



ED Christmas Party



Get out your Christmas jumpers!!

We are pleased to announce this year's ED Christmas party will be held on Saturday 3rd December

At the fully air-conditioned Jury's Inn Hotel

12pm – 5pm.

There will be children's entertainment including music, games, stories, a craft table, face painting and a bubble machine, along with a great buffet catered for all.

Father Christmas is popping along for the fun too!

Ticket prices are as follows;

Adults £13.50

Children with ED and sibling are free

Additional children £10



We will be holding a raffle, prizes include; £100, £75, £50 and £25. All proceeds of ticket sales go towards the costs of the party.

If you think you could sell some raffle tickets for us, please get in touch and we will be happy to get some posted to you.

Family and friends are also welcome – the more the merrier!

Please ensure you return your registration forms by 7th November so that any accommodation can be booked.

We have some pre-booked rooms for the Saturday night, 3rd December, at the Travelodge should anyone require one.

Any request for accommodation after the 7th November will not be funded by the ED Society.

Financial assistance is available towards your travel and accommodation upon application.

The venue has ample parking and is close to the M5 motorway, Cheltenham coach and rail stations.

Jury's Inn, Gloucester Road,
Cheltenham, Glos. GL51 0TS

WE LOOK FORWARD TO SEEING YOU ALL



We have a place!

The ED Society are pleased to say we have a member running in the London Marathon next

Please read the article and sponsor Clive

He's Too Young for Dentures
and
8 Tips for Getting Your Child To Wear Dentures

Medical Advisory Board Members

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

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Melanie Davis		
Stephen Ayland		
Simon Lees-Jones		
Stuart Atkiss		Fundraising Co-ordinator
Sharon Cooper		
Scott Gallacher		

Staff

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

Volunteers

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

MEMBERSHIP

You will be unable to gain access to the members' section of our website until we are in receipt of your 2017 membership form.

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

SYMPTOMS QUESTIONNAIRE

Could you please ensure you have completed a symptoms questionnaire for each individual who has ED in your family. This document hugely helps us when answering any of your concerns or when assisting you with DLA applications, appeals, tribunals, schools and doctors etc.

It would be helpful to have an up to date form, so if you have not completed one for many years, they are available to download from our website.

DISABILITY LIVING ALLOWANCE, CARER'S ALLOWANCE & P.I.P.

We are always happy to help you complete the forms.

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

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

BLUE BADGE

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

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

We are making some changes!

You may have noticed the ED Society have a new logo – we hope you like it!

We are currently in the middle of getting the new logo in place on all our paper work, so you may be receiving pieces with the old logo as well as the new; please bear with us whilst we make the change over. Thank you!



Our thanks go to Amy Cox who very kindly designed the logo for the ED Society.



New Website

We are still in the process of building our new website. It is looking fab and we can't wait for you all to see it.

It would be great if we could have some lovely digital family photos, any fundraising stories, etc., etc.

If you could please email us – info@edsociety.co.uk it would be very much appreciated.

All photo's will need to be in high resolution



We would also be interested to know our members' thoughts.

Is there anything you would like to see new on the new site?

Is there something you would like to know more about?

Any ideas would be greatly received.

Thank you Daniel!

The ED Society would like to give a huge thank you to Daniel Sanchez.

As you know, over the last year Daniel has been keeping a diary on his National 4 qualification in Uniformed and Emergency Services course for the newsletter.

I am sure you will all agree they have been a fantastic and inspiring read, especially to all our younger members!



WELL DONE AND CONGRATULATIONS DANIEL

Save the Date

Saturday 4th March 2017

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

The band, GOTTA GROOVE, will get you all on your feet to dance the night away.

There will also be a quality finger buffet to enjoy.

On the night there will be an auction. If you, your work place, or anyone else you know wish to donate something for the auction, that will be fantastic and much appreciated.

Tickets are £15 per adult, kids £5, and under 5s are free!



The event will be held at;
**The British Legion, Ruiton street,
Dudley, DY3 2EH**

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

We hope to see you there!!

THANK YOU

We would like to give Stuart a huge thanks from all of us here at the Society. All your hard work and time spent on organising this event is very much appreciated, and any money raised will play an enormous part in helping the Society continue supporting our members.

If anyone has any raffle prizes they could donate please let Stuart know.

Keeping it Cool!

This blog is about one family's journey with Ectodermal Dysplasia. Megan Jones, one of our members, is mum to 2-year-old Hamish who has HED.

'When we were researching "Ectodermal Dysplasia", we found the 'scary stuff' first. We didn't find information or stories on families in the same or similar situation, and fretted – unnecessarily – about the 'small stuff'. So, Keeping It Cool is not only here for our family and friends to follow Hamish's progress, but for others living 'Life with Ectodermal Dysplasia'.

Please go to www.edkeepingitcoolblog.wordpress.com and have a read, it really is a great blog! Well done Megan and thank you!!



Virgin London Marathon 2017

The ED Society have managed to secure a place for the London Marathon 2017!

Small charities find it extremely difficult to obtain a place in the marathon and it has taken us many years of applications. We were therefore absolutely thrilled to get the news that we had received a place through the charity ballot!

We would like to thank all our members who showed their support and interest in wanting to take part.

Clive Bentley put his name forward for the place, and has been chosen to run for the Society;

"I had the opportunity to run the London Marathon in 2001. I had undergone surgery to remove a brain tumour ten months before, and although the prognosis was very grim (I was actually only given six months to live), I got myself fit enough to complete the marathon. I raised a lot of money to donate to The Brain Tumour Charity, formerly known as the Samantha Dickson Brain Tumour Trust.

Miraculously, and against all the odds, I am still fit (relatively) and healthy. I am still under the hospital and yearly scans have not seen the tumour come back. So 15 years later and two stone heavier, I still run but not to the level I did before. I have turned 50, but still feel I have the mental and physical determination to get myself fit enough to complete the marathon, once again raising lots of money for a cause that is close to my heart.

Our youngest son, who is now 20, has Hypohydrotic ED. Over the years, we have seen him cope with lots of issues with overheating and his lack of teeth. He has undergone a lot of dental treatment which is on-going, and last year implants were tried in both his upper and lower jaws. These were not 100% successful due to the lack of bone on the bottom jaw, and seeing him beside himself with pain was very distressing. He faces further work which

may well include a bone graft before the next attempt to provide implants.

We are very grateful for the support and knowledge that the ED Society has provided us with. The opportunity to be able to raise several thousand pounds in sponsorship would be the least I could do to show my appreciation to an organisation that has provided so much good advice, encouragement and helpful medical support to us, and so many others who either have ED or family members who are affected by it.

I have a wide network of friends and family who have seen first-hand the issues our son has faced growing up. We have moved several times over the years and the support and generosity we have experienced from them has been phenomenal.

I am employed by a national based company and support from work colleagues for fund raising is the norm. I belong to a local church of 800 people who are like a large group of close friends to us.

My wife thinks running the marathon for the ED Society is a great idea. She has got some great ideas of fund raising events to help increase the total raised which I can donate. I am sure she would also welcome getting a slimmer, fitter husband once more!"



Please help show your support to Clive and the ED Society by going to the virgin money giving page and making a donation. No matter how big or small, your generosity is much appreciated.

<http://uk.virginmoneygiving.com/CliveBentley>



He's Too Young for Dentures

By Frank H. F. Frank H. Farrington, D.D.S., M.S.

Virginia Commonwealth University, School of Dentistry

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He is too young! He'll never wear dentures! He'll never be able to keep them in? Let's wait until he is 7 or 8! We'll make him an upper denture only around age 7! You're just thinking of yourself! It can't be done!

There are probably many, many more, but these maybe some of the responses that you as parents have when you take your preschool child for a dental appointment to inquire about dentures to replace missing teeth.

These are most certainly negative responses and do nothing more than frustrate you as a parent especially since you have nowhere else to turn. What the dentist may really be saying is: "I have been making dentures for adults, and you expect me to treat this 2- or 3-year-old? "I'm really uninformed about the nature of the problems associated with ectodermal dysplasia." "I've never really made dentures for someone this small." "I was not taught this in dental school."

To me, these responses indicate the dental profession needs to consider realigning the thinking of many of us regarding early treatment for these children. Let me assure you that dentures can be made, should be made and are being made successfully for children at an early age.

It must be realized that the chance of finding a dentist with any experience, let alone extensive experience, in treating the dental needs of children with ectodermal dysplasia is going to be rare. The chance of treating a pediatric case during training, even in specialty programs, is not very great. The chance of seeing cases in the average dental practice is also rare.

"Let me assure you that dentures can be made, should be made and are being made successfully for children at an early age."



Joseph Sylvester, age 5, shows off his new dentures and his million dollar smile!

Most of us have become educated in these cases through trial and error, and I admit that I too, was somewhat skeptical about proceeding with making dentures for 2- and 3- year olds. When encountering my first patient, my feeling was then and remains so today that we have much more to gain if the dentures are successful than we have to lose if unsuccessful.

The basic procedures for denture construction is the same for a child as for an adult, everything is just smaller and we, dentist and parents, have to be aware that treating what the teeth are attached to – the child – is as important as the mechanics involved. The overall experience for the child, family and dentist will make further treatment easier for everyone in the future.

Let's look at some of the positive results that can be accomplished with dentures for the young child affected by ectodermal dysplasia.

Improved jaw development and tissue development around the mouth.

Improved esthetics – Dentures will create an age-appropriate facial appearance. The child does not have the "old man" appearance resulting from over closure of the jaws.

Improved social well-being – The child becomes happy and smiles instead of frowning; for the most part, he looks like his peers. He is not afraid to interact with other children.

Improved psychological well-being – The child will feel better about himself and as a result will exhibit more self-confidence. Small children affected with an obvious physical deformity, such as the lack of teeth, run the risk of low self-esteem.

Improved mastication – There is no doubt that the child will function better with teeth than without teeth and quite possibly will not be affected with some of the digestive disorders which may be associated with having no teeth.

Improved speech development – Speech will be much improved resulting in an increased vocabulary and communicative skills as well as interpersonal relations.

Psychological uplift to the entire family.

Early treatment for the child without teeth is important and necessary. By improving the child's appearance, we provide for a more normal physical development through better nutrition and psychological development through better social and emotional adjustment. The impact can be quite dramatic.

The transition may not be without traumatic incidences. Problems do and will arise. But in most instances, these hurdles can be cleared through a cooperative effort between the child, parents and the dentist.

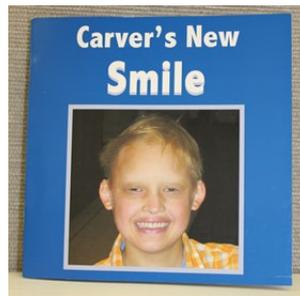
8 Tips for Getting Your Child To Wear Dentures

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We asked our families for their best advice. Here's what they said.

1. **Bribery!** Determine treats or prizes that the child would earn for wearing their dentures "x" amount of time each day. Increase the times until he or she is wearing them all day, every day. You could do a star chart if they are younger. Or, you and your child (of any age) could create in advance a list of the prizes they would like to have if they wear their dentures for a week.
2. **Ask grandparents to help.** Have an adult, such as a grandparent, who wears dentures talk and help your child throughout the process. They can help teach them. Also, the child will feel better with someone they know having them, too.
3. **Be persistent.** Don't give in. It's much easier to get children to wear them for the first time when they are young than when they are in junior high. Follow them around for the first week. Every time they take them out, put them back in. Don't let them stop wearing them! One mom said, "My son had dentures at age five and refused to wear them and we relented. He is now 19 and trying again but has very little bone. Implants are probably in his future and who knows what all. I so wish we had made him wear them."
4. **Read Carver's New Smile with your child.** NFED mom, Julie Claeys, created this children's book which tells the story of her son, Carver, and his adventure getting his dentures. It's

a must have for your younger children. Order yours at NFED.org.



5. **Be sure they fit right.** Remember that your child is growing, but those dentures do not. She needs a new set every one to two years, depending on how much she's growing. Don't be afraid to make SEVERAL trips to the dentist. They need to fit right!
6. **Have fun with it.** My son likes it when we make his teeth talk to him before putting them in. His teeth are "silly" and always excited about being in his mouth. He loves it and really looks forward to putting them in his mouth.
7. **Let them eat steak!** Ok, that may not be at the top of their list, but find things they couldn't eat before the dentures. Have them write down the foods they can't eat but want to once they have their dentures. Once the dentures are in place, try these new foods they have been waiting to eat.
8. **Celebrate!** If they are younger, download the Tooth Party Kit from our website. Have your Tooth Party to celebrate their new smile and the fact they are wearing them. If they are older, figure out what kind of party interests them and host one.

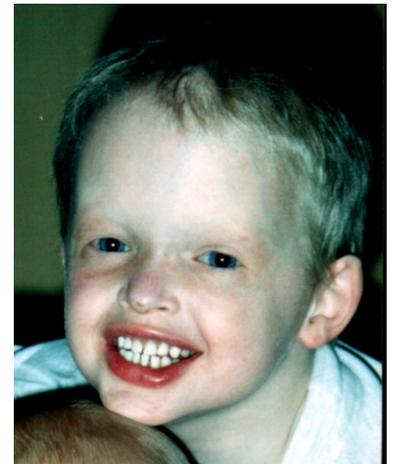
So how do you put the dentures in? I asked my elderly mother – put the top dentures in your mouth, place your middle finger on the roof of the dentures, push up, suck and swallow, and this should create a suction. The lower dentures are much easier and just need pushing down into place using two fingers on either side – they are held in place by facial muscles rather than suction.

Dentures Rubbing? If you are having treatment at a dental hospital it is not necessary to travel all the way back for minor adjustments – you can pop to your local dentist who will be happy to help.

Why Dentures?



To have a happy smile



Everyone should have a happy smile

Dealing with bullying



Contact a Family have a huge library of resources for parents.

One of their popular guides *Dealing with bullying* for parents of disabled children explains how to

- spot the signs of bullying
- how to support your child if they're being bullied
- dealing with the school
- what you can do to stop the bullying
- stories and tips from other parents
- tips on dealing with cyberbullying
- how to get help if your child is exhibiting bullying behaviour

Contact a Family is one of a group of organisations led by the Anti-Bullying Alliance who are working to reduce the bullying of children with special needs.

Contact a Family offer a range of free information sessions for parents of children with disabilities or additional needs around the UK. They also run free sessions for professionals supporting families with disabled children.

For all information, resources and support visit www.cafamily.org.uk or call 020 7608 8700

*This article has been taken from Contact a Family
Connected magazine*

Fundraising Our grateful thanks

The many donations that have been coming in over the past 3 months amounted to over £3200.00

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

Many thanks to Mark and Vicky Macnair for their continuing support raising another £336.50.

Thanks again to Bottomline Technologies for a further £100.

We have received further donations in memory of Fergus Gordon and the total is now just over £2000.

Many thanks to Gordano Djukanovic who works for Kroll Ontrack and raised £147.34 from holding a charity bake sale.

Huge thanks to Dave and Tracey Willats for holding their 12th Race Day and raising the fantastic amount of £1,357.50.

Thanks also to Sarah Jones for holding a charity event and raising £225.



The Ectodermal Dysplasia Society, Unit 1 Maida Vale Business Centre, Cheltenham, Gloucestershire. GL53 7ER England

Tel: +44 (0) 1242 261332 Mobile: +44 (0) 7774 465712

www.ectodermaldysplasia.org

Email: info@edsociety.co.uk

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