eds
ectodermal dysplasia society

edlines

Summer 2018
Issue 80

SUPPORTING A NORMAL LIFESTYLE

IN THIS ISSUE

Society in crisis!!

WE NEED YOUR HELP NOW

The Society is totally dependent on our ED community, families and friends for funding the support we provide, but our funds are depleting so fast that our future is in your hands.

As you are aware, the ED Society provides free vital support to members, working together with people who are affected by ED, their families, researchers, health and other professionals to develop and share expertise, assisting with the day-to-day management of ED and increasing awareness and understanding.

Over the past few years, we have received many generous donations, however, recently for the first time in many years, expenditure now exceeds income and, in order to continue providing support at the same level, we need to increase our income.

For over 20 years we have been here for you, but due to the increased work involved in supporting you, the costs of giving that support has resulted in the need for more staff (be it only part time), and a bigger office as of 2016 to accommodate us.

But we are now at the stage where the money to continue helping you is running out!

We are therefore holding a fundraising fortnight to help kickstart the funds coming in.

10th - 23rd September

Can you help by organising a small event to raise much needed funds? Fundraising ideas/packs can be found on our website. Even if you are not able to fundraise (we appreciate you are all busy) you can still help by making a donation directly to the Society. We may be able to boost your donation by 25% through Gift Aid.

If every family sent just a £10 donation it would help to secure our support for another year.

Thank you to all who have sent in donations so far.

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then do all your shopping through easyfundraising and raise funds for the ED Society

Thousands of retailers are linked to easyfundraising

Read more on

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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 Physcologist

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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

2019 Membership form
Out in October 2018

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.

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

Trichiasis: ingrowing eyelashes

What is Trichiasis?

The term trichiasis describes the misdirection of eyelashes such that instead of them growing outwards normally, they point inwards and touch the eyeball causing irritation, watering and discomfort

What causes Trichiasis?

There are several ways in which trichiasis can result.

In the UK, the commonest cause of trichiasis is marginal entropion. This is where the hair bearing skin of the edge of the eyelid, has migrated towards ocular surface. Looking from the side, the edge of the eyelid is seen to rotate slightly inwards causing the eyelashes to start pointing inwards, touching and abrading the cornea. This is quite commonly due to blepharitis or meibomian gland disease, a condition characterised by chronic inflammation of the eyelid margins which in turn causes scarring of the edge of the eyelid. This continual scarring results in migration of the eyelid marginal skin. Marginal entropion is more common in the elderly due to age related weakening of some of the stabilising tendons that keep the eyelid skin in check.

Injury to the eyelid can cause trichiasis, especially if the eyelid is torn near its margin. If an eyelid wound is allowed to heal in a misaligned position, the eyelashes may start to grow inwards and rub against the eyeball.

Trichiasis can also arise from a rare condition called distichiasis, where an extra row of eyelashes is present. These extra eyelashes may grow inwards and also rub against the eyeball.

What are the signs and symptoms of trichiasis?

- Irritation of the eyeball
- Watering of the eye
- Redness of the eye
- Discomfort when looking at a bright light (photophobia). This is may be due to corneal surface damage
- In severe untreated cases, the constant rubbing of the surface of the eye may result in corneal ulceration, which, if left untreated, may result in loss of vision.

How is Trichiasis treated?

Trichiasis can be treated in a variety of ways, depending upon the number of lashes involved, the cause of trichiasis and the preference of the patient.

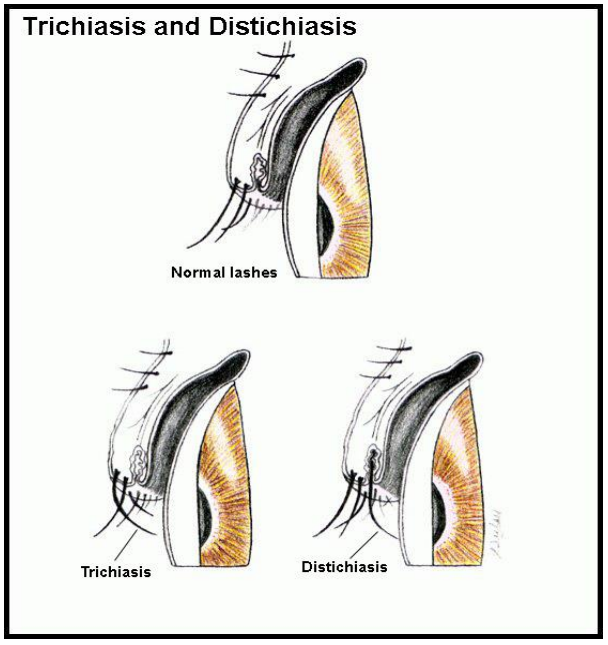
Epilation - If there are only 1 or 2 abnormally growing eyelashes, it may be possible to just to pluck out the offending lashes (epilation). This quick method however is just a temporary measure, since the lashes will regrow again usually within 6 weeks.

Electrolysis - A more permanent method of treatment to destroy a small number of abnormally growing eyelashes is by applying a small electric current using a needle electrode next hair follicle bulb. A small injection of local anesthetic is usually given into the eyelid prior to the treatment to ensure the procedure is pain free. An imperfect success rate of approximately 80% exists and is due to the inability to be 100% sure that the eyelash follicle bulb is receiving the damaging electrical current.

Surgery - Occasionally surgery to the eyelid itself may be required to either:

- change the direction of growth of the eyelashes or
- permanently remove the eyelashes by removing the eyelash hair bearing skin.

Most trichiasis correction surgery can be done quickly and safely with very good long-term results under local anesthetic only as a day case.



Mr David Cheung Bsc(Hons), MB ChB, FRCOphth, FRCSEd Consultant Ophthalmic and Oculoplastic Interest in Lid, Lacriminal and Orbital Surgery

(This article has been reproduced with the kind permission of Mr. Cheung)

We are very proud to have produced two books about Ectodermal Dysplasia

Everybody's Different

This introduction to Ectodermal Dysplasia has been designed for children aged 4+, whether they are affected by ED or not, 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.

Over recent years, the ED Society have become more aware of a lack of information for children and, in collaboration with Envision Pharma Group have developed a patient information booklet aimed at children that raises awareness and support.

We are extremely grateful to Envision who, pro bono, utilised its services in patient-focused content strategy, copywriting, illustration and graphic design to work closely with the Society to co-create the booklet that helps children explore visible and invisible differences – as well as thinking about the emotional impact of those variances.

"Everybody's Different"

A wipe clean book

£6.49 incl. p&p.

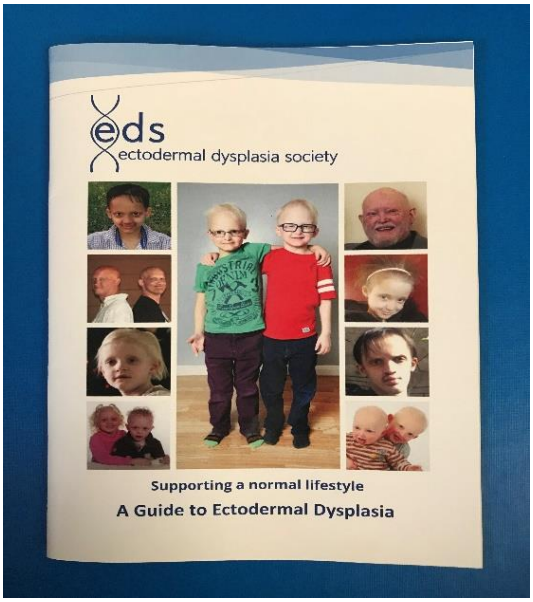
Buy 2 and give one to your local school

A Guide to Ectodermal Dysplasia

Since the ED Society was formed in 1996, we have been compiling and producing information leaflets about ED for individuals, parents, families, medical professionals and other community officials in the UK.

However, we are delighted that these leaflets have reached the point of relative stability and have been brought together into a single extensive 48-page booklet.

This booklet will enable people to have all the information at their fingertips and will make it easier for them to take information to medical professionals, schools and other authorities to help further explain ED.



"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.

We would love to hear your feedback!

Membership:

In October, new forms will be sent out for the 2019 membership.

Last year membership was increased to £20, this reflects a considerable 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 application forms, together with assistance with appeals and tribunals
- the opportunity to apply for financial assistance to attend events provided by the Society (UK members only)
- access to expert support and our medical specialist network

Your membership:

- Enables the ED Society 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 new Website

The new ED Society website is now live, and we hope you are enjoying it! We are still working on the website, updating it with new photos, current information and the latest news – so keep browsing!

If there is anything you would like to see on the website or something you would like to know about, please let us know – 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 you pay regular donations by standing order.

Also:

Lisa Kennedy - fundraising -£695
Jessica Van Coevorden - fundraising - £600
Mohammed Mulla - donation - £750
John Banks – fundraising - £348 so far
Sarah Jones – fundraising - £300
Rowley Turton – fundraising - £50
Gemma Walczyk – fundraising - £230
Bottomline Technologies - £100
Mark McNair - £275
Gillian Squires - £123
Mark Lloyd – fundraising - £123
Aston & Fincher (Stuart Atkiss and friends bike ride) - £3411.25.

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

Please send us your messages:

Most of our new contacts we see come through our Facebook page.

The group is a great support network and we are so pleased to see so many of you offering your advice, tips and stories to one another.

We just want to remind everyone to please send us messages with any questions you have or concerns, we would like to help you in any way we can and do not want you to feel you are alone.

We need a Graphic Designer?

We are in need of someone who could help us with designing an ED visual page to go in our Welcome Pack leaflet. If you, or someone you know is a graphic designer and would like to help, please get in touch with us.

Fundraising Stories:

The Society are fortunate to have such wonderful members who want to take time out of their busy lives to help raise much needed funds for the them, and are grateful that they wish to share their fundraising stories with all of us…..

"Fundraising had always been part of my working life, I enjoyed approaching people and companies to request donations or support in some way.

I recently totally retired and lost the collective fundraising audience I had; I needed to find pastures new for raising funds. I was introduced to our village coffee club and asked if I could organise a coffee morning to raise money for the ED Society.

There are four ladies who offer support by making tea and coffee, plus donating freshly baked cakes they made. They have made my donation of bought choccy biccies look poor, I'm no baker! We had prizes donated for a raffle.

I collated a little family history letter explaining our circumstances and placed one of these with one of the ED Society flyers on each table.

I thank the ladies who supported the coffee morning and all who attended, donated or bought the little goodies we had for sale; this time we also sold good old-fashioned peg bags and bubble sets.

On this coffee morning we raised £123 for the ED Society, roll on our next coffee morning!!"

Gill Squires

Wolverhampton to Aberdovey Cycle Ride

"Friday 15th June 2018 - Well what a day that turned out to be!!

For this year's bike ride we had two new recruits joining myself (Stuart Atkiss) and David Winnington.

We had Patrick and Ben with us. So, we thought we might have a little challenge on our hands as these two newbies are younger and fitter than us, or are they?

For the first time we stayed over in Wolverhampton, so we knew we would all be at the start together. Well that's what happened, we started together then that was it really. I thought I was feeling good and positive for the day, the new lads were a bit nervous and David, well he is just a machine. So, like I say, we started together, but about 10 miles in I thought, where are they? I looked behind and they were nowhere to be seen - I thought this is my year for bragging rights at our work.

About another 10 miles in David came to my side with some other cyclists he'd latched onto and then he carried on. I thought I'm not going to start chasing this early into the ride. The weather was very humid, so lots of liquid was being taken on board.

35 miles in and we were at our first check point. David and I waited for the other two lads, but after waiting around nearly 45minutes we decided we needed to carry on. We had a support vehicle with us who waited for them. So, as the day went on we were doing well. I had lost David again he must have put some new legs on or a battery on his bike, but I continued to cycle with other riders as there were over 700 riders this year, so you were never on your own.

DILEMA!! I was half a mile from the last but one check point and a car, who thought he only wanted to leave a foot or so between me and his car, came past at about 70mph on a country lane! As I tried to hold my bike from wobbling and telling him what I thought, he drove on. I didn't look at the foot deep pot hole in front and hit it at around 18mph, which was not very nice on my front wheel or my arms.

As I carried on a few more yards I found the wheel wasn't going around properly. I called the support van who took me to get my front wheel fixed then had to take me back to where I was to continue. Now I was well behind the other riders but carried on and in a total of 9 hours (that includes stops and breaks) I reached Aberdovey! David had already been there for 45 minutes and about 30 minutes behind me came Ben and Patrick.

We all completed the ride and were very happy, mainly because we also raised a great amount of

money for the wonderful Charity Ectodermal Dysplasia Society!!

Bring on next year's ride!!

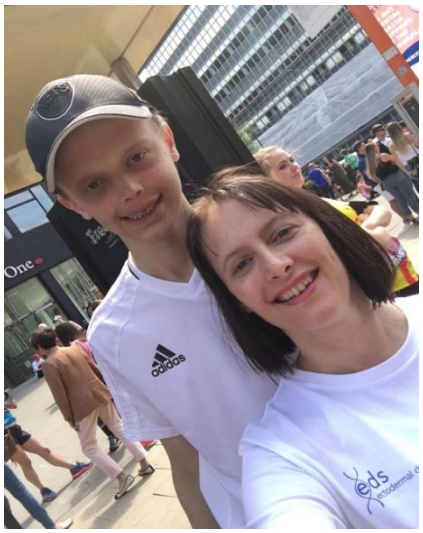
Stuart Atkiss (ED Society Trustee and Fundraising Coordinator), David, Ben and Patrick

Great Manchester Run

"On Sunday 20th May 2018 at 3pm, I took part in the Great Manchester 10k Run in an attempt to raise funds for the ED Society. I did this because like many of those who are reading this are affected in one way or another by the genetic disorder Ectodermal Dysplasia.

My son Daniel who is 15 years old, along with my brother Tom who is now almost 32 years old, and my nephew Joe who is now 6, all suffer from the Hypohidrotic form of ED. Having grown up with this I have become used to dealing with the problems that our loved ones all suffer on a daily basis, the majority of the time feeling quite useless and thinking what I can do to help.

With this in mind the only way I thought I could truly help was to raise funds, and at the same time raise awareness bringing the condition to light in a world where in most cases haven't heard of this.



As mentioned I have now officially taken part in my first ever 10k run on what had to be the hottest day so far this year (in Manchester anyway) raising £695.00, and yes when I said I would sweat for those who can't I kept to my word and I definitely did.

I finished with a time of one hour twelve minutes and felt incredibly proud of myself but most of all proud of why I ran - my ED family. Living with ED can be difficult but with the help and support from the ED Society I personally feel that they are the true heroes, helping us all to get through the daily challenges that we all face. - Forever thankful!"

Lisa Kennedy and son, Daniel

Charity Tuck Shop

I work for a big organisation and we have various charity tuck shops dotted around the offices. I put forward the ED Society as a good cause that could be supported, explaining what a help they had been when Martha, now 2, was newly diagnosed with Incontinentia Pigmenti (IP). The team were happy to oblige and over a few months we raised £600 just from people buying snacks and drinks. I'm so pleased it will go to help more families being supported in the way that we have been.

Jessica Van Coevorden

How can YOU help?

As mentioned on the front page of this newsletter, the Society is in crisis and we need you!

Maybe you could help by:

- Making a donation - We have seen incredibly generous donations over the years, but no amount is too small – a simple donation of just £10 from each member would help cover the cost of almost a year's rent for the Society's office.
- Donating the simple and easy way, using PayPal – info@edsociety.co.uk
- Holding a fundraising event - this doesn't have to be as big as running a marathon, but smaller simple events such as cake sales, coffee mornings, car washes, raffles, a picnic in the park with your friends etc.
- Signing up to Easy Fundraising – shop through the app or online and hundreds of big named retailers generate a donation to us once you have shopped!
- Asking your school or workplace to join the 50/50 Jeans for Genes programme. Please see article on page 9. If your school or workplace joined in 2017 please ask them to re-register for 21st September 2018 Jeans for Genes Day.
- Selling some of our wristbands, pens, or key fobs at your child's school or to your friends and families?

Get in touch with us and we will be happy to help by sending you an ED Society fundraising pack.

This would help the Society to be able to survive and for us to continue providing increased support to all of those in need.

easyfundraising
feel good shopping

Everyone uses the internet nowadays to do their shopping!

Did you know that most of the websites you use to do your shopping are registered with **easyfundraising**?

Big name retailers such as Amazon, eBay, John Lewis, Next, Sky, Marks & Spencer's Sainsburys, Tescos, all generate donations to your registered charity, and there are hundreds more.

If you go through the easyfundraising site, search for the retailer you want and shop from there, the ED Society will earn donations on all the money you spend.

All you need to do is go to www.edsociety.co.uk click on the easy fundraising icon on the main page and register – it is that simple! Don't forget to select the ED Society as your chosen charity.

To make it even easier, you can now download the easyfundraising app to your phone or tablet.

Once you've downloaded the app, select this every time you shop to ensure the ED Society get the donations.

Please ask all your family and friends to do the same

It is so easy to generate much needed funds

Upcoming fundraising:

- David Tayler – bike ride over the Pyrenees in September.
- Rebecca Clements – walking up Pen-y-fan mountain with friends.
- Jessica Banks – tough mudder event 29th September
- Toby Shortman – obstacle race 15th September 2018
- Kerry Russ, Chantelle Cooke and Nadia Powell are all taking part in a sky dive in October.
- Mark Lloyd is holding a birthday fundraiser and walking 10k.
- Stuart Atkiss will be running the London Marathon in 2019

All of the above are either affected by ED themselves or are raising this money in support of a Family member or friend.

If you are on our Facebook group, you will find their Virgin money giving pages – it would be great if you could make a donation to encourage and support them.

Help Joe raise funds Download his music now

"It's always a great privilege to have the opportunity to communicate with fellow people who are affected by ED through this great publication.

I'm Joe Pearson and I'm 35 years old. I'm a professional musician and composer, and I have ED. I've had a great relationship with Diana and her wonderful team for many years.

This Autumn, I will be releasing a new EP of around 6 tracks, which will be available on iTunes and a few other outlets. Hopefully the music will be available from the end of September. I've decided to donate a substantial proportion of any sales to the ED Society - I'm hoping that I'll be able to achieve 30-40% of revenue from purchased digital downloads. I'll also be adding a new page to my website (joepearson.co.uk) which will give information about ED and provide a link to the ED Society website.

As a guitarist, my hands are pretty much always in the spotlight, so I'm in a unique position to increase our reach to families who may not know about the Society and the valuable work it undertakes.

I also found out in the past few weeks that I've come one step closer to appearing in the Guitarist Of The Year 2018 final - an international competition which seeks out the best emerging guitar talent. Hopefully this will further increase my reach, allowing me to bring ED, and people affected by it, more into the spotlight. You can read about Guitarist Of The Year here: https://bit.ly/2M64B4L, and you can watch my entry here: https://youtu.be/-ssu11QWz2s.

I hope to update you all on the progress of all of the above in a newsletter in the near future. For questions about managing symptoms of ED when learning an instrument, please feel free to reach out through the Society."

Joe Pearson

Jeans for Genes Day Friday 21st September

The ED Society have joined the Jeans for Genes 50/50 income share scheme

eds ectodermal dysplasia society

PROUDLY PARTNERING WITH JEANS FOR GENES DAY

Please wear your jeans to school/work and join in the fun! The money raised provides vital care and support for thousands of children living with genetic disorders.

Please take a £1 donation (or more!) for your school or workplace collection box.

Put your jeans on and help us transform the lives of children with Ectodermal Dysplasia.

Jeans for Genes Day raises funds from school children and employees who wear their jeans to school and work in exchange for a small donation.

Under our 50/50 income share scheme, the ED Society will be given half the proceeds from a Jeans for Genes Day event provided the school or workplace has been encouraged to take part by one of our members.

All the school or workplace have to do is select the ED Society's name at the bottom of the Jeans for Genes Day registration page.

How the scheme works

First, approach your local nursery, primary school, secondary school or workplace to see if they will hold a Jeans for Genes Day. Then speak with the key member of staff who organises charitable fundraising, to explain that

- you are supporting the initiative to fundraise for the ED Society and
- should the school hold a Jeans for Genes Day, half the money raised will support the ED Society's families and half will support all those affected by a genetic disorder in the UK.

To ensure the school or workplace is linked to the ED Society, you must ask them to check that the Society has been selected from the list of affiliated partners at the bottom of the registration page when going to the Jeans for Genes Day SIGN UP page.

Once this has been done, the school or workplace will be flagged on the Jeans for Genes Day database as being recruited by the ED Society. This means that the system will automatically allocate 50% of the income raised by the school or workplace to the ED Society.

Once the school or workplace confirm to you that they have signed up to hold a Jeans for Genes Day, you should inform the ED Society, so we can also keep a record of the schools and workplaces that have recruited us.

That's it!

We hope you have an awesome day and raise much needed funds for the ED Society

Dentures

So how do you put the dentures in?
I asked my elderly mother – put the top dentures in your mouth, place your thumb on the roof of the dentures, push up, suck and swallow, and this should create a suction. The lower dentures are much easier and just need pushing down into place using two fingers on either side – they are held in place by facial muscles rather than suction.

Keep them in a box with a little water overnight. You can buy colourful boxes to keep them in - go to **Easyfundraising** and then Amazon and type in Orthodontic retainer box they only cost about £3.00.

Remember to fill the sink when cleaning dentures in case you accidentally drop them.

How did you tackle the heat?

It sure has been hot over the last few months here in the UK – but luckily it seems to be cooling off now!

The Sun newspaper recently posted an article "How to keep cool in the heatwave under £15" with some great products which we think you would all be interested to know about:

Neck cooler - Amazon:
Soak the fabric in water and then stick in the freezer for a few hours - it will keep you cool.

Cooling wrist wraps – Amazon:
The wrist bands cool you down when you put them in water and they stay cold for 5 to 10 hours.

Slush Puppie making cup – Genie Gadgets:
Make your own slush puppie in 10 minutes with a cup that grinds the ice to make a frozen beverage (not just for the kids!!)

Climate control Pillow – Amazon:
The pillows are made with Dacron hollowfiber, which is designed to carry excess heat and moisture away from your head and body.

Female-Specific Issues in Ectodermal Dysplasias

The NFED sponsored a survey to further characterize female-specific issues and their possible connection to ectodermal dysplasias.

Background
Seventy-nine female respondents affected by the ectodermal dysplasias completed a pilot survey about topics ranging from breast development and function, to menstruation and puberty. This survey laid the groundwork to verify that breast and vaginal concerns are associated with ectodermal dysplasias. A larger, follow-up survey provided results which fostered the growing correlation between these characteristics and ectodermal dysplasias.

Of the 2,333 surveys sent, 427 women between the ages of 12 and 83 responded. These women had many different diagnoses of ectodermal dysplasias, but the majority (118 women) were hypohidrotic ectodermal dysplasia (HED) or HED carriers (159 women). Here is what we learned with their help.

Sweating
- 55% of all respondents reported decreased sweating, while 35% had normal or excessive sweating. 10% claimed to have no sweating at all.
- 64% of women with HED also reported having decreased sweating. 21% had no sweating at all, and 15% had normal to excessive sweating.

Puberty
52% of the women reported having their first menstrual period at age 12 or 13. Both women with HED and HED carriers reported that they had their first period between the ages of 11 and 14. The majority (73%) of the total group reported that their regular cycles last between 4-7 days.

Breast Issues
- 25% of the total group have one or both of their nipples that were either absent or hypoplastic, or, in other words, abnormally small.

- At close to 30%, the majority of those surveyed with HED also reported having underdevelopment or incomplete development of nipples. Other issues included no breast development on either the left or right side, or no breast development on both sides. A small percentage also reported to either having no right or no left nipple.
- HED carriers had a smaller percentage of reported breast issues. The biggest concern at 5% was that there had been no breast development on either their right or their left side. Less than 1% reported the absence of a nipple.

Breastfeeding

One of the predominant concerns was breastfeeding. While 76.2% of the total group wanted to breastfeed, only 31.4% were successful. Almost half of the women needed to supplement breastfeeding with formula.

Pubic Hair

- 23% of the total group has absent or sparse pubic hair, while 40% reported absent or sparse axillary, or armpit, hair.
- A more significant number of women with HED reported having this problem. 85% reported sparse or thin head hair, while 64% said they had absent of thinning axillary hair.
- For HED carriers, the majority at 66% claimed to have sparse, absent, or thin head hair. 44% said they experienced sparse, or thin pubic hair and 51% reported having these symptoms with their axillary hair.

Vaginal Issues

- Unlike the commonly reported breast abnormalities, there was not a large reported increase of abnormal uterus or vagina development as compared to the general population.
- A troubling characteristic that is shared among these women affected by ectodermal dysplasias, however, is the reported percentages of those who stated intercourse was often painful. 85% of the total group of 18 to 40-year-olds reported this as well as 100% of the women who were 41 years and older. 40% of HED women reported chronically painful intercourse.
- Yeast infections also seemed to be prevalent in these surveys. 62% reported them as a frequent occurrence. The majority of the women who reported this as a recurrent problem were 41 years and older.
- 14.5% reported having reoccurring bladder infections. Frequent, nighttime, or painful urination was also reported as well as urinary incontinence. These results, however, are not increased above general population rates.

Infertility (Only Reported for Women With HED)

- The majority of the women with HED reported having no problems with conception.
- Only 5% of the 18 to 40-year-olds reported having difficulty.
- 21% of women older than 41 reported having previous difficulty.

Back to School

Don't forget we can help

We have a School Care Plan which helps explain in more detail how a child is affected by Ectodermal Dysplasia and the procedures that should be put in place to ensure their safety and maximization of their education.

We also have a sample Student Information Card which has the medical issue on the one side and the permissions granted by the school on the other.

Lack of concentration in school may be caused by the lack of temperature control and not because of learning difficulties. If your child is struggling or has struggled in the past, please contact us info@edsociety.co.uk and we will help.

EspeRare Update:

"Since acquiring the rights to the project from Edimer in April 2018, EspeRare has submitted a Briefing Package to the EMA (European Medicines Agency) for a first assessment and will submit a final revised version by the end of August. Feedback by the Agency is expected in November 2018 and will help finalise some keys points for the clinical study. In the meantime, all activities needed to launch this clinical study are being put into place, and, at this present time, EspeRare is on track for the study to start in Germany in Q2 2019".

Research Posted by NFED

Edimer Pharmaceuticals began the Natural History and Outcomes in X-Linked Hypohidrotic Ectodermal Dysplasia (XLHED) Study in 2014 and enrolled about 150 boys and girls under the age of three who are affected by XLHED. They captured information on how XLHED affected them.

When Edimer closed its doors, Dr. Holm Schneider took over the study. The results are critical as we move to the next stage of XLHED research with the prenatal trial. Recognizing this importance, we have granted funding to Dr. Schneider to help him complete the study.

Understanding the natural progression of XLHED will help us understand the effects that treating the babies in-utero with the protein ER-004 has on their symptoms. The information from the Natural History Study will make it easier to evaluate the effects of the treatment to see if the therapy changes the course of the syndrome progression and quality of life of the affected individuals.

The following is an update from Dr. Schneider and his team on the study.

By Dr. Holm Schneider and His Team

"Thanks to the National Foundation for Ectodermal Dysplasias (NFED) funding, this important study is running as planned and will be completed in December 2018. Boys and also some girls with x-linked hypohidrotic ectodermal dysplasia (XLHED), all enrolled before 36 months of age, have been followed continuously until their 5th birthday, some over more than four years.

So far, 24 of 25 infants have completed the study. We are happy to report that full data sets, including data on growth and development, sweat ducts, respiratory issues, eye surface involvement, facial characteristics, primary dentition, secondary tooth germs, adverse events, and medication during the study period, are available for each of these children.

There has been not a single drop-out of patients enrolled in the years 2014 and 2015, but this required substantial efforts. For example, Dr. Schneider recently had to travel to Murcia, Italy to perform the final examination of an Italian patient whose family was unable to keep the appointment in Erlangen because of a missing passport.

Many data from the XLHED Natural History Study have to be reported by the end of 2018 to the health authorities which then decide on the start of the prenatal trial with the EDA1 replacement protein. Later on, the data will also be published in a scientific journal."

Dr. Schneider will follow-up with these two boys who received ER-004 in utero to collect data on its effects.

In addition, Dr. Schneider's team plans to continue the long-term follow-up of the four XLHED patients who were treated as neonates in Erlangen (together with their untreated male siblings, three older brothers in total) and of the three infants who were treated *in utero*. All of them will be followed until five years of age, which requires continuous support of this extension study by the NFED.

NFED, August 2018 Newsletter