

# JEANS FOR GENES

Mon 19 Sept – Sun 25 Sept

# How do you WEAR YOURS?

## YOUR FUNDRAISING CHANGES LIVES.

Last year, in direct response to the COVID pandemic, we decided to give no-strings-attached funding to all our groups – giving them the chance to use the money when and where they needed it most.

**Last year, your incredible fundraising helped us keep a beloved support programme going**

The Ectodermal Dysplasia Society ([edsociety.co.uk](http://edsociety.co.uk)) is dedicated to improving the health and wellbeing of individuals whose lives are affected by ED. They provide support to over 600 people in the UK and 150 families who live abroad via email.

ED is not a single disorder, but a group of closely related conditions which affect the development or function of teeth, hair, nails and sweat glands. There are life threatening aspects to this condition – namely overheating and hypothermia, due to lack of body temperature control.

Thanks to you they were able to keep their support service going through the pandemic – at a time when funds were extremely tight, and their families needed it most.

**JEANSECTODERMAL  
FORDYSPLASIA  
GENESSOCIETY**



**Last year, your incredible fundraising helped us provide improved IT services to ensure meetings with Clinically Extremely Vulnerable and isolated families continued through COVID**

Fanconi Hope ([fanconihope.org](http://fanconihope.org)) is a volunteer run organisation, set up by parents of Fanconi Anaemia (FA) affected children – the only one of its kind in the UK. FA is a rare, inherited, life-limiting genetic cancer-predisposing disorder affecting between 150 and 250 children and adults in the UK

**JEANS  
FORFANCONI  
GENESHOPE**



[jeansforgenes.org](http://jeansforgenes.org)

**Last year, your incredible fundraising helped us  
ensure a vital telephone call was always answered**

**JEANS THE  
FOR SMITH-MAGENIS  
GENES SYNDROME**

**Thanks to you** they were able to offer meetings, conferences, updates and gatherings for some much needed face to face time. This helped support the mental wellbeing of young adults who had been particularly affected by enforced isolation and who were extremely worried about COVID.

The Smith-Magenis Syndrome (SMS) Foundation ([smith-magenis.org](http://smith-magenis.org)) is a safety net, catching families upon diagnosis of SMS and supporting them through their lives for as long as they need.

SMS is a rare genetic condition as a result of the microdeletion or abnormality of chromosome 17, affecting around 4,500 children or adults in the UK.

Thanks to you they could continue to offer an online mobilisation of their Information and Support Service, handling telephone calls and on-line drop in sessions, bringing their peers and professionals together.



**The last two years have been hard on us all. Health anxiety has hit an all-time high and many – if not all – of the groups we support are considered ‘Extremely Clinical Vulnerable’. This added a whole new dimension to the pandemic for our groups - with enforced isolation not only closing them to the outside world but also closing the opportunity for much needed guidance, support and services.**

**Our charity partners worked harder to adapt and thanks to you, lifelines were offered, programmes were taken online, and people were seen and heard.**

**You MADE THIS HAPPEN.  
SO, THANK YOU, BRILLIANT YOU.**

[jeansforgenes.org](http://jeansforgenes.org)