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Winter 2014

ECTODERMAL DYSPLASIA SOCIETY

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Fundraising Support

Why should you fundraise? What do we spend your money on?

Directly out of the Support Fund we have spent money on

4 x School visits to assist parents and Schools in creating Health Care Plans; attending school meetings; assisting with the Statementing application process

Disability Living Allowance – assisting families in completing DLA application forms; writing appeal letters, accompanying and preparing families for tribunals

Assisting families to attend the Christmas Party through providing accommodation and travel

We have provided :

- 1 x Natural Hair Wig
- 1 x Air Purifier
- 2 Air-conditioning Units
- 1 x Telecoil Hearing Link

Our Achievements in 2013

Assisting families in finding Dentists who have experience of ED through the Dental network set up by one of the Medical Advisory Board members

Created a medical professional database

Produced four Newsletters

Assisted Edimer Pharmaceuticals in bringing awareness of the EDI200 treatment therapy

Made Presentations to medical organisations and organisations for funding

Assisted families in obtaining wigs on the NHS

Creating an international ED website aimed at medical professionals and support organisation leaders around the world. Assisting countries to create their own support organisation

Attending Conferences to obtain information, learn of the latest research and bring awareness

Your fundraising efforts are important to enable the Society to provide all of the above and more to support each and every ED individual known to us.

Many companies support charities, please help us by nominating the Society

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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
Mr. M Harrison	-	Paediatric Dentistry
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

Membership

Please remember membership runs from
1st January to 31st December

If we have not received a membership form from you,
you will not be able to gain access to the Members
Area of our Website

Please return your form as soon as possible so your
membership does not lapse

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

Symptoms Questionnaire

Could you please return the Symptoms Questionnaire
for each ED individual 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.

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/744270/
dlaforchildrenfinalastup-
dated_march_2012_amended_january_2014_web.pdf](http://www.cafamily.org.uk/media/744270/dlaforchildrenfinalastup-dated_march_2012_amended_january_2014_web.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.

Our Grateful Thanks

For the fundraising events which have been organised and the many donations that have been coming in over the past 3 months amounting to a staggering £6,335; also to all the families who sent in donations with their membership and to all those families who make regular donations.

Our special thanks go to....

- the Bradshaw family who, due to Paul's illness, are going through a very difficult time, but they still managed to raise a staggering £1100 by selling raffle tickets in aid of the Christmas party! An enormous thank you from all of us
- Julie Stanford for selling £105 pounds worth of raffle tickets in aid of the Christmas party
- Sara Stehlik for donating £500
- Dave Willats and family for raising £1720 from his Annual Race Day - an extra thank you for your continued support. Also a huge thank you to Dave's friend who donated £260 to the Support Fund
- to St. Mary's Church Charlton Kings, Cheltenham for another donation for £192.29
- Mark and Vicky Macnair who have been busy, once again, selling preserves on their stall raising another £349 for the Society
- Dunblane Rotary Club who donated £100, many thanks to Fergus Gordon for his continuing fundraising efforts
- The Bishops Lacy Pub for their fundraising quiz night which raised £150 for the Society
- Graham and Nikki Kelly for donating £500
- Nikki Moxam for a further £120 from their fundraising 'Team Gracie'
- Kevin Holdham and his twin for taking part in the Great North Run in October 2013 raising the fantastic amount of £1,012.50 for the Society.

From the Support Fund



Many thanks to the ED Society for being there when we have needed you and for being so kind to fund a loop system for our daughter Hannah. She doesn't need asking twice now to do anything and her school work has improved considerably. Hannah can't thank you all enough and a special thank you to Fergus Gordon who suggested the system for her.

We wish you all a happy new year - the Harpin family

We have had many individuals with ED obtain DLA over the last year, some had to appeal resulting in the initial decision being overturned, some went to tribunal of which only one was lost. We are extremely pleased with the results and want to encourage you all to apply for DLA, appeal and go to tribunal if necessary.

An application is less likely to be turned down if the wording is right and all symptoms of ED are recorded. I am more than happy to help with completing the forms, all you need to do is photocopy the original, complete as best you can, send to me for checking and I will return for you to complete the original.

If it is necessary to appeal, again I am happy to help by writing a draft letter for you. Should it then go to tribunal I am happy to be your representative and attend the hearing with you.

Some families have sought the help from Citizens Advice Bureau but unfortunately they do not know the condition well and a lot of information is missing from the forms, hence the application is refused.

Diana Perry

diana@ectodermaldysplasia.org

Carer's Allowance

Carer's Allowance is a Government benefit to help you look after someone with substantial caring needs. If you or a member of your family receive the middle or high rate care component of the Disability Living Allowance you may be entitled to receive Carer's Allowance.

Please go to <https://www.gov.uk/carers-allowance> for more information regarding eligibility and application form.

Blue Badge

The following are extracts from the Blue Badge website.

The Blue Badge scheme is designed to give registered severely visually impaired people and those who are unable or virtually unable to walk the ability to park close to the facilities and services they need to use, so as to improve their lifestyle, independence and freedom of choice.

All badges issued are blue and are usable in all European Union countries (EU). For greater security and to help prevent abuse of parking privileges, the badge holder's photograph is printed onto the back of the badge.

The eligibility under which individuals with ED apply is *permanent and substantial and makes them unable or virtually unable to walk*, for example, applicants should generally be physically incapable of visiting shops, public buildings and other places unless allowed to park close to their destination. The applicant's inability to walk or severe difficulty in walking must be permanent and not just intermittent or temporary. Things such as difficulty in carrying parcels are not taken into account.

Under current regulations governing the scheme badges may be issued without further assessment to disabled people if they receive the higher rate of the mobility component of Disability Living Allowance (DLA) (help with getting about).

Children under three years of age may be eligible for a badge if they need to have bulky medical equipment with them at all times, such as an oxygen supply, or if they have a specific condition which may require them to be near a vehicle, either to receive treatment in the vehicle, or be transported quickly to a place where they can be treated, such as hospital.

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.

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



Raffle Prizes

Drawn at the Christmas Party December 2013

1st —Owen Lendy
2nd—Sarah Hague
3rd—Claire Johnson (Virgin Media)
4th—Eileen Sweeny

Holiday Voucher—E. Harpin

Cake Raffle—Scott Gallacher

Date for your Diary!

Christmas Party

6th December 2014 at 12.00 noon

The Thistle Hotel, Cheltenham



ED Ireland 2013/2014



Family Day

We held our annual ED family day on Sunday 3rd November 2013 in the Louis Fitzgerald Hotel in Dublin. Twelve families attended from all corners of Ireland and even Scotland. A great day was had by all catching up with friends made in previous years and of course meeting new friends this year. A special thanks to the Donahy family who entertained the kids for the afternoon.

Fundraising 2013

A huge Thank You to James Murphy (Sharon Geoghegan's brother) and friends who took part in Ireland's toughest most challenging 10k Challenge-Hell and Back. They raised over €900 for the ED Society. Well done lads.

Fundraising 2014

A few members have expressed an interest in participating in this years Flora Women's Mini Marathon in Dublin, Bank Holiday Monday 2nd June 2014. Anyone interested please contact me for registration details, sponsorship cards and t-shirts. The more the merrier!



Christmas Party 2013

Had a lovely day at the EDS Xmas party. Meeting up with old and new friends alike. Special thank you to Di, Sue and Julie for all the wonderful organization you put in every year. I know it all starts early and is so worthwhile. Xx



We would like to thank Diana, Sue and rest of crew for putting together another brilliant party. It was nice to see everybody and Hannah met a new friend. It doesn't seem 2 minutes since the party last year.



First of all thank you for inviting me to the ED Christmas Party. It was great fun and I met a lot of very lovely people. Congratulations to you and Sue and Julie - it was a great success.



What a great weekend Diana, fantastic effort from all involved. Thank you for having us, it was great to meet so many wonderful people, Katie really felt comfortable and reassured by Angus, and Joseph was worn out!!!!



Had a great time at the Xmas party, thanks to everyone who helped organise it. Looking forward to next year already x



Thank you Sue, Diana and Julie for another wonderful party! You all make such a great effort and it's such a wonderful start to our Christmas celebrations. So wonderful to see everyone. Harriet xx



Just got home from the ED party weekend. Thanks to everyone involved with the organisation you all do a great job. This was our 6th year of attending and is defiantly part of our Christmas celebrations each year. See you all next year xxx

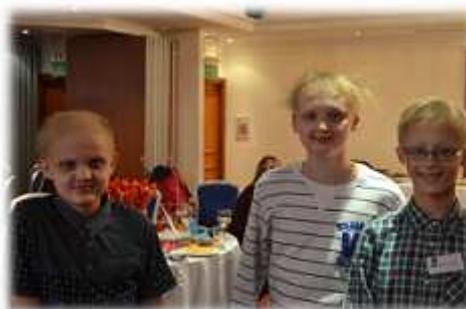
Thank you so much for such an amazing afternoon at the Ectodermal Dysplasia Society Christmas party.



Michael wrote: "So glad me, Katie and Joseph came to Cheltenham for the Ectodermal Dysplasia Christmas do. Its clear to see how much work and dedication Diana and the rest of the team put into their resilient crusade for ED. So thank you! A truly memorable day, meeting some remarkable young children and families alike. Sorry if i missed any tags, feel free to add them in the comment box! Thank you!"



Massive thanks to everyone who helped out with the Ectodermal Dysplasia Society Christmas party, especially Sue, Diana and not forgetting everyone's favourite taxi driver, the lovely Rob. We all had a wonderful weekend, definitely one of the best we have been to. Nice to see some new faces as well as catching up with old friends. Presents for the children as usual of a very high standard as well. Think everything was just perfect. Well done and thanks again. Looking forward to 2014 x





Katie Mary Eleanor Ling – 1st Day at School

This is a small synopsis of my daughter's ED story; I hope it doesn't bore you to tears! I would hate you to think that due to my diatribe, that her life has been an endless tale of scary and depressing woe; I wanted to share some poignant experiences but I would like to add that these were but hiccups in a life that is full of love, smiles, laughter and as many happy moments that we could hope for.

My daughter Katherine Mary Eleanor was born on the 23rd May 1998, a beautiful sister to Matthew and was welcomed into our little family with a joy that could not be equalled. We used to laugh at her lack of hair and say how sure we were that she would soon have a head of blonde curls like her brother. Temperatures were high and nose bleeds rife but as she was a second child I didn't panic and dutifully sat up with her through the night, not thinking for a moment that this was especially abnormal or that they seemed harder to get down in that first year. We called her a 'Drama Queen' as the tantrums were explosive but again, in my book, just a personality trait and not to be confused with anything to do with what may have been a cry for help. Oh the guilt!

I can remember the day that I took Katie to the dentist, her first check up when she was just a tot at two years old. I was very uncomfortable about her very sharp abnormal looking teeth and the fact that only a couple had emerged. She sat in the chair like a 'big girl' and after examination, I distinctly remember the dentist disappearing for about 10 minutes and coming back with a book open on a page. He said, "I think your daughter has this condition". At that moment my world fell apart as I slowly read in intricate detail about every possible extreme case of ED contained in the book and looked at all the pictures of children and adults with the condition, focusing on the worst case scenarios in graphic detail. I was told that I should make a hospital appointment immediately so that this diagnosis could be confirmed. I can remember being very polite and thanking the dentist profusely before putting the children in the car, putting a nursery rhyme tape on and crying silently all the way home.

I had never heard of ED and nor had anybody that I knew. I spent a number of years working for a big Pharmaceutical Company full of Medics but even those that I contacted in desperation knew little or nothing about the condition. I made a Doctor's appointment for a referral, the Doctor had to get a medical journal out to look the condition up; I was referred on to a hospital and dedicated all of my time leading up to it, finding out everything I could about ED.

Katie was 3 years old by the time she had her first hospital appointment. Again, a medical directory was produced alongside a blank look admitting (to my horror) that the Consultant had not come across it before, or bothered to look it up before we came. I gave the Consultant a thick file of information that I had gathered, largely from the ED Society, in the hope that it might help. After a lot of 'discussion with colleagues' it was agreed that Katie should have a sweat test and that the first thing she would have to do was to get sweaty by running up and down the hospital stairs. Katie had iodine painted on her back and I asked if I could also be painted so that we were 'in it' together (not a great look and was stained yellow for ages!) It wasn't until we got to the top of the very steep, very slippery, very hard hospital stairs, it dawned on me that my daughter was not that adept with the stairs at home and needed the banister to keep her balance, let alone run up and down these hospital steps. As I had waited so long for the appointment and didn't have any other choice we slowly clambered up and down amongst the general public covered in yellow dye and after the third ridiculous slow attempt we went back to see the Doctor in defeat. His next grand plan was for us to go down to the Physiotherapy Pool where the humidity was high and 'blow' my daughter with a hair dryer to heat her up! I cringe when I think that I actually did as he asked – it was absolutely bonkers - modern medicine – I think not! After failing miserably to get Katie to sweat he said that we needed to go home and come back to our next appointment with a fan heater – they didn't have any in the hospital that we could use!

Cutting a very, very long story short, over the next few years we became regular attendees at a number of clinics

and eventually Katie was given an unconfirmed diagnosis of Hypohydrotic Ectodermal Dysplasia. When I asked what the future expectations might be (in addition to those symptoms that Katie already had, lack of sweating, tooth and mouth deformity, lack of hair which didn't grow in places, nail problems, eczema, nosebleeds, an enlarged pupil in her eye and 'thin skin'), I was given a list of possible scenarios to be aware of which frankly scared the life out of me for a number of years (most of which have never happened). I was determined to try and get a confirmed diagnosis so that we would have as much information as possible to hand, however, after years of having her bloods tested in various trials on the MSX1 and EDAR genes in this country and abroad, I have been told that her diagnosis still goes unconfirmed but "Hypohydrotic ED cannot be ruled out" (I feel it is fairly obvious what her condition is).

At this point in our lives, my husband upped and left, moving on to pastures new and my children at 4 and 5 had to deal with this horribly emotional change on top of everything else. I went to work at my children's Primary School, allowing me flexibility for hospital appointments and immediate access to Katie when she needed me in those early days of too hot/too cold (she used to go into a catatonic state).

Due to the problems that Katie was experiencing with chewing, eating and speaking, also with her self esteem in the tooth department, we started to attend the Eastman Dental Hospital where she was introduced to our saviour, Prof. John Hobkirk who, for the next few years until his retirement, spent hours fashioning the most perfect set of top dentures any little girl could ask for. Katie loved them (and him) and all other dentures (and dentists) since have paled into insignificance against those amazing hand finished creations. I will never cease to be amazed by Katie's bravery and patience in the Dentist's chair; she recently sat for a total of 5 hours with a rubber mat over her face and her mouth forced open having a procedure carried out, with not a word of complaint. When she was very young she needed some compacted teeth taken out of her gum and the Dentist said that it might be best if she had a general anesthetic as the work was quite tricky and extensive. She asked them if they could just 'get on and do it' as she 'didn't want to go home and worry about it'. They went ahead, much to my trepidation, with lots of local anesthetic injections and gas and air and managed the procedure on both sides of her mouth. When they had finished, her gums were bleeding and very bruised and they suggested that she might have to have time off school to recover. She got out of the chair and shoved in her denture (with everybody wincing) ready for the two and a half hour train journey back from London. She did not complain about the pain once and insisted on going to school the following day despite not being able to eat and the inside of her mouth being black with bruising! Katie, despite persistent oral infections and many oral complications over the years, will not leave the house without her 'Hollywood Whites' as we call them. She has a bottom set but has never really got on with them and presently has some caps topping precariously wobbly baby teeth with no roots at the bottom and nothing to replace them with. There is still a long road ahead for Katie in this department; we have always been told that she will be offered implants but I am not sure that this is going to be possible now, I am told that this is due to the lack of density in her jawbone and needing too much grafting – although I have an appointment at the Eastman shortly to discuss this. Sadly, as money in the NHS becomes tighter and waiting lists longer, recently I have had to fight hard to make sure that she gets the care that she needs and deserves.

After those early years of being mistaken for a boy over and over again because of her lack of hair, incredibly upsetting for a little girl, Katie was strategically chosen as Mary in the Pre-School Nativity Play. Overjoyed, we went on the hunt around the charity shops for some royal blue material to make her a costume. Sadly, in one shop the lady serving us commented, "Why on earth would they choose a little boy to be Mary, how ridiculous!" We walked out with Katie in tears. When we went swimming, children laughed at 'the boy in the bikini'. After a couple of terms in her Reception Class, it was time for a wig!

One day, sporting a blond bob (not a very nice acrylic wig – you can get gorgeous real hair ones nowadays) that she was very proud of, Katie was sat with the rest of the Reception class listening to a story that I was telling. A 'lively' little lad sat behind her and was having great fun pulling the back of her wig so that it came off the front of her head, Katie would patiently pull it forwards again. I was acutely aware that this was happening over and over again and I could see that Katie was getting more and more annoyed, as was I. I had to stop myself from interrupting the story and telling the boy off which would have embarrassed Katie and I am very glad I did. Katie suddenly whipped off her wig and swiped it around the boy's face before quickly putting it back on. I am not sure who was more

edlines

shocked, Katie, the boy or me; either way it did the trick and he didn't touch it again! The wigs lasted for a couple of years until they got in the way of life, they were then demoted to the Dressing Up Basket and I took out a second mortgage to spend on hair products (which had little effect) and top Hairdressers who charged £50 for the two minutes it took to cut approximately three of Katie's hairs! Katie spent the best part of about four years wearing a 'Hoodie' or hats - whatever the weather or occasion, before having her hair cut really short all over which suits her down to the ground!

We also realised around that time that Katie had become violently allergic to horses and cats. She had her first riding lesson and was absolutely fine and then suddenly, taking her on a horse and trap ride, she came back with a very swollen, red face. With each exposure she got worse until even walking through our local high street and encountering a Jockey (we live near Newmarket, with its racecourse) was a trial. Her face would swell so much and so quickly, that it would be bruised when the swelling went down but luckily did not affect her airways; a real shame as we have horses in the family and I thought that this would be a fantastic hobby for Katie to have. My poor sister would have to clean her car, house and herself extensively on our regular visits and Katie had to be monitored very closely on school trips and trips out. Her allergy seems to have abated slightly as she has got older and is not as severe as it was.

Temperature control was a nightmare when Katie was younger often leaving her with very high temperatures for long periods and in the extreme, in a catatonic state. There are too many incidences to mention here that left her in severe difficulties. However, moving on to today, apart from her acute awareness of how to manage her temperature control, she also only seems to be affected when the temperature changes suddenly, ie. from extremely cold to hot or vice versa which I find interesting as when she was younger I thought that she was only affected when it was either really hot or really cold and didn't really think about how a sudden change would affect her..I am a little dim. OH THE GUILT!

Katie and I talked endlessly, about life, people and the world. I wanted Katie to be able to deal with difficult situations when I wasn't around to protect her from every Mother's worst nightmare - bullying. I was quite hard on her and would try not to get involved in her issues, instead giving her strategies to use herself and then talk about their effectiveness. I would never allow her to use ED as a means to get the sympathy vote or, in as many situations as possible, stop her from leading a perfectly normal life. Having coped beautifully at Primary School in her 'little family' of 220 and her Mum at hand, it was with huge trepidation on both our parts that Katie started senior school and was thrown headfirst into approximately 1,350 other children and immersed in the boiling pot of life!

From an early age Katie has had to deal with prejudice and bullying and learnt that people can be very cruel. ED or no ED, there is nothing worse for a Mother than to see your child crumble and their world destroyed by flippant comments made, not only by children but adults too. Katie has been called 'Worzel' (Gummage) and 'Jaws' amongst other wicked names over the years; she has been told that she couldn't be part of a group because she 'fell out of the ugly tree' and has been laughed at on many occasions. I remember the day she came home at 11 years old, with no shoes and a huge cut and lump on her forehead, her shoes had been 'stolen', disposed of over a fence and she had a stone thrown at her head - I don't think I have ever been so angry in my life and the situation was taken to the highest level and dealt with immediately. We have learnt over the years that this type of behaviour can be directed at any child, no matter what appearance whether it be glasses, colour of hair or size and actually, having ED does not necessarily make you an automatic target, although it doesn't help!

Each year brought different challenges for Katie and her early teens were beset with the normal horrors of teenage angst with a large dollop of lack of self esteem. I was therefore surprised that one day Katie came home and told me that she was 'in love'. I met the young man of her 14 year old dreams, a very attractive and popular boy at school and although horrified in one sense (protective Mummy syndrome) I had never seen Katie so happy. Three weeks into the romance and Katie announced to me that she was going to tell her beau about her condition, as she knew he wasn't aware that she had ED. I pointed out to Katie that as he obviously loved her for who she was, why would her having ED make any difference to him? She said that she wanted to be honest with him from the outset and so told him later that day - he dumped her on the spot and then made a sport of telling everybody at school it was because she had false teeth and was a weirdo.

The six months that followed are best skipped over as I dealt with the fall out of a very trying year for Katie, when

fickle friendships came to the fore in loyalty tested by a popularity poll. Emotions ran high with some pretty difficult behavioural consequences. The limited contact over the years and total refusal to discuss her condition on the part of her Father came to the fore amongst many other issues and I felt myself gripping to that cliff edge with white knuckles alongside Katie in her attempts to pull herself out of the dark place she was in. Refusing to speak to a Councillor or accept any help that was offered, Katie slowly addressed that difficult time, again spending hours cuddled up on the sofa with me talking about life, society and people...she slowly picked herself up....she came through that chapter and into her bright future.

There are not enough adjectives to describe my daughter. Brave, beautiful (inside and out), kind, empathetic and loving are but a few. Katie is not defined by her ED, however, it is a part of who she is. Each challenging life event she has had to face as she has grown, has shaped her personality and enabled her to become a stronger and emotionally deeper human being; one that everybody loves. Obviously I am her Mum and very biased but this is not just my opinion and you would be hard pressed to find anyone who feels otherwise.

If ever there is a child at school who has a problem or is being bullied, Katie is there for them, sometimes to her own detriment. Throughout her education her teachers have always commented that, alongside being a lovely young lady with a wonderful sense of humour, she is very wise for her age and is one of the most empathetic children they have taught. Her debating skills are phenomenal and she often will leave me speechless and feeling somewhat at a loss!

We are extremely close and I know that this will never change whatever the future holds. She is a huge support to me and we only have to look at each other to know what the other is thinking. Katie is hilarious; very laid back (although has a fiery temper), she will always find something funny in any situation, however dire. She loves her brother, when she is not fighting with him (and winning) and I know that they too will still be very close when they are older. She still suffers from a lack of self esteem and is very body conscious, she still has obstacles to overcome with regard to her teeth but she is quite frankly an amazing young lady for whom nothing is insurmountable, and who puts most adults I know to shame in the 'non complaining' category.

We are all individuals, from all walks of life, with different personalities, ideals, dreams and hopes but if you are reading this, we all have one thing in common; ED is a part of our lives. I hope that by writing about Katie, you may be able to see that you are not alone, I am sure that we all have similar stories to tell. Parents I salute and applaud you, it can be a long, hard road at times and I'm right there with you on that one! However, as Katie's sixteenth birthday looms, I look at myself in the mirror and examine the lines, which are not caused by stress - but laughter - and I look back at all the wonderful years full of smiles and love that nothing, least of all ED, can touch!

Sue Ling (Mum)



Katie Mary Eleanor Ling

Do You Enjoy Reading Other Member's Stories? Do You Have A Story To Tell?

We are in need of articles! They can be as long or as short as you like, about you, your child, a personal experience, implants, bullying, how we look, playing sport, your profession, how we cope as ED individuals or parents, emotions, fathers, grandparents; and you do not have to live in the UK to write an article. We would love to hear from anyone affected by the Ectodermal Dysplasias.

Special Educational Needs - Proposed Changes To be known as the EHC Plan

The following are extracts from the Government Special Educational needs website <https://www.gov.uk/government/news/special-educational-needs-support-families-to-be-given-personal-budgets>

Parents are to get a new legal right to buy in specialist special educational needs (SEN) and disabled care for their children, under plans set out today by Children's Minister Sarah Teather.

For the first time ever, parents will be given the power to control personal budgets for their children with severe, profound or multiple health and learning - meaning they can choose the expert support that is right for their child, instead of local authorities (LAs) being the sole provider.

The biggest reform of SEN for 30 years will also force education, health and social care services to plan services together by law - so when their children are assessed, parents will be assured they will get full provision to address their children's needs.

Often it is not clear to parents, and to local services, who is responsible for delivering on the statement of special needs. Services such as speech and language therapy may appear in the statement but are funded and commissioned by local health services.

The main elements are:

- Replacing SEN statements and separate learning difficulty assessments (for older children) with a single, simpler birth to 25 years assessment process and education, health and care plan from 2014. Parents with the plans would have the right to a personal budget for their support.
- Providing statutory protections comparable to those currently associated with a statement of SEN to up to 25-years-old in further education - instead of there being a 'cliff edge' when it is cut off at 16, to help young people into employment and independent living.
- LAs and health services will be required to link up services for disabled children and young people - so they are jointly planned and commissioned.
- Requiring LAs to publish a local offer showing the support available to disabled children and young people and those with SEN, and their families.
- Introducing mediation for disputes and trialling giving children the right to appeal if they are unhappy with their support.

Children would have a new legal right to seek a place at state academies and Free Schools - currently it is limited to maintained mainstream and special schools. LAs would have to name the parent's preferred school so long it was suitable for the child.

Children's Minister Sarah Teather said:

The current system is outdated and not fit for purpose. Thousands of families have had to battle for months, even years, with different agencies to get the specialist care their children need. It is unacceptable they are forced to go from pillar to post, facing agonising delays and bureaucracy to get support, therapy and equipment.

These reforms will put parents in charge. We trust parents to do the right thing for their own child because they know what is best. The right to a personal budget will give them real choice and control of care, instead of councils and health services dictating how they get support.

It is a huge step forward to require health, education and care services work together. The reforms will give parents better information and a comprehensive package of support that meets their needs.