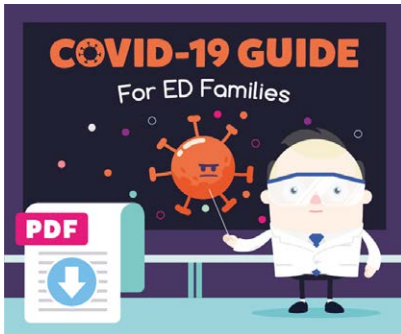


We have been thinking about all of our ED family during the strange and uncertain times we are all facing. The 'new normal' is about as far from normal as any of us could imagine and we know that can be stressful. The ED Society want to assure you that we are here for you, your family and all our ED community. Remember, we are here to listen and offer our support, advice and resources on those hard days - we are #StrongerTogether.

Please remember to keep checking our website, we have a dedicated page to all [Coronavirus related updates](#) as well as our Covid-19 guide for our ED families.



---

In a wildly changing world - we need our ED community now more than ever.

With most fundraising income wiped out, many charities are struggling. The nature of this crisis means that charities like us are also experiencing increased demand for their services as communities self-isolate and vulnerable seek people advice and support

We know it is a big ask as most of us are facing our own financial struggles during this time, but what ever you can do, what ever you can give, goes along way to help the Society to thrive.

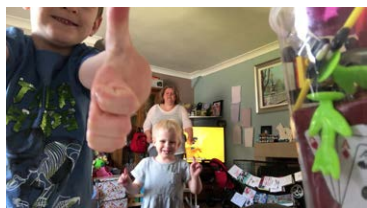


Our ask is small - could you set up a standing order of just £1 a month? If 50 people did this, that is a guaranteed £50 a month the Society will be receiving. Check out our [Donate](#) and [Fundraising](#) pages to help and get involved.

---

We would like to thank everyone who took part in the 2.6 challenge and donated to the ED Society at the end of April.

The 2.6 challenge was created in light of this years London Marathon being postponed, to help charities like us who would have been relying on much needed funds raised from this event.



Thank you to the Willats family who walked 2.6 miles and donated £26 ♂

Liane Clarke donated £26

And the Keen family for doing 26 minutes of Disco and donating £26.35



---

Thank you to all other donations which have come in over the last couple of months.

You have helped to raise £340 from PayPal giving, these are mostly from donations on Facebook ie. birthday fundraisers

Chantelle Epton - £23 from the collection box at her workplace

Manda Shortman - £385 raised by Coldecott Playing Fields

Julie Patterson - £85 raised so far for Leeds half marathon (currently postponed)

Chris Gallagher - £1000

Donations made in memory of Margaret Good £160 and Robert Smith £629.63

£40 - raised by Nikita Heskett's daughter designed and sold an ED football card



### **Messages of Support**

**“I appreciate all the help and advice the ED Society gives me and it helps to know that someone, apart from family, is interested in my daughters welfare and the challenges she faces with ED, so I thank everyone at the Society .”**

---

We would like to thank Allison and Nigel Smith for the donation of £629.63 in lieu of flowers at the funeral of their son Robert. Thank you so much for thinking of the ED Society at such a very tragically sad time.

Many of you will remember Robert from the Christmas parties about 10 years ago which he loved and where he made lots of friends. He was truly a great kid, always caring, very friendly and special to so many. We are honoured to have

met him when he was younger and to have watched his progress over the years.

Our thoughts and prayers remain with you and especially the girls as you all try to move forward.

We would also like to thank Maggie Good and family for the donation of £160 in memory of Margaret Good who was our eldest member at the age of 109. Margaret was still giving reflexology to her clients when she was in her late 90s – an amazing woman. Our thoughts and prayers remain with all Margaret's family.

---

Eleanor was born with a rare genetic condition called Incontinentia Pigmenti, which is a syndrome of Ectodermal Dysplasia.

Eleanor was also blind until 2018 when she spontaneously regained her vision in an event that science has yet to explain.

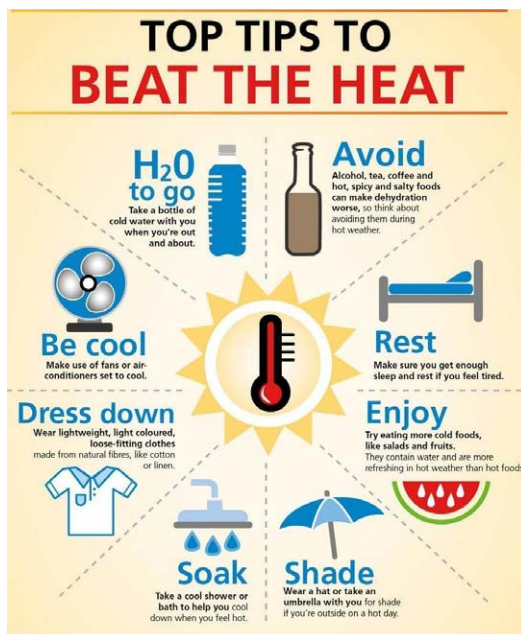
Eleanor is now at a point where she can use her vision to control an Eye-gaze communication system, which will enable

her to proactively communicate for the first time in her life.

Take a look at Eleanor's Go Fund Me page to find out more and read about her journey.



## A Voice for Eleanor



Having the warmer weather is lovely for most people during this lockdown, but we know it is a struggle for our ED community.

Ectodermal Dysplasia can cause serious problems with overheating due to lack of sweat glands. The benefits of damp T-shirts, wet hats & refillable water spray bottles that produce a fine mist is great for spraying on your head, arms & legs to #beattheheat.

Please remember to take a look at the [cooling advice and tips](#) on our website, and if there is a product that has worked well for you, we would be grateful if you could share it with us.

---

## Connect With Us



**Copyright © 2020 Ectodermal Dysplasia Society, All rights reserved.**

You received this email because you are a friend of the Ectodermal Dysplasia Society.  
The ED Society sends notices as an informational service to its friends, donors and families.

**Our mailing address is:**

Unit 1 Maida Vale Business Centre, Maida Vale Road, Cheltenham, Glos. GL53 7ER

**Want to change how you receive these emails?**

You can [update your preferences](#) or [unsubscribe](#) from this mailing.