THANK YOU FROM NEWCASTLE

During 1997 we made a donation to the University of Newcastle Child Dental Health Department to help fund a Hypodontia team to visit the toothbank in Copenhagen. I enclose a copy of the report made by Dr. Nunn in December 1997. In a letter Dr. Nunn states “The visit was extremely useful and we have already begun discussions with colleagues in the Medical School as well as relevant manufacturers as to the setting up of a toothbank here in Newcastle. This would appear to be eminently feasible; all that we require now is some funding to purchase the appropriate equipment. As soon as that becomes available we will be in a position to significantly extend the range of treatment we can offer patients with hypodontia. We are most grateful to you for your interest in this project and in particular for the funding of our visit”.

Dr. J.H. Nunn, Senior Lecturer/Honorary Consultant in Paediatric Dentistry

NEWS FROM LIVERPOOL

I received a letter in July from Colin Willoughby which reads:-

“Just to let you know how things are progressing. I have been awarded the John William Clark Award from the BMA. This is to fund preliminary laboratory work and the visiting of families in the UK with ectodermal dysplasia. We have already commenced work on skin culture in the laboratory to look at growth receptors. Regarding EEC syndrome I have a contact in Holland and the USA looking for the EEC gene and they are keen to help with the research. My plans now are to start research with local families in the Northwest and develop things from there. I would like to thank you and all the members who returned questionnaires. I will write/to contact each family individually about the proposed study in the next few months. Many thanks once again as without your support the BMA funding would not have occurred and this grant will hopefully lead to larger funding.”

Colin Willoughby, Research Fellow, St. Pauls Eye Unit, Royal Liverpool University Hospitals

THANK YOU

Many thanks to Lesley Councill and her family for recommending the Support Group to their local school ‘Wellsprings’ for a donation of the monies collected from parents and staff during a recent school performance, the cheque we received totaled £79.82.

BREAST AUGMENTATION

Laura Gerrard

I am writing to ask if there are any women reading this newsletter who have recently undergone breast augmentation. I am a woman of 33 years of age with ED. One manifestation of my particular form of ED (Hypohidrotic Ectodermal Dysplasia) is a lack of breast tissue. This underdevelopment has caused me great anxiety, making me feel deeply self-conscious and uncomfortable with my body. In 1997 I underwent breast augmentation, after finally getting up the courage to speak to my GP and request a referral to a plastic surgeon. The operation I had involved the use of tissue expanders (by name of Beckers). These are generally used for women who have had breast reconstruction, but can also be
used on women who have breast hypoplasia.
I was overjoyed with my surgery. It was wonderful to have a bust at long last. My plastic surgeon gave me a bust which looked completely normal.
Unfortunately, just a couple of days after leaving hospital I developed an infection around the implants. The infection was caused by the bacteria known as staphylococcus aureus. The implants had to be removed. It is partly because I suffer with ED that I got the infection, as skin on a person with ED is extremely dry and thus prone to a large microbial load.
Despite the pain and devastating sense of disappointment I experienced, I am going ahead with a second operation for breast augmentation, next year. I will be given a course of antibiotics, to take a few days prior to surgery, in the hope that this will decrease the risk of infection.
I would be very interested to hear from any other women who have had breast augmentation and whether or not their surgery resulted in the kind of complication I have detailed in this letter. It would be nice to hear of a success story!

**FATHERS**

_Diana Perry_

I owe you all a huge apology as I am not including you when replying to letters received from your family. This is partly because I do not have your name and partly because I am replying to the person who wrote to me. However, I will put this right but will need your help; please ensure that when your wife/partner contacts me she passes on your name.

**HUMIDIFIERS**

The Air Improvement Centre Limited is an independent company, established in 1982, which specialise in all aspects of indoor air quality. They give free, unbiased advice to help people select the best humidifier or air purifier for their particular problems.
The Company has agreed to give a 10% discount to our members/ referrals and offer a free mail order for those unable to visit them. If you are interested contact
The Air Improvement Centre Limited, 23 Denbigh Street, London, SW1V 2HF.

**MY STORY**

My name is Peter. I have Hypohidrotic Ectodermal Dysplasia. I am eight years old. The problems with ED are it is harder to chew food, but then nice things last longer!! Sometimes people call me names such as Fangs, Sharp tooth or Dracula, but soon I will have my teeth fixed and then they will have to think of other names!! When I run I do get

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Lesley Councill

My son, Jack, who will be 3 at Christmas has X-Linked Hypohidrotic ED; he has been diagnosed for just over a year now, so we are still very much on the learning curve. We seem to live in an area where no one has hardly heard of the condition let alone seen it, so whatever we are faced with next is a bit trial and error, When Jack first started getting severe leg cramps we were rushed to our nearest hospital (this was before ED was diagnosed). After X-rays and numerous doctors checking him over we were sent home with antibiotics and no answers!
Jack is still suffering these severe leg pains both day and night, so we would very much like to know if this rings any bells with anyone else who has suffered or is still suffering with the same problem. It may be that the two have not yet been connected and that it is yet another part of the condition. It you can help please get in touch so we can compare notes or perhaps give some helpful tips on how to control or relieve this very upsetting time for Jack.

Debbie McKinlay

It was a sunny morning and I had just taken my daughter Lucy, who is 5 and born with Ectrodactyly Ectodermal Dysplasia, to her first day at school. I came back home, made a cup of tea and opened the post. I proceeded to read through the ED newsletter Issue 4 August 1998. When I had finished reading Angela’s letter I just broke down in tears. It was the first letter I had ever read that I could relate to. My heart went out to Angela. Although Lucy is only 5 and at present oblivious to what is ahead of her, my worries and fears were exactly what Angela had experienced. Lucy was also born with missing fingers and toes, and has problems with hair, skin, teeth, nails and eyes. Lucy was born 10-12 weeks premature and was 2 ½lb at birth. She is very small and very immature for her age. Her main problems are with her bladder and also constipation. She has constant urinary infections and because of the pain she has learnt to hold on for hours causing her bladder to become very large and floppy. We have been in and out of Great Ormond Street Hospital because of this. Has anyone else experienced similar problems? I would like to thank Mrs. Perry for printing Angela’s letter, it was honest and I hope more letters are printed like this giving true experiences of the syndrome. A big thank you to Angela and I am so pleased you are starting to enjoy your life because you are special like Lucy!
quite hot sometimes, but it hasn’t stopped me winning races. My best one is the 1000 meters. Football is my favourite sport and my favourite team is Man United. If anybody would like a pen pal I would be pleased.

FROM DESPAIR TO HOPE
Jean Kingston
I am sure all you Mums and Dads remember very well the day your little one was diagnosed. Suddenly things that seemed so pressing got completely forgotten and the only thing you could think about was your child and what his/her future now held. For months I had been worried about our first born son Peter. I related these concerns to my GP but I think he had me down as an over-anxious first mother. But finally, when Peter was fourteen months old, I found myself sitting opposite a Consultant’s desk, and he had a name for all those problems that had been concerning us. A name I might add I could neither pronounce nor even read. The good gentleman wrote it on a piece of paper for me, but true to form, in a complete scribble. He could not tell me what it was, 'if you are concerned having more children I think you should know you have a 50/50 chance of having another affected child’. I was three months pregnant at the time. Like any parent I wanted everything to be perfect for my children, I was devastated that he should have to carry this burden. I used to kneel beside his cot at night and pray that some miracle would happen and my little son would be cured. I was insulted and cross if anyone said ‘they always thought he looked different’. I read everything I could about ED. Being a nurse I at least knew people to turn to who had access to some information. The most help came from the NFED in USA and a wonderful dentist in Dublin, also Prof. Nevin a genetic Consultant in Belfast. By then our second son had arrived and we were pleased that he was not affected. We decided to finish our family then and put our energy into raising the two little boys we were given. God had other plans!! One year later Michael came screaming into our lives. At this stage I only had to hear his first hoarse cry to know that Michael was also affected. But I was not so sad this time, for watching Peter I was learning something. Peter had problems, but God had known about that long before Peter was ever born. And from very early days I could see that this young man had many talents to compensate. He was very clever. He had a strong personality, and he could take difficulties in his stride. Even at that young age he bravely sat for hours while his dentist crowned his teeth and fitted dentures, asking him loads of questions every time the dentist took his hands out of his mouth!

I watched to see how God had compensated for Michael. For a start his chap would not tolerate dentures at the age of two and a half like his older brother, and reading and writing was not how he passed his spare time, but Michael is so laid back and easy going, nothing ever fusses him, and he is always making us laugh. He sees the funny side of life, and if things get to stressful he just ‘chills out’ and puts his feet up!! I have often collected him from school to find him sitting relaxed with his feet on the desk, and the crazy thing is, he is the only kid I know who gets away with it. Peter on the other hand, enjoys being top of his class, and is quite keen to excel on the sports field too. Irish weather suits Peter as it’s seldom hot and he can get on with his sports. Michael was still stretching his calf muscles, as he observed all the professionals do, but hadn’t even noticed the whistle had gone and all his mates were half-way down the pitch!! I worried about my boys, I cried so many times for them. But these days I just trust God for their future because I believe God has given them all the qualities they need to cope. I guess you could say, I am just a proud Mummy and I will be there for them good days and bad, but I really believe they can be whatever they wish to be and Ectodermal Dysplasia has only served to make them stronger people.

NARROW FEET?
Diana Perry
Do any of you have particularly narrow feet? I have terrific trouble trying to find shoes to fit two of my sons, Joseph and Jack. They are a B fitting, but have extremely narrow heels and their feet are very shallow in depth. The smallest shoes in the shops either slop off at the back or are baggy across the front. I have found an extremely good Boot makers in Bristol who use hardwearing soft leather and make them to fit. Although they are about £10 more expensive than Startrite, Clarks, etc., once the children have outgrown the shoes, the Boot makers will take off the upper part of the shoe and stretch it onto a size bigger sole for half the cost of a new pair, then the shoes last at least a year! If anyone else is experiencing foot problems please give me a call, it will be interesting to see if this is a characteristic of ED.
EYE PROBLEMS

Stephen Thomas

I have suffered from different forms of eye problems all through my life. Firstly my eyes used to water all the time due to drainage problems. My vision was OK right through school and my twenties, although I sometimes get pain from them and I use Vaseline every night on my lids to prevent them from sticking. All was OK up until 1978/79. My vision began to suffer. I was under my local Hospital and they sorted me out. I kept making 6 monthly visits. I even took driving lessons in 1990/92 as my eyesight was so good. In 1993 my eyes were hurting me more and more, but the sight was OK and then I got double vision and I could not see as far as I used to. In early 1994 my doctor asked me if I would consider a graft on my right eye. I agreed and in June 1994 I had my graft. All was going well until 4 days after the op I got a bad infection in the graft and we all thought that was it. But the doctor saved it and I am grateful for that. The vision improved for 2 ½ years but has gone down a bit in the last 1 ½ years due to the scarring and the dryness of my eyes, as I do not produce any or little tears. The left eye is prone to abrasions more so than the right eye and I see my doctor almost every two weeks. My treatment is a steroid eye drop every morning and evening plus a lubricant to keep my eyes moist. The main problem is vision. I used to lip-read very well (self-taught) as I am a bit deaf (and daft) but now I find it hard to do this as my vision is so bad. I sometimes wear a bandage contact lens on my right eye, but it causes blood vessels to grow onto the eyes so I can only use them now and then. I hope this helps fellow EDs and family.

WILL YOU RUN?

Alison House

Dreams if wishes, Thought to never come true. Dreams of fears, Thought to somehow be here.

I dreamt of you, Wished you true, Now you’re here, My dreams still fear….

When I tell you, My past, When I tell you, My future, Will you run…. …. from the task?

When I tell you, My form, My abnormal appearance, Will you run….. …. To the clearance?

You wait patiently, For the truth. You tell me to let you know, In my own time. I will with no doubt, Though my heart will drop, When time has run out.

Will you take me, For who I am? Will you love me, All the same? Will your lips, Still touch mine? Will our arms, Still entwine? Love me or leave me, My tears will, Never fall. Though my heart, Will never again, Stand tall.

I wrote this poem for my boyfriend Nigel just before I had to tell him about my condition, hence the title “Will you Run?”. Needless to say he hasn’t!

And Finally…..

Disclaimer: The views expressed in this newsletter are taken in good faith and are not necessarily endorsed by the editor or British Ectodermal Dysplasia Support Group. The use of a product name does not constitute a recommendation or endorsement by the Support Group.

A big thank you to those who have sent in articles, please keep them coming as I don’t have enough for the next newsletter! For all those lucky people who possess a PC – if you type your article could you possibly send me a hard copy and disc, it would save me an awful lot of time re-typing. Thanks. We have had our first article from a younger person – well done Peter and I hope you find a pen pal soon. A huge thank you to those who have sent in donations – we’re going to need as much as possible to produce and send out our new leaflet. Do any of you know where we could go for sponsorship to print and post the leaflet to all major hospitals in the UK? The leaflet has taken up a lot of my time lately so I am sorry if I haven’t as yet replied to your letters – I’m getting there and will reply as soon as I can. If you have asked me to look something up or find something out and haven’t heard from me, please jog my memory. With 5 children, a home to run and all you members to look after you may have slipped through the net – please call me. Merry Christmas and a Happy New Year.