on 01698 424210.

Do you cut out rough labels or remove itchy collars?

#ShowYourSeams

while you shop!

Staff and volunteers in your local DEBRA shop will be delighted to help you take your #ShowYourSeams photo. Find your nearest shop at www.debra.org.uk/shopsearch or call 01344 771961.

The team at the DEBRA shop in Coatbridge taking part in #ShowYourSeams.
The Educational Journey

This is the first of two articles which we hope will provide you with information about the milestones which you and your child may experience when starting nursery or school. We will look at some issues which might arise in the transition period from primary to secondary school. Some information will also be included for young adults who may be planning to go on to further education.

You are the best person to speak

When you are preparing to send your child to nursery or school for the first time, it can be a challenging time for you both. If your child has a disability, the planning required to enable your child to have the best experience can be difficult and stressful.

Every family’s experience is unique. Your experience makes you the best person to talk about your child’s condition on a day-to-day basis. The school should consider the needs of your child. You should be included in discussions with the school and health and social care professionals when planning your child’s educational journey. If you would find it helpful, your local DEBRA EB Community Support Manager will be happy to attend a meeting at school to offer you support. We can also write letters or phone the school on your behalf.

The law

Current laws provide support and protection for your child at school and rights and support for you as both a parent and carer.

The Equality Act 2010 defines a disability as ‘a physical or mental impairment’ that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities. The Act states that a person with a disability is protected under the law and that reasonable adjustment should be made to enable the disabled person (child or adult) to have equal opportunities. It is unlawful for a school to discriminate against a pupil or prospective pupil by treating them less favourably because of certain characteristics, including disability.

The Care Act 2014 recognises the rights of the carer. Your DEBRA EB Community Support Manager will be able to offer practical help, information and signposting to access support if you have caring responsibilities. We can assist you with getting on to the Carers’ Register at your GP surgery or with your local council, which can have a number of benefits. In addition, we can signpost you to your local carers’ support group. It can be good to share experiences with other parents or carers.

Sondra Butterworth and Gyll Curtis-Machin – DEBRA EB Community Support Managers

Useful information

DEBRA and the specialist centres for EB have produced a number of leaflets on different types of EB and aspects of life with the condition, which may be useful to share with the school. These can be downloaded here: [www.debra.org.uk/publications](http://www.debra.org.uk/publications). For hard copies please call the DEBRA head office on 01344 771961.

Essential reading

These resources and more are available at [www.debra.org.uk/othersupport#education](http://www.debra.org.uk/othersupport#education)

Cerebra has prepared helpful guides for parents of children with special educational needs and disabilities including Education in England: A Guide for Parents and The Problem-Solving Toolkit. [www.cerebra.org.uk](http://www.cerebra.org.uk)


Contact your local council for information on services in the local area for parents, children and young people from 0 to 25 years old, who have special educational needs and/or disabilities (SEND) [www.gov.uk/find-your-local-council](http://www.gov.uk/find-your-local-council)
Transferring to **Personal Independence Payments (PIP)** from Disability Living Allowance (DLA)

Following the introduction of PIP, we are experiencing a high level of requests for support from those who are being transferred from DLA to PIP. A lot of these requests come from those who had lifetime awards granted at a time when the criteria was less strict.

The assessment for a PIP award is different from DLA and is calculated by a points scoring system, both for the daily living and mobility components. A lot of existing DLA claimants have joined the Motability scheme and there have been a lot of reports in the press about the high number of people who have lost this entitlement and also their vehicles.

With PIP, to be entitled to the enhanced mobility rate the claimant must only be able to mobilise up to 20m or between 20m and 50m and need support to avoid overwhelming psychological distress. The standard rate, which does not allow the claimant to join the Motability scheme, is for those who can only mobilise between 20m and 50m. This is calculated by looking at the form, the supporting information and the medical report carried out by the assessor.

We are also supporting a lot of members with appeals and attending tribunals. The process of appeal is called Mandatory Reconsideration and this is where a formal request is made to the DWP to review their decision. If the claimant is still not happy with this reviewed decision, they can request it is heard at an independent tribunal. The tribunal will look at all the evidence that has been presented to the DWP and make a judgement based on whether the DWP made an error in law in making their decision.

It is important to be honest when completing the PIP application form and at assessment as there is a risk of being prosecuted for fraud by the DWP.

Currently there is a scheme in place for people who lose their Motability vehicles following transition from DLA to PIP. This is in the form of a one off payment of £2,000 to be used towards the cost of purchasing another vehicle. Your local Motability dealership will have full details of the scheme and will provide support in applying for the payment. For more information on Motability in general please visit [www.motability.co.uk](http://www.motability.co.uk) or call 0300 4564566.

If you would like to discuss your individual application for PIP then please contact your EB Community Support Manager using the details on the back of this magazine or call 01344 771961 to get in touch.

*Miranda Hartley – DEBRA EB Community Support Manager*
Member’s story

Far beyond my boyhood dreams

How I wish DEBRA had been around when I was a child. Then my parents wouldn’t have been told it would be a good idea to let me run shoeless and sockless through wooded areas to toughen up my skin.

There was very little known about the condition when I was born with EB Simplex in 1934. My parents even took me to a Harley Street specialist to find out what was wrong with the skin on my hands and feet, which constantly tore and blistered. It was from this specialist that they heard that wonderfully misguided piece of advice. Among other outlandish recommendations given was that, if a blister became infected (always a high risk during a time when Penicillin was not available), Epsom Salts should be applied. Thankfully I think I only suffered that once. It was agony. If only DEBRA had been there to give out the reliable information and support it offers now!

EB is a part of my life and I accept that. I have a high pain threshold and a ‘put up with it’ attitude, but it still hurts. I can identify with so much of what others with EB Simplex say: I did not declare the condition at school – it was referred to merely as ‘bad feet’ – I played sports as far as possible, not wanting to appear different, and I squeezed my blistered feet into ‘normal’ shoes. I feel almost guilty when I read of the pain suffered by others with different strains of EB.

When I married in 1959 I did so in the mistaken belief that any offspring would not be affected, my parents having been told that it could only be passed on by the female and that it would hit only one person in every generation. When our son Russell was born blisters appeared at nine weeks. We saw a geneticist and were told that the information given to my parents was complete rubbish: EB was caused by a faulty gene, and in my case, each child stood a 50/50 chance of

Pictured above: Keith (left) and his son Russell (right), who both have EB, are keen sportsmen.
There was very little known about the condition when I was born receiving it. The fault could be passed on by both males and females. Although I wish Russell did not have EB, I’m glad to say that he has still gone on to have a very successful career and a happy life.

When Russell was six, my wife and I believed that humidity and friction were the big enemies and decided that the ideal holiday would be in winter: then he could enjoy exercise by skiing. Big mistake. In those days, ski boots were hard leather lace-ups with no precise fitting. That first year was just awful and his shins blistered in large raw patches, but it was too late. He was hooked on the sport! With advances in boot technology and friction-free, precise fittings, he is still skiing today.

For myself, my EB has become more manageable over the years and being able to adapt my lifestyle in retirement has also helped. The worst thing about my EB is that it makes it impossible for me to walk very far. My wife and I can’t walk together and we can’t see everything we want to together. It remains constantly frustrating, although we work round it and still go cycling together. I find that clip-in pedals do help to reduce the pressure on my feet so I can still enjoy the exercise.

The work being done today is truly amazing – far beyond whatever I could have dreamt in my boyhood days. DEBRA continues to raise public awareness of the condition and increase understanding of it in social and medical settings, and to offer useful information on techniques for managing the condition and minimising its effects. Thanks to the money DEBRA has put into research, perhaps in the not too distant future the successful isolation of the faulty gene will enable future generations to be blister-free.

Keith Barnett

DEBRA can make a difference

DEBRA member Mrs Javid emailed us to say what a difference support from DEBRA has made to her and her family.

‘DEBRA has been such a great help to us. Through DEBRA we received a fan for our daughter who has EB. The heat makes her blistering so much worse – having this fan has made such a difference, helping to keep her cool and more comfortable in the hot summer weather. The grant was dealt with very quickly and we received the fan the following day. Our EB Community Support Manager, Zainib Hussain, is also supporting us with guidance on applying for DLA for our daughter, which is still ongoing.

We have also had the privilege of using the DEBRA holiday homes. Without DEBRA we wouldn’t have been able to have a holiday for our family – we have made such beautiful and countless memories. It gave us an opportunity to have fun, happy moments with our children which would have been impossible without DEBRA.’
2017 DEBRA holiday home bookings

Lots of people have been asking when they can book a stay in one of DEBRA’s holiday homes in 2017. Due to the high demand for the DEBRA holiday homes there is a priority booking system in place.

1 October – Priority 1 bookings
Bookings open to members wishing to holiday next year who did not stay at a holiday home this year.

1 November – Priority 2 bookings
Bookings open to members living with EB wishing to stay in a DEBRA holiday home next year who stayed in a holiday home this year but not during one of the peak periods.

1 December – Other bookings
Bookings open to all members living with EB who would like to book a stay in a DEBRA holiday home next year.

If a priority booking date falls on a bank holiday or public holiday, or a Saturday or Sunday, the next working day will be considered the priority booking date.

Call Sharon Hyde on 01344 771961 to book your stay now.

Did you know?

There’s still time to take a holiday in 2016 – the DEBRA holiday homes in Weymouth and Poole are open until the beginning of November and the holiday home in Brynteg closes over January and February every year.

DEBRA members living with any type of EB can use the holiday homes.

You can read the full DEBRA holiday home booking policy, download the brochure and check what dates are available in each of the holiday homes at www.debra.org.uk/holidayhomes.
I don’t let my EB define me. My name is Matt. I’m 23. I work as a producer for a video games developer, I volunteer as a Scout leader, and I’m standing for election to my local council. I like to climb mountains in any spare time I have left. I also have Dominant Dystrophic EB, which shows itself most across my knees and shins. There’s faded scarring and historical injuries on my spine, on the backs of my hands and on both my ankles.

As a child I was rather self-conscious about my EB and it did stop me from doing things that I wanted to – the risk of injury seemed too great. However, the tipping point came when I was around eight years old and I joined the Cub Scouts. The leaders really took EB in their stride, encouraging me to do the same activities as the other kids, and when the inevitable bumps, wounds, scrapes and blisters arose they dealt with it without being phased by it. Without that support and the push from them, my friends and my family, to do ‘normal things’, I wouldn’t have done half of what I have! I’ve been ice climbing and mountaineering, I’ve worked abroad and been camping around the globe, sailing in the Irish Sea on a tall ship. I’m also proud to have had a key role in the development of the global video game DayZ and others. I’m not going to stop there either – I’ll always take on more adventurous activities!

I’m a massive fan of the survival expert Bear Grylls. He once wrote, ‘When we try to strip our kids’ world of risk we do them a gross disservice. We teach them nothing about handling life. All children have a right to adventure... these moments allow children to get excited about the possibilities the world has to offer.’ I think there’s a lot to be said for that, whether you have EB or not.

Going on my own experience, I would say if your children have EB and you’re worried about them, don’t be. Support them when things don’t go as intended, be there for them, but serve them best by going against your parental instincts and allowing them out into the world – only then will they reach their full potential.

Matt Lightfoot

‘If you’re worried, don’t be!’

If anyone would like to know more about anything I’ve written about or have questions that they think I can help with, please don’t hesitate to contact me at matt@mattlightfoot.com.
We’re highly aware of the fragility of the skin in EB, particularly on lips and cheeks, and mucosal membranes in the mouth, and work very gently and slowly to prevent any blistering during dental treatment. There’s no pressure on time during special care dentistry – we can take as long as you need to carry out treatment during an appointment, and we have facilities to give sedation or general anaesthetic if necessary. We’re also used to working with very small mouths and have access to smaller dental tools which help us get to hard to reach areas safely.

If you have EB please make sure you get regular dental check-ups. We know that the wide ranging and time consuming care required by EB can mean that teeth are often forgotten about, but it’s still important to maintain good oral health and deal with any dental problems as they arise. If dental phobia is preventing you from visiting the dentist or if you’re worried or scared about going, a special care dentist can work round this with you to make sure you get the care you need.

If you would like to speak to a special care dentist please ask your EB nurse or doctor at your specialist centre for EB for a referral. As well as seeing you at a hospital, a special care dentist can also work with your EB team and local dentist or community dental service to make sure you get the right dental care close to home.

Chris Dickinson – Special Care Dentist, Guy’s Hospital (London)

Support for you

Gentle dental care

I’m a consultant in special care dentistry at Guy’s and St Thomas NHS Trust, one of the specialist centres for EB. Working closely with the multi-disciplinary EB team, I provide dental care to people with medical conditions who require additional expertise (and sometimes different facilities or equipment) to meet their needs, including people with EB.

Celebrating the life of a loved one

If you have lost a loved one, please remember that DEBRA’s EB community support managers are here to give you emotional and practical support. Always remember you can contact the community support team for one-to-one help using the numbers on the back of this magazine.

DEBRA’s website has two remembrance areas where you can celebrate the life of a loved one. If you would like some help writing a eulogy, please contact us. To visit the pages, upload a eulogy or poem and find other useful resources please go to www.debra.org.uk/bereavementsupport.

If you are unsure who your EB Community Support Manager is, please call 01344 771961 to get in touch.

Beth Davenport – DEBRA EB Community Manager
A pulse is an edible seed that grows in a pod. Pulses include all beans, peas and lentils. They are a cheap, low-fat source of protein, fibre, vitamins and minerals and they can be soft to eat. One portion is 80g, which is equivalent to around three heaped tablespoons of cooked pulses.

Why eat pulses?
Pulses are a great source of protein, so can be particularly important for people who do not get protein by eating meat, fish or dairy products. But meat eaters can add pulses to soups, casseroles and meat sauces to add extra texture and flavour. This means you can use less meat, which can makes the dish softer and easier to eat. Pulses are a good source of iron for non-meat-eaters and add fibre to your meal. Eating a diet high in iron and fibre is very important if you have EB. As well as all this, they are delicious!

Cooking pulses safely
Tinned pulses have already been soaked and cooked, so you only need to heat them up or you can eat them cold. Dried pulses need to be soaked and cooked before they can be eaten.

Dried kidney beans and soya beans contain toxins, so it is important to ensure they have been cooked properly before you eat them. Always follow the instructions on the packet or in the recipe.

More information
For more information on using beans and pulses in your diet, including cooking preparation and storage, visit www.nhs.uk/Livewell/Goodfood/Pages/pulses.aspx. Contact your specialist EB dietitian for specific advice. Ask your EB nurse or doctor for a referral or contact your EB centre using the numbers on the back of this magazine.

Lynne Hubbard – Specialist EB Dietitian, Guy’s and St Thomas’ NHS Foundation Trust and Rosie Jones – Specialist EB Dietitian, Birmingham Children’s Hospital

Recipe – Falafel
2 tablespoons olive oil
1 small onion
1 clove garlic
400g tinned chickpeas
2 teaspoons cumin
1 teaspoon mixed herbs
Handful of flat leaf parsley or fresh coriander
2 tablespoons plain flour
1 egg, beaten

Method
Pat the chickpeas dry then put them into a food processor or mini-chopper with chopped onion, garlic, fresh parsley/coriander and process until all the contents are ground into small pieces.
Place them into a large bowl and mix with the flour, spices and the beaten egg.
Divide into eight portions and shape them into patties. Fry in hot olive oil for 3 minutes. Serve with salad, olives and warm pitta bread or rice.
Support for you

Make your own feelings wheel

Sometimes people, especially children, can feel unheard or might be embarrassed about talking about how they feel. This feelings wheel is a great way to start the conversation. It’s a good way to find out how your child or children are coping and it can give parents a chance to talk about what is going on in their lives too.

The feelings wheel is fun to make and it can be useful to have at home or at school. All you will need is a template of a wheel with the different emotions on and faces which describe each emotion (download one at www.debra.org.uk/feelingswheel, cut it out of this magazine or call the Membership team on 01344 771961 to get a copy). You might even want to make your own using a large dinner plate.

How to make

Let your child choose the colour of the feeling faces on the wheel, such as green for happy or red for angry. It is up to the child and each wheel should be as individual as they are.

Cut out an arrow and using a fastener (adult supervision might be needed for younger children) to attach it to the middle of your wheel.

Have the feelings check-in wheel available somewhere at home so your child can discuss their emotions and feelings. Ask your child to point the arrow to the emotion they are feeling (it is important to know when the feelings wheel is in use, so tell your child to notify you when the wheel has been changed).

Sit somewhere quiet and talk about that particular feeling or emotion. If you need guidance about a particular feeling or emotion then seek advice from pastoral care at the child’s school or call your EB Community Support Manager at DEBRA who might be able to help. Enjoy making it!

Many thanks to mental health therapist Kristina Marcelli Sargent, who blogs at www.artofsocialwork.com, for kindly giving permission for her feelings wheel to be reproduced in this magazine.

Beth Davenport – DEBRA EB Community Support Manager
Support for you

My feelings come and go, and all feelings are okay to have! I can think of safe things to do with my feelings.

Instructions

- Cut out the arrow to the right.
- Use a tightener to poke a hole through the arrow & the feelings circle.
- Point the arrow to how you are feeling!
Birmingham Children's Hospital launches a new book

Birmingham Children's Hospital (BCH) has released a new booklet called *EB: My Story*. The booklet, jointly sponsored by DEBRA UK, DEBRA Ireland and BCH Charity, celebrates the real-life stories of some of the children and young people living with EB who visit the hospital for treatment.

Developed by Consultant Dermatologists Professor Celia Moss OBE and Dr Fiona Browne, together with children's author Mandy Ross, the new publication aims to explore the social and emotional impact of the condition. There is limited unbiased material accessible to children about what the experience of the condition is really like and the booklet aims to fill that gap.

Copies of the book are available free from DEBRA. Please email DEBRA's Membership Team at membership@debra.org.uk or call 01344 771961 to order yours.

The launch of the new book was celebrated with a tea party at the hospital.

Brilliant Butterflies run for DEBRA

EB Clinical Nurse Specialists Victoria and Lisa, from Birmingham Children's Hospital, and DEBRA's Community Support Managers, Sondra Butterworth and Zainib Hussain took part in the Birmingham Color Run to support DEBRA.

‘It was a fantastic day,’ said Sondra. ‘The sun came out for us. There was a great feeling of camaraderie, with the nurses and the community support team working together. People asked us about EB so we were able to not only raise money but awareness too!’

‘Ultimately, we wanted to raise awareness of EB as well as raising as much money as possible. We were so thankful and touched by the donations and kind wishes that people wrote – they spurred us on! Thankfully, we managed to avoid the rain but not the paint, as you can see from our picture!’ added Victoria.

A big thank you to the Brilliant Butterflies for giving up their time and going beyond the call of duty to fight EB. So far they've raised £350.62 (visit their page at [www.justgiving.com/fundraising/thebrilliantbutterflies](http://www.justgiving.com/fundraising/thebrilliantbutterflies)), smashing their original target. Well done Butterflies!
Drug repurposing for EB

A number of laboratories around the world have started to explore the possibility of taking existing drugs, already being given to people with conditions unrelated to EB, and using these drugs to treat people with EB. This is called ‘repurposing’.

As many testing procedures, such as proving the drug is safe for use in humans, will already have been carried out to approve the drug for its originally intended purpose, the time it takes to bring a repurposed drug to clinical trial stage for use in EB can be much shorter.

A study in Freiburg, Germany, (led by Dr Alexander Nyström) showed benefit in an animal model of Recessive Dystrophic EB (RDEB). After administering Losartan, a drug widely used to treat high blood pressure, inflammation and fibrosis (thickening and scarring of connective tissue) were reduced. You can read about the findings in the journal EMBO Molecular Medicine at http://onlinelibrary.wiley.com/doi/10.15252/emmm.201505061/abstract.

In Philadelphia, America, a number of studies (led by Dr Andrew South) on repurposing drugs to treat Recessive Dystrophic EB and the cancer associated with it, are taking place. One such drug shows remarkable accuracy in destroying cancer cells in EB without affecting non-cancerous skin cells.

‘Before doctors are able to offer any of these drugs for widespread use it is important to take the experiments out of the lab and into people, in the form of a clinical trial. Although the time scales for drug repurposing are much shorter, it is still necessary to perform careful, controlled assessment of such drugs, to make sure that there is clear patient benefit with limited side-effects says Dr South.

‘None of this would be possible without the generous support of individuals and organizations with the foresight to invest in research such as DEBRA organisations, the Sohana Research Fund and the EB Research Partnership. Together we continue to find better ways to help patients.’
## Useful Numbers

### DEBRA Office

<table>
<thead>
<tr>
<th>Role</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Director of Healthcare, Membership and EB Community Support – Claire Mather</td>
<td><strong>01344 771961</strong></td>
</tr>
<tr>
<td>Membership enquiries</td>
<td><strong>01344 771961</strong></td>
</tr>
<tr>
<td>Membership Manager – Hazel Ewens</td>
<td><strong>01344 771961</strong></td>
</tr>
<tr>
<td>Membership Assistant (inc. holiday home bookings) – Sharon Hyde</td>
<td><strong>01344 771961</strong></td>
</tr>
<tr>
<td>Communications Officer (inc. In Touch) – Miranda Lloyd</td>
<td><strong>01344 771961</strong></td>
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### EB Community Support

<table>
<thead>
<tr>
<th>Region</th>
<th>Manager</th>
<th>Contact Information</th>
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</thead>
<tbody>
<tr>
<td>North of England, Wales, Scotland and NI</td>
<td>Sondra Butterworth</td>
<td><strong>07920 231271</strong></td>
</tr>
<tr>
<td>Central England and Wales</td>
<td>Zainib Hussain</td>
<td><strong>07920 231270</strong></td>
</tr>
<tr>
<td>Scotland and the Far North</td>
<td>Beth Davenport</td>
<td><strong>07917 230105</strong></td>
</tr>
<tr>
<td>South of England Regional</td>
<td>Helen Weaver</td>
<td><strong>07880 193118</strong></td>
</tr>
<tr>
<td>South of England</td>
<td>Gyll Curtis-Machin</td>
<td><strong>07747 474051</strong></td>
</tr>
<tr>
<td>South of England</td>
<td>Miranda Hartley</td>
<td><strong>07717 774553</strong></td>
</tr>
<tr>
<td>South of England</td>
<td>Sallie-Ann Nicol</td>
<td><strong>07747 474454</strong></td>
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### Volunteering or fundraising for DEBRA

**01344 771961**

### Healthcare

#### Children’s Nursing Service – Great Ormond Street Hospital

<table>
<thead>
<tr>
<th>Role</th>
<th>Contact Information</th>
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</thead>
<tbody>
<tr>
<td>EB Clinical Nurse Specialists – Debbie Brown, Katie Plevey, Finola Sheehan, Angela Whelan</td>
<td><strong>0207 829 7808</strong></td>
</tr>
<tr>
<td>Service Co-ordinator – Sonia Ama</td>
<td><strong>0207 829 7808</strong></td>
</tr>
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#### Children’s Nursing Service – Birmingham Children’s Hospital

<table>
<thead>
<tr>
<th>Role</th>
<th>Contact Information</th>
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</thead>
<tbody>
<tr>
<td>(out of hours emergencies only: ask for the dermatologist on call stating that this is an EB child)</td>
<td><strong>0121 333 8224</strong></td>
</tr>
<tr>
<td>EB Clinical Nurse Specialists – Dawn James, Victoria Warren, Danielle Cunnington</td>
<td><strong>0121 333 8224</strong></td>
</tr>
</tbody>
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#### Adult Nursing Service – St Thomas’ Hospital

<table>
<thead>
<tr>
<th>Role</th>
<th>Contact Information</th>
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</thead>
<tbody>
<tr>
<td>Lead EB Clinical Nurse Specialist – Jane Clapham</td>
<td><strong>07775 648472</strong></td>
</tr>
<tr>
<td>EB Clinical Nurse Specialist – Chris Bloor</td>
<td><strong>07554 223358</strong></td>
</tr>
<tr>
<td>EB Clinical Nurse Specialist – Annette Downe</td>
<td><strong>07786 850684</strong></td>
</tr>
<tr>
<td>EB Clinical Nurse Specialist – Caroline Mackenzie</td>
<td><strong>07833 401838</strong></td>
</tr>
<tr>
<td>EB Clinical Nurse Specialist – Pauline Graham-King</td>
<td><strong>07786 850683</strong></td>
</tr>
<tr>
<td>Service Co-ordinator – Frances Skeehan</td>
<td><strong>0207 1880843</strong></td>
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#### Adult Nursing Service – Solihull Hospital

<table>
<thead>
<tr>
<th>Role</th>
<th>Contact Information</th>
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<tbody>
<tr>
<td>EB Clinical Nurse Specialist – Tracy Adni</td>
<td><strong>07846 986987</strong></td>
</tr>
<tr>
<td>EB Clinical Nurse Specialist – Kal Begum</td>
<td><strong>07966 801710</strong></td>
</tr>
<tr>
<td>EB Clinical Nurse Specialist – Bryony Jay</td>
<td><strong>07816341465</strong></td>
</tr>
<tr>
<td>EB Clinical Nurse Specialist – Carol Knowles</td>
<td><strong>07527 679679</strong></td>
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#### Scottish Healthcare Team

<table>
<thead>
<tr>
<th>Role</th>
<th>Contact Information</th>
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</thead>
<tbody>
<tr>
<td>EB Clinical Nurse Specialist (adults) – Debbie Johnston</td>
<td><strong>0141 2118773</strong></td>
</tr>
<tr>
<td>EB Clinical Nurse Specialist (paediatrics) – Sharon Fisher</td>
<td><strong>0141 2019220</strong></td>
</tr>
<tr>
<td>Administrative Assistant – Tracy Scott (Mon – Wed, 9am – 3.30pm)</td>
<td><strong>0141 2118773</strong></td>
</tr>
</tbody>
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In an emergency call 112. Out of hours for urgent medical help contact NHS 111 or your GP. If they require further information about your condition they should be advised to speak to the on call dermatology registrar at your specialist centre for EB. To contact the EB nursing teams by email please visit [www.debra.org.uk/nursingcontacts](http://www.debra.org.uk/nursingcontacts).

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Clinidirect is a bespoke home delivery service for all prescribed items. Call 0800 0126779 to find out more.

DEBRA, DEBRA House, 13 Wellington Business Park, Dukes Ride, Crowthorne, Berkshire, RG45 6LS.

Email: membership@debra.org.uk  Web: [www.debra.org.uk](http://www.debra.org.uk)

Follow us on [Twitter](https://twitter.com/charityDEBRA)  Visit us on [Facebook](https://www.facebook.com/DEBRAcharity)

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