

## ECTODERMAL DYSPLASIA SOCIETY

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Registered Charity No. 1089135



## Fundraising - What a Fantastic Year

We are so proud of our members, their families, friends and colleagues

2012 was an absolutely brilliant fundraising year and will enable us to continue our support work and will help to partially finance some research projects that are currently in the pipeline.

In 1996 we had 20 members, barely any funds and struggled to meet our financial commitments every year - we now have 500+ members and enough funds to carry us through 2013 working to support you all and new members.

If we could continue to fundraise at this level your support will help us to

- carry out the temperature regulation research for which we are having difficulty in obtaining the £40,000 needed to fund staff, equipment, consumables, laboratory venue, accommodation & travel for families who will take part
- provide air-conditioning units, humidifiers, fans, wigs, etc., through our Support Fund



- support families with information packs for schools, doctors, etc.,
- help members apply for financial benefits
- Christmas Party
- etc.



**Don't forget - the summer months are great times to hold fundraising events**

## 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
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
Steve Preston	-	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  
Steve Preston

## Staff

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

## Membership Forms and Website

Please send back your 2013 Membership form as soon as possible.

Access to the Members section of the website ceased for all members on the 31st December and will be re-activated on receipt of your 2013 membership form.



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.

## Temperature Research

We are still trying to obtain a grant to carry out the temperature regulation 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

## 2013 Christmas Party

A date for your diary - Saturday 7<sup>th</sup>  
December

More details to follow in the summer  
newsletter

# Christmas Party

The 2012 Christmas party was another huge success with families joining us from all over the UK.

We had a wonderful turnout of over 120 adults and children attending. We are very grateful to members of our Medical Advisory Board who joined us at the party.

The children were entertained all afternoon, giving the adults plenty of time to chat and make new friends.



*Had a wonderful day would like to thank Diana, Sue and Julie for such a great party and to all my old and new Ectodermal Dysplasia Society friends*



*We had a great time meeting old and new friends at the party*

*We all had a brilliant time at the xmas party so thank you everyone. Can't wait until next year. I've never seen my little boy being so outgoing in a big group he doesn't normally leave my side - he is so shy!*



*Just wanted to say a big thanks to Diana, Sue and everyone else who took part in organising the xmas party - we had a great time and the children had a super day - it was great to meet you all - thanks.*



*Thank you to Diana and Sue for a great party again - we've all had a great time*



## The Rain Can't Ruin Our Race Day!



Regular readers of this newsletter may already know or have heard of our Race Day that we have held every July since 2005 in our own back garden. It's a unique and intimate gathering that attracts family and friends from all over the country and has helped us raise the best part of £15,000 over the years.

For our last event in July 2012, the weather did its utmost best to ruin our day, so much so that with a week to go and the constant summer rainfall showing no signs of let up we were all ready to cancel. But no, we couldn't give up that easy.

A vacant hall was found and a hire fee negotiated, 'come on this is for a very worthwhile charity!' Invited guests were advised of the new location; thank heavens for the email and modern technology! Logistic arrangements were made moving television, speakers, laptops and people from home to hall. We were determined to get the day on and we most definitely succeeded. As the first guests arrived the heavens opened but we didn't care, we were now inside!

The rest of the Race Day ran smoothly throwing up nine very entertaining races, but more importantly raising plenty of money.

Winning owners received a bottle of wine or if under 18 a box of chocolates! Winning bets were immediately reinvested on the next race.

A raffle swelled the coffers and then a late collection to cover the cost of the hall was donated. Max topped the day off by singing a few songs. Overall, a terrific day was held and more than a £1,000 was raised. The rain may have ruined our summer; it didn't ruin our race day.



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## I ran for Gracie

My daughter, Gracie has Incontinentia Pigmenti (IP) which is an Ectodermal Dysplasia syndrome. The ED Society has been really supportive so I wanted to do some fundraising to give something back and also to raise more awareness of IP which is very rare. I therefore decided to run a half marathon at Stanwick Lakes in Northamptonshire.

I trained for 6 weeks, running 3 times a week. I started off running 4 miles & within a few weeks was able to run 10 miles without stopping. My longest training run was 10.5 miles, but before the half marathon I hadn't run that far; I completed the race in 2hrs 26 mins without stopping once, which is all down to the support of my family and not forgetting my good friends Mark & Victoria Risby who trained with me & showed me I could do this. My Husband, Leon Moxam, and Mark also took part.



Running a half marathon was always a goal for me but something I never got around to. I am not an experienced runner; before I had started my training I was lucky if I could run round the block without struggling! Within 5 runs I went from 4 miles to 10 miles although I had to stop, but with more training I was able to run without stopping. So if I can do a half marathon anyone thinking they can't, will be surprised that with training how much they can do.

I would like to say a big thank you everyone who sponsored me and helped me raise the fantastic amount of £1,262.00.

*Nikki Moxam*

## Behaviour in School

As the Mum of a child with ED, I find that we don't often talk about or even think about her condition on a daily basis, but on occasions we have needed to explain in detail what she has and why and that can often be more complicated than I think it's going to be.

Leonie, my daughter is now 11 and was first diagnosed when she was 3 years old, after months of tests and trips to the doctors, we then found ourselves in touch with the ED Society. At that time, we didn't notice much more than the missing teeth, which was her most obvious sign of ED, so that was our focus. We had some information from the ED Society, which we used to talk to her primary school when she was 5, and then didn't really think much more about it. Leonie got her first set of teeth at 6, and so her classmates saw that transition and accepted it. Other than the teeth, and time off for trips to the dental hospital she seemed to have no other problems at school.

We had to move schools when she was 9, and as always we gave the basic information to her new Head and Class teacher - the teeth, the potential to overheat, nosebleeds, but didn't really say much more, we didn't really think she exhibited any other signs.

By now she had her 3<sup>rd</sup> set of dentures, and was very determined that she didn't want anyone to know, so we explained the situation, including the time off school for the dentist and all was fine for about a year. Until one parents evening, when we were told that our usually very well behaved child was acting up in class, starting to be disruptive, not paying attention... behaviour we thought was at odds with how she was at home. As the teacher was explaining in more detail what was going on, it all suddenly clicked into place. I remembered reading in the information we'd received when she was first diagnosed about aspects of the condition that we just didn't see in her at home.

As the teacher and I discussed this, it became clear to both of us, that what they were seeing as disruptive behaviour was because she was overheating in class. Until that year she'd always been in colder classrooms, and at 9 she, along with the rest of the class were expected to sit still for longer, as they practised tests, did more book work rather than more active tasks.

Diana shared with me a special pack of information designed specifically for helping schools understand the condition and how to help children do their best at school. I shared that with the teacher, and she said it was a revelation. All of a sudden, all of these actions that Leonie took suddenly made so much more sense.

The bright child they had been teaching wasn't changing, her environment was impacting her. As a direct result of the pack, we agreed a variety of actions, Leonie would be asked to make random errands if she seemed to get distracted, to get her cool air, she was moved around to find the best place to sit, but wasn't singled out - they made it a fun activity for all.

And the result, the disruptions stopped, she has continued to be able to study harder, and achieved great results in her tests, and is heading towards her SATs in a far better place than she would have been without that intervention.

In sharing this story, as one parent to others, I'd encourage you to get hold of the information pack and share it with your child's teachers if you haven't already, to look at it closely and even if you don't see the behaviour described, understand that it may be there, perhaps not as extreme as it might be described in the booklet, but there all the same.

We're so grateful for the help that small book of information has given us, it really has transformed Leonie's school year. You can get a hold of a copy from Diana at the ED Society office - either call 01242 261332 or email [diana@ectodermaldysplasia.org](mailto:diana@ectodermaldysplasia.org)

*Sharon Cooper*

## Living with ED for 93 Years!

When Diana asked me to write a bit about older times I thought 'where to start?' it's like a history, so I have started at the beginning.

I was born in 1920 when nothing was known of ED; I am the eldest of eight children and all the others are ok. I had normal hair, slightly misshapen teeth, very bad circulation, chilblains and catarrh; I used to get spots a lot which the doctors said were German measles – mother used to say “how many times can you have German measles!”

During the war I was in the Land Army; the other girls used to think I was lucky as they would be wet with sweat and I was always bone dry, although I often felt ill. In later years we found out about ED and then I understood a lot of things about myself. I still regularly have itchy skin and nose trouble, together with really bad arthritis and now have to use a wheelchair.

My first child, Michael, was born in hospital in 1945 weighing 8lb 4oz after a normal pregnancy. Sadly he lived for just 4 days. After my other children were born I realised that my first baby had ED as he had the same transparent skin and cotton wool hair.

My second child, Glenys was born at home in 1947 weighing 8lbs. She was a lovely healthy baby with normal skin and hair.

When Glenys grew up and wanted to get married, we all went to the hospital to have tests carried out to see which of my children had inherited ED; my own mother was ok, Glenys was normal, I am a carrier and have fairly mild symptoms, Margaret is a carrier and has symptoms more severe than I and Allan has full blown ED. The test was to see if we sweated by putting our hands on a piece of paper. Glenys then got married and went on to have 2 children, a boy and a girl, and are now grandparents of 2 children, all of whom are ok.

My third child, Margaret, was born in 1952 and looked quite healthy. However, when she started teething she began having high temperatures, ear ache, vomited, wasn't eating properly, but did drink a lot. She would cough all day and night, spots would come out anywhere on her body, her temperature would rise rapidly, but no one knew what was wrong. When Margaret was about 3/4 years old I took her to the dental school to see Professor Jackson; he was wonderful with her and gave us the first idea of what was wrong. She had a perfect set of teeth except for her two front ones which were missing. Over a period of time Prof. Jackson moved her teeth around to close the gaps and also sent us to a doctor who explained more about the condition, but said nothing could be done about it. I was now pregnant with my next child. As Margaret got older we learned how to cope with her temperatures; her hair was very thin which gave her lots of problems, she always suffered with colds, rashes and ear problems. She got married to David when she was 18 years old, but decided not to have children as she didn't want to pass ED on. When Margaret was 22 they adopted a 6 week old baby girl and are now grandparents to 3 year old little Holly. Margaret and David have had 40+ years of very happy marriage and are now both retired.

My fourth child, Alan, was born at home in 1961 weighing 10lbs. I had quite a difficult pregnancy and as soon as he was born I knew he had ED as he had the same skin and hair as Michael and Margaret. When he was 2 weeks old the weather was very cold so I wrapped him up well, put him in his cot and watched him. He began to look really ill later so we called the doctor who took us straight to the hospital. Alan's temperature was very high! They didn't think he would last the night; they put him in a cot in the duty doctor's room and began testing for all sorts of things. Later they moved him to Seacroft Hospital into a

room of his own; the Sister was very good and looked after him really well; she told me they had put a dry sponge on his back and put a hot water bottle on him to test his ability to sweat, his temperature rose to well over 100f but he was bone dry and very poorly. When we arrived to see him he was a mass of tubes and pipes, but then began to get better and once he was normal again we then had another fight as Alan would pull the feeding tubes out and struggled to feed. They tried giving him salt water one hour and then milk the next hour, but nothing worked. The Sister felt he would be better at home, but Dr. Alibone was in against this. However, he allowed us to take him home at 12 weeks weighing just 7lb. The doctor came to see him twice a day; after 2 weeks Alan had put on over a 1lb.

The next few years were a nightmare, his temperature would shoot up without any warning, the mucus from his nose made him choke, he would go off his food, would often be sick if he went near our food, such as fruit and salad, etc., as he couldn't stand the smell; even now he won't touch them. He doesn't eat bread, eggs, beans, bacon, but thankfully does like a good dinner with lots of vegetables.

Up to about 9 years old Alan was happy to attend all Dr. Alibone's lectures/classes and made films for other doctors at the dental school, but then Dr. Alibone retired, so Alan stopped going. Alan had a lot of trouble at school. He had false teeth at the age of 3, but couldn't wear the bottom set as there was no gum; I am sure this is why he can't eat many things and his indigestion is a real problem.

Margaret will talk about ED, but Alan wont, he just wants to get on with his life.

We all get a dry cough around December time that goes on until Easter! It is not a chesty cough, more a throat irritation which is difficult for Alan as he works with the public. Alan gets very tired when he is hot and coughing doesn't help as this makes him hotter. He has had his own flat for about 20 years now and has worked in public offices since being 16 years old; he is now senior manager and gets on well with his work colleagues. He still has friends from when he was at school which is wonderful as they are very supportive. Since my husband died Alan has taken great care of me and rings me every morning to make sure I am ok.

We are all very proud of Alan and how he has coped over the years.

*Nell Bedford*

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## **Christmas Party Raffle Ticket Winners**

1 <sup>st</sup>	£100	-	05085	Dannie McGrath
2 <sup>nd</sup>	£75	-	05499	Helen Mercuri
3 <sup>rd</sup>	£50	-	01298	Joanne Smallwood
4 <sup>th</sup>	£25	-	04667	Ros Boyd

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## **The ED Society 2013 Annual General Meeting**

This year's AGM will be held at the Thistle Hotel in Cheltenham, GL51 0TS on the 24<sup>th</sup> April 2013 at 1.15 pm please see enclosed Notification and Trustee Nomination Form.

If you would like to join our Executive Committee and become a Trustee please ensure that you return the Nomination Form by the closing date of 31<sup>st</sup> March 2013.

## 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 over a staggering £13574.

The following families; Lay, Wolff, Harpin, Oldbury, Fannon, Chick, Robinson, Green, Bataju, Dorlin, Beeson, Willats, Harding, Cunningham, Atkinson, Davis, Turner, Jones, Smith, Harper, Stehlik, Goodfield, Alrasbi, Ivery, Squires, Stockin, Lees-Jones, Pipe, Rodgers, Farrant, Mills Shortman, Dane, Cook, Macnair, Jones, Shortman, Hay, Cooper, Creron-Jones & Garford. - thank you.

Thanks to Mark & Vicky Macnair for raising another £400 from sales on their stall - many thanks once again for your continued support.

Many thanks to George Milligan of the Misbourne Lodge in Beaconsfield for donating £2958.10 which was raised from the masters list and the Ladies festival. A special thank you to Gemma Milligan, George's daughter, for putting the ED Society forward to the Misbourne Lodge as a charity. Gemma works with Professor Tipton (MAB member) at the Portsmouth University and is assisting with the ED temperature regulation research.

Huge thanks once again to Gabrielle Beeson for raising £310.89 at Chalford School in Essex - well done Gaby.

Grateful thanks to Martin Williams (Diana Perry's nephew) of St James Foundation for raising £318.35 for completing the Iron man. Martin had to withdraw from the previous year's Iron Man as he broke his collar bone in a cycling accident, but trained hard to make a comeback and completed the 2012 running, swimming, cycling Iron Man race.

Huge thanks to Stella Stirling for nominating the ED Society to the Friends of Glenesk School who held various events during 2012 and raised a fantastic £4500.

Many thanks to all at All Fleet Services Gloucester for raising £105.80 and especially to Christine Flynn for nominating the ED Society.

Grateful thanks to Julie Stanford who works at Cambridge Econometrics and donated £200 - thank you Julie for nominating the ED Society to your Company.

Huge thanks to Debbie Groves for raising £338 by holding an evening event and auction. Thank you for thinking of us.

Many thanks to Hilary Huckstep for her donation of £100.

Huge thanks to Karen Brady who is a colleague of Paul Bradshaw's. Karen ran the Workshop Half Marathon and raised just under £400. Thank Karen for thinking of us.

A massive thanks to Paul Bradshaw for selling £461.00 pounds of raffle tickets - wow thanks Paul.

Thanks to Nikki Moxam ran a half marathon for raising £1262. (See article)

Thanks to Daniel Sanchez's friends Rachel and Aimee £15 for Carol singing. (See article)

Thanks to Dave Willats once again held his annual Race Day and raised £1080. (See article)

Thanks to Callum Whyte for climbing Mount Snowdon and raising £50. (See article)

Thanks to Andy Squires and the Strategic Team Group for raising £16,682.25 (See article)

## Strategic Team Group

### Adrenaline Junkie Builders Pedal, Pound, Putt & Pass for Charity



Four teams of high octane, sports enthusiasts and property professionals from construction firm, Strategic Team Group, raced for the finish line as they took part in the first Strategic Lions Sports Challenge on the weekend of 11th, 12th and 13th May 2012. The four teams of cyclists, runners, golfers and footballers, collectively covered 2,000 miles as they raced the length and breadth of the UK on foot and bikes, played 90 holes of golf and two back to back football matches.

Andy Squires who works for the Company and whose son Bailey has ED nominated The Ectodermal Dysplasia Society to receive monies donated along with Help the Heros. We are so grateful to Andy and the Strategic Team Group for raising the fantastic sum of £16,682.25 for us.



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## Ectodermal Dysplasia Ireland

ED Ireland had their 3<sup>rd</sup> Annual get together on Sunday November 4<sup>th</sup> 2012 in the Louis Fitzgerald Hotel in Dublin. Twelve families attended from all corners of Ireland and even as far as Scotland. A great day was had by all.



A big thank you to Helen Donahy and her family for organising the kids entertainment. This year we decided to focus on Dental issues associated with ED and there was a presentation from Dr Joseph Mahon, a prosthodontics specialist and his wife Dr Catherine McKinley, a paediatric dentist. Both are based in Co. Kilkenny, Ireland. This talk was very informative as Joseph had previous experience of treating ED patients while working in the United States. The presentation was followed by a question and answer session. Most families had the same concerns regarding funding and accessing adequate dental treatment in the Republic of Ireland (Northern Ireland have a different health system). It was very beneficial to be able to discuss these issues as a group.

ED Ireland would like to express their thanks to Joseph and Catherine for volunteering their time and giving such a detailed presentation.

### Fundraising

A charity table quiz and raffle was organised by my work colleagues in the HSE West in November 2012 in order to raise money for ED Ireland. Thanks to everyone who attended or supported in any way. Over €2700 was raised between the quiz and the raffle.

Fundraising is essential on a continuous basis for the Ectodermal Dysplasia Society and ED Ireland to exist, grow and continue to support members. I would encourage all members to put on their thinking caps and make Ectodermal Dysplasia their charity this year. And remember no event or contribution is too small.

For further details feel free to contact me - Elaine Aylward 087-6951979 [elaine@ectodermaldysplasia.org](mailto:elaine@ectodermaldysplasia.org)  
[or ectodermaldysplasia@hotmail.com](mailto:ectodermaldysplasia@hotmail.com)

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## Our Overseas Friends

For the last 6 years the AFED in France have organised a summer holiday camp for ED families and this year they would like to extend their invitation to any families who have ED from the UK. If you are interested please contact Diana Perry for more information or contact Olivia at the AFED.



Association Francaise Dysplasies Ectodermiques (AFDE), 3 rue d'Alsace-Lorraine, 92100 Boulogne, France  
Tel: +33 622 172 222 Website: [www.afde.net](http://www.afde.net) Email: [oliviagross@me.com](mailto:oliviagross@me.com)

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## Hearing & Ear Wax Removal



One top tip that has come out of our recent experience is the new technology kit that hospitals now have for “air suction” clearing of little ears with tiny ducts, as opposed to the traditional syringing – it really is truly brilliant and has made a massive overnight difference to Tessa’s hearing – she now has it done every 3 to 4 months & the TV volume in the play room has reduced from 25 on the scale to 7 – hooray ! Most of all, having been recommended to have a hearing aid by several doctors, it has proved to be completely wrong and unnecessary.

We would recommend it to anyone with ear wax related hearing problems, young or old – it’s worth the trip to hospital and is available privately at Nuffield BUPA hospitals

*Simon Lees-Jones*

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## Mount Snowdon - I did it!

My name is Calum Whyte, I am 17 and I have a mild case of Ectodermal Dysplasia. Last summer I climbed Mt. Snowdon and raised £50 for the ED Society. My family and I decided to do the walk and I felt it was too long a walk to just do it for my own achievement, so I decided that I would do it for the Society, which is, obviously, close to my heart.



## Natural Hair Wigs on the NHS



One of our young members, Daisy, now has a beautiful long wig that Mum, Jill, says has increased her confidence tenfold! As any young teenager, Daisy wants to curl, straighten and style her hair so Mum ensured she has been provided with human hair wigs.

The first wig was paid for by Little Princess Trust, who primarily provide wigs for children with cancer, but do also provide one wig for children with other reasons for hair loss - fantastic people. Now, after a bit of a struggle to get the funding the NHS has funded two human hair wigs over 3 years! Daisy’s GP was unaware that natural hair wigs could be obtained from the NHS, so it took a few phone calls and letters back and forwards, but absolutely worth it in the end to see how happy and confident Daisy now is.

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## Benefits

Most people know that if you have Ectodermal Dysplasia you can apply for Disability Living Allowance.

But do you also know you can get other discounts or benefits?

The Blue Badge scheme runs throughout the UK. This allows for parking, usually free - especially useful for hospital or dental appointments. It also means you can park closer to your destination, for example, an air conditioned shopping centre or museum on a hot day. The badge is for the person, not the car, so if the person with ED is travelling with a friend or relative they can bring their badge along. You can apply through your local council.



The Cinema Exhibitors' Association Card costs £5.50 and lasts for one year. This is accepted at most major cinemas and allows one free ticket for a person to accompany the person who owns the card (ie the person with ED pays and the companion gets in free). You can download an application form at [www.ceacard.co.uk](http://www.ceacard.co.uk) or phone 0845 1231292.

The Concessionary Travel Scheme runs in each part of the UK. You can normally apply via your local council, or sometimes at the library. This allows free bus travel and can include a discount on rail travel. For a child, an adult is allowed to accompany them for free.

Most zoos have a disabled person ticket. If you buy an annual pass for a child you can usually have a carer who gets in free. Some other tourist venues may offer a concessionary ticket - try asking!



Do you know of any other discounts or benefits available? Why not share them on our Facebook page?

*Julie Atkinson*

## Disability Living Allowance



Why do so many applications for DLA end up going to appeal and tribunal?

It is very difficult for a parent to complete such harrowing forms about their child. We deal with the day to day management of ED so well that we often don't realise how different every day and night is compared to children who do not have ED. We use wording which doesn't emphasize the enormity of dealing with ED on a daily basis and sometimes don't recognise a symptom of ED as we see it as a normal characteristic of our child.

I know these problems all too easily as I also have two children with ED and from experience am able to regularly help families put letters of appeal together or accompany them to a tribunal.

I am happy to help you complete the initial application form in the hope that it doesn't have to go to appeal or tribunal. I will help with the wording, phrasing, reminders of any symptoms you may have forgotten, etc.

The easiest way for me to help is for you to complete a copy of the form and send to me; I will then read through this and amend as necessary, however to do this I will need a completed Symptoms Questionnaire which you can obtain from the website [www.ectodermaldysplasia.org](http://www.ectodermaldysplasia.org) or email [diana@ectodermaldysplasia.org](mailto:diana@ectodermaldysplasia.org) or call the office 01242 261332

## Carol Singing

Unbeknown to the Sanchez family on Christmas Eve two of Daniel's friends, Rachel and Aimee went around the doors in their cul de sac carol singing. Rachel & Aimee collected £15 for the ED Society.

Thank you so much girls for supporting the ED Society and more importantly for supporting Daniel.



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## Exams and Overheating

As spring and summer approach many parents begin to worry about their child overheating in school, college or university and not focusing or concentrating properly, especially when it comes to the exam period.



Obviously children are not allowed to have a fan in the exam room as this may be a distraction to other children, making it near impossible for children with ED to complete their exam papers to their maximum ability.

We have a Health Care Plan which explains fully the difficulties children with ED have and how they are affected by overheating. Producing a document such as this to the school will enable them to fully appreciate the difficulties with overheating and how it affects the child's ability to focus and concentrate.

An exam room full of children on a warm day is very worrying. Provision should be put in place whereby the child with ED can take their exam in a different room where a fan can be used. During exam time it is possible for the school to have an invigilator on standby; if the child has began the exam along with all their peers and discover they are struggling due to the heat, the clock can be stopped, the child taken to a different room and the clock restarted. This has happened for both my children several times over the years.

Looking to the future, if your child is heading off to university or higher education in September it is time to begin thinking of all the equipment they may need, such as air-conditioning, humidifier, fan, etc. You may like to apply for a Disability Student Allowance (DSA) which will help towards the purchase of such equipment. 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.

If you would like to discuss this further, request a Health Care Plan or more information about DSAs please contact me [diana@ectodermaldysplasia.org](mailto:diana@ectodermaldysplasia.org) or call 01242 261332

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