

Supporting a normal lifestyle

ECTODERMAL DYSPLASIA SOCIETY

Unit 1 Maida Vale Business Centre, Leckhampton, Cheltenham, Glos. GL53 7ER England.
Tel: +44 (0) 1242 261332 Mobile: + 44 (0) 7774 465712 Reg. Charity No. 1089135
www.ectodermaldysplasia.org Email: info@edsociety.co.uk



Fergus Gordon

It is with great sadness and heavy heart that we announce the loss of Fergus Gordon. Fergus had the AEC syndrome of Ectodermal Dysplasia and had been a member of the ED Society since we began in 1996.

I have known Fergus since 1996 when I first took over running the Ectodermal Dysplasia Society. I believe he first joined the support group in 1984. Over the years he raised thousands of pounds for the Society, the last event of which was to camp in a field overnight even though he was very fearful of the cows nearby!

In the early years, before the internet, Fergus used to go to the library and photocopy anything he could find on Ectodermal Dysplasia and send it to me! This provided me with much

needed information to help me help our members. I still have the huge fat file!

From that point on, he became our Scottish Representative and regarded me as "the Boss".

I have always been astounded by his ability and determination to travel alone, particularly to attend our Conferences and Christmas parties where he has been an inspiration to many of our younger members and their parents.

He personally helped several of our young members, giving them strength and encouragement to face and overcome some of life's challenges, to know that with determination there is nothing in life that they couldn't do and more importantly to be themselves.

He had a wonderful sense of humour which left us in fits of giggles many times. To me personally he has been an inspiration, an encourager, a colleague and a friend.

Fergus, you are going to be sorely missed by the ED community.

A huge thank you to Margaret Gordon (Fergus' Mum) for requesting donations to the ED Society in lieu of flowers in memory of Fergus totalling £910 so far. Thank you so much to all his family and friends for thinking of the ED Society.

Diana Perry

Medical Advisory Board Members

| | |
|-------------------------|------------------------------------|
| Prof. Angus Clarke | - Clinical Genetics (MAB Chairman) |
| Prof. John Hobkirk | - Prosthetic Dentistry (Implants) |
| Prof. John McGrath | - Genetics, Molecular Dermatology |
| Prof. June Nunn | - Paediatric Dental Surgery |
| Mr. Colin Willoughby | - Ophthalmology |
| Mr. Martin Bailey | - ENT |
| Prof. Michael Tipton | - Human Applied Physiology |
| Prof. Nichola Rumsey | - Psychologist |
| Mr. Mike Harrison | - Paediatric Dentistry |
| Dr. Claire Forbes-Haley | - Restorative Dentistry |
| Prof. John Harper | - Paediatric Dermatology |
| Mrs. E. Howard | - Clinical Fellow |
| Dr. Fiona Browne | - Dermatologist |
| Dr. E. Jones | - Clinical Genetics |
| Prof. Celia Moss OBE | - Paediatric Dermatologist |

Trustees

| | |
|------------------|-------------------------------------|
| Paul Collacott | - Chairman |
| Alan Waller | - Treasurer |
| Diana Perry | - Secretary |
| Mandy White | - Air-Conditioning / School Liaison |
| Melanie Davis | |
| Stephen Ayland | |
| Simon Lees-Jones | |
| Stuart Atkiss | |
| Sharon Cooper | |
| Scott Gallacher | |

Staff

| | |
|--------------|----------------------|
| Sue Beard | - Accounts / Website |
| Julie Cox | - Administrator |
| Danielle Gue | - Administrator |

Volunteers

| | |
|----------------|----------------------------|
| Diana Perry | - Chief Executive Officer |
| Fergus Gordon | - Scotland |
| Elaine Aylward | - Ireland |
| Kerry Russ | - Fundraising Co-Ordinator |
| Stuart Atkiss | - Fundraising Co-Ordinator |

Membership

You will be unable to gain access to the Members' Area of our Website until we are in receipt of your 2016 membership form.

Please return your form as soon as possible to ensure you have access.

Blue Badge

To obtain a Blue Badge you can either apply online at <https://www.gov.uk/apply-blue-badge> or telephone your local Social Services Blue Badge Team Department for an application form.

Many of our families already have a Blue Badge; if you would like Diana to help you complete the forms or appeal if your application is turned down please email diana@edsociety.co.uk

Symptoms Questionnaire

Could you please complete a Symptoms Questionnaire for each individual who has ED in your family? This document will hugely help us when answering any of your questions or assisting you with DLA, appeals, tribunals, schools, doctors, etc. If you have not completed for many years this is available for download from our website.

Disability Living Allowance, Carer's Allowance and P.I.P

Diana is always happy to help you complete the forms.

It's best if the forms are right from the beginning in the hope that the claim will not have to go to appeal or tribunal.

If you are unsuccessful, Diana is happy to write an appeal letter for you and if necessary, attend a tribunal with you.

The Haute Route—7 Day Ski Tour

Simon Lees-Jones and friends, April 2016

The Haute Route is a classic high-altitude 180 km crossing of the Alps, from Chamonix in France through Italy & Switzerland to Zermatt, staying in mountain huts perched on peaks above the glaciers, along the way. This challenge has been on my “bucket-list”, ever since my great parents took me on our first attempt with them in 1980, when I was aged just 14. That year the weather was foul; we missed the first 2 days and then got stuck in a hut called Plarfluerie, with no food for 3 days whilst our surroundings avalanched, only managing to escape through an old disused quarry tunnel to the valley below.



In my 30's I tried to complete the tour several times, without success, apart from one bonkers event, which was a Swiss Army event called the “Patrouille des Glaciers”, racing over-night in the opposite direction from Zermatt to Verbier ... but that all seems like a long time ago now ...

In April 2016, it was going to be my 50th Birthday. A great old school friend invited me to join his team (Johnny Waterhouse & 2 ex-army guys Jamie Jenkinson & Angus Lawson) to try the Haute Route again. My gorgeous wife Chrissy issued a “pick ticket” and we started getting fit in September. We are lucky to live near the Peckforton & Beeston Hills in Cheshire and the Llangollen Valley on the Welsh Borders, which became our training ground. The Haute Route is 70% fitness, 30% technique.

We met our 62 year old guide, Phillipe Grenier, in Chamonix for a trial day on the “Valley Blanche”. He turned out to be quite fantastic – not only had he climbed Everest twice, he was a Frenchman who smiled and was utterly charming company throughout. The weather forecast for the week was very mixed, so when the next day boded well, we set off early to the Argentiere cable car, with all our kit for the week in our ruck-sacks on our backs.

Day 1 –the first decent from 3500 metres, was spectacular with high jagged peaks, towering over the massive glacier below, skiing through seracs of broken deep-blue-pure ice, beautiful white powder snow, clear blue skies and hot sunshine. Soon the hard work started as we strapped the skis to the ruck-sacks, fixed our crampons to our boots and climbed the first of many nasty rocky, icy gullies, to the next glacier above, making our way towards the Trient hut.

Our climb on skis & skins (to make the skis grip) was like many more to come – long (about 3 to 5 hours), steep and hot, but utterly beautiful. We were pretty much alone in a great massif of un-touched virgin snow, deep in spectacular glacial landscape heading to endless mountain horizons.

As we neared the hut, other groups converged for the final short walk to meet over beers and a very hearty late lunch.

Each day was very much the same routine – waking in our snoring-bunkbed-dormitories at about 5.30am, kitting-up and breakfast, before leaving as a team – sometimes in complete white-out conditions, but always keen to make it to the next hut. The idea was to get away early and arrive before the heat of the afternoon could trigger any avalanche danger. The afternoons and evenings in the huts were spent mixing with fellow tourers of all Nationalities, playing cards, reading and relaxing in blissful absence of any mobile or internet signal for the entire week.

edlines

Day 2 – gloomy, with another nasty crampon ridge climb to start the day, followed by big ski down, in terrible frozen broken snow, followed by pretty wooded spring-snow (our single re-visit to the valley on the tour) followed by cable car ascent to the next hut, Mont Fort in Verbier.

Day 3 – the dream day, with absolutely perfect calm sunny weather and powder snow – heaven ! We climbed the most beautiful rolling big tracks of the trip, skied down in gorgeous light virgin powder snow, to arrive at the infamous Plarflourie hut, where I had been stuck all those years ago, but this time in hot sunshine, with an-all-new-fully-catered hut serving the best rosti in the Alps and a fully stocked bar.

Day 4 – the longest day ... gloomy again, with a long lakeside traverse followed by a very long steep climb to Cabanne de Dix. There, the hut-keeper specialised in cheese fondue ... we were becoming very Alpine by then and got stuck in, with the local wine flowing. Our guide told us that we were being talked about for being the group that had the biggest bar bill every night!

Day 5 – the storm gathered ... a very long day and by the time we arrived at the Vigniettes Hut, it felt like we had been with Scott in the Antarctic, with the wind howling, horizontal snow storm and absolute zero visibility. That evening, none of the guides would commit to their plans to complete the tour, because the weather was so terrible.

Day 6 – quite tense ... we compared notes over breakfast and committed to go on to an un-manned hut as a "Plan-B" to complete the tour, carrying food and wine. After ½ an hour in complete white out, I was very surprised that we hadn't turned back, which would have been heart-breaking, but we got a break in the cloud to allow us to check our position and continue to battle the elements to reach the tiny shack in early afternoon. Phillipe the guide was delighted. We lit the tiny stove, melted snow for tea and prepared our evening meal, warming all the time. The storm continued to rage and we were still not sure that we would make it ... we were then the last of all of the other groups who we had met along the way – the others had returned to catch their flights home – luckily we had allowed an extra day, in case of bad weather.

Day 7 – most nights sleeping at high altitude were quite restless – that night we all seemed to wake every hour, to listen to the wind, in the hope that it would calm. By about 3.00am it started to calm and we were all quietly very excited over breakfast, without any premature celebration. Outside the storm had created a mix of windblown icy ridges and deep filled light powder snow gullies. Our first crampon climb of the day was awfully steep, very deep and very hard work – 1 step forward 2 steps back. The sky started to clear and we had just one more, long climb on skis to our final peak, the Dent Blanche, overlooking the Matterhorn and Zermatt. Conditions were near perfect and we were all beaming, not quite believing our luck. We had our last decent on an incredibly dramatic glacier in powder snow and sunshine. The valley slightly disappointed us, with grey cloud and sticky snow, but by this stage we were entirely focused on beers and lunch. Zermatt never disappoints and we celebrated our venture over more Alpine cheese and wine – the most wonderful, un-forgettable experience we could have hoped for. I am sure that it will live with us all forever.

As ever, it is the friends who make such wonderful times so special. We had a truly great team who never had a cross word through all our dramas and are now friends for life. Phillipe was a completely excellent charming guide. Personally, I also happen to think that time in the mountains helped take us a little nearer to Heaven.

Happily our successful tour also helped raise some much needed funds for The ED Society. My daughter Tessa and I both share ED P63 Hey-Wells. I hope to take her ski-touring one day too. ED has held many challenges for me but never prevented me from great adventures.

Leading Professor's years of dedicated work helping young people with skin conditions honoured with OBE

Extract from Birmingham Children's Hospital Website

Celia Moss, a Professor at Birmingham Children's Hospital, who has dedicated her professional life to helping young people with skin conditions has been awarded an OBE in the Queen's Birthday Honours.

Consultant Dermatologist, Professor Celia Moss, has worked tirelessly to improve and push the boundaries of care provided to thousands of children since joining the hospital in 1990.

From a part-time minor outreach of neighbouring adult services 26 years ago, Professor Moss has been the driving force behind what is today a full-time specialist service that treats patients from across the country.

A key element of the success of the now world-renowned service has been the pioneering work in bringing together a multi-disciplinary team. Professor Moss realised that children with skin conditions, such as eczema and the rare genetic skin fragility disease, epidermolysis bullosa, have other problems beyond their skin condition that require support, physically and emotionally. Specialist nurses and experts from other healthcare fields are now part of a team that provides holistic care.

Along with the care she has provided at the hospital, Professor Moss is committed to teaching the next generation of paediatric dermatologists. She set up an acclaimed course, now in its 18th year, which has provided training to most of the current generation of consultants in this field.

Internationally respected, Professor Moss has shared her knowledge through lectures and meetings across the globe, particularly helping colleagues in India, by providing training placements and mentorships. Her commitment and expertise in diagnosing and treating rare and complex genetic skin conditions, has resulted in patient referrals from across the UK and beyond.

Professor Celia Moss OBE said:

"I know you hear a lot of people in this position say this, but I was totally surprised when I was told the news. I feel highly honoured but also very fortunate as I'm just doing what I really enjoy doing. I'm so grateful to my colleagues at Birmingham Children's Hospital and proud to be part of a wonderful team dedicated to caring for and supporting young people. My colleagues deserve this credit and recognition too."

Professor Moss has held several national roles, including Chairman of the British Society for Paediatric Dermatology and is also Honorary Professor of Paediatric Dermatology at the University of Birmingham. Her contributions in the field have previously been recognised with a WellChild Doctor of the Year Award in 2011 and a Lifetime Achievement Award from Birmingham Children's Hospital in 2012, when she was also named as a Sunday Times Top Doctor.

Sarah-Jane Marsh, Birmingham Children's Hospital Chief Executive, said:

"Professor Moss is at the forefront of treatment and innovation in paediatric dermatology, and is world renowned for her expertise, but to us she is also a wonderful children's doctor who always has time for patients and staff alike. She richly deserves this tremendous honour and everyone at the hospital is bursting with pride for our fabulous Celia."



Daniel Sanchez US Diary Entry

This is my ninth and final diary entry for my Uniformed Services course.

This term I completed my two year National 4 qualification in Uniformed and Emergency Services. We did a lot of field craft exercises, which means we practice attacking and defending safe points. We put up waterproof sheets on bungee cords tied to trees to make an 'A' shape to shelter under. This is called a basher.



One weekend we went to Barry Buddon which is in Angus, Scotland. When we arrived on the Friday night we were issued with helmets, ration packs, weapons, webbing (to carry rifle magazines), bergens (a huge bag to carry our kit), and the sheets to build our bashers. We had to sleep under the bashers, but we thought we would be ambushed and stayed awake the first night. We didn't get ambushed so we were very tired the next day when we got up at 4.30am.

I was Second in Command for this camp, so I had to arrange the group into an all-round defence position, and check how many rounds people had left and if they had any injuries. The second day we patrolled to collect a pretend sample for a cure for Ebola. We got ambushed on the way and had to return fire. It was pretty intense but we beat the seniors, and it was the best bit of the weekend. I came home on Sunday sunburned, with stings, cuts and grazes, a sore wrist, back, shoulders and chin! It was a fun weekend but I was exhausted after so little sleep.

I took part in an athletics competition with the cadets, and ran the 200m and the 800m. It was freezing that day and I had worn shorts so I didn't get too hot. I was so cold!

I also went on my practice and final Duke of Edinburgh expeditions in May. The weather had been nice until the day we left, then it rained and was foggy and cold until we came home. On our hike we got lost about five times and were more than three hours late in arriving at the camp, but we all survived. One person had to leave as he couldn't manage the hiking. It was a great experience and I am pleased I was able to complete the award.

I have really enjoyed the Uniformed Services course. It was a lot of fun, and I have learned many new skills. I was able to do most things with my HED, and the staff were always helpful to me if I needed them. I would say if anyone gets the chance they should do this course or join the Army Cadets.

| Menu PD 08/15 |
|---|
| Product Description |
| Cinnamon Bun |
| Meat Stick & Rice |
| Mango Cake |
| Tabasco Red |
| Fruit Puree Mango / Banana / Apple |
| Cranberry Cereal Bar* |
| Cookies & Cream Cereal Bar |
| Peanut Butter* |
| Cherry Flavour Boiled Sweets |
| BBQ Peanuts |
| Tuna Light Mayonnaise |
| Digestive Biscuits |
| Mexican Tuna Pasta |
| Orange Flavour Isotonic Drink Tablet |
| Tutti Fruity Flavour Drink Powder |
| Tropical Flavour Drink Powder |
| Cola Flavour Drink Powder |
| Regular Flavour Hot Chocolate Drink Powder |
| Common Components |
| Instant Coffee* x 2, Teabags* x 2, Sugar x 4, Beverage Whitener* x 4, Water Purification Tablets x 6, Tissues, Matches x 5, Wet Wipes x 2, Assorted Chewing Gums x 3, Spork, Re-useable Polybag |

(Ration food packs given out at camp)

Note from Daniel's parents: We both would also highly recommend this course. (It is only available in Scotland though). We would definitely recommend the Army Cadet Force for anyone from age 12. They are open to everyone and are very accommodating. The staff are so friendly and helpful, they make everyone feel welcome and encourage the kids to improve without putting them under undue pressure. For example, in fitness they set their own targets, so it's always about taking their own ability into account. Daniel has studied team building, leadership, first aid, community work, fitness, risk assessment, communication, map and compass work, and much more. As well as a national qualification for his cv, Daniel has developed an excellent skill set which will benefit him in the future.

The ED Society have been given a grant from Jeans for Genes Day 2016



The ED Society is celebrating after receiving the news we are being given a grant from Genetic Disorders UK, the national charity that organises the annual fundraising Jeans for Genes Day.

This grant is wonderful news. It means we can fund and create an Education Health and Care Plan specific for Ectodermal Dysplasia.

Caroline Harding, the CEO of Genetic Disorders UK said: "We are delighted to be helping The ED Society support children with Ectodermal Dysplasia. Our grant programme is open to all UK support groups and registered charities who work to improve the lives of children and families affected by genetic disorders. In 2016, 22 charities will benefit from the funds raised by the public on Jeans for Genes Day."

This years Jeans for Genes Day takes place on **Friday 23rd September** and is aiming to raise £2 million to provide care and support to children with genetic disorders.

Genetic Disorders UK's Jeans for Genes Day is an annual fundraising event when school children and office workers wear their jeans in exchange for a donation to the charity. Although individually genetic disorders are rare, together they affect 1 in 25 children. This means that more than 30,000 babies each year are born in the UK with a genetic condition. Sadly, genetic disorders and their associated health problems mean that they are the biggest cause in death of children aged 14 years and under. Funds from Jeans for Genes Day are granted to specialised charities to provide care and support for children affected by genetic disorders.



Jeans for Genes Day provides vital funding for the care and support of children with genetic disorders. In 2015, 20 charities benefited from the funds raised on Jeans for Genes Day.



To show your support, why not invest in a Jeans for Genes limited edition fashion t-shirt? Or a box of SpongeBob Square pants trolley tokens? <https://www.jeansforgenesday.org/webshop/>

You can order a free fundraising pack from www.jeansforgenes.org or call 0800 980 4800.

Fundraising – Our Grateful Thanks

Thank you to everyone who sent in donations with their membership forms and to all those who pay regular donations by standing order.

The many donations that have been coming in over the past 3 months amounted to over £6535.

A huge thank you once again to Simon Lees-Jones, for completing the Haute Route 7day ski tour across the Alps, raising £5000!

Thank you so much to Ellie Stafford, a family friend of Sue Ling, for donating £425. Ellie works for a marketing company called Open who give money to each employee to donate to a charity of their choice and she chose the ED Society as she is very close to Sue's daughter Katie who has ED. Thank you for thinking of us Ellie.

Cooling Hand Immersion

Professor Michael Tipton from our Medical Advisory Board advised that “Hand immersion in cold water is a good way (as good/better than ice-vests) of cooling people down, provided that they have decent blood flow to the hands and a bucket is cheaper than an ice vest!



Tip for keeping cool



Professor Tipton from our Medical Advisory Board has said “Don’t waste your money buying pressurised mist spray bottles, just purchase a cheap garden or hair water spray bottle, fill it with cold water and set it to mist; it will do exactly the same job and you don’t have to run back to the shops to buy another when it runs out – just refill it with tap water.

Are you feeling the heat?

A tip from one of our members

“don’t laugh....everyone else does! FROZEN HOT WATER BOTTLE!!

they are great....started doing this last year” - only half fill it with water though



Be Prepared - Stay Cool!

Whether we have a scorching summer or a typical British summer it will be hot for everyone who is affected by ED - we can help them be prepared

- Drink water to stay hydrated - always take a refillable thermos of cool water with you
- Wet yourself down - use a spray bottle of water, hose pipe - whatever you need to wet your clothing, hair, hat and body
- Wet T-Shirt - soak your t-shirt in water or pack a wet cotton t-shirt in a Ziploc bag to wear when hot
- Cool bandanas - Soak a bandana in water and wrap it around the back of your neck. You could also soak two bandanas and wrap one around each wrist
- Frozen wash cloths - Freeze wet wash cloths in Zip lock bag. Take with you in a cooler. They will be thawed by the time you need them
- Terry cloth wrist bands - Soak them in water and wear on the wrists
- Spray bottle - Carry with you to spray and cool down
- Plan ahead - Plan outdoor activities on days and at times when risks can be minimized such as early morning, evenings or on cloudy days

- Instant shade - Determine if outdoor activities will have access to shade and water. If not, take a golf umbrella or a pop-up canopy to provide relief from the sun
- Damp towels - Take damp towels in a cooler. A damp towel around the neck brings quick relief
- Cool the car down before entering
- Gallons of water- take bottles of water to outdoor sporting events if your child is an athlete. Water can be used to drink, soak shirts, or pour on body as needed
- Cool clothes - Wear light-coloured, loose-fitting, open-weave clothes
- Wear a wet cap/hat or you can purchase cooling caps
- Cool gel packs - great for putting your feet on, especially for children in class at school
- Cool packs in car seats - Use to help keep babies and toddlers cool in the car
- Frozen Hot Water Bottle - great for cooling the bed

Use good common sense and you will get through each warm day just fine!

Nosebleeds

These appear to be a common occurrence for ED individuals when the weather is hot, particularly at night. A nosebleed can be scary to get, or see, but try to stay calm. Most nosebleeds look much worse than they really are. Almost all nosebleeds can be treated at home. Place a cold compress (wet flannel) or an ice pack across the bridge of the nose, whilst at the same time placing a cold flannel on the back of the neck, as this will help slow the blood flow. Once the bleeding stops, don't do anything that may cause it to start again, such as bending over or blowing your nose. Most nosebleeds occur in the front part of the nose and stop within a few minutes. You may need to seek medical attention if a nosebleed lasts for more than 15-20 minutes.



When outdoor temperatures escalate, be prepared.

Take a thermos of cool drinking water and a spray bottle in the car just in case it is needed. Plan outdoor activities on days when risks can be minimized. Access to shade and water is always helpful. If your child is an athlete, you may find taking an umbrella, damp towels in a cooler, and a spray bottle to be useful. It doesn't take long for active athletes to discover that a cool spray of water on the head or a damp towel around the neck brings quick relief. Others soak their hat or shirt in water. Very often others with the ability to perspire begin to bring similar gear to athletic events as they too learn the benefits of keeping cool.

Don't take unnecessary risks.

Trips in non air-conditioned cars on warm days are not appropriate. The same is true for activities that require lengthy outdoor exposure with limited or no access to cooling. Use good common sense and you will get through each warm day just fine.

Cooling Vests

By Scott Gallacher—Trustee

Having two boys, Ryan aged 11 and Daniel aged 9, both with X-Linked Hypohidrotic Ectodermal Dysplasia, we worry about whether or not it might be too hot for them to enjoy the summer holidays. Consequently I looked into the 'Cooling Vests' I had read about online from fellow ED Society members.

Wikipedia explains that there are four types of vest:

- ♦ *Evaporative cooling vests are typically submersed in water for around 3 – 5 minutes and lightly wrung out or blot dried. They are usually worn outside the clothing and as the water in the vest interacts with specially treated cooling crystals or other cooling agents, the water evaporates and body temperature is effectively reduced.*
- ♦ *Ice chilled cooling vests make use of cooling energy packs that are activated inside of a freezer and then placed in pockets inside of the cooling vest. Because they are very cold to the touch, this type of cooling vest is always worn outside the clothes.*
- ♦ *A phase change cooling vest makes use of cooling packs that maintain much higher temperatures. These phase-change packs often contain liquids (typically nontoxic oils and fats) that solidify (like wax) typically between 55 to 65 degrees and usually last between 4 – 6 hours.*
- ♦ *A cool flow cooling vest makes use of a water flow system that pumps water through the vest using hoses.*

I decided to buy two Evaporative Vests as these were the easiest and cheapest option.

Online I found the Techniche HyperKewl™ Evaporative Cooling Vest which seemed to fit the bill. This comes in a choice of four colours (Black, Silver, Blue and Lime) and sizes from XS upwards. I chose two black XS ones on the grounds they looked like trendy quilted gilets. I also figured that Ryan would get away with wearing a black one for school.

Upon receiving the vests, I soaked them for two minutes in a sink of cold water and left them to dry on a hanger. This apparently is to activate them and I'd suggest this is a good idea as the first time you soak the vests they have a slightly slimy feel; consequently it is best to do this before you wear them.



The first test for the vests was last August, at the Leicester City vs Sunderland football match, with the temperature being 24 degrees Celsius. Previously when it was this hot we had watched Leicester's games on the TV screens beneath the stands inside the stadium comforted by the cool concrete.

Just before leaving for the match, I soaked both vests for 2 minutes in a sink full of cold water, squeezing (but not ringing) out the excess water. Walking to the stadium I suspect we might have had some strange looks with my boys apparently wearing quilted gilets over their new Leicester City shirts on a glorious summer day, but the vests seemed to be doing their job.

We were out for about 3 hours in total and not once did the boys complain about the heat. I checked them constantly throughout the match and whilst other areas of their bodies might have been warm, their torsos were nice and cool. The vests definitely weren't simply wet T-shirts. They did make their shirts, and the tops of their trousers slightly damp, but not as you would experience wearing a wet t-shirt.

On the way back to the car I think the vests had stopped working as they were relatively dry, and the boys then started to complain they were a little hot and took off their vests. Had we been out any longer I would have recharged the vests by giving them another soaking at the stadium.

I bought the vest's online from TUK shop www.tuk-shop.com and they cost £63.54, but the kids really liked them and kept them on till the end when they felt they had stopped working. Allowing us to enjoy Leicester City without hiding from the heat made these a great buy. TUK also have a version without the pockets or collar which is only £44.77.



Techniche provide a range of cooling products, including hats, towels and vests with zippable sleeves giving you a full jacket. The cooling vests with sleeves look similar to my quilted jacket so I'd say they were cool in more ways than one.

The ED Society is pleased to announce that Techniche UK Limited have granted our members a 10% discount. Use code, XB108, which will apply an instant 10% discount on all of the products available from their online shop www.tuk-shop.com

Cool Pads

By Elizabeth Dane

My grandson has Ectodermal Dysplasia and can get uncomfortably hot in the summer. When he was a few months old I did some research and came upon the cool pad from www.lifemaxuk.co.uk (follow the link for Relieving Discomfort). I believe they are marketed for relief of menopausal hot flushes, but similar products are also marketed for sports injuries.

The product is not suitable for small babies so it remained unused, but my grandson is now 3 and it has been very useful this summer. He doesn't sleep on it but takes it to nursery and they put it in the fridge to make it super cool, though this is not necessary.



On hot days he pops in from playing outside and has a lie down on it, and then when he has cooled off a bit, runs off again to play. At home it is there for him to have a lie down if he needs it. On really hot and humid days I have folded it up and put it on the pushchair as a cushion and back rest. I bought the single bed size, there are smaller ones, and this was quite expensive, but it has proved to be very robust. It is gel filled and hasn't suffered any leaks yet. If you haven't already got a similar product, it may be worth exploring. We certainly have found it hugely useful.

Sunshine and Vitamin D

Extract from NHS Choices website

<http://www.nhs.uk/news/2016/07July/Pages/The-new-guidelines-on-vitamin-D-what-you-need-to-know.aspx>

What is the new vitamin D advice?

The new advice from PHE is that adults and children over the age of one should consider taking a daily supplement containing 10mcg of vitamin D, particularly during autumn and winter.

People who have a higher risk of vitamin D deficiency are being advised to take a supplement all year round. SACN's review concluded that these at-risk groups include people whose skin has little or no exposure to the sun, like those in care homes, or people who cover their skin when they are outside.

People with dark skin, from African, African-Caribbean and South Asian backgrounds, may also not get enough vitamin D from sunlight in the summer. They should consider taking a supplement all year round as well.

Is there new vitamin advice for children too?

Yes. It's recommended that children aged one to four years should have a daily 10mcg vitamin D supplement all year round.

As a precaution, all babies under one year should have a daily 8.5-10mcg vitamin D supplement to make sure they get enough.

However, babies who have more than 500ml (about a pint) of infant formula a day don't need a vitamin D supplement as formula is already fortified.

The government recommends that babies are exclusively breastfed until around six months of age.

Are you put off by going to theme parks because the queue's may cause your child to overheat?



Many attractions, museums, theme parks, etc., have a disabled policy such as Legoland's section "Ride Access Passes are reserved for guests who do not understand the concept of queuing; have difficulties with everyday social interaction; have a limited capacity to follow instruction or to understand others' emotional feelings of expressions, and may therefore become agitated or distressed if they had to queue for a ride for an extended period of time".

As the major symptom of some of the Ectodermal Dysplasias is the lack of temperature control due to missing or non-functioning sweat glands causing overheating in the summer months and hypothermia in the winter, it would be extremely difficult for some individuals affected by ED to queue for any length of time, thereby turning a happy exciting family outing into a nightmare and placing them in possible extreme danger.

If you are thinking of visiting any attractions and would like to take advantage of the disabled policy to avoid queuing, it will be necessary to produce a letter of support explaining how Ectodermal Dysplasia affects you or your child. If you would like help with the letter of support please email diana@edsociety.co.uk and Diana will help you.

Give your child's teeth the best chance they have

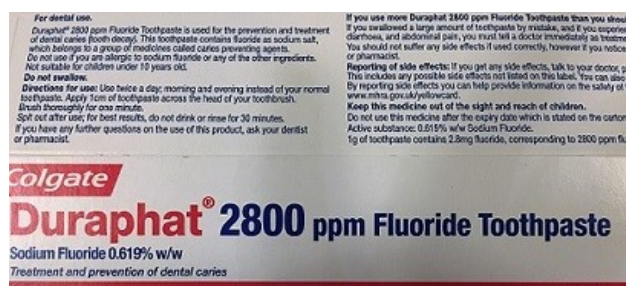
Sharon Cooper – mum to Leonie, 15

As part of my daughter Leonie's dental treatment, she had her first dentures at around 5 years old and at about the same time her dentist gave her a stronger fluoride toothpaste to use, which you can buy in the shops, to try to protect the baby teeth that would not be replaced by adult teeth, teeth she would need for the rest of her life.

Since then, Leonie has always had the toothpaste **free on prescription**, either from her specialist at the dental hospital or from her normal dentist in our local town. She has also had all of her teeth fissure sealed and those seals are replaced when worn, again free on the NHS – it's a simple paste that is painted onto the teeth and then light set. The only complaint she makes is that it tasted of "horrid banana".

If you want to ask your dentist for the toothpaste, you need to ask for Duraphat 2800ppm fluoride toothpaste.

I don't know how much it has protected Leonie's teeth, she is now nearly 15 and has no fillings or cavities and her teeth remain strong. She's had no noticeable side effects with the constant use of a stronger toothpaste - so based on our experience I would highly recommend it to give your child's teeth the best chance they have.



Help Support the ED Society

You can make a real difference in the lives of children and adults affected by the Ectodermal Dysplasia syndromes by supporting the Ectodermal Dysplasia Society. When you donate to the ED Society, your gift will immediately go to work by providing support services and hope to our families affected by ED.

Ways to donate

The ED Society depends on donations for its existence and there are several ways in which you can help:

- Make a one off donation by sending a cheque made payable to the ED Society
- Make regular donations via a standing order from your Bank
- Send a book of stamps to help us with postage costs
- Hold a fundraising event
- Buy an ED Society wristband or help to sell wristbands



Any donation, no matter how big or small, will be of tremendous help to the work we do in supporting all individuals who have experience of ED.



The ED Society would like to give a huge thank you to one of our members, Chris Brown. Chris lives in Hong Kong with his wife, and their son Connor who has ED. Chris has helped to sell our wristbands and has raised almost £300 by doing so. Thank you for all of your hard work and support to the Society Chris, it is much appreciated.

Our wristbands come in 3 sizes; small 150mm, medium 180mm and large 202mm. If you would like to purchase any, they cost £1.50 incl. p&p for the first one, and each additional is 50p. Please email me, danielle@edsociety.co.uk if you would like any.

Hello everyone!

I suffer from HED and being a part of this page (ED Society UK Facebook Page) has allowed me to not only be able to hear from those in a similar position to myself, but it also has reminded me that I am not alone (which is important as I've never met anyone like me)

I decided that I would write a blog, some of which will be about how living with ED has effected me in my day to day life. Seeing as I know how much it can help to just read stories of other similar people, I thought it would be an idea to share my blog as maybe some people may benefit from reading some of my posts.



Thanks; Grant Elsey

Here is the blog: <http://livingwithhed.blogspot.co.uk/>

If you haven't done so already, please join our Facebook page. It is ever growing, full of support and tips for individuals who have ED and a community where you too can share your questions and stories.

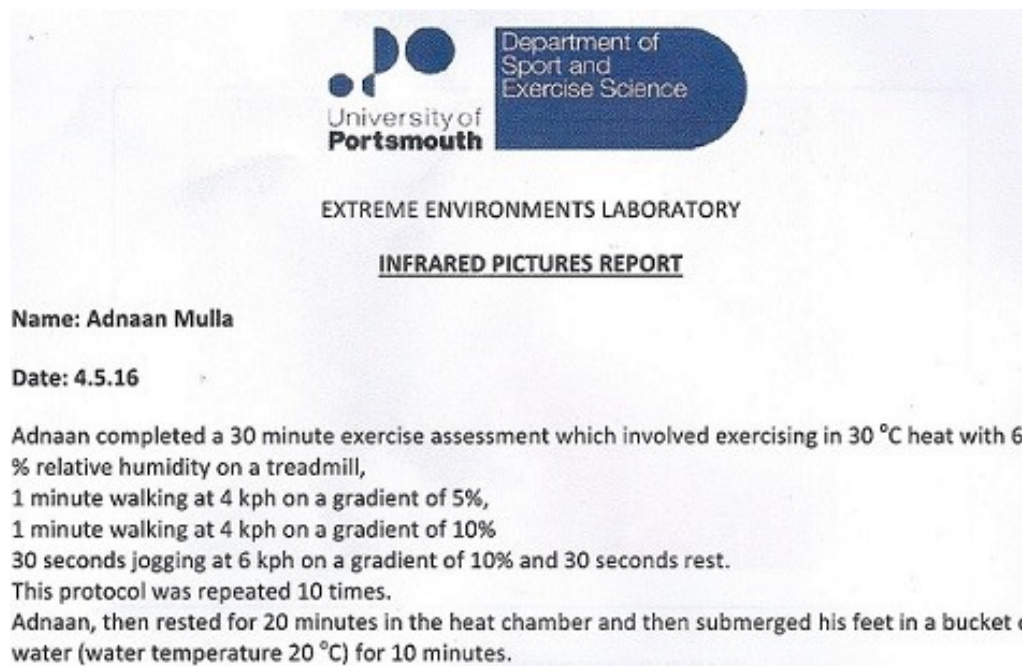
<https://www.facebook.com/groups/ectodermaldysplasiasociety/>

Temperature Regulation Research Project— Update

In May 2016, Adnaam Mulla, aged 14, took part in the Temperature Regulation Research Project at the University of Portsmouth.

The project is to find out how individuals with ED, especially children, suffer with their temperature and to have this topic documented. To have such a document will save so much disappointment, hurt, fighting, frustration, anger, etc., not just for us in the UK but for people with ED around the world.

Here Adnaam shares his experience, along with the results of the study from the University of Portsmouth;



PICTURE 1 – BEFORE EXERCISE FRONT



“Hello, my name is Adnaam Mulla and I am 14 years old. Part of the reason I took part in the study is because I am taking PE for my GCSE’s. The University asked me if I wanted to take part in their study so I could get a better understanding of my condition. I have HED, which means I have less teeth, cannot sweat and have thin hair.

When we got to the university, Heather Massey introduced herself and the two lab workers, Liam and Danielli. We also met Mike, Danny and Geoff who were helping me too. They told me everything I was going to do, starting by weighing my clothes and me. I got changed into my clothes and then I had to wear 6 thermistors on my body, 1 thermistor in my ear canal, 2 sweat capsules and 2 chest straps. I was put in a room where the temperature was 30c and asked to sit on a chair for approximately 30 minutes To keep me entertained they gave me a selection of movies I could watch.

Behind me there was a screen which showed my temperature. The darker colours showed I was cool and the brightest that I was very hot. I had to walk and run when Liam and Danielli asked me to. This gave me a better understanding of myself when hot.

PICTURE 2 – BEFORE EXERCISE BACK



PICTURE 3 – AFTER EXERCISE SOUT BACK



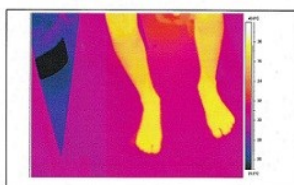
I looked at the temperature screen and it showed me that I was boiling hot, almost fully white (the hottest temperature).

I did this for two days, but on the second day I put my feet in cold water for around ten minutes. When I looked at my feet on the temperature screen, it was dark blue (cool).

PICTURE 4 – AFTER EXERCISE BOUT FRONT

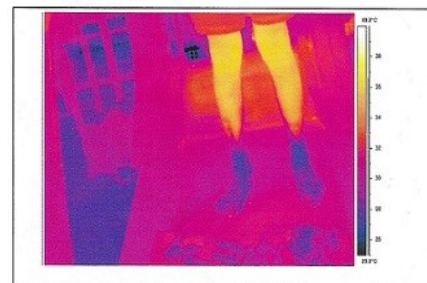


PICTURE 5 – END OF EXERCISE



I would like to offer a magnificent thank you to Heather, Liam, Danielli, Mike, Danny and Geoff for helping me and making me feel very welcome. I hope others like me who are reading this will do what I have done and take part in this study so you too can get a better understanding of HED."

PICTURE 6 – END OF EXERCISE AFTER 10 MINS OF COOLING



ED Christmas Party 2016

We are pleased to announce the ED Society Christmas Party will be held on

Saturday, 3rd December 2016 12.00pm - 5.00pm

At the fully air-conditioned "Jury's Inn Hotel"

Children's Entertainment including games, stories, music, craft table and a bubble machine, buffet and Father Christmas

Tickets - Adult £13.50, children with ED and siblings free,
other children £10.00. 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 1.5 miles from Cheltenham coach and rail stations and close to a range of hotels.

We have been very lucky to get one place for the ED Society in the 2017 London marathon.

The cost of this place is almost £400. Therefore, we will be offering it to the person who thinks they can raise the most money for the Society.

If you are interested and wish to apply for this place, please contact

sue@edsociety.co.uk



KEEP THE DATE - Friday 16th September 2016

Hello Everyone—my name is Kerry Russ, I am one of the fundraising co-ordinators for the ED Society and I have organised an 80's fundraiser night to help raise some much needed funds for the Society.

On the night there will be an 80's tribute band, AK47 and Kyle Tomlinson (who was on Britain's Got Talent).

There will be a raffle and I have managed to get some fab prizes so far, but I am still on the look out for more to help raise even more money! If anyone could help with any raffle prizes that would be great.

The event will be held at the Phoenix Pavilion in Rotherham on **16th September 2016 at 7pm.**

(Pavilion Lane, Brinsworth, Rotherham, South Yorkshire, S60 5PA.)

If you do not live locally there are two hotels, The Fairway and The Holiday Inn, which are only a 5-10 minute walk away.

Myself, along with the ED Society, really hope many of you can come along to help show your support for the Society and raise some money.

If anyone would like more information or to donate a prize, buy raffle tickets, etc., please contact me either through Facebook or email—k.russ0478@googlemail.com

Tickets are £5, and £1 per strip for raffle tickets.

Thank you—and we hope to see you on 16th September!!



KEEP THE DATE - Saturday 4th March 2017

Fancy a good night of fun, dancing, food, raffle, and auction? Look no further.

Let's get our masks on and raise some money for the Ectodermal Dysplasia Society.

The Band, GOTTA GROOVE, will get you all on your feet to dance the night away. With a quality finger buffet to enjoy.

Tickets are £15 per adult, kids £5, and under 5s are free! The event will be held at: The British Legion, Ruiton street, Dudley, DY3 2EH

Please contact Stuart Atkiss (Fundraising Co-ordinator for the ED Society) for tickets via email baggies07@hotmail.com or **07824633302**

We hope to see you there!!

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 before acting on these views. The use of a product name does not constitute a recommendation or endorsement by the author or the Society.