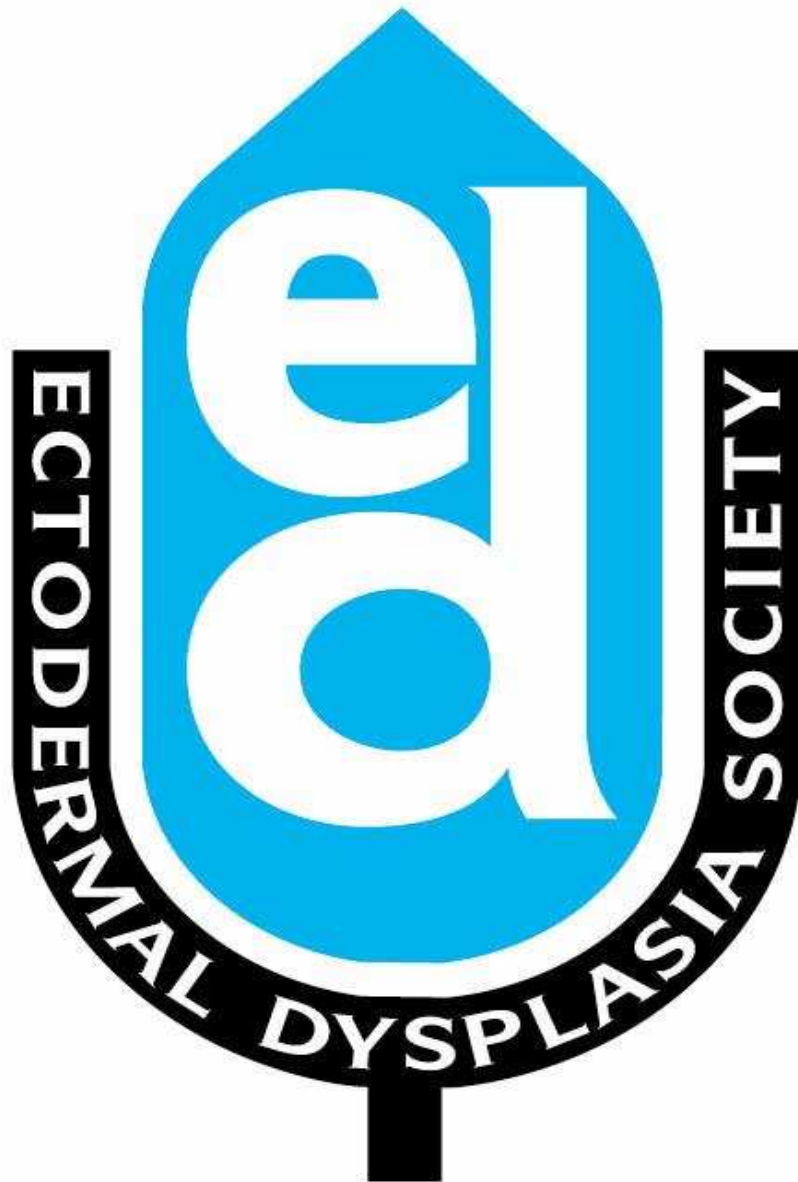


# The Ectodermal Dysplasia Society

## FUNDRAISING PACK



Charity No. 1089135

# Why Fundraise?

Fundraising events and activities are principally about raising much needed funds for the Ectodermal Dysplasia Society to:

- raise public and professional awareness of Ectodermal Dysplasia
- aid and support the work the ED Society provides to individuals and families affected by Ectodermal Dysplasia

Fundraising should be about having fun. We go to different events to enjoy ourselves and while doing that, we can generate additional support and general awareness of the Ectodermal Dysplasia Society and the support we provide.

The key to a successful event, full of fun and enjoyment, is to ensure that, you, as the organiser, enjoy organising it. The best way to do that is to plan your event effectively.

This pack, will not only give you the ideas to stage an event, but can also help you in your planning and hopefully, avoid some of the pitfalls along the way.

Whilst this pack is by no means comprehensive, its aims are to help you on your way. There are endless ways to fundraise and you are only limited by your imagination, so whether you are an experienced fundraiser or a complete novice, get your thinking caps on, and go for it, but don't forget.....**ENJOY YOURSELF!!**

# What shall I do first?

- When giving money to charity, people want to know how it is going to be spent. It is important to know what the Ectodermal Dysplasia Society does and where the money you raise will go
- Enthusiasm rubs off on other people. Your enthusiasm for the Ectodermal Dysplasia Society and the work it does will encourage other people and they will be more willing to support you
- There are thousands of charities all fundraising together, if we can make ours sound the best, people will support us
- Be prepared. Decide what you want to do, when you want to do it and how you are going to achieve it. Being organised is the key to success
- Family and friends will always support you, but what about their family and friends? Widen the net and you will be surprised how much support you will receive
- People warm to new and original ideas. The unusual and attractive will also pull in more supporters. Potential donors are more likely to give money if you are making an effort to do something; just shaking a tin, won't encourage much support.

# An ED Guide to Fundraising Ideas

Easter egg hunt

Coffee Mornings

Theme Nights

Obstacle Races

Disco

Eighties Night

Race Night

Murder Mystery Evening

Auction

Line dancing

Dinner Party

Your own ideas..... (Let us know!!)

Sponsored events

Penalty Shoot Out

Ladies tug of war.....

Alternative (fancy) dress party.....

Sports Tournament

It's a Knockout

Anything you like.....!!

## Other Ideas for Fundraising

Quiz night

Board Game/tournaments, e.g. Scrabble or games console competitions

Sponsored diet, swim, silence, run, walk or cycle

Karaoke night

# The ED Steps to Success

## Step 1 - What, When, Where, Who & Why?

- Do a bit of research to find possible interest of your event, and make sure it doesn't clash with other events that might rob you of potential supporters.
- Work out in advance what your expenses will be and price your tickets accordingly. Calculate your break even point. Be realistic in the numbers you expect when setting a ticket price, but don't price yourself too high and out the market.
- Ensure that you can get the venue and other bookable items on the date required, before you start advertising the event or create publicity material. For outdoor events, e.g. BBQs you may wish to come up with a contingency plan in case of bad weather.
- When using public halls make sure you get the keys well in advance and ensure that there is adequate seating and tables for your event. Find out from the hirers where all the light switches are, ensure there are adequate power points for your needs. For winter events ensure that there is adequate heating and find out the location and how to work the heating controls — no one likes to spend the evening etc in a freezing cold hall. Check to see if the hall hirer will turn the heating on for you beforehand or do you need to arrive earlier to do this. Also find out how to reset the fuse box if a bulb blows and trips the main lighting circuit. In some halls all the light switches are hidden in cupboards! Some halls have a noise limiter, so ensure you know how to turn that back on if it trips. Also ensure that there is enough toilet paper and hand washing facilities in the lavatories. If providing food, see if cutlery and plates etc are provided or do you need to bring your own. Some halls are very dusty so you may need a bit of a cleanup before the event.
- Consider if you want to sell tickets in advance, so that you have an idea of numbers on the day, especially if you will be doing catering.
- You may also wish to collect the entrance money in advance to protect against non attendance, as it can be a bit risky to rely on people turning up and paying on the door. It is common for people to say they will turn up and then don't attend; at least then if they don't come you have got their money in advance and covered your expenses. This could be particularly important for outdoor events, as an assurance against making a loss in the case of rain.
- Be realistic as to the numbers you can fit in or are allowed in your venue and plan your advertising strategy accordingly. If you intend to advertise on local

radio or in the paper etc, then don't hire a small hall that can only fit 100 people!

- Keep all your receipts of expenses together and monies collected separate from your own funds. It makes life a lot easier when trying to work out how much you have raised. If selling tickets in advance, numbering the tickets can also help, so you know who has bought which tickets etc and gives you an instant note of the numbers sold. Keep a note of the people who will be selling tickets for you, how many you gave them and the ticket numbers. When you sell tickets make a list of the buyer's name, ticket numbers and amount sold. Again this helps in the balancing of the accounts and makes it easy to track the money raised with the amount you have in front of you.
- Consider the time of year when holding an event— obviously winter is not the best time for an outdoor event.
- Make sure that you cover all legal requirements applicable to your event. See the guides below.

## **Step 2 - Expenses**

### **Possible expenses to be taken into consideration:**

You may get all these expenses at reduced cost or for free if you tell the provider it is for a charity. Take some ED leaflets with you to show them; leaflets introducing the Charity are available from the ED office.

- Venue Hire.
- Advertising.
- Ticket and poster/leaflet manufacture - can you reduce costs by using your own computer where possible?
- Food and drink, and the necessary cutlery and plates.
- Raffle tickets and Prizes- you can try and get friends and local businesses to donate prizes.
- Other non raffle prizes.
- Security.
- Licences- see legal requirements below.
- First aid cover?

- Microphone and amplifier hire.
- Entertainment provider cost e.g. DJ or other.
- Petrol and transport if appropriate.
- Postage if sending out tickets/flyers or letters etc.

### **Step 3 - Support**

- Give tickets to your friends for them to sell to their contacts.
- Allocate different roles to different people and have them report to a central co-ordinator. This is especially important for large events.
- Make sure that you have sufficient help on the day and have extras in hand in case of sickness.
- Some venues may require you to put on security e.g. pubs if you hold a disco on their premises.

### **Step 4 - Publicity**

- Consider where and how you will advertise the event, bearing in mind the maximum numbers that you can cope with. For example, expect lots of people if you advertise in the local paper or public places e.g. libraries.
- Press Release - see Addendum A for a sample.
- If you belong to a club or society see if you can put a poster up there, and see if any friends or work colleagues can do the same at any clubs they belong to.
- Can you or your friends advertise in the work place?
- Local radio.
- Local shops often have a bulletin board, e.g. newsagents and some supermarkets. Local shops may put a poster in their window for you.
- Libraries.

### **Step 5 - On the day**

- Allow plenty of preparation time on the day, especially if you need to turn on the heating to allow the venue time to warm up.

- Bring bin bags with you so you can take the rubbish away with you if there is insufficient waste disposal at the venue or if using an outdoor site.
- Clear away tables and chairs from halls where required after the event.
- Ensure people leave quietly if in a residential area.

#### **Step 6 - After the event**

- Thank any sponsors to your event and inform them of how much you raised.
- Pay the money raised to the ED Society.

## **Instructions for Paying Your Money into the Ectodermal Dysplasia Society**

For security reasons please contact the ED Society office for banking details.

# Legal Requirements

- THE INSTRUCTIONS BELOW ARE A GUIDE AND NOT INTENDED TO BE LEGALLY BINDING.
- BEFORE DOING ANY PUBLIC COLLECTIONS OR EVENTS, CONTACT YOUR LOCAL COUNCIL TO CHECK THE CURRENT LEGAL REQUIREMENTS, ESPECIALLY IF IN SCOTLAND.
- THE ECTODERMAL DYSPLASIA SOCIETY CANNOT BE HELD RESPONSIBLE FOR ANY BREACHES IN THE LAW FOR FUNDRAISING EVENTS ORGANISED BY OTHER BODIES OR INDIVIDUALS.

## Collecting Money

- Legally, when soliciting funds you must put on all leaflets, posters, collecting cans, publications etc., the name of the Charity and our Charity number 1089135. This number appears just under the logo on all our stickers, headed notepaper and other official publications.
- To collect on the street you need a Street Collecting Licence from your Local Authority. However, if collecting on private property you only need permission from the property owner.
- Collection boxes must be sealed. Please use our official boxes which are available from the ED office and can be posted to you.

### Face to face collections (England and Wales)

- All collectors of monies must be at least 18 years of age.

- All cash collections need to be collected, counted and recorded by two unrelated individuals, for their protection. However this is not a legal requirement.

### **House to House Collections (England and Wales)**

This is where individuals go from door to door of private residences or businesses.

- All collectors of money must be at least 16 years of age.
- You need a House to House Collection Licence available from your Local Authority.
- The law on this method of collecting is quite complicated and best explained in this link

<http://www.institute-of-fundraising.org.uk/NR/rdonlyres/794C7531-05B0-40DE-99F6-2421C3E0B8C2/0/HousetoHouseCollections.pdf>

The rules for Scotland are slightly different, including the age ranges allowed to collect.

Please see:

[http://216.239.59.104/search?q=cache:uPQE\\_KjZW5QJ:www.aberdeencity.gov.uk/acci/web/files/RM\\_licences/public\\_charitable\\_collection\\_guidance\\_note.pdf+charity+collection+box+legalities&hl=en&ct=clnk&cd=8&gl=uk](http://216.239.59.104/search?q=cache:uPQE_KjZW5QJ:www.aberdeencity.gov.uk/acci/web/files/RM_licences/public_charitable_collection_guidance_note.pdf+charity+collection+box+legalities&hl=en&ct=clnk&cd=8&gl=uk)

## **THE GAMBLING ACT 2005**

- **Raffles**  
You do not need a licence if you plan to hold a raffle at your event providing the following criteria are met:
  - The tickets must be sold during the event.
  - The draw must also take place during the event.
  - You must not have cash prizes or spend more than £250 on the prizes (donated prizes do not count).
  - Tickets must not be more than £1 each.

- All alcoholic raffle prizes must be in a sealed container, otherwise you will need a temporary Alcohol Licence - see below.
  - If you plan to sell raffle tickets prior to the event then you need to register your raffle with your Local Authority or the Gambling Commission. For further information check out - [www.Gamblingcommission.govt.uk](http://www.Gamblingcommission.govt.uk) or your Local Authority website.
- **Bingo, Whist Drives, Bridge evenings etc**

You do not need a licence provided the event is not for personal gain. All participants must be informed as to where the proceeds are going.

See the website below for further information

<http://216.239.59.104/search?q=cache:8iSy4EpyVJgJ:www.funderfinder.org.uk/pack/raffles%2520and%2520bingo.pdf+alcoholic+prizes+in+raffles&hl=en&ct=clnk&cd=1&gl=uk>

## **ALCOHOL LICENCES**

A licence is only necessary if you plan to sell alcohol.

The premises on which your event will be held must have a current Premises Licence under the Licensing Act 2003. If it has not, then you need to contact your Local Licensing Authority. Under this Act, short term, small events can be held if the event organiser sends a Temporary Event Notice to the Local Licensing Authority and police within ten working days prior to event.

### **Further information**

The Gambling Commission, Victoria Square House, Victoria Square, Birmingham B2 4BP, Tel: 0121 230 6500, Fax: 0121 237 2236

Website: [www.gamblingcommission.gov.uk](http://www.gamblingcommission.gov.uk)

Factsheets on bingo, "race nights", gaming and gaming machines in clubs and alcohol-licensed premises, and similar fundraising activities are available on the Department for Culture, Media and Sport website at [tinyurl.com/2dlpbd](http://tinyurl.com/2dlpbd)

Sandy Adirondack's Legal Update gives updates in the law for Voluntary Organisations website: <http://www.sandy-a.co.uk/managing.htm#gamblingact> which updates the Voluntary Sector Legal Handbook (new edition due in 2008).

# FOOD

Any event involving the production, supply or sale of food must comply with both of the following

- **Food Safety Act 1990** see Office of Public Sector website:  
[http://www.opsi.gov.uk/acts/acts1990/ukpga\\_19900016\\_en\\_1.htm](http://www.opsi.gov.uk/acts/acts1990/ukpga_19900016_en_1.htm)
- **Food Safety Regulations 1995**  
The NEM Business Solutions website gives a good summary of this act:  
<http://www.cip.ukcentre.com/food1x.htm>
- A copy of the act can also available on the Office of Public Sector website:  
[http://www.opsi.gov.uk/si/si1995/uksi\\_19951763\\_en\\_1.htm](http://www.opsi.gov.uk/si/si1995/uksi_19951763_en_1.htm)

If you produce food yourself, proper hygiene requirements must be observed e.g. wash your hands and ensure utensils and containers are clean. Keep raw and cooked foods separate, keep food chilled and ensure preparation surfaces are clean at all times.

## Music Licences

See Department of Media, Culture and Sport website for more details. Sections of the website that have been copied below are in inverted commas.

[http://www.culture.gov.uk/www.culture.gov.uk/i/Publishing/Subject.aspx?NRMODE=Published&NRNODEGUID=%7b129463A2-7416-4A6F-9CDC-3DOB8406BBE3%7d&NRORIGINALURL=%2fwhat\\_we\\_do%2fAlcohol\\_entertainment%2flicensing\\_act\\_2003\\_explained%2fregulated\\_entertainment%2eh.htm&NRCACHEHINT=NoModifyGuest#8](http://www.culture.gov.uk/www.culture.gov.uk/i/Publishing/Subject.aspx?NRMODE=Published&NRNODEGUID=%7b129463A2-7416-4A6F-9CDC-3DOB8406BBE3%7d&NRORIGINALURL=%2fwhat_we_do%2fAlcohol_entertainment%2flicensing_act_2003_explained%2fregulated_entertainment%2eh.htm&NRCACHEHINT=NoModifyGuest#8)

"If regulated entertainment is being provided at a public event or if a charge is made to a private audience with a view to profit, including for a charity, a Premises Licence or temporary Event Notice would be required.

If the public is not invited and a charge is made to a private audience (such as family and friends) purely to cover costs - and not to make a profit - then this will not be the provision of regulated entertainment and a Licence will not be required. Similarly, if anyone invited to a private performance was not charged for attending the event, but was free to make a voluntary donation to a charity of their own choice, then no Licence will be necessary. However, if the performance is to any extent open to the public (whether the public are charged or not) a Licence will be required."

### **Regulated entertainment under the Licensing Act 2003**

"The provision of regulated entertainment covers the provision of entertainment or of entertainment facilities. The descriptions of entertainment in the Licensing Act are:

- the performance of a play
- an exhibition of a film
- an indoor sporting event
- boxing or wrestling entertainment
- a performance of live music
- any playing of recorded music
- a performance of dance
- or entertainment of a similar description to live music, recorded music or dance

For ad hoc public events where your venue does not already hold a Licence you will need to obtain a temporary Event Notice, provided that there are no more than 499 people attending. "The premises user must, no later than 10 working days before the day on which the event is to start, give duplicate copies of the Notice to the relevant Licensing Authority, together with the fee of £21. A copy of the Notice must also be given to the relevant Chief Officer of Police no later than 10 working days before the day on which the event is to start."

## **Public Liability Insurance and Occupiers Liability**

It may be advisable to ensure that your venue has Public Liability Insurance in case of accidents. If you are using your own premises you will need this if you are opening it to the public. Also make sure you observe the Occupiers Liability Act. This Act basically states that the premises must be safe for all visitors and all potential hazards eliminated.

## For Extra Information

- Although the ED Society is not a member, The Institute of Fundraising website below gives lots of advice and information. Just click on the links for their code in the section that you require

<http://www.institute-of-fundraising.org.uk/informationaboutfundraising/forfundraisers/howtofundraise/fundraisingstrategy/>

The organising events section is particularly good for initial event setup.

## ED Safety Advice

- Always ensure that children are safe and do not allow them to solicit money without the presence of an adult.
- Try and ensure you have the provisions of a First Aider at your event. For large public events you may need the services of the Red Cross or St Johns ambulance.
- Keep the collected money somewhere safe and out of public sight at your venue. Money should be kept in a secure container and ensure that 2 people are with the money at all times.
- When planning an event think in advance of all the hazards and risks, and eliminate them where possible, e.g. trailing wires, loose fittings. Go through all possible solutions to emergencies should the worse happen e.g. know where the fire escape exits and fire extinguishers are located.
- Ensure all electrical equipment has been properly maintained and is safe e.g. no loose wires.
- Ensure that you dispose of all your waste safely in bins and ensure that all breakages and spillages are cleared up immediately. If there is not sufficient bin space bring along black sacks.
- When fund raising on the streets ensure that there is ample room around you for public access so you do not block paths etc., and cause danger to pedestrians.
- When handling money outdoors ensure that you do not leave the cash handler on their own. Ensure that there is a group of you at any one time and ensure

that your collection points are in busy public places. This is to deter any potential muggers.

- If you are organising a sponsored cycle or running event you must have properly trained marshals at all relevant places e.g. street corners, and plenty of crowd control and first aid facilities. See the institute of Fundraising Guide to Outdoor Events for more guidelines <http://www.institute-of-fundraising.org.uk/NR/rdonlyres/E1AC991C-411F-4FF2-B300-31FB7CDA3E0A/0/OutdoorFundraisingintheUK.pdf>
- If you are entering a physical event e.g. marathon etc., or an event which involves danger e.g. a parachute jump, then ensure that you have sufficient personal insurance just in case things should go wrong, and that you are fully trained.

## Successful Events

Include stories of successful events.

If people can read or see a successful event it may inspire them to organise their own.

The more diverse we can get the better.

## And Finally.....

A Thank You, maybe a personal thank you written by Diana or Sue



## Ectodermal Dysplasia Society Fundraising Press Release

I/ we are holding the following event to raise funds for the Ectodermal Dysplasia Society.

**EVENT** .....

**VENUE ADDRESS** .....

**TIME** .....

**TICKET PRICE** £ ..... in advance/ at the door/ both ( circle as appropriate)

**ANY OTHER INFORMATION (e.g. description)**

.....  
 .....  
 .....

**CONTACT DETAILS OF ORGANISER**

**NAME** .....

**ADDRESS** .....

**PHONE (Home)** ..... **(Mobile)** .....

**EMAIL** .....

The following page briefly explains about Ectodermal Dysplasia and the ED Society.....

# ABOUT ECTODERMAL DYSPLASIA

Ectodermal Dysplasia (ED) is not a single disorder, but a group of closely related conditions of which more than 150 different syndromes have been identified. The Ectodermal Dysplasias (EDs) are genetic disorders affecting the development or function of the teeth, hair, nails and sweat glands. Depending on the particular syndrome ED can also affect the skin, the lens or retina of the eye, parts of the inner ear, the development of fingers and toes, the nerves and other parts of the body.

Each syndrome usually involves a different combination of symptoms, which can range from mild to severe, such as:

- Absence or abnormality of hair growth
- Absence or malformation of some or all teeth
- Inability to perspire, which causes overheating
- Impairment or loss of hearing or vision
- Frequent infections due to immune system deficiencies or, in some cases, the inability of cracked or eroded skin to keep out disease-causing bacteria
- Absence or malformation of some fingers or toes
- Cleft lip and/or palate
- Irregular skin pigmentation.

In addition to the above they may have:

- Sensitivity to light
- Respiratory problems
- A lack of breast development
- A host of other challenges

Individuals affected by ED face a lifetime of special needs which may include:

- Dentures at a young age with frequent adjustments and replacements
- Special diets to meet dental/nutritional needs
- Air conditioned environments
- Wigs to conceal hair and scalp conditions
- Carrier identification testing
- Protective devices from direct sunlight
- Osseointegrated dental implants
- Respiratory therapies

## Specific Syndromes

The inheritance patterns are variable according to the specific type of ED. Patterns include spontaneous mutations, autosomal dominant, autosomal recessive, X-linked dominant and X-linked recessive. When questions of a diagnosis exist, the expertise of a geneticist or other doctor with experience with the EDs is strongly recommended.

It is important to remember that not all individuals affected by the EDs will have physical features that fit the description of a specific syndrome. There may be a great deal of variation in the physical appearance of the same type of ED from one affected person to the next. It is also conceivable for a person to have a type of ED that has not been described yet. Nonetheless, the EDs share certain features, an understanding of which makes it possible to appreciate the ramifications for most affected individuals and allows everyone involved to respond appropriately to the individual's needs.

# About the Ectodermal Dysplasia Society

In 1984 a support group was established by two mothers. The group had grown by 1996 to a membership of 50 and, largely due to additional information available on the internet, this number continues to grow with membership now standing at over 500.

The Ectodermal Dysplasia Society aims to:

- 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 ED affects them
- liaise with Head Teachers, Health Authorities and medical professionals
- help families get the right care for their child in schools, such as full or part time Carers, fans, air-conditioning and so on.
- help more families obtain Disability Living Allowance and Disability Carers Allowance
- put people in touch with each other if requested
- find pen pals for the younger members
- help families obtain information regarding ante-natal testing
- put the Society on the databases of Health Authorities, NHS Trusts, Health organisations, etc.

The Ectodermal Dysplasia Society produces a newsletter four times a year. The Society is run on a purely voluntary basis and, as a non profit-making organisation, it relies on donations and fundraising by individual members.

The Society aims to hold a Family Christmas Party each year. At this even there will be members from the Medical Advisory Board, a time to share, socialise, and meet other members from around the country.

The Ectodermal Dysplasia  
Society

108 Charlton Lane, Cheltenham, Glos. GL53 9EA, England

Email: [diana@ectodermaldysplasia.org](mailto:diana@ectodermaldysplasia.org)

IP Website: [www.incontinentia-pigmenti.org](http://www.incontinentia-pigmenti.org)

ED Website: [www.ectodermaldysplasia.org](http://www.ectodermaldysplasia.org)

Disclaimer: Any views or opinions are made by the author in good faith. No liability whatsoever is accepted by the author or the Ectodermal Dysplasia Society. Recipients should make their own additional enquiries of medical and other relevant authorities



Charity No. 1089135

## Sponsorship Form

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The Ectodermal Dysplasia Society, 108 Charlton Lane, Cheltenham, Glos. GL53 9EA. England  
 Tel: 01242 261332 Email: [diana@ectodermaldysplasia.org](mailto:diana@ectodermaldysplasia.org) Website: <http://www.ectodermaldysplasia.org>  
 Ectodermal Dysplasia Society (Registered Charity No. 1089135). A full list of Trustees is available from the above address.