# edlines

**Volume 13 Issue 2 (59)** **Spring 2013**



**ECTODERMAL DYSPLASIA SOCIETY**

Unit 1 Maida Vale Business Centre, Leckhampton, Cheltenham, Glos. GL53 7ER England.

Tel: +44 (0) 1242 261332 Mobile: + 44 (0) 7805 775 703

Registered Charity No. 1089135

www.ectodermaldysplasia.org Email: diana@ectodermaldysplasia.org sue@ectodermaldysplasia.org


## Charity Fitton Dinner

Kelly Fitton whose daughter has ED has organised a wonderful Charity Ball with all the proceeds going to the ED Society

**Saturday, 1st June 2013 at 7.00 pm**

Bolton Albert Halls

Victoria Square, Bolton, BL1 1RU

**On the night**

3 course meal

Band, Singer, Disco,

Raffle, Auction, Candy Cart

And much more

Tickets at £35.00 per person

Please join us at this event and support Kelly

**Medical Advisory Board Members**

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

**Trustees**

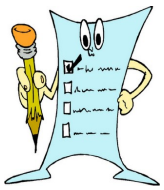
| | | |
|---|---|---|
| Paul Collacott | - | Chairman |
| Alan Waller | - | Treasurer |
| Diana Perry | - | Secretary |
| Mandy White | - | Air-Conditioning / School Liaison |
| Melanie Davis | | |
| Stephen Ayland | | |
| Simon Lees-Jones | | |
| David Wyatt | | |
| Mark Macnair | | |
| Liz Beckmann | | |
| Sharon Cooper | | |

**Staff**

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

# Membership Forms and Website

Please send back your 2013 Membership form ASAP. Access to the Members section of the website ceased for all members on the 31st December 2012 and will be reactivated on receipt of your 2013 membership form.



# Temperature Research

We are still trying to obtain a grant 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 every-one once we have funding.
Diana Perry


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

Join us and make lots of new friends.

# Disability Living Allowance

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

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

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

## Sponsor Forms

With the fundraising season fast approaching, many people will be taking part in events and asking us for Sponsorship Forms or creating their own.

We should be very grateful if you could please ensure that the forms are filled in correctly using full names. When people only write the department they work in or just use their Christian name this results us in being unable to claim Gift Aid.

Last year we missed out on claiming almost £200 of Gift aid due to forms being incorrectly filled in!

Please ensure you complete their Full names, Address and more importantly tick the 'Gift Aid' box

---

## Charity Flowers


### Do you have a special occasion soon?

Our Chairman has suggested using Charity Flowers Direct www.charityflowers.co.uk Tel: 0870 5300 600.

When you buy flowers by post from Charity Flowers Direct 15% of the retail price will be given to the ED Society of your choice.

"They are beautiful flowers that keep a long time"

*The use of a product name does not constitute a recommendation or endorsement by the ED Society*

---

## Shopping Online?

Online retailer Amazon has partnerships with numerous charities, who each offer links to its catalogue through their own website. Visit Amazon through the ED Society website, instead of going direct, and the Society will receive a percentage of what you spend.

Please try to remember to access Amazon through the ED Society website and help us raise 'easy' money.

You do not need to be a member to shop on Amazon via the ED Society website.

---

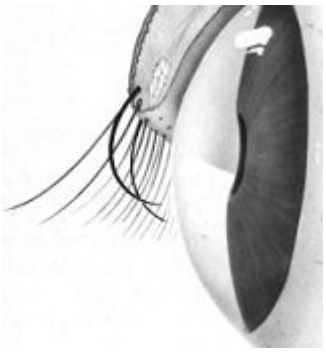
## Fundraising Season

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

**Please let us know if you need any sponsorship forms, leaflets, t-shirts, etc.**

# Trichiasis: ingrowing eyelashes

**What is Trichiasis?**
The term trichiasis describes the misdirection of eyelashes such that instead of them growing outwards normally, they point inwards and touch the eyeball causing irritation, watering and discomfort



**What causes Trichiasis?**
There are several ways in which trichiasis can result.

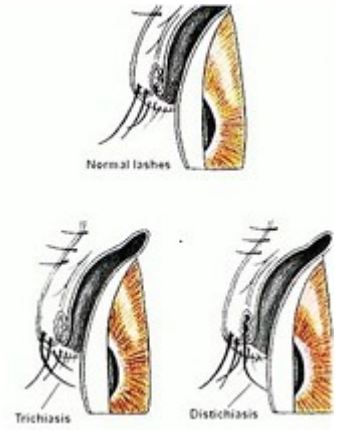
In the UK, the commonest cause of trichiasis is marginal entropion. This is where the hair bearing skin of the edge of the eyelid, has migrated towards ocular surface. Looking from the side, the edge of the eyelid is seen to rotate slightly inwards causing the eyelashes to start pointing inwards, touching and abrading the cornea. This is quite commonly due to blepharitis or meibomian gland disease, a condition characterised by chronic inflammation of the eyelid margins which in turn causes scarring of the edge of the eyelid. This continual scarring results in migration of the eyelid marginal skin. Marginal entropion is more common in the elderly due to age related weakening of some of the stabilising tendons that keep the eyelid skin in check.

Injury to the eyelid can cause trichiasis, especially if the eyelid is torn near its margin. If an eyelid wound is allowed to heal in a misaligned position, the eyelashes may start to grow inwards and rub against the eyeball.

Trichiasis can also arise from a rare condition called distichiasis, where an extra row of eyelashes is present. These extra eyelashes may grow inwards and also rub against the eyeball.

**What are the signs and symptoms of trichiasis?**

- Irritation of the eyeball
- Watering of the eye
- Redness of the eye
- Discomfort when looking at a bright light (photophobia). This is may be due to corneal surface damage
- In severe untreated cases, the constant rubbing of the surface of the eye may result in corneal ulceration, which, if left untreated, may result in loss of vision.




**How is Trichiasis treated?**
Trichiasis can be treated in a variety of ways, depending upon the number of lashes involved, the cause of trichiasis and the preference of the patient.

**Epilation -** If there are only 1 or 2 abnormally growing eyelashes, it may be possible to just to pluck out the offending lashes (epilation). This quick method however is just a temporary measure, since the lashes will regrow again usually within 6 weeks.

**Electrolysis** - A more permanent method of treatment to destroy a small number of abnormally growing eyelashes is by applying a small electric current using a needle electrode next hair follicle bulb. A small injection of local anaesthetic is usually given into the eyelid prior to the treatment to ensure the procedure is pain free. An imperfect success rate of approximately 80% exists and is due to the inability to be 100% sure that the eyelash follicle bulb is receiving the damaging electrical current.

**Surgery** - Occasionally surgery to the eyelid itself may be required to either:

- change the direction of growth of the eyelashes or
- permanently remove the eyelashes by removing the eyelash hair bearing skin.

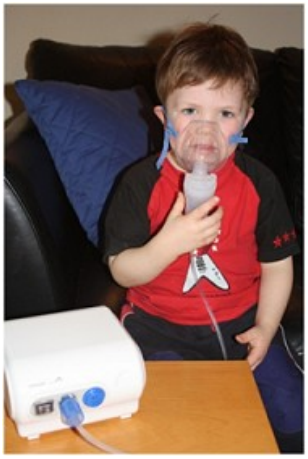
Most trichiasis correction surgery can be done quickly and safely with very good long term results under local anaesthetic only as a day case.

Mr David Cheung Bsc(Hons), MB ChB, FRCOphth, FRCSEd
Consultant Ophthalmic and Oculoplastic Interest in Lid, Lacriminal and Orbital Surgery

# Nebuliser has helped our son



My eldest Son Lucas has ED. As a baby the first signs were regular episodes of overheating and temperatures that had us all regularly in A&E.



Like many with ED, he also had far more than his fair share of chest infections. I can remember him being on antibiotics for chest infections at least once a month. Every cough would end up as a chest infection - it was inevitable. We got through antibiotics so quickly that we were given the powdered form so we could mix some up whenever a cough went to his chest.

We wrestled with the idea of steam inhalations, believing that they would help him but aware that steam is hot and more heat was the last thing that he needed. Then we came to a decision to find him a sterile and cool vapour inhalation that would give him the same benefit as steam but without the heating effect.

We spoke with the GP about our plan to buy a nebuliser. He was supportive and found a plain saline nebuliser solution that he could prescribe. We went straight on Amazon and bought a simple nebuliser which we could use at home with the prescribed saline and it arrived just before Lucas' second birthday.

Now every time Lucas gets a cough he is allowed 10-15 minutes of TV whilst he uses the nebuliser twice a day. Lucas is four this month and has not had one chest infection in the 2 years he has been using the nebuliser.

Lucas uses an "Omron Comp Air Nebuliser" which was £45 on Amazon with prescriptions of Ivax Saline Steri -Ned nebuliser solution.

*The use of a product name does not constitute a recommendation or endorsement by the ED Society*

---

# Grandparents raising money for the ED Society

Our 5 year old grandson, Bailey Squires, was diagnosed with ED 3 years ago. He and his family were introduced to the ED Society and have attended their Christmas Parties for children with Ectodermal Dysplasia.


Andrew and Kelly our son and our daughter-in-law, have received lots of advice and support from Diana and the Society enabling them to live a more secure and stable life. We, as grandparents, wanted to "do our bit" so we asked our group of caravanning friends from the Yorkshire BCC to help raise funds over last season. We held raffles, tombolas and a Harvest Auction raising a total of £276. We are going to continue fundraising this year and hopefully raise some more money.

Thank you to North Yorkshire BCC members.

Gillian Squires proud grandparent of Bailey.

---

# MY SOUTH AFRICAN ADVENTURE

My name is Jack Councill I'm 17 and live in Taunton, Somerset. I was first diagnosed with Hypohidrotic Ectodermal Dysplasia by my dentist when I was 2 years old. I have been through many challenges in my life what with all the hospital and dental visits, the bullying, teasing and just in general dealing with the condition and overcoming many of the problems that go with not sweating, problems with eating, not been able to talk clearly and then there's the hair, skin and nail issues. I am also dyslexic and have scoliosis which is twisting of the spine, but in 2012 I took on one of the toughest challenges so far.

In 2010 I put my name forward to take part in a 3 week expedition to South Africa to help in an orphanage and I was lucky enough to be accepted, then the hard work began, I had to raise the £3000 to go!

With the support of my family I set about coming up with a fundraising programme this involved raffles, race nights, skittle matches, a sponsored 12 mile walk with my Mum. The worst of all the fundraising endeavours was collecting empty drinks cans which we sorted into steel and aluminium, then crushed them and sold them as scrap, although it was a wet, dirty and smelly job it was a great way to recycle and meant family and friends could feel they had supported me even though it didn't cost them any money to help. I eventually raised all the money and a group of 40 sixteen year olds left Taunton with great trepidation and fear, but also an overwhelming feeling of excitement. Three weeks in a foreign hot country with a condition like ED could go anyway, but there we go we were off!

How can I sum up this amazing experience, well we left Taunton on 24th July to travel to Heathrow and then onto Johannesburg where the adventure began. We met our first guide Reggie who took us on the Zulu battlefield tour and Rorkes Drift, from here we went onto the Pongola River where we went canoeing which was one of the highlights of the trip, then onto Kosi Bay which was our R&R where we went spear fishing and swimming. We then moved onto the hardest part of the trip, the Zulufader Orphanage and the painting of the school. One thing that amazed all of us was that the children were so happy even though they had nothing, we spent many hours playing games with them and with the small things we had taken such as pots of bubbles, bouncy balls and especially our cameras which they found fascinating, but the real eye opener and the most shocking part of the trip for me was when a small group of us went on a home visit. There were 8 members of one family living in a small round mud hut with only two beds in the one room, they had no parents as they had died through Aids, so they were being looked after by an aunt and their older brothers and sisters, they had also lost their grandparents the previous year. The little girl was severely disabled but had no support and could hardly walk, this was so hard and one that will stay with me forever. The next part was the painting of the classrooms, this took us three days and was hard work but well worth all the effort. The teachers and children appreciated it so much, this was when they all got together and danced and sang to us which was amazing and we really had to fight back the tears.

ED took its toll some days as the days were very hot and the nights very cold so my body had to adjust which was quite difficult. We also did a lot of travelling which I found tiring. I had told all the members in my group of 12 that I had ED so they really made an effort to support me, but also to leave me alone when I needed time out!

The final part of the expedition was the bush camp where we did a safari. We saw the most amazing rarest animal in South Africa which was the African wild dog, we not only saw one but 5, which our guide had not even seen before! We also saw white rhino, giraffe, zebra, elephants, cheetah and many others. This just finished off one amazing experience, one that will stay with me for the rest of my life and really made me feel so lucky that I only have ED, I still have my life, my Mum, Step Dad (I lost my Dad to cancer when I was 4 years old) my 2 brothers and my Nan, what more could I ask for. We all have so much to deal with in life but when you see these children who have nothing and they are happy, smiling and so grateful for the small things in life, it makes you stop and think how lucky we really are!

# Trustees

Good-bye to David Wyatt

David has been a Trustee and Webmaster for 16 years. We would particularly wish to recognise the great work he undertook in setting up the Board of Trustees, the original website and maintaining it for many years.

The Board would like to acknowledge the Charity's indebtedness to David for all his work, dedication, commitment and enthusiasm he undertook on behalf of the Society during his time as Trustee and Chairman of the Board.

Hello to Alan Waller.

After the resignation of Steve Preston, we welcome Alan Waller who joined us as Treasurer a few months ago and at the recent AGM become a Trustee.

---

# Professional Database


We would like to put together a database of professionals in the UK who have knowledge and understanding of the Ectodermal Dysplasias (Dentists, Eye Specialists, Dermatologists, ENT, etc).

We would value your recommendations of someone who you have consulted and who has been caring, understanding, supportive, etc., of the different ED symptoms.

Please provide their name, title, work address, email and telephone number if available.

---

# For Your Diary
# ED Christmas Party 2013

*We are pleased to announce the EDS Christmas Party*

*will be held on Saturday, 7th December 2013 12.30pm -5.00pm*

*At the fully air-conditioned*

*Thistle Hotel, Cheltenham*

*Children's Entertainment, Buffet and Father Christmas*

*Family and friends welcome*

*Financial assistance is available towards travel and accommodation on application*

*The venue has ample parking and is close to the M5 motorway, about 2 miles from*

*Cheltenham coach and rail stations and close to a range of hotels.*

*Registration forms and directions will be given in the July newsletter.*

# Treatment for X-linked Hypohidrotic Ectodermal Dysplasia (HED): The Edimer Trial

Angus Clarke, Medical Genetics, Cardiff

As many families will already be aware, an ingenious treatment for the X-linked form of HED in mice was devised 'in principle' some ten years ago by two Swiss researchers. It was successful when given either before or after birth, although somewhat more successful the earlier it was given. Since then, this has been shown to be effective in dogs before and (to a somewhat lesser extent) after birth. These treatments work because the product of the XHED gene does not seem to be required continuously throughout life but, for many functions, is only necessary during certain critical phases of development, i.e. while the patterns of sweat glands, hair bulbs, and teeth are being established. The exact period when the gene product is required differs for the various ectodermal structures in different areas of the body. This is being worked out in animals but remains uncertain in humans.

The US pharmaceutical company Edimer has taken over the commercial development of this treatment and has carried out initial safety studies in adult men affected by XHED. These studies have given no signs that the treatment (known as EDI200) has any harmful effects but no-one expects much benefit from the treatment in adults. The USA's Food and Drugs Administration is allowing Edimer to work towards trials of affected newborn infants. It will be difficult to recruit affected infants but a study in such infants will be very helpful: it may turn out that there is some benefit from treatment in newborn boys but it will certainly be essential to demonstrate that this is safe before any of the regulatory authorities would be prepared to allow EDI200 to be administered to a pregnant woman carrying an affected fetus. And that is likely to be the most effective stage of life at which to give (or at least to begin) this treatment.

In the future - if all the trials work out as hoped - then women who carry XHED may be able to have a combination of blood tests and ultrasound scans to demonstrate that their fetus is an affected male. Then they would be given a few doses of the treatment in the pregnancy (to correct the early processes of sweat gland, hair and tooth production and also perhaps improve development of the skin and the mucous glands in the airways and the bowel) with a number of booster injections given to the child after birth, so that the second set of teeth can be induced to form correctly. The details of how many doses would be required at what stages of pregnancy and at what ages after birth remains (inevitably) unclear but the evidence from the animal studies is encouraging in that a course of very few doses given early in life seem to be highly effective.

We hope that there will be centres recruiting newborn infants to this trial from later this year in USA, UK (Cardiff) and Germany (Erlangen). This is not yet certain as we and the other centres are going through the process of applying for ethics committee approvals and permission from the other necessary regulatory agencies. But we hope it will be possible to start the treatment and monitoring of affected newborn boys from later this year in Cardiff as well as elsewhere.

Now to the difficulties! First, participation in the UK will only be feasible if the condition is diagnosed within the first few days of life and if the mother and child (with or without father and other children) then move to Cardiff for some 3 weeks for the treatments to be given and for the safety of these injections to be monitored. In effect, this will make it very difficult except for women who know they carry XHED and that they may have an affected son. Given that we don't know it will work - or how much it will work - and that it has not yet been shown to be safe in infants, this move soon after giving birth may be a major barrier to people who might otherwise be willing to take part. And staying in hospital for about 3 weeks will feel very different from returning from hospital to the comfort of your own home! Of course the costs will be met by the company but it is still an enormous ask of anyone to suggest they go through this.

If there is someone out there who knows that she is a carrier of XHED and that she will be delivering her baby later this year (or next year), and if the baby is or may be male, and if this article has not put them off the idea of joining in with the research, then it would make sense for them to contact me as soon as we know that we have approval for the research to go ahead. Taking part in this will require a lot of planning in advance as well as a lot of discussion and several formal steps necessary to confirm the parents' consent to the research. It would be best to begin this as early in the process as possible. The best way to contact me about this may be email clarkeaj@cardiff.ac.uk or via Diana Perry.

It is my intention to up date you all from time to time with progress via the ED Society newsletter or via email through the Society's office.

# International Conference on Ectodermal Dysplasias

A distinguished group of well vested international experts in Ectodermal Dysplasias (EDs) met for second time in Charleston, SC. Representatives from Italy, Norway, France, Sweden, Finland, Ireland, Wales, Germany, Brazil, Switzerland, USA come to discuss new classification approach for ED's.

Dr. Carlos Salinas, Professor of the Division of Craniofacial Genetics of the College of Dental Medicine was the Chair of the Conference and the PI of the NIH Conference Grant. Mary Fete, Director of Research of the National Foundation for Ectodermal Dysplasias was the Co –Chair.

The Ectodermal Dysplasias is a clinically large and etiological heterogeneous group of genetic disorders characterized by abnormalities in tissues derived from the embryonic ectoderm such as hair, teeth, nails and sweat pores. So far there are over 180 disorders with Ectodermal Dysplasia.

This Conference is a follow up to the 2008 International Conference on the Classification of Ectodermal Dysplasias that was also held here in Charleston SC . Both conferences were supported by NIH-NIDCR Conference Grant and the National Foundation for Ectodermal Dysplasias.

"We clearly understand that the classification of complex disorders is a dynamic and long process. This is particularly true for diverse genetic disorders such as Ectodermal Dysplasias, a large and heterogeneous group of disorders, as we are constantly learning about the new advances in clinical and molecular genetics".

Indeed the study of the human genome has accelerated the knowledge in gene identification and gene function making this time very appropriate to host a second international conference Salinas said.

"We are interested to further development of systematic approaches of an internet based bioinformatics model that can incorporate classification schemes that have different purposes but that pertain to the same clinical disorders.

Thus we envisioned that the clinical and molecular knowledge will be integrated by using an interactive internet based database that can be accessed by clinicians and scientists.

Salinas further explain; "This can be accomplished using a multi-axis system approach to include a Clinical/ Phenotype axis, a Gene based axis, and a Functional/ Pathways axis."

The recognition that a multidimensional classification which could serve multiple purposes is a strong driving force in support of this effort. To this end an interdisciplinary group of clinicians and basic science investigators met here in Charleston.

We expect that the conference will result in a new classification that will foster a better understanding of ectodermal dysplasias and will also open up new fields of research. This classification approach may also end up serving as a model for the classification of other complex disorders.

The Conference was quite successful because by consensus we were able to develop a new clinical criteria for the clinical classification based upon new evidences and we decided to implement the proposed three axis classification

The implementation will be carried out with the NIH NCBI support and an international network of experts will act as Scientific Advisors.

We also learn from Dr. Kenneth Huttner about the advances made in the treatment approach of the Hypohidrotic Ectodermal Dysplasia X-linked which is the most common of the ED.s The goal here is to translate to humans what the molecular therapy has demonstrate possible in laboratory animals which is a permanent and significant correction of the disease.

Also Dr. Maranke Kostner presented a very sophisticated treatment approach for Hay Wells ( AEC) syndrome in which the goal is to develop new skin from cells from the affected patient and then replace the affected sections of skin with new and healthy skin that will not be rejected.

Both researchers emphasize the importance of implementing a classification approach that will serve the scientists by providing an intellectual and practical guide

Furthermore we plan to publish the proceedings at the Am. J. Med. Genetics.

In addition to Dr. Salinas , Dr. Michael Kern, Associate Professor MUSC Department of Regenerative Medicine and Cell Biology and Dr Wenle Zhao , Research Associate Professor of the Division of Biostatistics and Epidemiology were invited participants. These faculty are active participants of the Center for Oral Health Research from the College of Dental Medicine.

The Conference was sponsored by the Medical University of South Carolina and the National Foundation for Ectodermal Dysplasias. And was supported by a Conference Grant from the NIH-NIDCR and the NIH Office of Rare Diseases Research #1R13DE023034-01and by funding support from the National Foundation for Ectodermal Dysplasias.

# It's that time of year again
# Cooling Tips

Having read some of the summer 2013 weather forecasts it appears it may be cool, hot, warm, muggy, humid—in other words they are not sure!! We therefore need to be prepared.

**Suncream**

Whilst we want to protect our children's delicate skin from the sun's harmful rays, I believe we also need to allow our children to have the essential natural vitamin D from the sun. The spring is a good time to acclimatise our children.


The controversies surrounding the best ways to obtain vitamin D continue to confuse most of us. Studies have proven that Vitamin D is important for our overall health. Low levels have been linked to muscle weakness, diabetes, rickets in children and osteoporosis in adults, multiple sclerosis and numerous autoimmune problems, including cancer. There is no question that we need Vitamin D. The controversy is about how to get it, and how much we need.

Through a combination of the food we eat and some exposure to the sun we can get the vitamin D we need. From October to March our skin cannot make vitamin D because of low levels of UVB in winter sunlight, but for most people if normal levels are built up in the summer, our bodies store enough of the vitamin to last us through winter. You don't need to spend hours in the sun to feel the benefits of sunlight. In fact, extra time in the sun doesn't mean you keep on producing more vitamin D. When your body has healthy levels of the vitamin any extra is just broken down.

Whilst much research is being done by dermatologists and other doctors in this area and into the role of vitamin D in disease prevention., it may be sensible advice is to get some sunshine as you go about your daily life without getting a heavy tan or burning, and to get vitamin D through your diet.

It is difficult to know how fair our children's skin is and how much exposure to the sun is ok, but it is important to remember the lighter the skin, the greater tendency there is to burn. Vitamin D can be produced by sitting in the shade outside and thereby avoiding direct ultraviolet radiation. There is sufficient UVB light reflected by surrounding objects to stimulate some vitamin D production. However, shaded sunlight will not produce enough vitamin-D for those of darker skin tones. The key, at any time of day or for any skin type, is to avoid burning.

**Tips**

- Protect the skin with clothing, including a hat, T shirt and sunglasses
- Seek shade between 11am and 3pm when it's sunny
- Use a 'high protection' sunscreen of at least SPF 30 which also has high UVA protection, and make sure you apply it generously and frequently when in the sun.
- Keep babies and young children out of direct sunlight

The British Association of Dermatology has a very good section on skin and sun http://www.bad.org.uk

**What are the signs of overheating?**

It doesn't take long for a parent to recognize when a child is overheating. Parents of children affected by ED often mention reddening of the ears as an early indicator, also irritability, unco-operation, bad behaviour and lethargy. More serious situations can be accompanied by dizziness, headaches, nausea and may serve as a precursor to heat stroke.

**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 place a cold wet 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 make it start again, such as bending over or blowing your nose. Most nosebleeds occur in the front part of the nose and stop in a few minutes. You may need to get medical attention if a nosebleed goes on for more than 15-20 minutes.

**Lack of temperature control**

A concern for many parents is whether their children will recognise they are becoming hot and seek relief; there are some children who may not want to acknowledge that they are hot because they are absorbed in an activity, generally experience has shown that they catch on quickly and soon learn helpful cooling techniques. It's amazing how they will seek out shade or use resources at hand. Young sports players have sought the shade of a tree in the sports field, toddlers have used icepops for head coolers, and others have sought the coolness of a linoleum/ceramic tile floor by laying on it. Some children wear dampened shirts or caps, some carry spray bottles, and others plan their activities to limit risks on days with very warm temperatures.

Family outings to amusement parks, zoos, etc., are best on cloudy days, it is important to plan for safe outings using whatever precautions are deemed appropriate for the situation. As the child grows, families may want to act as chaperones on school outings as a precaution. When school buses that are not air-conditioned are used for field trips, parents may find it useful to accompany the group in a separate vehicle just in case a source of air-conditioning may be needed.

Any trip out should be planned and items carried to use if they become hot such as, a thermos of cool water to drink, a spray bottle to cool the skin, spare bottles of water in the car for pouring over the child, even if you have air -conditioning (this may breakdown!), park in shaded areas, etc. If your child is athletic, take a golf umbrella, damp towels in a coolbox and a spray bottle. 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. Keep the fan on all through the night, preferably directed at the child's head. They will soon burrow under the bed clothes if they are cold.

Put an ice pack under the child's feet when they go to bed to help them stay cool or a cold damp cloth around their neck; this will help them settle better. One Mum suggested filling a hotwater bottle with cold water and then putting it in the freezer!

**Can children affected by lack of temperature control participate in sports?**

Allowing the child to try various activities during the summer months enables them to learn whether or not they like the sport; how to accommodate their inability to perspire and when to acknowledge that some activities may require more than their bodies can comfortably cope with. A bucket of water on the touch line, wet t-shirt, spray bottle, drinking water, wet hat are all that are needed to enable them to join in sporting activities.

**Don't take unnecessary risks.**

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

If there is a hosepipe ban in your area you can still fill the paddling pool with buckets of water, they don't need much water to cool down. It may help to keep the pool in the shade.

# Cooling Hand Immersion

In the last issue we covered 'cooling' in great detail. Since then Michael Tipton from our Medical Advisory Board came up with this additional tip.

"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"

## 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 £2506.

The following families; Hawkey, Cunningham, Harding, Collacott, Raleigh, Kaye, Dewsbury, Creron-Jones, Pennington, Baker, Shortman, Willats, Fenwick, Hare, Beeson, Dewsbury, Burden, Woodburn, and Andrews.

Many thanks to Mark & Vicky Macnair for their continued support raising another £130 from sales on their stall.

Huge thanks once again to Benny Goodman who raised £40 by giving a speech at the Probus Club.

Huge thanks to Louise Holmes for raising £397.58 by holding a Horse Fun Day.

Many thanks once again to Fergus Gordon (Scottish Representative) for raising £153.60 from our collection boxes.

Grateful thanks to Claire Jelfs who completed the London marathon in 5 hrs 10 mins and raised £606 for the Society – Well done Claire and thank you.

Thanks to Sophie Bullman's Mother Peta who raised £33 by having a collection box and asking for a donation from anyone wanting to use the facilities at the Union Inn in Porth Madog.

Many thanks to Gillian Squires (Grandmother of Bailey) and a group of caravaning friends from the North Yorkshire BCC, who raised £276 by holding various fundraising events last year and are hoping to continue this year.

Thanks also to the Parish of St. Mary Church, Charlton Kings, who featured us as the Charity of the month and raised £245.75. Thank you to Marjorie Robbie (Diana Perry's Mother) for nominating the ED Society.