

## Data Protection New Regulations

**Please Read**  
**This affects all our Members and Contacts**

On the 25<sup>th</sup> May 2018 the new General Data Protection Regulation (GDPR) will come into force.

The GDPR (Regulation (EU) 2016/679) is a regulation by which the European Parliament, the Council of the European Union and the European Commission intend to strengthen and unify data protection for all individuals. After Brexit the GDPR will become UK legislation.

The new ruling states every organisation that process personal data, including charities, must be compliant

The very nature of our work means we store highly sensitive confidential information about all our members and contacts. To this end, the ED Society must make changes to protect all information stored.

We will shortly be sending more information and a consent form to everyone in line with the new GDPR. This will highlight the importance of receiving a signed consent form from existing members and contacts within a specific time enabling us to store personal information. Simply ticking a box will no longer be acceptable.

If the consent form is not received within the specified time the ED Society may have to destroy all information they hold either in hard copy or digitally on any member or contact. Under the new GDPR, the ED Society will destroy all information held at the request of any member or contact.

The ED Society must comply with the new rules and are therefore asking that once you receive the information and consent form, you return it within the time limit.

We will be in touch shortly.

Diana Perry  
CEO

ERN Skin – putting ED  
“firmly on the main  
stage!”

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Meeting - 5<sup>th</sup> May 2018  
at 10.30am

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## Medical Advisory Board Members

Prof. Angus Clarke	-	Clinical Genetics (MAB Chairman)
Prof. John Hobkirk	-	Prosthetic Dentistry (Implants)
Prof. John McGrath	-	Genetics, Molecular Dermatology
Mike Saunders	-	Consultant in Otolaryngology
Kirsten FitzGerald	-	Paediatric Dentist
Mr. Colin Willoughby	-	Ophthalmology
Prof. Michael Tipton	-	Human Applied Physiology
Mr. Mike Harrison	-	Paediatric Dentistry
Dr. Claire Forbes-Haley	-	Restorative Dentistry
Prof. John Harper	-	Paediatric Dermatology
Mrs. E. Howard	-	Paediatric Dermatology
Dr. E. Jones	-	Clinical Genetics
Prof. Celia Moss OBE	-	Paediatric Dermatologist
Dr. Heidi Williamson	-	Health Psychologist

## Trustees

Paul Collacott	-	Chairman
Alan Waller	-	Treasurer
Diana Perry	-	Secretary
Mandy White	-	Air-Conditioning / School Liaison
Andy Ponting		
Stephen Ayland		
Simon Lees-Jones		
Stuart Atkiss		Fundraising Co-Ordinator
Sharon Cooper		
Scott Gallacher		

## Staff

Sue Beard, Dip. L.A.M	-	Accounts / Website Manager
Danielle Gue	-	Senior Administrator
Jaye-Leigh Dix	-	Administrator

## Volunteers

Diana Perry	-	Chief Executive Officer
Elaine Aylward	-	Irish Group
Kerry Russ	-	Fundraising Co-Ordinator
Stuart Atkiss	-	Fundraising Co-Ordinator

## MEMBERSHIP

Membership will give you access to the Support Fund, newsletters, assistance to obtain DLA/PIP etc., and voting rights.

Please return your form as soon as possible to ensure you have full access to these benefits.

## SYMPTOMS QUESTIONNAIRE

Could you please ensure you have completed a Symptoms Questionnaire for each individual who is affected by ED in your family. This document hugely helps us when answering any of your concerns or when assisting you with DLA applications, appeals, tribunals, schools, doctors, etc.

So, if you have not completed one for many years could you please complete a new one; they are available to download from our website.

## DISABILITY LIVING ALLOWANCE, CARER'S ALLOWANCE & P.I.P.

We are always happy to help you complete the forms.

It's best if the forms are right from the beginning in the hope that the claim will not have to go to appeal or tribunal.

If you are unsuccessful, we are happy to write an appeal letter for you and if necessary, attend a tribunal with you.

## BLUE BADGE

To obtain a Blue Badge you can either apply online at <https://www.gov.uk/apply-blue-badge> or telephone your local Social Services Blue Badge Team for an application form.

Many of our families already have a Blue Badge. If you would like our help to complete the forms or if your application has been turned down, help to appeal please email [info@edsociety.co.uk](mailto:info@edsociety.co.uk)

## Fundraising – Our Grateful Thanks....

For the many donations that have been coming in over the past 3 months.

Thank you to everyone who sent in donations with their membership form and to all those who pay regular donations by standing order.

An enormous thank you to Simon and Chrissy Lees-Jones for their donation of £5,000 and also to Chrissy's mother, Elizabeth Pickering for her wonderful donation of £5,000.

Mark and Vicky Macnair - Many thanks for once again fundraising and sending a further £175.

Thank you again to Bottomline Technologies for sending in another £100 donation. Richard Pettigrew nominated the ED Society as the charity for receiving their fundraising donations.

A huge thank you to Pamela Perry for donating £1000.

Many thanks to Gill Squires for holding various events and raising £571 and receiving a donation from Archbishop Halgate Hospital who selected the ED Society as their charity for the month.

**Please keep your donations coming in and if you don't do it already, please sign a Gift Aid declaration to enable us to receive an extra 25% !**

### Donations & Membership via Paypal

Whilst building our new website, we have set up an account enabling us to take payments via PayPal.

Should you choose to use PayPal when paying your membership or making a donation, could you please select the "friends and family" option. Selecting this option ensures the Society do not have to pay any fees.

### Annual General Meeting

Our next Annual General Meeting (AGM) will be held on Saturday 5<sup>th</sup> May 2018 at 10.30am.

Enclosed with this month's newsletter are the AGM Notification and Trustee Application Form.

We are always looking for people to join our Board of Trustees.

The role involves attending two meetings a year, held in Cheltenham on a Saturday, occasionally proof-reading documents written by the office staff, answering some general questions from the office, sharing any ideas you may have and offering general support to us in the office. We also need someone who would help with co-ordinating fundraising events.

If you think this is something that would be of interest to you, please email [info@edsociety.co.uk](mailto:info@edsociety.co.uk)

### 2018 Fundraising Summer Family Event

We are very lucky to have a member who is willing to offer her time and help us to organise a fun summer family event in June, but we are keen for more helpers.

If you are able to help, even in the smallest way, please let us know [info@edsociety.co.uk](mailto:info@edsociety.co.uk)

We are hoping this will be a big event raising a lot of money and will need all our ED families to attend to make it a huge success.

As soon as we have a date and more information we will let you know.

## Upcoming fundraising by our members.....

### Virgin London Marathon 2018

We are very lucky to have 2 runners in this year's London Marathon.



**Laura Page** was selected from her local running club to take part in the London Marathon on behalf of the ED Society.

"I will be hoping to raise as much as I can for the Ectodermal Dysplasia Society.

The reason being that our family sadly lost my brother Dave to the condition in 2001. The disorder did not just affect him in one way, but a group of closely related conditions affecting his development and function of his teeth, hair, skin, sweat glands; and many more besides. This will be my first (and most likely!) only marathon".

<http://uk.virginmoneygiving.com/LauraPage85>

**Clive Bentley** put his name forward for the place and has been chosen to run for the ED Society; "I had the opportunity to run the London Marathon in 2001. I had undergone surgery to remove a brain tumour ten months before, and although the prognosis was very grim (I was actually only given six months to live), I got myself fit enough to complete the marathon.



Miraculously, and against all the odds, I am still fit (relatively) and healthy.

Our youngest son, who is now 21, has Hypohidrotic ED. Over the years, we have seen him cope with lots of issues with overheating and his lack of teeth. He has undergone a lot of dental treatment which is on-going. He faces a lot of work which may well include a bone graft before the next attempt to provide implants".

<http://uk.virginmoneygiving.com/CliveBentley>

### Reading Half Marathon 2018

On 18<sup>th</sup> March, Lisa Harrington will be taking part in the Reading Half Marathon to raise funds for the ED Society. Please go to Lisa's virgin page and show your support by making a donation ☺

<https://uk.virginmoneygiving.com/fundraiser-display/showROFundraiserPage?userUrl=LisaHarrington2&pageUrl=1>

### Manchester 10k Marathon

Lisa Kennedy will be running the Manchester 10k Marathon on the 25<sup>th</sup> May to raise funds for the ED Society. Lisa will be setting up a virginmoneygiving page shortly and we will email this to everyone.

### Other Fundraising

Estelle Palma is kindly organising various fundraising events and raffles at a toddler group she helps to run – thank you for thinking of us Estelle!

***Please help show your support to Clive, Lisa, Laura, Lisa and the ED Society by going to their virgin money giving pages and making a donation. No matter how big or small, your generosity is much appreciated.***

***Please, please, please support them all!  
Marathon places are really hard to come by***

# Fundraising Merchandise

Please contact us to let us know your requirements to help make your event successful



Banners, leaflets, sponsor forms, collection boxes & more



A sponsor form is at the end of this newsletter, but if you require more forms or would like help in setting up your online fundraising page, then simply contact us [info@edsociety.co.uk](mailto:info@edsociety.co.uk)

## Making Fundraising Easy

Our top tips to help make your event successful

- Take time to plan your event.
- Think about the space you need, especially if you are holding your event indoors.
- Mention to the venue staff that you are raising money for charity – you may get a discount on room rates.
- Set yourself a target, this will keep you motivated.
- Ask local businesses for donations, prizes etc., mention you work for a charity and they may offer a discount.
- Spread the word and use Facebook and Twitter to tell everyone why you are fundraising and keep them up to date with your progress.
- Set up an online fundraising page with Virgin Money Giving and share the link on Facebook/Twitter and with colleagues and friends.
- Matched giving – many companies run matched giving schemes, this could double the total you raise. Don't forget to check with your employer to see if they run such a scheme, it's also tax-efficient for them.
- Please ensure all donors sign a Gift-Aid declaration, this enables the ED Society to claim an extra 25%!

## Growing Up with Ectodermal Dysplasia

I am writing this article in the hope that my experiences of growing up and dealing with all aspects of Ectodermal Dysplasia may help some of you who are going through the same process.

Whilst I know that having ED places a number of limitations on what I can do with my life (for example, playing rugby in the height of summer in Australia was never going to happen), for me, ED has never been a limitation in itself but more of a challenge. Watching your friends go off and do activities in the sun soon makes you realise that you do not want to miss out, and so I have always strived to push myself, and to not let ED determine what I can and cannot do. The perfect example I have of this is that I love history and have always been interested in Greek and Roman history in particular. In 2016 I went travelling around Europe during the summer, and one of the places I visited was Rome. The temperature was roughly 40-42 degrees, and we had two days to visit every site we wanted in Rome; I was not going to miss this opportunity and sit inside by a fan all day. Somehow, I managed to walk 18 miles across two days around the city in order to see everything (thankfully they have a lot of taps on the streets).

What has annoyed me most about ED is the fact that you have to push yourself or take precautions in order to do things which most other people would find easy. For me, the fact that you have to take a spray bottle, or wet your T-shirt, or even wear dentures, is annoying. It is easy to sit there and go "why do I have to do this, this is so unfair, why can't I be like everyone else," but sadly, complaining isn't going to do anything expect put you down. I have never let ED dictate what I can and cannot do and neither should you, if you want to go and do something then get out and do it.

I'd like to talk about bullying, because I know that most children, and even teenagers and adults, who have ED have at some point in their life have been bullied or are currently. I'm afraid to say that bullying is just something you will have to deal with. Usually

it is children or teenagers that bully, because they don't know any better and find taking the micky out of someone to be a cheap laugh. On countless times I have walked past a group of kids or teenagers and heard them all whisper and laugh quietly. I was bullied a lot in school when I was younger, but I stood up for myself and never let bullying get the better of me. I know for some of you this may be harder, but just think, why let someone put you down just because you look slightly different to them? I have always been of the mind-set that, they can laugh now, but I guarantee that I will be better than them; if I work harder and push myself further then I will be the one laughing in 20 years. I remember once there was this one boy in junior school who just would not leave me alone, he had been annoying me all day and I was fed up, so I tricked him and locked him in a shed. I got in trouble, but I didn't care because he had been bullying me and I had stood up for myself, and from then on, he didn't bully me anymore. Now, I'm not saying you should go around locking people in sheds, but certainly stand up for yourself. ED does not make you any bigger or smaller, dumber or smarter, stronger or weaker than anyone else, so why let other people bully you just for the way you look.

Even as an adult you will experience bullying. It has happened numerous times in bars or clubs where some drunken fool will say some passing comment to me, but I will always say something back and stand up for myself. When they turn around and ask if I want to fight, the simple answer is usually no; I'm quite small and will probably lose so why would I fight you? I have been very fortunate in that I have a group of friends who are non-judgmental, very understanding and will stand up for me if anyone ever makes a passing comment to me, which is nice. Surround yourself with people who don't care what you look like or whether you can run a marathon in a desert, but like you for who you are. Ultimately, I am quite a positive person and so have never really been affected by bullying; every bully has just made my skin that little bit thicker. Having ED will let you see the worst in some people, but also the best in others, an insight which many people may not get to experience.

Finally, I'd just like to touch on dentures and teeth briefly because I am certain that many people will feel extremely self-conscious about their teeth. I got called a vampire hundreds of times when I was younger for having pointy teeth, and some of you may have been on the brunt end of the same unoriginal joke. I'm sure you will realise that once you have dentures, no one will notice your teeth. I am currently in the process of having a bone graft and dental implants, but this is not because I am self-conscious about the way my teeth look. I am having them done because I am sick to death of having to clean three sets of teeth every night. I have a close friend who I have known for 10 years who did not even realise I wore dentures until a couple of months ago; it makes you realise that as you grow up people

start looking less at your appearance and pay more attention to who you are as a person.

Having Ectodermal Dysplasia is extremely unfortunate and there is not a day that goes by that I wish I did not have it. When I have children, I do not want to have girls as I do not want to pass ED on any further in my family. But, whilst I wish I did not have it, I have not let it affect the way I live my life. There is no use in moaning and complaining about having ED. Instead, use it as a positive influence. Think of it as a unique insight into the difficulties of life that most people will never understand or experience. Use it as motivation to achieve things you might not otherwise, and to push yourself that little bit further.

Jack Perry

## Working together at last for Rare Diseases: ERN-Skin

Professor Celia Moss OBE, 21<sup>st</sup> November 2017



From right to left in the picture

Holm Schneider  
Ulrika Holtzer  
Smail Hadj-Rabia (Necker)  
Lenja Wiehe (Eurodis)  
Celia Moss  
Johanna Hammersen (Erlangen)  
Olivia Khalifa

People with rare conditions suffer on many levels from disconnected health care. Patients often feel isolated; support groups may feel ignored by doctors; GPs struggle to find specialist information; experts lack forums for discussion, training and research. Care is uneven – some patients are referred promptly to the right specialists while others wait months or even years. No single hospital or even country has the expertise to treat all rare conditions. But rare disease has moved up the political agenda, and at last Europe, to which happily we still belong, has provided a solution.

The “European Reference Network for Rare or Low Prevalence Diseases”, launched in March 2017, recognises the difficulties of providing high-quality, cost-effective care for these conditions which affect the lives of around 30 million EU citizens. Twenty-four specialties are covered, one of which is Dermatology. Of only 8 conditions under “ERN-Skin” one is “Ectodermal Dysplasia, Incontinentia Pigmenti and Related Disorders.” This is a triumph and puts ED firmly on the main stage.

The 56 ERN-Skin participating centers (“healthcare providers” or HCPs) in 18 European countries were

selected following a tough bidding process; 7 are in the UK (see list); indications are that Brexit will not exclude us. Further information is available via the links below. Patients and support groups are firmly embedded in the networks. Europe provides infrastructure for networking and grants but does not fund care. Continued membership after 5 years will depend on our performance.

I'm writing this on Eurostar after attending the first working meeting of ERN-Skin in Paris. The ED subgroup (photo) was chaired by two experts, Holm Schneider, paediatrician from Germany and Smail Hadj-Rabia, dermatologist in Paris, and included patient representatives and medical experts. We had already met "virtually" by email and in a web-based conference. Our first task was to map available resources and define priorities for the next 5 years. We had 2 hours to put our findings together and 10 minutes to share them with the other ERN-Skin members. Like many groups, we found few up-to-date guidelines for managing these conditions; tests are not always available; training opportunities are patchy. We need more "outcome measures", that is ways to measure the performance of HCPs and to determine whether they actually make any difference to patients. These should include basic clinical measures such as how many ED babies die from over-heating, patient-reported outcome measures (PROMs) such as whether families received appropriate information, and "burden of disease" questionnaires about symptoms, time lost from work or school, financial costs and quality of life. We should also measure "process issues" such as waiting times for appointments and accessibility of the multidisciplinary team.

This meeting introduced the Clinical Patient Management System (CPMS), a secure, web-based IT platform, accessible to all ERN members, which will enable experts to discuss cases. ERNs are not directly accessible to individual patients: their doctor would

refer their case to the relevant ERN member in their country. The referring doctor can invite experts from any ERN, an important point for ED disorders which affect more than just skin. Patients will receive summarised conclusions from this virtual panel.

By combining resources scattered across countries, the ERNs will give healthcare providers access to a much larger pool of expertise. The networks will enable experts to share best-practice guidelines and training resources, and to focus on innovation rather than "re-inventing the wheel". The future looks brighter for people with rare disease.

#### Further information

ERN website: [https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)

ERN factsheet: [http://europa.eu/rapid/press-release MEMO-17-324\\_en.htm](http://europa.eu/rapid/press-release_MEMO-17-324_en.htm)

ERN-Skin website: <http://www.genodermatoses-network.org/spip.php?article483>

ERN-Skin factsheet: [https://ec.europa.eu/health/sites/health/files/ern/docs/ernskin\\_factsheet\\_en.pdf](https://ec.europa.eu/health/sites/health/files/ern/docs/ernskin_factsheet_en.pdf)

#### List of UK and Ireland ERN-Skin Healthcare Providers

Barts Health NHS Trust

Birmingham Children's Hospital NHS Foundation Trust

Guy's and St Thomas' NHS Foundation Trust

NHS Tayside

Great Ormond Street Hospital for Children NHS Foundation Trust

The Leeds Teaching Hospitals NHS Trust

Cardiff and Vale University Health Board

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## Proud of the ED Society

My first son was born in 1991 and diagnosed with ED 2.5 years later, my second son was born in 1995 and was diagnosed with ED within days. Once we had a diagnosis I realised I had a lot to learn to help the boys and found a support group. The group set up in 1984 when two mothers of children affected by ED met by chance, and with the help of Angus Clarke arranged a meeting for the few families known to them. At that time there was no internet or emails, so running a

support group and finding new families was extremely difficult. However, I contacted the group in 1996 to offer some help. The next I knew, I was sent the address book of families who were part of the group, given the Building Society book which held £200, and my journey began.

I worked from home and produced our first newsletter in 1997, together with a leaflet which I sent to every NHS Trust in the UK.

During 1998 the NFED in America, who have been a wonderful support to me over the years, mooted the



idea of holding their annual family conference in the UK. Two years later in August 2000, the NFED held their first annual family conference outside the US here in the UK. After this, with the help of Angus Clarke, I created a Medical Advisory Board to add credibility to the group. At the same time, I created a Board of Trustees and moved forward to becoming a Charity in 2001.

In 2002 the very first International ED Conference was held in Sweden and was organised for medical professionals, specifically dental. I was invited to make a presentation which was very scary as I had never done anything like this before, but it was well received.

By this time a few bits of paper and an address book soon turned into a filing cabinet and I needed help. In 2003 Sue joined me, and although she had no knowledge of ED, she brought her expertise in organisation and accounting.

2004 saw the launch of the second International ED Conference at the Eastman Dental Hospital in London, organised by Prof. John Hobkirk who had become a member of our Medical Advisory Board in 2000. These conferences are now held every three years.

The International ED Support Groups came together for their first meeting in 2007 and these meetings are now held every 18 months, which I co-chair.

Soon, two people became three and we could no longer fit into the little room in my home; it was time to find our own offices.

In 2011 we moved into our new office, we continued to go from strength to strength, the filing cabinets multiplied, and we were receiving national and

international recognition. During 2016 a fourth person joined us, we increased our office space by renting the office next door to ours and refurbished them into one larger office.

From the little address book in 1996 we now have over 1600 contacts worldwide, an eminent Medical Advisory Board, a Board of Trustees bringing highly skilled expertise, an array of information, are involved in research programs (some of which have been instigated by the ED Society), assist other countries in setting up their own support organisations, assist individuals and families in their applications, appeals and tribunals for Disability Living Allowance and Personal Independent Payment, assist schools to provide the correct level of care for children affected by ED, the list goes on.

In 2018 we will be launching our new website which will be mobile friendly, and an ED dedicated booklet.

I am so proud of how far we have come but couldn't have done it without the help and support of the Trustees, Medical Advisory Board, Staff, and most importantly Sue who has been a huge asset.

Thank you to all our members for your support and encouragement over the years, especially in helping us survive the hard times and making the Society the success we are today.

For the future, we can only continue to grow and bring Ectodermal Dysplasia to the forefront.

Please continue to support us by bringing awareness of Ectodermal Dysplasia and funding through your donations and fundraising events.

*Diana Perry*



## 2018 Membership

We would just like to remind all our members that membership has now increased to £20 a year.

If you have a standing order set up to pay your membership, could we please remind you to adjust it to £20.

The ED Society is a non-profit organisation which depends solely on donations and membership for its future.

### Your membership helps:

- enable the ED Society to provide the help and support individuals and families need,
- give a voice to the thousands of people in the UK and overseas who live with ED, by pushing for change in the recognition of ED and by sharing their experiences,
- enable the ED Society to produce informative literature,
- provide support and assistance with benefit applications and appeals
- secure the future of the ED Society

You can find new membership forms for the year on our website or please email [info@edsociety.co.uk](mailto:info@edsociety.co.uk)

## Help with Disability Living Allowance (DLA) and Personal Independent Payment (PIP)

We are more than happy to help and support you with your DLA/PIP claim, but as these forms take a considerable amount of time to complete, we ask that if your claim is successful, perhaps you could make a donation or hold a small fundraising event.

Monies raised by our members helps us to cover some of the costs, but sometimes these run into hundreds of pounds if we are required to travel to tribunals, etc.

We currently hold a 100% success rate for DLA applications and tribunals where we have helped families.

## Apologies -

We would like to apologise to Jessica for publishing the wrong wording for her article about her daughter, Martha, in our last newsletter. Please see below the correct and revised article;

### IP Awareness Month

*Jessica Van CoeVorden – mum to Martha*



Our daughter Martha is 19 months old and she was diagnosed with Incontinentia Pigmenti (IP) at ten days old. October is IP awareness month, so I have written a little piece

about how it affects her and how we view it.

IP is a genetic condition most commonly affecting skin, teeth, eyes and hair, but Martha didn't inherit it from either of us, it is just something that happened when she was conceived. She was born covered in blisters which gradually came off over the first 6-7 months of her life. She then developed lines in her skin where there is more pigment, she's got a stripy little tummy. Her teeth are coming through late and somewhat misshapen, but she still manages to eat very well, and she can say quite a few words now too! Regular eye checks haven't shown anything concerning, thankfully.

We are very aware how lucky we are – IP can have neurological effects and cause serious eye problems, so Martha is definitely towards the middle end of the spectrum. It is something she is going to have to live with, so we try to normalise it as much as possible: although Martha is too young to understand, she has a 3-year-old brother who will tell anyone who will listen: "Martha has IP. I have eczema!"

There are a lot of unknowns, but we try to remember that that's true for all children. We've been very well supported by friends and family and of course by the ED Society, who put us in touch with other families who had daughters affected by IP. And although it was such a big shock at the beginning, we genuinely don't think about it very much anymore: it's just one part of who she is, and as you can see she's a beautiful, funny and happy little girl, who is a delight to have around.

# Do you Enjoy Reading Members Stories?

## Articles Needed

We are always in need of more articles for the newsletter as we know how members love to read real stories and experiences.

Please send in any tips, personal stories, experiences, recommendations of professionals who know and understand ED, how you cope with ED and what it means to you, etc., etc. The article can be as long or as short as you wish.

Many of our members take comfort from reading other members stories, it often makes them feel less alone in the world –so please share with each other via the newsletter.

Here are some ideas:

- the biggest problems you experienced when dealing with Ectodermal Dysplasia,
- the helpfulness of the medical profession,
- the understanding and co-operation of the school,
- bullying and how you coped,
- the understanding and co-operation of your local or hospital dentist,
- tell us about any tips you have found helpful,
- positive stories of dental treatment/operations,
- tips encouraging your child to wear dentures,
- recommend medical specialists who understand ED and the affects it has on individuals,
- fundraising stories.

If we have helped with your application, appeal or tribunal for Disability Living Allowance or Personal Independent Payment, perhaps you could write an article about your experience and the support we gave.

Anything you would like to share with us to make the newsletter more interesting would be hugely appreciated.

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