

## SUPPORTING A NORMAL LIFESTYLE



I am so encouraged and grateful for the generosity many of you have shown since my recent request for help in an email and the last newsletter!

As you know I began the ED Society in 1996, whose aim is to bring awareness of Ectodermal Dysplasia to all walks of life and to provide a service of support to everyone who either has experience of or is affected by Ectodermal Dysplasia.

As you will appreciate this type of work doesn't generate any income, but does generate expenses such as office rent, salaries, computers, office supplies, etc. The Society has 3 part time staff, Sue, Danielle and Jaye who work Monday, Tuesday and Thursday 8.00 – 1.30 and I am and have always been totally voluntary.

When we need money for projects, equipment, computers, etc., we try to obtain grants, but sadly, there are very few organisations who will provide grants for core costs. So, the majority of money received from donations, fundraising, etc., go towards our core costs of running the office providing the service you all need.

The Society still and will always need your support and I would like to encourage you all to start the New Year by making a Standing Order either £3+ monthly or £20+ annually. If every family could do this, it would go a long way towards our main expenses of office rent and salaries.

Some of our individuals and families have dug very deep into their pockets and I am extremely grateful, others have taken on fundraising events bringing in lots of money for which I am also extremely grateful.

So, thank you again and I hope we continue to have your support. I hope you all have a wonderful Christmas and a very Happy New Year.

**Diana Perry**  
CEO

## IN THIS ISSUE

### 2019 Membership

Membership forms for 2019 are attached to this Newsletter.

Page 6

### Exciting News -We Are Award Nominees!

We were all extremely excited this month to receive an email telling us that our children's book, "Everybody's different" has been nominated for an award.

Page 3

### IP Our Story

The Munn's family experience of living with Incontinentia Pigmenti

Page 7

### 2019 Christmas Party

It's back – diarise the date

Page 7

### Fundraising

Lots of information and stories

Page 4

### Christmas Raffle

Page 3

### Dental Check by One

Page 8

## 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
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 has 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 do 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.

Unfortunately, we are unable to offer any help with ESA.

## 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)

## Exciting news – we are Award Nominees!!

We were all extremely excited this month to receive an email telling us that our children's book, "Everybody's different" has been nominated for an award.

We collaborated with Envision Pharma Group to develop a patient information booklet aimed at children that raises awareness and support for the disorder.

"Everybody's different: An introduction to Ectodermal Dysplasia" has been designed for children aged 4+, with and without ED, and allows parents and schools to explain the condition in child-friendly terms. It facilitates empathy and gives children the ideas and motivation to then help their peers.

Envision utilised its services in patient-focused content strategy, copywriting, illustration and graphic design to work closely with us to co-create the booklets that help children explore visible and invisible differences – as well as thinking about the emotional impact of those variances.



As a result of this collaboration, Envision Pharma Group are now among the finalists in the Global Healthcare and Pharma Advertising Awards for the Ectodermal Dysplasia booklet, under a "Health Awareness and Advocacy" category.

Please take a look at <https://www.envisionpharmagroup.com/> and have a read of the full press release 😊

## Fundraising – Our grateful thanks.....

For the many donations that have been coming in over the past 3 months, to everyone who sent in donations with their membership form and to all those who pay regular donations by standing order.

The total so far is £13,266.11.

Our thanks also to...

Toby Shortman - Warrior Adrenaline Race - £315.66

John Banks - Sky dive - over £400.00

Sarah Crosby - Birthday Fundraiser £35.00

Dave Taylor - Bike ride over the Pyrenees - £1010.00

Mark Lloyd - 10K run and birthday fundraiser - £240 so far....

Robyn Keane and Purford Primary School - Strictly Come Dancing Sweepstake - £30

Harry Sharman held a cake sale at his school and raised £56.40

Elaine Robinson - In memory of Alan Ratcliffe donation of £125.00

King Edward School Form 6I - weekly collections and chocolate tombola - £90

Jessica Banks - Tough Mudder - £1804.36

Megan Jones – raised £200 on Jeans for Genes day

Bottomline Technologies - £100.00

Mark McNair - £300.00

Some of these events are still to have Gift Aid added

**Please keep your donations coming in and if you don't do it already please sign a Gift Aid declaration.**

## ED Christmas Raffle

Tickets for our Christmas raffle are now ready and are being sent out with this newsletter. The raffle will be drawn on 14th December 2018.

If you think you are able to sell bulk tickets to friends, family, work colleagues etc. please get in touch – [info@edsociety.co.uk](mailto:info@edsociety.co.uk).



All proceeds from the sales of the tickets will help the Society tremendously in the need for new office equipment and to be able to offer vital support to our members.

**Let's get selling!!**

# Fundraising Stories

## Warrior Adrenaline Race



Having heard the ED Society were running short of funds, I wanted to do something to help. I decided to ask people to sponsor me to do a WAR race, which is a muddy obstacle race over 10km. Great fun to do and a great way to raise money for a great cause close to my heart. I was very pleased to manage to raise £315.66.

*Toby Shortman*

## Tough Mudder

Since birth we have tried to find a diagnosis for Thomas, we were finally told that he had Ectodermal Dysplasia over his third birthday. With a massive sense of relief, but also lots of questions we were introduced to the Ectodermal Dysplasia Society.



The help, support and understanding they have given us as a family has and is always appreciated!

Through them, we have learnt about Thomas' condition and met many other ED families, which we will continue to hold friendships with.

Without the Society, I'm unsure where we would be today with helping and understanding Thomas.

The ED Society needs and deserves just as much support and help back as they have given me, so I decided to run with two team mates the full Tough Mudder on 29th September in order to raise money.



I was SO nervous and scared, I didn't want to let anyone down, but I smashed it! And I absolutely loved every cold, wet

and muddy minute of it! It was incredibly hard work, and very tough at times (I won't lie), but that all added to pushing me and my team more to complete the course.

I was delighted when I finished and pleased to say we will be doing it all over again next year!

*Jess Banks*

Raised £1,612.86 - With gift aid £1,804.36

## Sky Dive

My wonderful five year old grandson Thomas suffers from the genetic condition Ectodermal Dysplasia and when my daughter Jessica told me she would be competing in a Tough Mudder event to raise funds for the ED Society, who have been a great help to the family, she also asked the question; "do you want to do the Tough Mudder with me?" At that moment, I was full of fatherly pride that Jessica would attempt a Tough Mudder, but simultaneously full of dreaded fear at the thought of attempting it myself. After all, I'm a middle-aged man whose idea of exercise nowadays is a long walk in the countryside or an hour in the local swimming pool. So, the thought of me putting in hours of training over several months, and then have to drag my middle aged body around a ten mile course of ever more challenging obstacles and pools of freezing muddy water, whilst dodging electrified wire, was not an appealing thought at all, so I politely declined the offer. However, I still wanted to do something that would be a personal challenge, exciting, with a dangerous element, and raise funds and awareness for the ED Society. It was at that moment I decided I would rather jump out of a plane, than participate in a Tough Mudder.



So, before I changed my mind, I immediately signed up to complete a tandem sky dive. My friends, relatives and work colleagues started making their donations to my Virgin Money Giving page and pretty soon I had raised well in excess of my £100 target. I was over joyed with the amount of support it had generated and the interest people were paying to the ED condition and the Society. People became genuinely interested in learning about the condition which my grandson "Iron Thomas" suffers from.

A few weeks passed and before I knew it the day of the parachute jump had arrived. Upon arrival at the

venue we were placed into small groups and introduced to our tandem sky diving partners. My partner for the sky dive would be Chris, an ex-military, professional sky diver who has been part of the Black Knights Parachute Team for about fifteen years. He has completed literally thousands of parachute jumps. This information was an obvious comfort to me, and after introductions and full training we were all fully kitted out and ready to go. It was only when we were actually waiting for the plane to taxi towards us that I became filled with excitement.

Upon entering the aircraft with Chris and taking our place on the bench, he ensured the pair of us were securely hooked up to each other. I then realised that we were the last couple to be seated, and therefore the closest pair to the door... which obviously meant that we would be the first to jump. Last in, first out! Eek!! "So, here we go" I thought as the plane began to speed along the runway before lifting off and climbing up through a layer of cloud. Climbing...climbing...still climbing... Then after a few minutes some obvious thoughts began to run through my mind, like; "wow, we are really...really high" and "err? we're still climbing" ... But then we started to level out and the sound of the engine became less intense, one of the instructors lifted the sliding door to the side of the plane. This was my key to prepare for the jump. But being enclosed and looking through the windows of the aircraft is entirely different to actually knowing that there's nothing between you and the ground, which by then was about 8,000 feet below.

As instructed I shuffled my backside along the bench toward the open doorway with Chris strapped to my back and hung my legs over the side. As I looked down at the cloud, far, far below, I thought "this is it...and it's amazing", how lucky I was to be able to actually go through this experience. Then, the quick tap on my shoulder from Chris was the cue for me to assume the correct position - put my head back, grip the harness, tuck my elbows in and get my legs bent back as far as possible, think "banana shaped"! And before I knew it we were tumbling and falling to the ground at about 130mph, but after only a couple of seconds Chris had used his skills to level us out into a stable sky dive. My arms and legs now fully stretched out, I was able to really enjoy the experience of free fall. I'm sure at this point I had the biggest smile ever. At that moment, nothing else in the world mattered, sheer and utter enjoyment filled every single part of me. I was completely consumed by the moment. This is the time where you really do feel as free as a bird.

After what was only a matter of seconds, our speedy free fall came to a rapid decrease as the parachute was deployed. With some minor harness adjustments, I was able to lift my legs into a seating position, making the slow gliding descent a very different experience to the last few minutes. Gliding through the air, twisting & turning, I was able to take in the scenery below. Landmarks were pointed out to me as we slowly completed several 360 degree turns.

Before I knew it, and all too soon we were going through the pre landing drill and the airfield landing marker was getting closer. With excellent precision we landed, and as we touched the ground, the earth had never felt so solid to me. Filled with adrenaline and joy I rushed to my wife and attempted to describe the amazing experience and feelings I was having. I was on a high for hours afterwards. Probably the single most, best experience of my life. And I managed to raise over £400 for ED Society in the process.



So, if you've ever considered doing a sky dive, but not gone through with it yet, I can 'highly' recommend you do it.

*John Banks*

## Important Message

Please ensure when you make any payments via PayPal that you send it as "friends family" and not pay via "goods services" as we do not receive the full amount that you are sending.



At the moment for every £10.00 you send PayPal take 34p leaving the Society with £9.66 – £20.00 is 68p, £30.00 is £1.02, etc.

One way around this is to access your PayPal account, enter [info@edsociety.co.uk](mailto:info@edsociety.co.uk), put in the amount and press next. **DO NOT** click on "goods services".

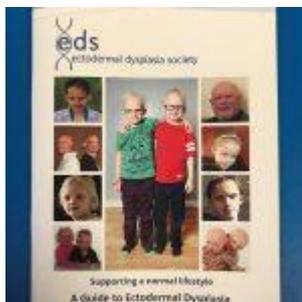
Thank you.

## ED Shop

If you have been on our new website, you will have seen the ED Society now have our own "shop". We have ED t-shirts, wristbands, pens and key fobs. Please check them out - [www.edsociety.co.uk](http://www.edsociety.co.uk).



Thank you to everyone who has shown interest in our new books and have purchased a copy. If you would like to order any, please email us [info@edsociety.co.uk](mailto:info@edsociety.co.uk). You can find more information on our website.



*"Everybody's Different" - A wipe clean book - £6.49 incl. p&p.*

*"A Guide to Ectodermal Dysplasia" - £4.99 incl. p&p*

**Buy both books together for £10.49 incl. p&p**

Both books are available to buy through our website or via email: [info@edsociety.co.uk](mailto:info@edsociety.co.uk).

Buy one to give to your family doctor or school.

The books will make great Christmas stocking fillers.

## Easyfundraising

With Christmas fast approaching, I am sure many of you are already thinking about it and have started your shopping!

Just a gentle reminder that before you start your online shopping could you please sign up to easy fundraising to help raise some much-needed donations for the Society.



It is really simple and fast to use - especially if you download the app.

Once you have registered, select the ED Society as the charity you wish to raise donations for. You can also download the "Donation Reminder".

Each time you go on to shop, go onto easy fundraising, search for the retailer you wish to use, and it will then redirect you to their site - once you have checked out it will then generate a percentage donation of your total to the Society.

Pretty much all the big named retailers are registered with easy fundraising now – there are hundreds!!

Thank you 😊

[www.easyfundraising.org.uk](http://www.easyfundraising.org.uk)

## 2019 Membership

Membership forms for 2019 are attached to this Newsletter.

Last year we increased the fee to £20 - this reflects the increase in our workload and the number of people contacting us, which continues to grow on a weekly basis.

Benefits of becoming an ED Society member:

- the opportunity to apply to the Support Fund (UK members only)
- free subscription to request printed literature (excluding the booklet)
- voting rights at the AGM
- help with completing DLA, PIP and Blue Badge forms, together with assistance with appeals and tribunals

- access to expert support and our medical specialist network

Your membership:

- Enables us to provide the help and support individuals and families need
- Gives 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.
- Enables the ED Society to produce informative literature
- Helps secure the future of the ED Society



## The ED Christmas Party is making a Comeback!!

Last year we announced we would no longer be holding our annual Christmas party – mainly due to lack of funds and also wanting to venture into other ideas of how to get together.

After many discussions in the ED office, taking feedback from our members and the recent questionnaires, we have decided to stick with our original party format.

However, at the last Trustee meeting it was decided that the ED Christmas Party should be held every 3 years.

So, our first party will be Saturday 7<sup>th</sup> December 2019. As before, it will be held at the Jurys Inn hotel in Cheltenham who have always been accommodating to our needs and it is the best situated hotel being just off the motorway and opposite the Travelodge for members wishing to stay over.

Once again, some of our Medical Advisory board will attend and will be there to help with any questions you may have for them regarding dental, dermatology, genetics etc.

It would be great to begin gauging everyone's interest so if you could let us know if you think you will be attending – great! Also, any ideas are still greatly welcomed, anything you wish to see that has been different to our previous parties please let us know!

## IP – Our Story

When Louise was born in 1999 she was covered in blisters. I held her briefly with my husband and then she was taken to another room where all I can remember is seeing this tiny baby with a group of doctors all looking at her with a huge light. I also remember feeling very faint as it all happened only minutes after she was born. She was so small - just over 5 lbs in weight.

We spent a week in hospital which was horrible, because at the time doctors didn't know it was Incontinentia Pigmenti (IP) and thought Louise had something that was contagious! We spent 3 days in a separate room that was just off the main ward and had a window. All the other mums would stare and whisper as they passed by – it was horrible.

Once we were told about IP I was allowed to go onto the main ward, but I couldn't make friends as they still remembered me being in that isolated room - I couldn't wait to leave. We had no idea what IP was and went up to London when Louise was 2 weeks old for her to have a skin biopsy to double check it was IP.

At her checkups we had many calls asking if doctors could take a look at Louise to help with future studies of IP, although we wanted to help others we eventually stopped this as it was all getting too much, and we didn't want Louise going through any more.

We tried to make sure Louise had the best childhood, yet at the same time we were always wondering what will happen next with this unknown IP. I always said that we would explain to Louise about IP when she was older which we have now done. Nothing much happened for the first 10 years apart from the usual IP stages, but we felt so alone - I thought there must be other people out there with IP and that's where the amazing Facebook group came in - I've learnt so much about IP since being in the group who have all become our second family.

When Louise turned 11 the seizures started. The doctors prescribed medication as they thought it was epilepsy even though nothing has ever shown up on the tests. When she was about 16 the doctors took Louise off the medication and said she has non-epileptic attack disorder (NEAD) which is similar to epilepsy but is more to do with stress and anxiety and no medication will help only something like talking therapies.

The main issues Louise has had with IP is her teeth and learning. She has dentures on her bottom teeth which took a few years to get and she went through painful procedures to get them, but wow what a difference they have made, I remember the dentist asking her why she wanted the dentures and because Louise was shy back in those days I answered "of course she wants teeth", but they said they needed hear it from Louise who said "I just want to eat properly"

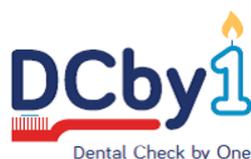
As she has got older (19 now) it seems things like seizures, that seem to be linked to her monthly's and anxiety, have got worse - is IP to blame? I'm not sure.

When Louise was about 2 and a half I became pregnant with my boy Matthew. We didn't ask the sex or if the baby had IP, we were anxious but knew we would love this baby the same no matter what. When he was born, and they said it was a boy, I said "are you sure?". Matthew doesn't have IP.

We have had tough times and amazing times over the years. Louise once said that if she had the chance to be born again without IP she wouldn't want to, because IP, as horrible as it is, has made her the strongest, craziest, unpredictable, funniest woman she is today, and we wouldn't want it any other way.

*Susan Munn*

## Dental Check by Age One



*Reproduced from the British Society of Paediatric Dentistry website*

All parents and guardians are advised to ensure that young children in their care are taken to see a dentist as soon as their first teeth come through, and before their first birthday.

### **Why by the age of one?**

The advice from Public Health England is that your child should see a dentist from six months because that's when first teeth usually come through. By the age of one, most of your baby's front teeth should be present. It's an opportunity for the dentist to look into his or her mouth and check that the teeth are developing as they should. We also know that 1 in 8 three-year-old children have visible dental decay, so we don't want children waiting until school age for their first dental visit. Dental decay is almost always preventable, and we want your child to grow up with healthy teeth that are free from decay.

### **What can the dentist do when a child is so young?**

The first appointment is an important one as it's a chance to meet your dentist and their team. Hopefully your child will feel at home there and be ready to open their mouth, so the dentist can do an examination, but don't worry if that is not the case! This visit is also an opportunity for you to check what sort of toothbrush and toothpaste is right for your child and to get advice on food and drink. You can also find out if the dentist offers fluoride varnish so that when your child is a bit older, he or she can be given a protective varnish for their back teeth which helps to prevent decay.

### **What happens if my child won't co-operate?**

Sometimes a child won't open their mouth. Don't worry. Some children take longer to adapt to new surroundings. If after some encouragement, your child keeps their teeth clamped together, there should still be time for you to chat to the dentist and get preventive advice for your child. Book to return in a few months and hopefully the dentist will have more luck in seeing into your child's mouth!

## Fluoride Varnish and Fissure Sealants

*Reproduced from the NHS website.*

Fissure sealants can be done once your child's permanent back teeth have started to come through (usually at the age of about 6 or 7) to protect them against decay. This is where the chewing surfaces of the back teeth are covered with a special thin plastic coating to keep germs and food particles out of the grooves. The sealant can last for as long as 5 to 10 years.

Fluoride varnish can be applied to both baby teeth and adult teeth. It involves painting a varnish that contains high levels of fluoride onto the surface of the tooth every 6 months to prevent decay. Some children may need this more often. It works by strengthening tooth enamel, making it more resistant to decay.

From the age of 3, children should be offered fluoride varnish application at least twice a year. Younger children may also be offered this treatment if your dentist thinks they need it.

As your dentist about fluoride varnish and fissure sealing.