edlines

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ECTODERMAL DYSPLASIA SOCIETY

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The ED Society Needs Your Help!!

(Treasurer's Plea—Alan Waller)

An inevitable consequence of being a retired accountant is that many charities are looking for a Treasurer and it is difficult to resist. As you will be aware, the ED Society provides vital support to members, working together with people who have ED, their families, researchers, health and other professionals to develop and share expertise, increase awareness and understanding, and assisting with the day-to-day management of ED.

The Society is totally dependent on its members, families and friends for funding the support provided. Over the past few years, generous donations have generated over 30% of the total income of the Society and fundraising a staggering 60%. However, last year, for the first time in many years, expenditure exceeded income and, in order to continue providing support at the same level, we need to increase our income. If you would like to help, you could think about doing one of the following:

- Making a donation - We have seen incredibly generous donations over the years, but no amount is too small.
- Hold a fundraising event - This doesn't always have to be as big as running a marathon, but more simple events such as cake sales, car washes, Easter egg hunts, raffles, etc.

If you would like to get involved, please get in touch with us and we will be happy to help you by sending an ED Society fundraising pack. This would help us to continue providing increased support to those in need and would also make one Treasurer of a charity very happy!

GET INVOLVED

Please note, we all have new email addresses -

diana@edsociety.co.uk / sue@edsociety.co.uk / julie@edsociety.co.uk / danielle@edsociety.co.uk

Medical Advisory Board Members

Prof. Angus Clarke	-	Clinical Genetics (MAB Chairman)
Prof. John Hobkirk	-	Prosthetic Dentistry (Implants)
Prof. John McGrath	-	Genetics, Molecular Dermatology
Prof. June Nunn	-	Paediatric Dental Surgery
Mr. Colin Willoughby	-	Ophthalmology
Mr. Martin Bailey	-	ENT
Prof. Michael Tipton	-	Human Applied Physiology
Prof. Nichola Rumsey	-	Psychologist
Mr. Mike Harrison	-	Paediatric Dentistry
Dr. Claire Forbes-Haley	-	Restorative Dentistry
Prof. John Harper	-	Paediatric Dermatology
Mr. Michael Kuo	-	Consultant Otolaryngologist
Dr. Fiona Browne		Dermatologist
Dr. E. Jones	-	Clinical Genetics
Prof. Celia Moss	-	Paediatric Dermatologist

Trustees

Paul Collacott	-	Chairman
Alan Waller	-	Treasurer
Diana Perry	-	Secretary
Mandy White	-	Air-Conditioning / School Liaison
Melanie Davis		
Stephen Ayland		
Simon Lees-Jones		
Mark Macnair		
Sharon Cooper		
Scott Gallacher		

Staff

Sue Beard	-	Accounts / Website
Julie Cox	-	Administrator
Danielle Gue	-	Administrator

Volunteers

Diana Perry	-	Chief Executive Officer
Fergus Gordon	-	Scotland
Elaine Aylward	-	Ireland
Kerry Russ	-	Fundraising Co-Ordinator
Stuart Atkiss	-	Fundraising Co-Ordinator

Membership

You will be unable to gain access to the Members' Area of our Website until we are in receipt of your 2016 membership form.

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

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 Department for an application form.

Many of our families already have a Blue Badge; if you would like Diana to help you complete the forms or appeal if your application is turned down please email **diana@edsociety.co.uk**

Symptoms Questionnaire

Could you please return the Symptoms Questionnaire for each individual who has ED in your family? This document will hugely help us when answering any of your questions or assisting you with DLA, appeals, tribunals, schools, doctors, etc.
This is available for download from our website.

Disability Living Allowance, Carer's Allowance and P.I.P

Diana is 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, Diana is happy to write an appeal letter for you and if necessary, attend a tribunal with you.

Fundraising

Our grateful thanks or the fundraising events which have been organised and the many donations we have received over the past 3 months, including those that came in with memberships and regular donations amount to £9765.

A huge thank you to:

Richard Pettigrew's employers Bottomline Technologies for sending in a further £200.

Rachel Goodfield for raising £436.25 through doing a Fun Run.

Robert Taylor who is 8 years old, raised £322.50 after taking part in the Bournemouth Children's Marathon back in October, he came fourth and broke his personal best running 1.5 km in 6.03 minutes!

(Robert Taylor)

Mark and Vicky Macnair for raising another £242.

Richard Harpin and friends for raising £423 by cycling from Scarborough to Whitby and back.

(Gabrielle Beeson & Friends)

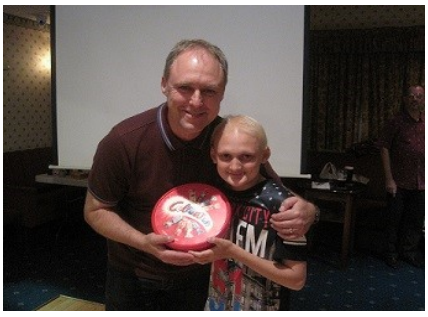
Mel Davis for money donated from a collection box she has in her opticians.

Stuart Atkiss' local church, Upper Gornal Methodist Church, who raised £760.79. Thank you for nominating the Society.

Gabrielle Beeson and Chafford School where she attends, for raising £150 on their Jeans for Genes day. The school allowed Gabby to take the leadership on organising the event.

The McGuire Family—whose daughter raised £57.20 by holding a cake sale at her school.

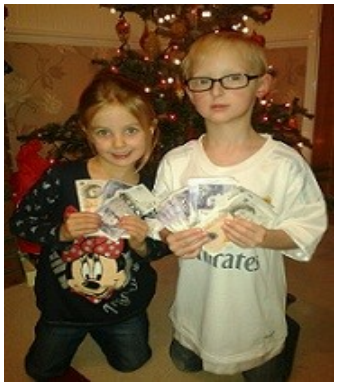
The Willats family for holding their annual race day and raising £2017.54.



(Dave and Max Willats)

Tessa Lee-Jones' Grandmother who donated £2,500.

Carr & Co Solicitors for donating £345.03



(Bailey Squires)

Gill Squires and family for their fantastic donation of £1000 and their continuous fundraising for the Society —

Bailey Squires' Nana (Gillian) has continued to make and sell home made goods such as Coffee, tea and wine sets to help raise funds for the society. Her daughter Kelly, kindly donated Benefit and MAC make up sets to also be sold to raise money. Gillian's neighbour, Sandra, has been helping to sell the sets from the Bakery where she works, Hinitt and Co. in Yorkshire. Not only this, but Gillian has held two stalls at Bailey's school fetes and the village gala to sell the sets to raise money.

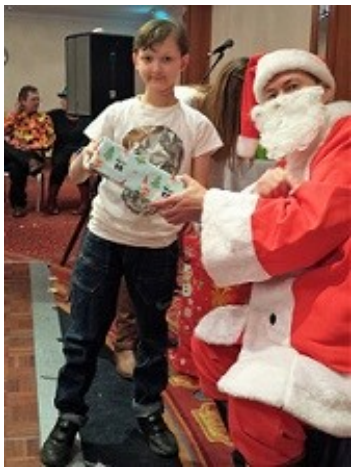
Christmas Party 2015

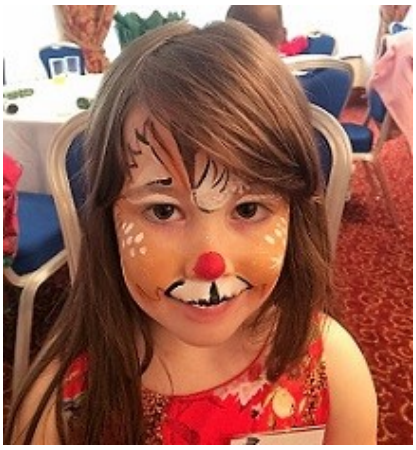
Thank you to everyone for coming to our Christmas party in December, it was a great success and was enjoyed by all! There was some fantastic face painting this year done by Hattie from Mad Hatter Face painting—Thank you Hattie!

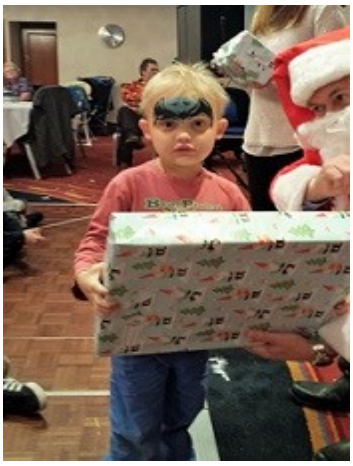
A special thank you to Kerry Russ and her son Tom for helping sell some of our wristbands and for taking the photos for us.

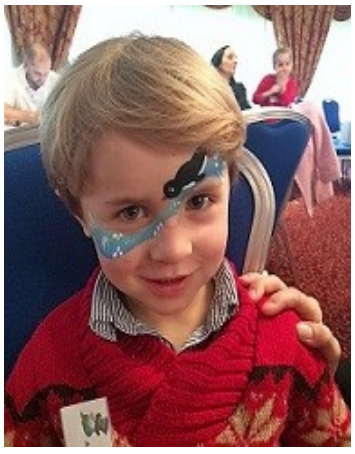
A big thank you to Fergus Gordon for the prizes he kindly sent to us for the party.

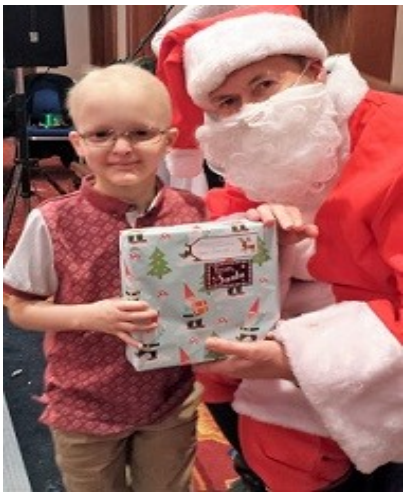
We would also like to thank Zoe Morgan and Helen Charnock from Lloyds TSB for donating half a day helping us in the office.

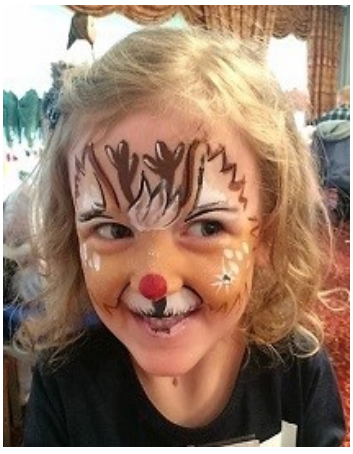












Raffle 2015

Drawn at the Christmas Party 2015

A huge thank you to everyone for selling so many raffle tickets this year in aid of our Christmas Party, we raised £1060 after prizes and costs. The winners were:

1st Prize £100	Ticket Number 6577	Val Lendy
2nd Prize £75	Ticket Number 4912	Pauline Witney
3rd Prize £50	Ticket Number 2868	Stuart Atkiss
4th Prize £25	Ticket Number 6288	Jason Griffin

We would like to say a big thank you to Pauline Witney who kindly donated her prize back to the society, it is much appreciated.

Do you qualify for a Grant?

Last year the Family Fund helped 72,043 families with over £33 million of grants and services. As a parent or carer, you know what your child or family might need to help them.

The Family Fund will look at any grant request that relates to the needs of a disabled or seriously ill child or young person and their family. This can be furniture, clothing, bedding, kitchen appliances, sensory toys, computers or tablets, a family break, or maybe something to help with college for 16-17 year olds.

You can apply to Family Fund if you live in the UK and:

- You are the parent or carer of a disabled or seriously ill child or young person aged 17 or under
- You get certain means-tested benefits (if you don't they will need some extra information about your household income)
- Are a UK resident.

If you would like to ask questions or discuss before you apply please contact them. Check their website for the full criteria. When applying, think about what would make a difference. They have contracts with a range of suppliers to provide the majority of their grants.

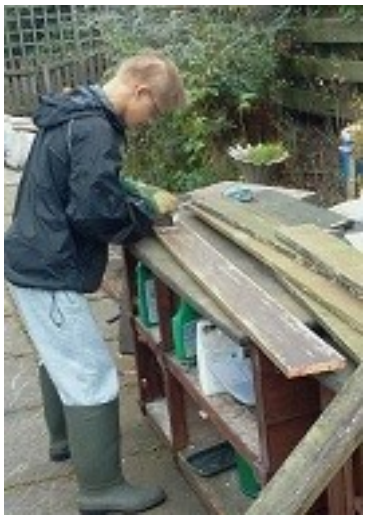
Go to **www.familyfund.org.uk.**

Family Fund
Helping disabled children

Uniformed Services Diary

(By Daniel Sanchez)

This is my seventh diary entry for my Uniformed Services course.



During the last few months I have completed the physical activity for my Duke of Edinburgh award, as well as my volunteering. Swimming was a good choice for me because I enjoy it and don't get too hot. The silicone ear plugs worked well and I did not get any problems with my ears like I normally would if I swam a lot. The volunteering was good fun but hard work at times. I enjoyed helping out with the chickens.

In November I took part in the Remembrance Day parade. Unfortunately, it was a very rainy and stormy day so the service was cut short. I kept having to wipe my glasses to see as they were covered in rain drops.

I went to another weekend camp in November. During the weekend we all went to watch an ice hockey game with the Edinburgh Capitals vs the Nottingham Panthers.

It was cold when we were watching, and very violent and exciting. We also went to paintball which I was dreading as I can't see the targets, my glasses steam up, and I can't see through the masks. But a 3-star corporal stayed with me and shouted out directions to help guide me so it was OK in the end.

I have been doing a lot of ceremonial rifle drill work and skill at arms. We are also working on first aid this term which is interesting and will be useful.

Before Christmas a policeman came to visit our class. He told us about working in the police force and we asked him questions about his job.

This week a fireman came to visit our class. He brought along his full uniform and equipment that he has to carry. We learned a lot about being a fireman - the uniform protects them up to 500 degrees. A bit too hot for me I think!

This term we are focusing on teamwork and raising money for the cadets. We will also be preparing for our Duke of Edinburgh expedition.

Wanted—photos for our new website

We are currently designing our brand new website and would like help from our members. If you would like to send in to us some photos to go onto the new website this would be greatly appreciated. It can be family photos or photos from any fundraising events you may have taken part in.

Please email to **danielle@edsociety.co.uk.** (photos will need to be high resolution)

Dental Treatment for Adults Diagnosed with ED

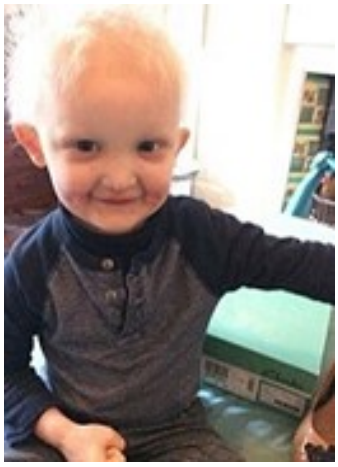
If you need dental treatment such as crowns or dentures, ask your dentist to refer you to a dental hospital as treatment due to a genetic condition should be free on the NHS. If you would like further information or help, please email **julie@edsociety.co.uk.**

Real Beauty Truly Is What We Are On The Inside

An abstract from Kirsty Herriott's Facebook Post

My youngest son is 3, I've done this age 3 times before and tonight while I calmed him and cuddled him, I realised it's possibly my favourite age. They are old enough to have their own wee personality, their character is developing daily and they are already becoming part of who they are going to be, but what makes it most special and magical is the innocence they still have. It's an innocence I wish we could hold onto for longer.

My youngest is such a caring wee boy, he literally melts my heart, every day. He's kind, he's funny, he's loving and I love spending time with him. If you ask him what his super power is he'll say "cuddles that make Mummy happy" and he's so right. His emotional intelligence astounds me in someone so young, he is sensitive to those around him, he can be downright soppy at times (that's probably my fault) and he genuinely cares about the people around him. He can be shy too, but once you've gained his trust he comes into his own.



I take him to nursery and I love seeing his smiling wee face when I go to pick him up. I love seeing how his confidence has grown (we had a shaky start) and how he is finding his place in his class with his peers.

When I pick him up now I can tell he has had fun, he is happy and confident and he feels at home with his friends and teachers. I can see him developing friendships and feeling part of a group and I love that. All those 3 year olds together, all with that lovely innocence that I wish they could keep.

You see, my son has a genetic disorder (one that I often tell myself in terms of possible genetic disorders isn't that bad) but one that still makes him a little bit different.

Tonight he had a really bad nose bleed that I know can be common for children with Ectodermal Dysplasia, but as I held him and eventually calmed him from the panic it made him feel, while I stroked him and told him it would be ok, I started to think and to worry. How long do I have for him to still believe me that everything will be ok, how long will he trust what I say; how long before the actions of others could eventually start to hurt him?

He has that lovely innocence and at three is totally unaware of the differences he has, of the struggles he will have to face or overcome. Just now he isn't even bothered about not having teeth, he doesn't think to compare his lack of hair with the heads of friends in his class. His 3-year-old friends are also completely unaware, they all just accept each other and are too young to even notice the differences yet. Why does that have to change; why does that accepting innocence of three year olds have to disappear?

As we have crossed the school playground to get to his nursery class, I have noticed older children, stare, point even giggle because they have reached an age where the differences are noticeable, where his look is different, not the norm, maybe even a little strange. It makes me realise I don't have long enough to protect his innocence and this makes me sad, sad that I can't keep him unaware, sad that I can't protect him forever and sad that I need to learn how to give him the tools he will need to be strong and confident and to not let this bother him.

Just now it only bothers me, he hasn't noticed, but how long do I have till he does? How can I as a parent prepare him so that he can grow up to be the boy, the teenager, the man he is already starting to become?

I worry that kids can be cruel and I don't want any difficulties he might have to face change or spoil the lovely person I can see in him already, to taint his personality. Is unconditional love enough? I worry that it isn't. I worry that people, especially children can be cruel and I don't want him to have to deal with that. I can't change the world. I can't make everybody be as kind and accepting as 3 year olds. So what can I do?

Those of you, who know me, will know this isn't a usual Facebook post for me. I like to keep it light, I don't really believe in plastering everything about my life on social media. I even get frustrated at some peoples posts, thinking why would you share that on here. Yet here I am sharing a very personal worry and I don't even really know why.

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Maybe I'm hoping for some sound advice or maybe I'm hoping it will make some of you think, it will make some of you aware that the innocence of three year olds is something to be cherished and something that we should try to hold onto in our children for as long as possible. That we should all teach our children that we are all different in so many ways even if there are lots of other ways in which we are the same. Let's teach our children, that what is important isn't how we look, but how we love and care for each other, how we treat each other. That real beauty truly is what we are on the inside and not on the outside. My wee boy is beautiful, inside and out, but he is a little bit different, I'm just hoping no one ever makes him feel that this is a bad thing.

Disabled Students' Allowances (DSAs)

For University and Higher Education Students

What you'll get

Disabled Students' Allowances (DSAs) are paid on top of your other student finance. They help you pay the extra costs you may have because of your disability. They don't have to be repaid.

How much you get depends on your individual needs - not your household income. If you're a part-time student your 'course intensity' can affect how much you get.

2016 to 2017 academic year

Type of student	**Specialist equipment Allowance**	**Non-medical helper allowance**	**General allowance**
Full-time	Up to £5,212 for the whole course	Up to £20,725 a year	Up to £1,741 a year
Part-time	Up to £5,212 for the whole course	Up to £15,543 a year	Up to £1,305 a year

Postgraduates can get a single allowance of up to £10,362 a year.

These figures are the maximum amounts - most students get less.

What DSAs can pay for

You can get help with the costs of:

- Specialist equipment, eg. a computer if you need one because of your disability
- Non-medical helpers, like a note-taker or reader
- Extra travel because of your disability
- Other things related to your studies, like photocopying

DSAs don't cover disability-related costs you'd have if you weren't attending a course or costs that any student might have.

Your 'needs assessment'

Once your eligibility for DSA is confirmed, Student Finance England will ask you to contact an assessment centre to work out what help you need. This is known as a needs assessment. Don't book this until Student Finance England asks you to. The assessment is paid for through any DSAs entitlement you may have. After the assessment, you'll get a report listing equipment and other support you can get for your course.

Don't buy any equipment until you've been assessed—you will not be reimbursed for it.

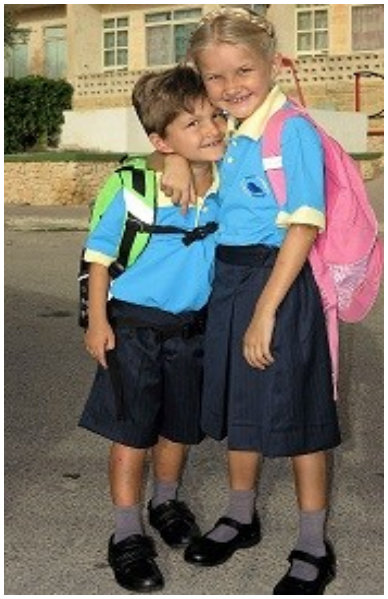
How DSAs are paid

Money is paid either into your bank account or directly to the organisation providing the service or equipment.

EDAR Variant—Living in Malta

(By Stephen Mifsud)

I have written several articles about the flora of Malta, being a professional Maltese Botanist qualified by a Masters in Biodiversity and taxonomy of plants from the University of Edinburgh, but I would have never imagined myself writing an article about myself and Ectodermal Dysplasia. One reason being that despite in my early 40s, I've discovered about this condition only a few years after the birth of my cute 9-year old daughter, when I noticed that she had the exact pattern of missing teeth that I and my mother have. I hoped that it might be just a coincidence, but when my second child, now a smart 6-year old boy, had again the same pattern of missing teeth, I was seriously concerned and I have been writing more regularly to the ED group in the UK. One of the many suggestions I received from this excellent support organisation was to perform a genetic test to confirm ED and to which trait it belongs.



First I performed the test on myself in 2013 and then on my children in 2014. ED was confirmed in all three of us. For me that was no news, just a hope-killer, because from the symptoms I was sure it must have been ED. However, the results still had a piece of news for me because the ED we carry seems to have never been reported, and whether undocumented or new to science, we still have to see. For scientific purposes, the result of our ED is EDAR c. 1264 G>T variant, dominant – just a single base substitution, as rare as winning the national lottery three times in a row!

This ED is very mild and almost without any symptoms, from birth to the start of teenage years. In all three of us (and assumingly my mother) the main visible symptom during childhood is lack of all four lower incisors and only two large incisors above. Teeth are evenly spaced and quite cute, there are no signs of missing teeth when smiling or even laughing, and eating without trouble. Nails, hair, sports activity and social life was perfect.

Unfortunately, I am seeing a developing symptom in my daughter which was neither manifested in me or is visible in my son, and I cannot tell if my mum had it, so maybe it effects females more. My daughter has obvious signs of late development and it was symptomatic mostly at school, when she could not cope with the same pace of her peer pupils. Reading was the worst. Thinking about it, she was late in many other tasks such as urine control, speech, vocabulary, reading (still a major problem at her age) and problem solving. Myself, I never liked reading, and at this present day I can't read more than five pages in one go. Her first milk tooth was replaced at the age of eight and a half years (normally six to seven). However, she is very astute, super-man vision, and difficult to beat her in memory card games (match a pair). She has a visual intelligence much above average, and she can remember such small details of experiences that happened many years ago. These are all good characters for a botanist!

So it seems for me that she has a slow biological clock, and her biological year does not consist of 12 but of 16 months. This is likely to have a negative effect for her progress in school and college, and she has already done a repeat in year 2. My son does not seem to show evidence of this and I was amongst the smartest in class.

In my case, a wave of secondary symptoms started after puberty, taking place very gradually but steadily. The first to appear was the falling of hair, and this was without doubt the most drastic of them all. I had beautiful, although uncared for, hair that was strong, plentiful, wavy brown and fast growing through all of my childhood, normal for Mediterranean boys. From fourteen it started to fall, and I remember very well that I used to have lots of head itching whilst doing my homework, and I would pick up a bunch of hair from the desk and toss it in the toilet with despair.

My self-esteem was decreasing rapidly and I was super aware of my looks. On the other hand, facial hair (beard) was normal. I had scanty normal body hair only on my thighs, pubic area and slightly in the armpits, between palm and elbow.

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At a later stage, more or less in the early thirties, I also started to see decreased tolerance to heat. I sweat only at the armpits, groin, toes and fingers. My body had really evolved and managed to adapt well to tolerate heat. I can't explain this, but I was amongst the most heat tolerant of the class or football team.

Not sweating heavily, I found advantages like not getting particularly dirty and with an unpleasant smell, or appearance with lots of sweat all over after a bit of exercise. Also, I rarely needed to drink or carry water with me, possibly because I did not lose any water in sweat. However, now that I am getting older, this virtue is lost and is affecting me badly in summer where I cannot tolerate the hot dry months as much as I used to in my young age.

My mother had more or less the same symptoms, perhaps more pronounced as she had lost her hair perhaps faster, and used to complain of heat and feeling lethargic for many summers in her fifties. Later I learnt that she also had unsymmetrical breasts. She also suffered from some paranoia and I don't know if that is related to ED, but I can see that I also have a mild form, perhaps developed over time due to hair loss, and hence you start suspecting at the time your hair is falling visibly and that everyone is looking at you and concerned with your looks. She solved the problem by having a wig.

Now that I am married with a pretty and adorable wife, I do not care that much about the symptoms described above, except the heat intolerance, but this transformation especially at the sensitive teenage to early twenties period, had affected my psychology and I am now very alert, open to worries, easily depressed, and possibly with delusional disorder. If I was a girl, I know that this effect would be much more magnified, since balding for a man is acceptable in today's society but for a girl is a huge shock. At the moment, my greatest worry is that my daughter, good looking as a model without any exaggeration, would not cope with the shock in this society, always pushing toward perfect physical demands, and in a society that depression is on the increase. My hope is that these symptoms will linger a bit longer until she has established a relationship and have a steady character. Personally, my worries are if this mutation will bring new conditions later on in my life, as it seems to manifest gradually with new symptoms.

But then to think positively, as my wife says, this ED has a number of characters that are in the wish list even of female VIPs: little body hair hence a perfect smooth skin without having to shave; look younger for your age (my 60-year old mum looked as if she was in her late forties!), no sweat-smelly body in hot days, and possibly a long-lived life, unless struck by an unfortunate terminal disease which my mum suffered. Perhaps who knows, my ED contributed to become a fine botanist, where visual perception and visual data processing have to be very acute to identify details and fine morphological differences that are important in natural studies, such high graphical IQ gained to balance the rather below average in literature.

If you would like to know more and have any questions, Stephen has kindly allowed us his email for you to contact him— marz@nextgen.net.mt

Date for your Diary— Annual General Meeting

The Annual General Meeting of the Ectodermal Dysplasia Society will be held at 10 Newcourt Park Cheltenham Glos GL53 9AY, on Saturday 7th May 2016 at 10.30am. If any members are interested in standing as a Trustee, please call or email the office to find out more information about what is involved, meeting commitments, etc. and to request a nomination form.

Living in Hong Kong—how the ED Society UK have helped

(Chris Brown—Dad to Connor 2 years)

We first discovered that Connor had ED in February 2015. We were shocked one Sunday morning when Connor had a seizure and we had to rush him to the hospital. Fortunately, the seizure was nothing to worry about but they kept him in overnight for observation. Whilst there one of the junior Doctors who just happened to be passing by, stopped and started asking questions about Connor's hair, teeth and sweat. This was not something I was previously concerned about, I thought he was just a late developer when it came to hair and teeth. She mentioned the condition Ectodermal Dysplasia to us, which at that time neither of us had heard of. I wasn't really concerned as dermal to me was related to skin conditions and his skin looked fine. Well, I was in for quite a shock when I got home and looked up the condition on the internet!

It was an upsetting and confusing time for us as we had so little information on the condition and the hospital didn't really provide any more information for us. That is where the ED Society in the UK came in so useful. I went into overdrive trying to find out as much information as possible, but the internet can throw up as many false facts as true ones, so to receive such an abundance of information from the ED Society was very helpful for us. It quickly helped us to come to terms with the condition and we soon realised that what our son was facing wasn't in fact anything to be overly concerned about at all.

Connor has had a few follow up appointments in the local health system and although the service is a little lacking, at least he does receive regular check-ups and some level of support. Whilst on one hospital visit we were introduced to a local Hong Kong family whose son also had ED. They seemed very distraught as there is such a lack of information here. I swapped contact details with them and have since emailed them all the fact sheets and information from the UK ED Society which they have read using a translation app (my Cantonese skills being less than impressive)! So this has also been a great help for them. We are currently in the public dental system at Prince Philip Hospital on Hong Kong Island and hopefully they will accept Connor as special case and we can receive some dental support in the years ahead.

It has been almost a year now since we first realised Connor has ED. It's been quite an emotional rollercoaster, but all we see is a healthy and happy boy. Connor attends a local play group, football classes once a week and has a good network of friends. He'll start school in August (just short of his 3rd birthday) and we are confident he will integrate well. The main problem in Hong Kong is the heat and humidity in the summer, we need to be very careful at that time where we take him and for how long he can stay outside. The humidity is brutal and everybody struggles in the summer months, so we're certainly taking advantage of these cooler winter months (in fact, as I write this we're off to Disneyland tomorrow).

The ED Society has been such a great help for us. All the team there are so helpful and quick to respond. When we saw that they were now selling wristbands, we bought some to sell to raise money and awareness of the condition. We were amazed at people's generosity and we had soon raised £200!

We are now actively selling a second batch in a bid to raise more money. It's been a great way of making people aware of ED and it's provided a talking point amongst friends who seem genuinely interested to know more and it's touching to bump into friends and to see them wearing the wristbands.

Continued…….

Continued……

We hope in the future to be able to attend some functions/activities within the UK so that we can meet other families who are similarly effected and to thank personally the staff at the ED Society who have done so much to make this first year so much more bearable and to provide answers where at first there was just confusion.

If you would like to purchase any wristbands to help support the Society, we have them available in three sizes:

Small—150mm Medium—180mm Large—202mm

For one wristband the cost is £1.50 including p+p and for each additional wristband the cost will be 50p each.

Please contact us via telephone or email julie@edsociety.co.uk if you would like any.

Debug the Bullies

Tips to Help Your Child Handle Bullying

(Reproduced with the kind permission of The Educator—Newsletter of the NFED)

One strategy that is very successful in changing the picture in bullying is called **"DEBUG".** DEBUG is five steps to use when someone is "bugging" or irritating you. This tool teaches problem solving, responsibility of choice and the beginning of conflict resolution.

The five steps of DEBUG are:

1. Ignore 2. Move away 3. Talk Friendly 4. Talk Firmly 5. Get adult help

Practicing **DEBUG** with your child at home is a way to really learn how to be assertive when facing a small problem or being bugged.

Tips:

Ignore— is to pretend the other person isn't there. Don't look at the person or say anything.

Walk Away—is just that! Walk, don't run. It doesn't hurt to walk toward an adult.

Talk Friendly and Talk Firmly—are both good to practice while looking in the mirror. A smile for talk friendly and a serious face for talk firmly both work well with an assertive posture of eye contact and shoulders back. Try to say what the person's doing that is bugging you—"Please, stop making noises. Its bugging me."

When you are at the Talk Firmly step, remind your child to use the persons name and to let them know if they do not stop what they are doing, you are going to get help from an adult.

When they decide to get help from an adult, its helpful to let the adult know that they tried all of the DEBUG steps first and none of them worked. That way, the adult knows what they have tried on their own before asking for their help.

Check out the following links for additional, helpful resources on bullying—

www.stopbullyingnow.com

www.violencepreventionworks.org

www.stopbullying.gov

www.micheleborba.com/Pages/7virtues.htm

www.cfchildren.org/steps-to-respect

www.operationrespect.org

Keep us Updated!

Please remember to let us know if you have moved house or changed any details/email addresses to ensure you keep receiving our newsletters and other correspondence.

CRITICAL UPDATE: NEWBORN XLHED CLINICAL TRIAL

By Mary Fete, Executive Director, NFED

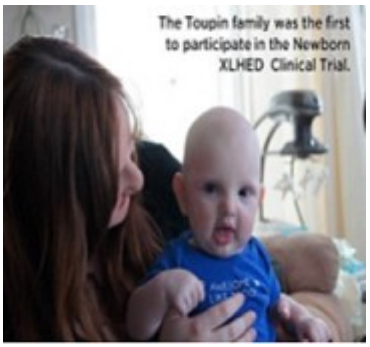
Reproduced with the kind permission of the NFED

Before sharing Mary Fete's article which explains the clinical trial update extremely well, I just want to thank all those in the UK who have participated or shown interest in supporting this research. It is not the end, at present we are looking for an expectant mum who would like to take part in the first in utero test which will be carried out in Erlangan Germany this year. If the test is successful this will be a huge step forward and will reopen the clinical trial and Edimer. If you would like to know more about this please contact me diana@edsociety.co.uk or call 07774 465712.

I want to share with you, our families, donors and friends, the latest developments regarding the Newborn X-Linked Hypohidrotic Ectodermal Dysplasia (XLHED) Clinical Trial being conducted by Edimer Pharmaceuticals. It has now been two years and three months since the first baby boy affected by XLHED received EDI200, a recombinant protein to replace the one missing in people affected by the condition. Ten babies participated in the trial. Edimer has received and reviewed six-month data from all enrolled participants and data up to two years for the first participant who enrolled. They have provided us with their findings which I will share with you now.

Unfortunately, the news isn't what we had hoped to hear. It is with a heavy heart that I tell you that the clinical trial did not achieve its expected outcomes. There were some modest signs of improvement in biologic activity, meaning the development and function of various body parts that XLHED affects. However, they didn't see significant changes in sweat gland function and other early markers of biologic activity at this time.

Dose Earlier?



In the trial, all of the babies enrolled received their first treatment of EDI200 within their first weeks of life. Edimer and the research investigators involved hypothesize that the babies didn't receive the protein early enough to have a significant impact. Edimer continues to have ongoing discussions with the investigators to find a way to explore earlier dosing. More information on this will be coming soon.

Dentition

According to Edimer, they are just getting to the time point when they can evaluate dentition. Their review of the earliest participants is potentially more encouraging in terms of the number of teeth that develop. Edimer received an orphan drug grant to continue the extension study, which will allow them to see if EDI200 had any impact on longer term markers, including dentition. Once they have that data, Edimer plans to publish their findings and share with our XLHED community.

A Doctor's Perspective

Dr. J. Timothy Wright from our Scientific Advisory Council (SAC) said, "Clinical investigations of new therapies and treatment approaches are time consuming and costly. Studies are designed to ensure safety. The clinical trials using a fusion protein to treat XLHED have followed this course with the first phase being conducted in adults and the second phase in infants. The initial results from the adult studies showed no evidence related to safety concerns.

"More recent results in the infants have shown that sweat gland and other ectodermal tissue derivatives that begin to form very early in utero were not improved using the dosages given. This is not altogether surprising as the dosages in the initial infants was lower than considered ideal to ensure safety and it was known that many of the ectodermally derived tissue components formed before birth and would likely not benefit from treatment after birth. The results on tooth formation, which continues after birth, are only now beginning to be evaluated," Wright said.

Edimer

The company will continue to collect long-term data. But, they will not enrol any additional babies in the Newborn XLHED Clinical Trial nor will they begin any new outreach programs. They do not yet know what will happen with the Natural History Study they have been conducting in which many of you, our families, participated.

edlines

This study was gathering better data on XLHED to help us understand and describe the syndrome. Edimer believes the study is important to helping our XLHED community and hope they can work with the research investigators, the NFED and other ectodermal dysplasias groups around the world to keep the study active. However, continuing the study will mean identifying and securing the necessary research funds.

XLHED Global GeneScreen

Edimer has disbanded this program and will no longer provide genetic testing for XLHED families.

Edimer Staff

Neil Kirby will continue to be Edimer's CEO but with a reduced time commitment. Tessa Field and Ramsey Johnson are no longer with Edimer but are available as consultants to them.

I'm confident you are feeling the great disappointment that we are here at the Foundation. All of us had such incredible hope that EDI200 would provide a viable treatment for our families affected by XLHED. While that doesn't appear to be the case, we remain hopeful that it will have a more significant impact on the long-term markers such as the teeth. Only time will tell.

While this is a huge letdown, it is the not the end for our commitment to XLHED research. We - the NFED and our families - began XLHED research in the late 1980s and advanced it to the point of this clinical trial. Yet, it is a definite setback. Unfortunately, in the world of research, especially novel research like the clinical trial, two steps forward and one step back is often the course until you achieve success.

Our work will and must continue. Having just received this news ourselves, we do not yet know what our exact next steps will be. Our SAC and Board of Directors will meet to discuss this development and consider our options. But, I can assure you, we are committed to XLHED research.

While the ultimate goal of the Newborn XLHED Clinical Trial was not met, numerous positive outcomes happened because of our partnership with Edimer Pharmaceuticals.

Edimer funding led to the development of our Ectodermal Dysplasias International Registry.

Numerous families received funding to help them attend an NFED Family Conference.

Edimer has generated some interesting data around ectodysplasin biology and wound healing. They are exploring if they could potentially apply this to other genetic skin diseases. Considering the significant skin erosions our families with other forms of ectodermal dysplasia experience, we are hopeful these findings can possibly benefit them.

Edimer funded our four Regional Family Conferences and Care Provider Symposia in 2015.

Edimer helped build a stronger international coalition of leaders in the ectodermal dysplasias community.

Edimer also provided funding to help the NFED rebrand our organization, build a new website and assist with funding for the Ectodermal Dysplasias Classification project.

We are truly grateful for all of Edimer's financial and staff support. Having spoken with our friends at Edimer, we know they, too, are also very disappointed in the 6-month outcomes in this study.

I realize this announcement is long but I wanted to provide you with all of the pertinent information as we know it. I suspect that you may have questions. I invite you to contact me at 618-566-2020 or mary@nfed.org and I will try to answer them as best I can. The information I shared here is what we know at this time. As we continue to work with Edimer and discuss the future, we will keep you informed.

Our determination to find answers and our families' unwavering commitment to assist the research progress for the last three decades has brought us great success. It is these qualities which will propel us to regroup, recharge and continue our quest to find better treatments, and ultimately a cure, for XLHED. We will not be deterred. But, we will need your help and support to work together and make it a reality.

Thank you for your dedication to research. We are here…Supporting you. Supporting each other.