Charity Update

ectodermal dysplasia society

Supporting A Normal Lifestyle

March 2020

What's New?

After this newsletter we will be issuing our new Charity Bulletin via email.

For those who have been in contact with the Society for some time will know we previously had 4 newsletters a year. However, we have made the decision to keep our annual October postal newsletter, and during the rest of the year we will be sending a regular charity bulletin by email to keep you updated with current information.

To send such a mailing, we need to ask you to subscribe. Enclosed with this newsletter is more information and a contact details form for you to complete stating the mailings you wish to opt in to. You can also do this on our website.

The importance of the enclosed contact details form is:

- to ensure we have your up to date correspondence details
- it will allow you to sign up to our new charity bulletin which includes news, articles and updates
- to instruct you on how to opt out of any mailings with us.

This form needs to be completed and emailed back to

info@edsociety.co.uk.

If you are unable to re-attach the form by email, you can type your answers into your email reply to us.

If you do not use email, you can complete and return the form by post.

Once opted in, you will begin to receive our Charity Bulletin email.

Coming up:

- AGM May 2020
- ED Awareness Month June 2020

Don't forget to:

- complete and return the membership form for 2020 with the fee and perhaps a donation
- sign up to the site 'easyfundraising' for all your everyday online shopping - so far £533.87 has been raised for the Society

The ED Community:

We have welcomed 43 new individuals & families affected by the Ectodermal Dysplasias over the last 4 months.

Important:

Add **info@edsociety.co.uk** to your address book to ensure you receive our emails.

What's next?

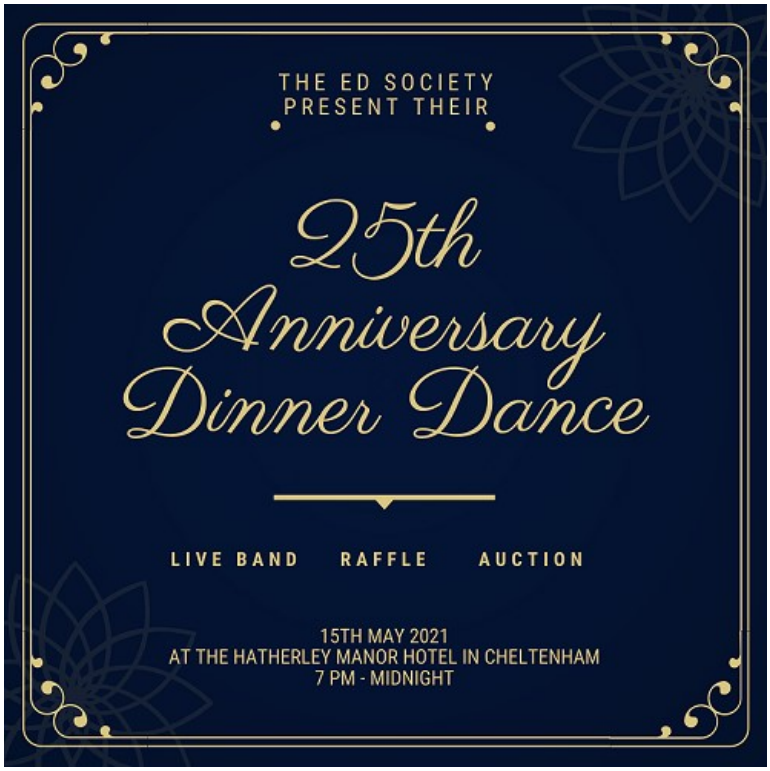
Keep an eye out for our Charity bulletin email which will include information about:

- Cooling tips for the warmer months
- Explaining EDAR
- Free driving lessons

Visit www.edsociety.co.uk to find out how you can support the ED Society.

Get involved and help spread awareness today!

Please join our celebration!



2021 marks a special year for the ED Society. It will be 25 years since the ED support organisation began, 20 years being established as a charity & 25 years of voluntary work from our CEO Diana Perry.

To celebrate we are holding a dinner & dance in on 15th May 2021. It will be held at the Hatherley Manor Hotel in Cheltenham, from 7pm until midnight.

On the night there will be a 3 course dinner, live band, entertainment, raffle and an auction.

Stuart Atkiss (our fundraising coordinator and trustee) is already hard at work planning and securing our photographer and band for the night—THANK YOU!

We really want our celebration to be a success and hope to see you all there showing your support — Please remember everyone is welcome, invite friends, family, colleagues, in fact anyone who would like to come—the more the merrier. This will be an adult only event (age 16 and over). Tickets will be £60 per person.

Can you please indicate your interest in this event via email **(info@edsociety.co.uk**), or on the enclosed contact details form.

We would be grateful if anyone could help with prizes for the raffle or items for the auction. Maybe your employer or a local company can help.

ED Christmas Party

Wow, it has been 3 months since the Christmas Party already. What a great time we had; we hope you all enjoyed it too.

Firstly, we would like to give a big thank you to our Medical Advisory Board, who came along and voluntarily gave their time to talk to many of you. Their time and expertise is invaluable and we are forever grateful to them.

Thank you to our Trustee and Fundraising Coordinator Stuart, for being the photographer on the day and for the cake which he made with his son Taylor. The cake was raffled and raised £129.

Donations and sales of merchandise on the day raised £268. Thank you!

It is hoped the next ED Christmas Party will take place in December 2021.

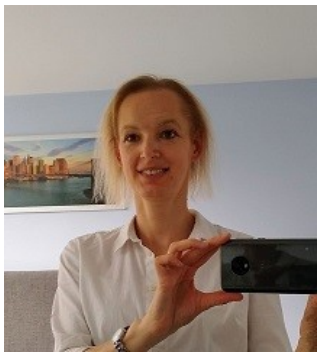
I Bought A Wig!

Hannah Cook

This is a tricky thing to write about, but here goes….

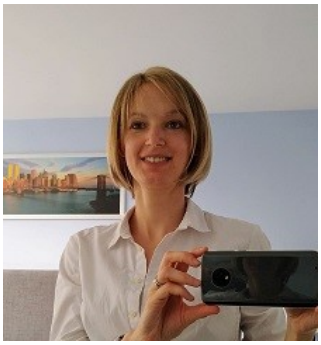
My hair has always been on the thin side, but it has got much thinner in the last 5-8 years, and receded a lot at the front. Special shampoos, salon treatments, vitamin supplements - nothing helps.

Fundamentally, it's down to my Ectodermal Dysplasia (ED), which is the genetic disorder that myself and Daniel have, affecting our teeth, hair and other things.



Still, I've become more and more self-conscious, particularly about the way you can see straight through it, see my scalp etc. So last week I bought a wig.

I'm planning to wear it for work, and for occasions when I want to look my best, a bit like putting 'going out' clothes on. As for the rest of the time, I'm not sure yet. I might be wearing it the next time you see me. So, the photos show my hair as it is now, and with the wig on…….



I hope you'll agree that it suits me. If you haven't seen me for a long time, maybe you'd never have guessed it wasn't my hair. I also hope you'll understand why I'm doing this. I don't want to pretend to be someone I'm not. I'm trying to accept the reality and embrace it positively.

If you'd like to show your support, please donate to the ED Society to help fund research into the disorder - because let's face it, I'm never going to run a marathon or anything, but being this open and vulnerable is as big a deal for me!

Thank you very much to my friends, family and ex-work colleague who donated and helped to raise £656 for the ED Society, I really appreciate it.

*Do you have a story for us? We would love to hear anything you have to say.

Please send stories to info@edsociety.co.uk*

2019 fundraising & donations We thank you!

A BIG thank you to our wonderful, supportive ED community for the amazing fundraising and donating that took place in 2019.

Fundraising for the year raised £18,297.68 and we received £16,040.20 in donations. Wow…..what a year!!

We solely rely on fundraising and donations to keep the Society alive. Your generosity enables the Society to continue to thrive. When you donate to the ED Society, your gift immediately goes to work to provide support services and hope to our families affected by ED.

Quick Tip…..

When you're removing your dentures, always remember to fill the sink with water. If you accidentally drop them, the water will prevent them from smashing .

Are you Pregnant?

In September 2019, Professor Angus Clarke, Cardiff University and the All Wales Medical Genetics Service and the ED Society Medical Advisory Board Chairman, received a grant of $25,000 from The National Foundation for Ectodermal Dysplasias (NFED) for a new research project Non-Invasive Prenatal Diagnosis (NIPD) or Testing (NIPT).

Prof. Clarke and his research team are testing a new way to diagnose X-Linked Hypohidrotic Ectodermal Dysplasia (XLHED). Both NIPD and NIPT can be carried out for sex determination and are called 'non-invasive' because it is carried out on a sample of blood from the mother. This could replace the need for an amniocentesis (taking fluid from around the baby) and CVS (taking a small sample from the placenta) both require the insertion of a needle into the womb and carry a small but not insignificant risk of miscarriage (0.5-1%).

The main advantages of NIPD are that it can be carried out earlier in pregnancy than current tests and that the procedure does not carry any risk of miscarriage.

However, at present, this test can only tell whether the baby is a boy or a girl and does not usually detect which genes the baby has inherited.

In principle, this technology could also be used to identify if a foetus is affected by XLHED early in a pregnancy. It is hoped that this will become possible within the NHS over the next couple of years. This may become very useful for the *in utero* treatment ER-004 EspeRare Therapeutic Programme which is currently being developed and introduced (but this is not yet available as an established treatment).

In Prof. Clarke's proposed method, a woman who is pregnant and knows she is a carrier for XLHED, would give a blood sample, from which researchers would extract DNA from the plasma portion. This DNA is a mixture from both the mother and the placenta, and so will contain the altered copy of the gene. However, if the foetus is affected, the amount of altered DNA will be slightly greater than the usual version of the gene. If the measurements can be made with sufficient accuracy, it can be determined whether the baby will be affected. This would be important because the new treatment involves a step like an amniocentesis and carries some risk, so one would only want to give the new treatment to a foetus already known to be affected.

XLHED is an x-linked disorder primarily affecting males and is the most common type of Ectodermal Dysplasia. XLHED is caused by mutations in the *EDA* gene, which result in defective ectodysplasin 'A' formation or functioning.

Ectodysplasin 'A' has a critical role in early embryonic development by bringing about the interactions between two embryonic cell layers called the ectoderm and the mesoderm. When ectodysplasin 'A' is non-functional, normal interactions between the ectoderm and the mesoderm are impaired, which leads to the defective development of hair, sweat glands, teeth and the lining membranes of the airways.

There are many symptoms associated with XLHED in infant males, with about 50% suffering failure to thrive and/or serious infections, especially pneumonia. (Failure to thrive refers to a child whose weight gain in the first year of life is less than that of their peers, but this can usually be managed with nutritional supplements). Therefore, any treatment that can be given early enough before birth to improve the development of teeth and the production of sweat glands and of mucus-secreting glands in the airways will bring substantial benefits.

Please get in touch with us if you are currently pregnant. and wish to find out more.

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