

eds

ectodermal dysplasia society

Fundraising pack



Tips,

advice

and support



Our

Mission

Mission (Why we exist)

The ED Society aims to promote awareness and understanding of the Ectodermal Dysplasias by providing detailed information and practical advice to those individuals and families affected by Ectodermal Dysplasia, and to the medical professionals, local authorities, etc., who support them in living life to the full.

The ED Society aims to:

- Be the first port of call for all those seeking information on the Ectodermal Dysplasias.
- Provide personalised support to affected individuals and families and provide personalised guidance to authorities in the UK and Eire (e.g. schools, social services, etc.) seeking to understand how to manage the effects of Ectodermal Dysplasia on individuals and families in their community.
- Raise the awareness of Ectodermal Dysplasia within the medical profession and other community officials in the UK (e.g. health visitors, social workers, etc.) in order to promote early diagnosis of babies and children with life-threatening symptoms of Ectodermal Dysplasia (e.g. over-heating, breathing difficulties, feeding difficulties).

Vision (What we want to be)

Our vision 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.

The ED Society seek to raise funds to provide support services, equipment and grants to affected families in the UK. Ultimately, the ED Society would like to be at the forefront of raising funds for research into the Ectodermal Dysplasia syndromes in the UK and Europe.

Strategy (How we will make this happen) - The work of the ED Society will be guided by 6 strategic objectives.

Communication - To make available information that is clearly written and easy to understand on the different Ectodermal Dysplasias, together with practical advice on how to manage their affects.

Membership Management - To build a solid membership database of both individuals and families affected by Ectodermal Dysplasia, and of those medical professionals with an interest in or experience of treating such individuals and families.

Liaison & Support - To liaise with individuals, families, professionals and members of the Medical Advisory Board with the aim of providing personal support and advice to those affected by Ectodermal Dysplasia.

Contact Network - To build relationships between individuals and families affected by Ectodermal Dysplasia to encourage mutual, practical and emotional support.

Marketing - To promote awareness and understanding of Ectodermal Dysplasia to both the medical profession and the general public.

Fundraising - To raise funds to support the ED Society in its work to provide services, equipment and grants to affected individuals and families. Ultimately, to raise funds for research into Ectodermal Dysplasia in the UK and Europe.

We believe everyone with Ectodermal Dysplasia has the right to a normal lifestyle

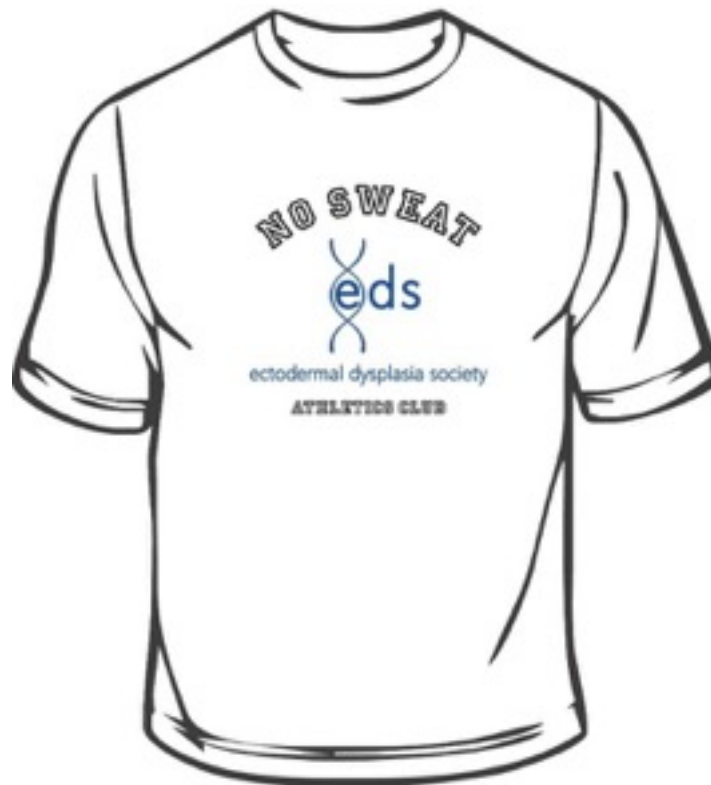
That's why everything we do is to better the lives of affected people. We receive almost all our funds from generous supporters.

Amazing people like you – who believe in our work – believe that everyone is worth supporting. We are incredibly grateful for your enthusiasm and effort, so thank you for joining us and helping to support the ED Society families.

In this pack, you'll find tips, advice and lots of inspiration to help you make your fundraising a success. You can also visit www.edsociety.co.uk/fundraising for more information or get in touch via email info@edsociety.co.uk

Fundraising shouldn't feel like a lot of hard work, it should be simple and make you smile. We're here to support you with whatever you decide to do, so you can focus on all the fun stuff. If you're stuck for ideas or want some advice on what fundraising materials you may need, don't hesitate to contact us.

Thanks again and have a great time fundraising!



Fundraising merchandise

Please contact us to let us know your requirements to help make your event successful



Banners, leaflets, sponsor forms, collection boxes & more



A sponsor form is at the end of this pack, but if you require more forms or would like help in setting up your online fundraising page, then simply contact us info@edsociety.co.uk

Thank you
to support



for
the



choosing



Ectodermal Dysplasia
Society

Masquerade Ball Hi, I'm Stuart Atkiss and this is a photograph of my wonderful fiancée Michelle Ford with our amazing 4-year-old son Taylor who has ED. I am a Trustee and fundraising coordinator for the ED Society, I wanted to do something to raise as much money as possible for the Society. So, with thinking caps on we came up with the idea of a masquerade ball.

It seemed the thinking part was the easiest, well to start with, but it all fell into place.

We held the Ball at the Royal British Legion in Lower Gornal who gave us the room for free

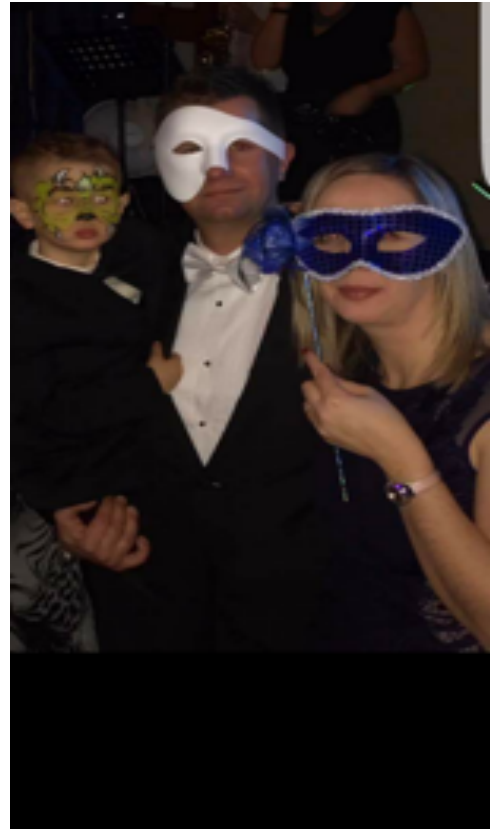
We had a great band GOTTA GROOVE who performed and gave their time for free.

Both of us then got out there and asked for donations towards the raffle prizes and auction items. I have to say the majority of shops were very generous. We then got two sponsors for the night, Aston & Fincher, who I have worked for just under 15yrs, and our friends Russ Cockburn and Joan Cockburn who have a company called Cucumber PR. With these sponsors, it meant the whole night was covered, so all the ticket and raffle money was going to ED Society.

We made it into the local paper who helped to promote the night which was great too. They asked, "what are you looking to raise at the event?" I looked at Michelle and we said, "well anything really as we haven't thought of a target to hit". They really wanted a target to put in the write up, so we said "£1500". When the reporter left we both said, "I hope we can get it now!"

Well the night was a huge success - it all went really well and everyone seemed to enjoy themselves and we raised a total of £1700.

So, from myself, Michelle and Taylor we want to say thank you to everyone who came, donated and helped the night be a success.



London Marathon April 2018

The ED Society managed to secure a place for the London Marathon 2018, it has taken us many years due to the difficulty of smaller charities like ourselves being able to get one, so we were thrilled to get the news we had received a place through the charity ballot.

We would like to thank all of our members who showed their support and interest in wanting to take part.

Clive Bentley put his name forward for the place, and has been chosen to run for the Society;

I had the opportunity to run the London Marathon in 2001. I had undergone surgery to remove a brain tumour ten months before, and although the prognosis was very grim (I was actually only given six months to live), I got myself fit enough to complete the marathon. I raised a lot of money to donate to The Brain Tumour Charity, formerly known as Samantha Dickson Brain Tumour Trust.

Miraculously, and against all the odds, I am still fit (relatively) and healthy. I am still under the hospital and yearly scans have not seen the tumour come back. So, 15 years later and two stone heavier, I still run but not to the level I did before. I have turned 50, but still feel I



have the mental and physical determination to get myself fit enough to complete the marathon, once again raising lots of money for a cause that is close to my heart.

Our youngest son, who is now 20, has Hypohydrotic ED. Over the years, we have seen him cope with lots of issues with overheating and his lack of teeth. He has undergone a lot of dental treatment which is on-going, and last year implants were tried in both his upper and lower jaws. These were not 100% successful due to the lack of bone on the bottom jaw and seeing him beside himself with pain was very distressing. He faces further work which may well include a bone graft before the next attempt to provide implants.

We are very grateful for the support and knowledge that the ED Society has provided us with. The opportunity to be able to raise several thousand pounds in sponsorship would be the least I could do to show my appreciation to an organisation that has provided so much good advice, encouragement and helpful medical support to us, and so many others who either have ED or family members who are affected by it.

I have a wide network of friends and family who have seen first-hand the issues our son has faced growing up. We have moved several times over the years and the support and generosity we have experienced from them has been phenomenal.

I am employed by a national based company and support from work colleagues for fund raising is the norm. I belong to a local church of 800 people who are like a large group of close friends to us.

My wife thinks running the marathon for the ED Society is a great idea. She has got some great ideas of fund raising events to help increase the total raised which I can donate. I am sure she would also welcome getting a slimmer, fitter husband once more!

How the money you raise by supporting the Ectodermal Dysplasia Society is used

By fundraising for the ED Society, you are helping to ensure everyone with Ectodermal Dysplasia lives a near normal lifestyle.

- Your support enables the ED Society to:
- be the first point of contact/reference for enquiries about Ectodermal Dysplasia,
- obtain answers from Medical professionals to members' specific questions,
- support families when they approach organisations such as Local Authorities, Social Services, etc., by putting together a personal report explaining very simply how Ectodermal Dysplasia affects them,
- liaise with Head Teachers, Health Authorities and medical professionals,
- ensure families get the right care for their child in schools, such as full or part-time Carers, fans, air-conditioning, etc.,
- support more families to obtain Disability Living Allowance, Carers Allowance, Personal Independence Payment, etc.,
- encourage members in their fundraising,
- connect individuals and families by putting people in touch with each other or via our Facebook group,
- ensure families obtain information regarding ante-natal testing,
- register the ED Society on the databases of Health Authorities, NHS Trusts, Health organisations, etc.,
- attend tribunals with individuals and families for Disability Living Allowance and Personal Independent Payment,
- provide a Support Fund to help families purchase air-conditioning, wigs, humidifiers, fans etc.

Making fundraising easy

Our tops tips to help make your event successful

- Take time to plan your event.
- Think about the space you need, especially if you are holding your event indoors.
- Mention to the venue staff that you are raising money for charity – you may get a discount on room rates.
- Set yourself a target, this will keep you motivated.
- Ask local businesses for donations, prizes etc., mention you work for a charity and they may offer a discount.
- Spread the word and use Facebook and Twitter, to tell everyone why you are fundraising and keep them up to date with your progress.
- Set up an online fundraising page with Virgin Money Giving or JustGiving, then share the link on Facebook/Twitter and, with colleagues and friends.
- Matched giving – many companies run matched giving schemes, this could double the total you raise, don't forget to check with your employer to see if they run such a scheme, it's also tax-efficient for them.
- Please ensure all donators sign a Gift-Aid declaration, this enables the ED Society to claim an extra 25%!

Making sure that your event is safe and meets legal criteria

Ectodermal Dysplasia Society branding

By law, the ED Society charity registration number must appear on all posters, advertisements and other fundraising materials. Please display this as follows: Registered Charity No. 1089135. Please contact us for permission for you or a third party to use the ED Society name or logo.

Insurance

As your event or activity hasn't been organised by the ED Society and isn't controlled by them, it will not be covered by the ED Society's Insurance Policy. Therefore, you may need to arrange your own insurance if appropriate, unless covered by your own home insurance for example.

Also, for any contractors, sub-contractors or external facilities used - make sure they have the relevant experience and can demonstrate evidence of the relevant insurance cover.

The ED Society will not be liable for any loss or injury arising out of the event or its organisation.

Food, hygiene and alcohol

Please take great care when handling food and work to basic rules for safe preparation, storage, display and cooking.

A license is needed if you have alcohol at your event. You can avoid this issue by either holding your event on licensed premises or by asking a local pub to organise a bar at your venue. Otherwise you'll need to submit a "Temporary Event Notice" to the Local District Borough Council to apply for a temporary license.

Health and safety

If you hold a fundraising event you will be responsible for the health and safety of all involved. The Institute of Fundraising and Government websites have useful information on this. Depending on your event you may need information from other sources as well.

Raffles, lotteries and prize draws


Raffles, lotteries and prize draws are a highly regulated area. Please refer to your Local District Borough Council for guidelines.

Collection Boxes

Collection boxes are a great way to raise money. If you're planning a collection that takes place in a publicly owned place, then this is governed by strict legal requirements and must be licensed by your Local Authority. Please let us know your plans and await approval before approaching your Local Authority. Licenses are not needed on privately owned land, but you'll need the permission of the owner or business.

How to get the money you raise to us

Please send the ED Society the total amount you've raised so we can put it straight towards supporting our families affect by Ectodermal Dysplasia.

If you've fundraised for the ED Society online through JustGiving or Virgin Money Giving all the money is automatically sent to us, or via  info@edsociety.co.uk, so you can sit back and relax!

If you collected donations, you can send the ED Society a cheque by post, made payable to ED Society along with the paying in form enclosed in this pack.

Send the money to the ED Society, Unit 1 Maida Vale Business Centre, Maida Vale Road, Cheltenham, Glos. GL53 7ER.

We really appreciate all the hard work and support you, your friends, family and colleagues have given the ED Society. You will receive a thank you letter or certificate from the ED Society within a week of receiving your donation.





Paying-in Form

Please complete this form in BLOCK CAPITALS and make cheques payable to the ED Society. Please do not send cash in the post. If you are sending sponsorship money, please also include your sponsor form so we can claim Gift Aid on your sponsorship donations.

Send this form to: ED Society, Unit 1 Maida Vale Business Centre, Maida Vale Road, Cheltenham, Glos. GL53 7ER.

Details about your fundraising activity

Amount enclosed £ Name
.....

Event Name Event Date
.....

Address
.....
.....

Fundraising online

Yes / No I have/have not raised money online

The link to my page
is.....

Matched Giving

Your employer may agree to match the funds you raise - ask them if they are happy to support you

Yes / No I have/have not applied for matched giving from my employer

The Company name is
.....

I expect to receive the following amount in matched giving £

SUPPORTING A NORMAL LIFESTYLE



Sponsor Form



Name Date of Event

Address

.....

Name	Address/Phone/Postcode	Amount	Total	Gift Aid*

*Gift Aid – Tick this box if you are a UK taxpayer and wish your donation to be treated as Gift aid.

The Ectodermal Dysplasia Society, Unit 1 Maida Vale Business Centre, Maida Vale Road, Cheltenham, Glos. GL53 7ER. England
 Charity No. 1089135 Tel: +44 (0)1242 261332 Mobile No: +44(0) 7774 465712 www.edssociety.co.uk mail: info@edsociety.co.uk.



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