

ECTODERMAL DYSPLASIA SOCIETY

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ED Christmas Party 2013

We are pleased to announce the

EDS Christmas Party will be held on

Saturday, 7th December 2013

12.30pm - 5.00pm

At the fully air-conditioned

"Thistle Cheltenham"



Children's Entertainment from Chris Brown and friends

Music and a Bubble Machine

Buffet and Father Christmas

Tickets - Adult £12.50 ED children free, non-ED children £6.25

Family and friends welcome

Financial assistance is available towards travel and accommodation on application

The venue has ample parking and is close to the M5 motorway, about 2 miles from Cheltenham coach and rail stations and close to a range of hotels.

Please return the enclosed registration form by 18th November 2013

Teenagers welcome – we have had a few 13-15year old who have expressed an interest in coming to the party to meet with other teenagers - the more the merrier!

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Medical Advisory Board Members

Prof. Angus Clarke	-	Clinical Genetics (MAB Chairman)
Prof. John Hobkirk	-	Prosthetic Dentistry (Implants)
Mr. Stephen Kaye	-	Ophthalmology
Prof. John McGrath	-	Genetics, Molecular Dermatology
Prof. June Nunn	-	Paediatric Dental Surgery
Dr. Helen Stewart	-	Clinical Genetics (IP)
Mr. Colin Willoughby	-	Ophthalmology
Mr. Martin Bailey	-	ENT
Prof. Michael Tipton	-	Human Applied Physiology
Prof. Nichola Rumsey	-	Psychologist
Dr. S. Aylett	-	Paediatric Neurologist
Mr Paul King	-	Restorative Dentistry (incl. Implants)
Prof. John Harper	-	Paediatric Dermatology
Mr. Michael Kuo	-	Consultant Otolaryngologist
Dr. Fiona Browne	-	Dermatologist
Dr. L. Albery	-	Speech / Language Therapist

Trustees

Paul Collacott	-	Chairman
Alan Waller	-	Treasurer
Diana Perry	-	Secretary
Mandy White	-	Air-Conditioning / School Liaison

Melanie Davis
Stephen Ayland
Simon Lees-Jones
David Wyatt
Mark Macnair
Liz Beckmann
Sharon Cooper

Staff

Sue Beard	-	Accounts / Website
Julie Cox	-	Administrator
Fergus Gordon	-	Scotland

Christmas Party

Are you able to help at the Christmas Party?

We need someone to take videos & photographs - you don't need to be an expert.

We need someone to do face painting and possibly nail art.

An extra pair of hands to help out generally.

Temperature Research

We are still trying to obtain funding to carry out this research; as soon as we are successful we will let you know and hopefully proceed to the next stage of the project.

I will send another email of invitation to everyone once we have funding.

Diana Perry



The Ectodermal Dysplasia Society Facebook page is buzzing with chat, lots of questions and answers, tips, support and much more.

Join us and make lots of new friends.

Disability Living Allowance And P.I.P

Contact a Family have a really helpful leaflet on how to apply for DLA and advice on how to complete the forms. You can find the leaflet at

http://www.cafamily.org.uk/media/379427/dla_factsheet.pdf

Diana is always happy to help complete the forms - it's best to get the forms right at the beginning in the hope it will not have to go to appeal or tribunal.



How we have spent some of the monies you have raised this year

2 Specialist natural hair wigs

2 Air-conditioning units

1 Air purifying unit

Christmas Party, travel and accommodation

Financially assisted individuals travel to attend specialist hospital appointment

Travel to visit families and attend several Tribunals for Disability Living Allowance with successful outcomes

Travel to attend several schools informing them of how children with ED are affected by their symptoms and how the schools can help them with the day to day management to help increase their concentration and maximise their education. These meetings were extremely helpful and successful.

Travel to meetings to obtain grants for ED research

If there is something you would like help with please contact diana@ectodermaldysplasia.org to make an application through the Support Fund.

We Need Your Photographs

We now have some great new notice boards in the office and would like to put pictures of our ED friends and families up. Could you please send us your photos so we don't have to look at a blank board!



Stay Informed. Stay Connected.
The XLHED Network.

The Edimer X-Linked Hypohidrotic Ectodermal Dysplasia Newborn

Boys Study

The Edimer newborn study trials have begun! Although Edimer is based in the USA a centre is being established by Prof. Clarke in Cardiff where all UK participating individuals or families will be able to attend. He would be delighted to hear from people that know or suspect they are XLHED carriers and who are pregnant or thinking of becoming pregnant. Baby boys that are born in the next 24 months may be eligible to participate in a study of EDI20.

EDI200—Ectodysplasin – A1 (EDA-A1) is a protein that occurs naturally in healthy people where it is involved in the formation and development of skin and teeth. This protein is missing in individuals with XLHED. EDI200 is a form of EDA-A1 being developed by Edimer Pharmaceuticals as a treatment for patients with XLHED.

If you would like to discuss this or receive more information please contact either Diana at the ED Society (diana@ectodermaldysplasia.org—Tel: 01242 261332) or Prof. Angus Clarke (Tel: 02920 744058)

Living Between Countries While Dealing With ED

I am an American international student living in the UK, and I have hypohidrotic Ectodermal Dysplasia. I am an archaeologist by profession, travelling all over the world. The last few years I have been working mostly in California and Nevada, where it is sunny, dry, and hot. Living in the UK has thus been quite a climate adjustment for me. There are many differences between living in the UK and the US, but the reasons are both positive and negative, as well as practical and mental.



One of the best things about living in the UK is the weather! In the UK, even if it's sunny, it's still a comfortable temperature. Since I have only a few sweat glands, it is fantastic not to have to worry about making sure I (or my family) have all the necessary equipment to keep cool. Many places in the US are very humid or very hot so that not only is it difficult to go anywhere near home without sufficient protection, but travelling must be thoroughly planned. Plus, no one else really knows exactly what I am feeling, so I must take care of myself. It's hard to be spontaneous when I have to worry about being uncomfortable in the heat. In England, this is no problem!

Health care is an international issue at this time, and there are major differences in the quality of medical services and the financial costs. In the US, people pay for insurance in order to get good quality health care. For someone with health issues, insurance can be difficult to obtain and much more expensive. A large portion of my income goes to my dental visits alone. However I always get great dental care in the US! In the UK, people are not obligated to spend out of pocket on health care - it's a national right for citizens. Appointments and consultations can usually be easily scheduled and there's no worry about added fees. That is truly an amazing privilege to have. Unfortunately the quality of care is not always satisfactory, but that is a repercussion of the lack of financial aid to the system when so many people are using the system. In addition, specialist consultations require additional payment, and therefore many with health issues either shell out for private insurance or just pay the excessive fees. Moreover, federal regulations for medications are also much more stringent in the US, but this also promotes higher quality medications. Because it is so easy to obtain medication in the UK for a very low cost, I have found that UK doctors are generally less apt to provide prescriptions, knowing that at such low costs, the NHS is practically giving away medicine.

When it comes to being a lone traveller, it is hard to find support or understanding if people know you are different. As I travel frequently for my occupation, I usually don't tell people that I have skin problems, dental issues, trouble making my hair look fuller, or that I get dehydrated easily. I have to take care of myself. I have to know my limits and when I need to seek help. In the US, my network of friends and family are able to identify symptoms of discomfort. I have dentists that understand that I need a quick appointment to fix a false tooth, dermatologists that understand I will always have to deal with eczema, or a hair stylist that won't constantly tell me that I have '*really thin hair*'. Anywhere I travel I constantly have to explain my condition to new doctors and dentists. Although I am helping spread the awareness, I usually have to sacrifice the privacy of my problems and tell them I have false teeth, dry skin, or a patchy scalp. It is uncomfortable to be looked at like I'm '*interesting*'. It is nice to have doctors that know me. But if I want to travel, if I want to live my life, I have to make sure I take care of myself, even if it means being brave enough to be different.

One of the best things I will take home from this country is hats! Hats hats hats! The British make hats look cool. In the US, the only 'cool' hat to wear is a baseball cap, or the now trendy 'trucker's cap'. The British men alone have bowlers, top hats, berets, fedoras, trilbies, boaters, deerstalkers (*for Sherlock Holmes*), porkpie caps, fez's, panamas, balmoral bonnets, flat caps, glengarrys... the list could go on. Any respectable woman going to any respectable social function MUST wear a hat—its etiquette. If you are British and you travel to the States, show those colonials what style means. I think I am going to return home much braver about feeling good wearing something that makes my hair (and fashion) look so much more chic, rogue, and unique.

Janet C. Niessner

Seaford Half Marathon

My name is Jonny Robinson. I am 18 years old and have recently finished school. I am taking a gap year to complete some dental implant work and will then be off to Sussex University to study American Studies with a year in America.



I have Hay Wells syndrome and although this has created obstacles for me at times I have found ways to overcome them and lead a normal, full and active life. I have a very supportive family and loads of great friends. One of my best friends, Toby Marriott, and I decided to do something to raise money for the ED Society before we left school. This came in the

form of running the Seaford Half Marathon on June 9th 2013. Neither of us had done one before but as we both have played sport to County level and above (Toby in cricket and me in hockey) we have good levels of general fitness. We enrolled, set up a donation page and did a training run along the seafront the week before. On the day we decided we would run together and finished a creditable 128 (me) and 132 (Toby) in a field of 500 runners.



We were delighted with the generosity of our family and friends and have managed to raise over £3,000. A great experience and one we will definitely do again.

Jonny Robinson



Fundraising for Irish Group

Sharon Geoghegan's brother James Murphy and her cousin Martin Haughney raised the fantastic sum of 900 Euros running the 'Hell and Back' 12km race to support the ED group in Ireland. Thank you so much, the money will go towards the Irish Support Fund.

Are You Off to University or Higher Education?



When Joe was going off to University we were thinking of all the equipment we were going to have to buy for him, air-conditioning unit, humidifier, etc., as his room in the Halls of Residence would be very small and very hot. We also had to liaise with the University Residence Department to ensure he was not going to be on the ground floor as this would not be safe and secure if he had his window open for the air-con unit. We were advised about Disability Student Allowances (DSAs).

We decided to apply for a grant to pay for the air-con unit and humidifier. Joe & I then had to go to a local Assessment Centre for them to interview Joe to determine his needs. The Interviewer took a complete history of how ED affects Joe and what affect it has on his academic life. From this she determined that overheating causes lack of concentration and suggested Joe would need a digital voice recorder to record lectures and playback later in case his concentration waned during lectures. He would also need his own laptop with assisted software programs to allow flexibility to move around environments that would be most suitable for him to allow him to continue working efficiently, together with a printer to allow him to photocopy from University library books as he may not be able to tolerate the temperatures in a library. Plus an air-con unit for his room and a humidifier. The interview took a long time, nearly two hours, but was well worth it as he was granted the cost of all the equipment, together with general allowance per annum for paper, printer ink, non-core books, etc.

Have a look at <https://www.gov.uk/disabled-students-allowances-dsas/overview>

'DSAs are grants to help meet the extra course costs students can face as a direct result of a disability, ongoing health condition, mental health condition or specific learning difficulty. They help disabled people to study in higher education on an equal basis with other students. They are paid on top of the standard student finance package and don't have to be paid back. The amount you get depends on the type of extra help you need - not on your household income.

What can DSAs be used for? They can help pay for:

- specialist equipment you need for studying - for example, computer software
- non-medical helpers, such as a note-taker or reader
- extra travel costs you have to pay because of your disability
- other costs - for example, tapes or Braille paper

You can apply if you are doing an undergraduate or postgraduate course (including a distance-learning course) that is:

- full-time and lasts at least one year
- part-time, lasts at least one year and doesn't take more than twice as long to complete as an equivalent full-time course

There are two ways to apply for DSAs:

1. if you're applying for DSAs only, you complete form DSA1

if you're also applying for the main student finance package, you indicate on the main application that you want to apply for DSAs – and then complete a 'short' version of the DSA1 form.

Whichever route applies to you, apply as early as possible. Don't wait until you've been offered a place at university. Make sure you send the form to the right address. Depending on your circumstances, this could be to Student Finance England, your local authority or the Open University (OU).'

If you would like to talk about this please call or email me diana@ectodermaldyplasia.org Tel: 01242 261332

University Campus Doctors

When my son Joe started University he registered at the Campus doctors and all his GP records were transferred there; he then became a temporary patient whenever he returned home and fell ill. I spoke with the campus doctors to explain about ED, Joe's allergies and his lack of temperature control, and was assured they would look after him. However, I did feel he thought I was a neurotic, over protective Mum! The first time he fell ill the Doctor assessed him (after a 3 hour wait) and told him he 'just had a virus' and it would go in time! After 2 weeks of suffering he came home, I immediately took him to our doctors who, knowing Joe's history, put him on anti-biotics – within 24 hours he was beginning to feel better and 3 days later was as fit as a fiddle.

As our doctors have cared for him since he was born and appreciate that sometimes Joe's symptoms don't manifest normally, they gave him a supply of anti-biotics to keep and use if and when needed. This basically meant that he didn't need to see the campus doctors and when he had a different illness he just came home and saw the doctors here. Our doctors felt it would be better if Joe transferred back to them which we did; meaning he would then be a temporary patient at the University.

Recently Joe was taken quite ill and went along to the campus doctors. He was told that as he was not registered with the doctors they would not see him! It transpired that he hadn't told them he was a temporary patient and needed to be seen as an emergency! I found another doctor local to Joe, but when I spoke with the doctor on the telephone I was told he would assess Joe and treat accordingly (fair enough), but then went on to tell me that ED was not a major problem and certainly wasn't life threatening!! Well, that left me with no confidence in him at all! I then so spoke to Joe's doctors here, who advised Joe take the anti-biotics he had and to come home and see them as soon as he could; they confirmed he had a chest and ear infection!

I thought when Joe went to University he would be old enough to sort out most things in his life, especially a simple procedure such as going to the doctors – how wrong I was, not because he is incapable but because the system isn't simple. I feel that if doctors don't understand ED then they have no idea how to assess and treat individuals who have ED. For Joe I am so happy that we have wonderful doctors at home who understand him and ED.

Blue Badge and University



If you hold a current Blue Badge you are entitled to purchase a parking permit at the University to allow you to park anywhere on campus and to keep your car close to residency. To obtain a permit you need to go to the student disability office.

London to Brighton Challenge

On Saturday May 25th Leon Moxam, Craig Fuller and Mark Risby took part in the London to Brighton Challenge, 100Km ultra-marathon. This was not a relay, all three lads had to run 100km (60 Miles) in under 15 hours.

They all did amazingly well finishing in 15hrs 35mins and raised a staggering £4884 for the ED Society.



Schools Help!



Thank you for the School Plan it was very helpful. In a recent meeting my son, Harry, has been granted Medical Funding, which was another route we were advised to go down when the Statement was refused.

The School will now employ an extra member of staff for 1.5 hours per day to look after Harry during lunchtime whilst eating and in the Playground at lunchtime, as the current Assistants would not be able to keep an eye on him well as all the other pupils whilst they are outside. Harry has his teacher and two assistants in the classroom each day who are willing to administer creams, eye drops and generally assist him whilst he in the classroom and on the shorter breaks.

The school have installed an air-conditioning unit and have said to let them know if there is anything else I can think of that would be helpful for Harry and they will provide it. What a difference a little extra funding makes!

Please pass onto other parents who have been refused Statementing for their child and tell them about the Medical Funding. The Medical Funding will also provide certain fans etc., if over £30 for the classroom.

Helen Kantas (mum of Harry with Hypohidrotic ED (aged 6))

School Health Care Plan

The ED Society have a standard School Health Care Plan to help parents obtain the correct care for their children in schools. The document covers many symptoms of the different ED syndromes and can be amended to suit individual children.

For a copy please email diana@ectodermaldysplasia.org or download it from the member's section of the website.

Change of Address

Please note Diana Perry no longer lives at 108 Charlton Lane where the ED Society office used to be. Could you please therefore ensure all correspondence is sent to the office address - Unit 1 Maida Vale Business Centre, Mead Road, Leckhampton, Cheltenham, Glos. GL53 7ER

Cooling Vests

Helen Kantas along with other members have been enquiring about cooling vests/jackets for children and although they are available from the USA they have had difficulty finding suitable ones in the UK as many companies only supply adult sizes.

As we are receiving more and more enquiries could you please let us know if you have managed to find a suitable cooling vest in the UK or Europe, the cost and whether you would recommend it.

What we help with

We will look at any grant request that relates to the needs of a disabled or seriously ill child, young person and their family.

Families often apply for essential items such as washing machines, but we can also help young people aged 17 and under with grants that have particular meaning to their age group, such as equipment for college.

Due to our limited funding, we are not always able to meet the full cost of every item requested.

How often we help

We try to help families raising a disabled or seriously ill child or young person once every year and will look at a grant application usually 12 months from the date of the last grant.

We do understand that sometimes the need for help can be greater, especially if there is an emergency or critical situation relating to a disabled child or young person. If this happens we try to be flexible and consider an early application. All our grants are discretionary and subject to available funding.

How we make awards

Depending upon what you have asked for, we will award your grant in a number of different ways. All of our grants are awarded on the basis that they are used only for the purpose they are given.

We may provide you with:

- A payment card for a request for kitchen appliances, clothing, furniture, home entertainment and leisure items.
- A product delivered to your home direct from a supplier for computers and tablets. If you live in Northern Ireland this will include kitchen appliances.
- A direct payment or travel card from a supplier towards a family break. We work with Butlins, Haven and Travel by Inspire for family breaks. Travel by Inspire can arrange flights, UK breaks and overseas breaks with many of the most popular travel companies.
- A payment may also be made into your account for other items where we do not have an arrangement with a supplier. If you do not have a bank account, you can nominate and provide the details of a person into whose account you may have your grant paid.

As the Family Fund has limited funding, and is unable to help all families caring for a disabled child or young person we use our own disability criteria to determine whether a child is eligible.

You do not need to wait for a diagnosis for your child to make an application for a grant if you think your child may meet the criteria below. Disability Living Allowance awards are not an indicator that a child would be eligible for a Family Fund grant as we use our own disability criteria.

To meet the Family Fund's disability criteria, children and young people must have additional complex needs, or have a serious or life threatening illness.

AND

There must be evidence that the child or young person's additional needs impact on a family's choices and their opportunity to enjoy ordinary life. The degree of planning and support required to meet their needs must also be much greater than that usually required to meet the needs of children and young people.

AND

They must require a high level of support in three or more of the following areas:

- The physical environment
- Education
- Communication
- Access to social activities

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- Personal care, supervision and vigilance
- Specialist resources, including Information and Communications Technology, required
- Medical or therapeutic treatment and condition management

AND

The child or young person's condition must be long term or life limiting. By long term we mean lasting or likely to last 12 months or more.

If you think your child or young person may meet the Fund's criteria, please apply.

Children with a confirmed diagnosis of certain conditions which may be degenerative, life limiting or life threatening are likely to meet the Fund's disability criteria.

For example, a child with a confirmed diagnosis of a degenerative syndrome, or a child with a current diagnosis of cancer or leukaemia

Children are not likely to meet the Fund's criteria where their main or only difficulty is one of the following:

- They have eczema, asthma or allergies
- They have specific educational difficulties – such as dyslexia, dyscalculia or poor literacy
- Their condition is stable and managed through medication, diet, monitoring, testing bloods or transfusions and there have been no recent medical crises as a result of their condition

My child was eligible last time – will they always be eligible for help?

We confirm a child meets our disability criteria each time an application is made. Although children may meet our criteria initially, this may change over time due to medical intervention, medication, dietary or other management of their condition or as they get older.

My child was not eligible for help before. Can I apply again?

Although a child may not meet our criteria and be eligible for help at first, this can change over time and they may well come within our criteria later on. Or a child's condition may have deteriorated since last time and you now feel they would meet our criteria.

If you are in doubt as to whether your child or young person would meet the Fund's criteria, please apply. When we receive your application, we will check that it meets all our eligibility criteria.

Fundraising

Our Grateful Thanks

The fundraising events which have been organised and the many donations that have been coming in over the past 3 months amount to just under a staggering £10,000

Many thanks to the following families who sent in donations; Springham, Cunningham, Harding, Dewsbury, Creron-Jones, Pennington, Shortman, Beeson, Burden, Woodburn and Andrews.

Huge thanks to Kelly Fitton for holding a hugely successful charity dinner and raising the fantastic amount of £998 so far - we will report the full total in the next issue.

Huge thanks to Leon Moxam, Craig Fuller and Mark Risby and raising the wonderful sum of £4884 taking part in the London to Brighton Challenge.

Many thanks to James Murphy and Martin Haughney in Ireland for raising £900 by doing the Hell and Back 12km run.

Grateful thanks to Jonny Robinson and his friend Toby Marriott for raising over £3000 by running a half marathon. Well done boys and thank you.

Huge thanks to Carol Cross whose mother recently passed away and donations of £420 were given to the Society - many thanks for thinking of us in such sad circumstances.

Benefits, Tax Credits and Recent Changes

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There are a number of benefits and tax credits that you may be entitled to. Some benefits can be paid because your child is disabled while others may be paid to you for other reasons. For example, you may be getting disability living allowance (DLA) for your child and carer's allowance as their carer. However depending on your income and certain other factors you may also be able to claim benefits such as income support, child tax credit and housing benefit.

Eligibility criteria

Each benefit and tax credit has its own set of eligibility criteria. This means you need to meet certain conditions to qualify.

To claim contribution-based benefits you need to have paid national insurance contributions in the past.

To claim means-tested benefits you must be on a low income, with savings of less than a certain amount.

To claim tax credits you must either have children or be in work - and the amount will depend on the household income but not savings.

For non-means-tested benefits like disability living allowance, the claimant will need to meet criteria not related to work, income or savings.

When to claim

When you know which benefit or tax credit to claim, phone the appropriate office straight away. It is difficult to get awards backdated. Some benefits (for example disability living allowance) can't be paid for a period before the date you claimed, no matter what the circumstances. So long as you are not subject to immigration control, you should claim now, even if you are not sure you qualify, as you could miss out if you delay.

Benefits are changing

Throughout the year the government plans to introduce a large number of changes to the current benefit and tax credits system. Together these will amount to the biggest shake up of the benefits system in generations.

These changes apply to England, Scotland and Wales. It is proposed that most of the changes will also eventually apply in Northern Ireland. But whether this happens and the date the changes are introduced there will depend on legislation being approved by the Northern Ireland Assembly.

In April of this year - council tax benefits scrapped and replaced with local schemes

The previous national system of council tax benefit has been scrapped. In England each local authority has introduced its own local scheme for support with council tax. However, with funding being cut many local schemes are less generous. In some council areas all working age householders now have to pay something towards council tax no matter how low their income. Pensioners are protected from any cut. In Wales and Scotland the schemes introduced by the devolved administrations have copied the previous council tax benefit rules.

April 2013 - introduction of 'bedroom tax'

Council and housing association tenants face a housing benefit cut if their home has more bedrooms than they are seen as needing. In deciding the size of property that you need, some children are expected to share a bedroom. If you are assessed as having more than one bedroom than you need your housing benefit is cut by 14

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per cent of your rent figure. If you have two or more extra bedrooms the cut is 25 per cent. Pensioners are exempt. If you are affected by this change seek advice from helplines about applying for discretionary housing payments towards the shortfall.

Although most children are usually expected to share a bedroom, you will not be penalised under the bedroom tax rules if you can show that your child is unable to share with a sibling due to their disability. This was made clear in urgent guidance issued to local housing benefit offices by the government on 12/3/13.

April 2013 - scrapping of community care grants and crisis loans

Families on low income benefits will no longer be able to apply to Jobcentre Plus for a crisis loan or a community care grant to help with one-off costs such as a bed or cooker. Instead you now need to approach your local council for help. In Scotland and Wales the respective devolved administrations have introduced new schemes within their nations.

From June 2013 - personal independence payments replace disability living allowance (DLA) for those aged 16+

DLA was scrapped for disabled people aged 16 or above. It will be replaced by a new disability benefit called the personal independence payment (PIP). Like DLA, PIP will have two types of payment - a mobility component and a daily living component. However, the decision about whether someone qualifies for PIP will be based on different rules from DLA and will depend on the number of points you score following a medical assessment.

Summer 2013 - 'benefit cap' for out of work families

The government plans to cap the total amount of benefit payments that a family can receive if they are out of work. The cap will be £500 per week (£350 per week for single people without children). This cap will not apply if you, your partner or any dependent child gets disability living allowance. It will also not apply if you work sufficient hours to be eligible for working tax credit (regardless of whether this is actually paid or not) and in certain other circumstances.

If you are affected by the benefits cap you should seek advice from helplines about applying for discretionary housing payments.

From October 2013 - universal credit (UC)

All means tested benefits and tax credits for people of working age will be replaced by a new universal credit. It will be introduced for new claims from October 2013, with claimants on existing means tested benefits being moved onto the new credit at some point between 2014 and 2017.

Temperature Research

We are still searching for funding to enable the Temperature Research project to be carried out. The total needed is £30,000!

If you know of any organisations or companies who we could apply to please let Diana know—
diana@ectodermaldysplasia.org .

Maybe you could nominate the ED Society to your company.

Without funding this research cannot be carried out and the question of lack of temperature control will remain undocumented making it difficult for authorities, schools, etc., to accept that overheating or hypothermia are life-threatening - please help all you can.

