

How your donations make all the difference.....

The ED Society's mission is that every individual and family affected by Ectodermal Dysplasia is equipped with the knowledge needed to manage Ectodermal Dysplasia effectively and live life to the full; and that medical professionals have the information and understanding they need to support those affected.

We seek to raise funds to provide support services, equipment and grants to families affected by Ectodermal Dysplasia in the UK.

Funds raised by our members, no matter how big or small the donation, goes a long way. It helps the Society to be able to thrive and succeed in helping our ED family with all of the following:



- write individual personal reports for your doctors, schools etc.,
- assist by writing letters and reports to help regarding rehousing,
- write appeal letters for Disability Living Allowance or Personal Independent Payment,
- assist when applying for a Blue Badge,
- assist when applying for an Education Health Care Plan (EHCP),
- provide a School Care Plan specific to Ectodermal Dysplasia,
- ensure schools are providing the correct care for your child such as a fan, having access to drinking water and water for cooling at all times, etc., by providing letters and, liaising with SENCO and the school,
- attend tribunals and school meetings with you,
- liaise with dentists or provide you with information to ensure you are not continually made to wait until your child is older before any treatment is carried out,
- ensure you have been given all the dental options for you or your child allowing you to make informed decisions; we have an excellent dental network around the UK,
- talk with you regarding the different symptoms of Ectodermal Dysplasia,
- provide t-shirts, leaflets, banners and support for fundraising activities you may be carrying out for us,
- liaise with medical professionals for assistance and advice on you or your child's care,
- help with obtaining wigs
- discuss genetics with you or your adult children to help informed decisions to be made,
- provide a get together for families to get to know each other and have the opportunity of speaking with the Medical Advisory Board on a personal basis,
- assist with the transition to University and Student Disability Finance,
- help you speak with others who have experience of Ectodermal Dysplasia via the ED Society's Facebook page,
- talk with you regarding lack of temperature control and behavioral problems which are connected for many individuals with Ectodermal Dysplasia.

From a little address book in 1996 when the Society was first established, we now have over 1600 contacts worldwide, an eminent Medical Advisory Board, a Board of Trustees bringing highly skilled expertise, an array of information, are involved in research programs (some of which have been instigated by the ED Society), assist other countries in setting up their own support organisations..... the list goes on!

Thank you to all our members for your continued support and encouragement over the years, especially in helping us survive the hard times and making the Society the success we are today.

For the future, we can only continue to grow and bring Ectodermal Dysplasia to the forefront. Please continue to support us by bringing awareness of Ectodermal Dysplasia and funding through your donations and fundraising events.

Supporting a normal lifestyle

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