

TCFSG NEWS



AGM TIME

As the Project enters the final stages of its first year it is pleasing to be able to report that our plans for the initial twelve months are well on the way to being met. Our Project Worker, Neil Moore, has done well to stay on track, often working on his own initiative, making the sub-committee's duties much easier.

Following receipt of completed questionnaires, Neil can now begin collating all the information onto a database which will assist the TCFSG identify the needs of its members.

Sources of funding for the continuation of the Project have been identified. However, it is difficult to predict how successful our applications will be.

Hopefully we can update you at the Annual General Meeting which this year will be held in North Shields. We trust this will prove popular and accessible to those of you who live in the north. It will certainly be enjoyable to meet those who, for various reasons, have been unable to travel south in past years, as well as catching up with familiar faces.

It's not too late should you wish to make a nomination for the Achievement Award, but you'll have to be quick! Address them to Alan Hird as soon as possible.

If you are unable to attend the AGM why not get in touch; either by letter, e-mail or give us a call. Help us to help you!

Best wishes

Stuart Dolton
(Chair, Subcommittee)



The 2001 AGM is being held at
Royal Quays Community Centre

North Shields, Tyne & Wear
Saturday 20th October, 2.30pm
Full details enclosed

(See also www.treachercollins.net for more information about accommodation, the local area etc.)

From The Daily Telegraph...

New ear makes Emma smile

By David Derbyshire, Science Correspondent

A GIRL born with most of her ear missing has received a replacement moulded from part of her ribcage.

Emma Bayliss, nine, had five hours of reconstructive surgery at Mount Vernon Hospital, Northwood, north-west London. Surgeons removed cartilage, the tough, connective tissue, from her ribcage, moulded it around a frame and attached it to her head. The cartilage frame was then covered with her skin.

Because the substance is cartilage instead of silicone, the ear should feel more like a real one than in traditional prosthetics. If it became damaged in an accident, it would be more likely to repair itself.

Emma, of Kilburn, north-west London, said that since the operation she had no longer been teased at school. "I was born with part of my ear missing and part of it tucked over it like an envelope," she said. "I feel a lot happier with my ear now."

Her mother, Jacki Bayliss, said the operation had changed Emma's life. She had been self-conscious before.

David Gault, the surgeon who performed the operation, said: "The effect of these operations can be quite remarkable."

Many thanks to Liz Brown for sending us this article



Can You Help?

As well as sending us the above article Liz Brown has a couple of questions.

Firstly she was wondering if a digital aid would work with a bone conductor and perhaps provide a better quality of sound.

There is no reason why a digital aid would not work but the quality would be restricted by the bone conductor itself and therefore (we are told) it is doubtful that there would be any noticeable improvement. However, in the early days of BAHA there was no actual proof (there is now) that it provided improved reception although everyone who had one said it did. Maybe we won't know definitely about the performance of digital aids until someone who has one can give their opinion.

Do you, or someone you know, have a digital hearing aid with a bone conductor which replaced an analogue one? If so please let us know how it compares.

Secondly, does anyone have any suggestions about aids which could be used in water for swimming lessons? There are covers available for protecting post-aural aids from water but these cannot be immersed in water as the microphone needs to remain uncovered. Has anyone dared to try sealing an aid in polythene or similar? It should work but.....

If anyone has any ideas, suggestions, tips or whatever on any aspect which they think may help others then please let us know. Perhaps this could be a regular section in the News.

The Questionnaire

Many thanks to everyone who has returned their questionnaire.

The response so far has been quite good but ideally we would like everyone to complete one so we can gather as much information as possible.

If you haven't sent your questionnaire yet please consider doing so.

Let us know if you need a replacement, we're more than happy to send another.

**Thanks to Dean Pepall, whose son has TC,
for his efforts in raising funds for the Group.**

Dean works at BBC Radio Sheffield and, with two colleagues, has entered a regional quiz three times now. They won the first two and were disappointed to only come second in the other! Altogether they have raised £500.

Think we know who we want on our team! Who knows, perhaps it will be "Who wants to be a Millionaire" next although we think their efforts already are worth a million to us.
Many, many thanks Dean and well done!

The TCFSG relies almost entirely on donations for its funding.

If you can help by holding an event, however large or small, then go for it!

It could be a sponsored swim or slim, a coffee morning or a car boot sale. The possibilities are endless.

If you are able to do something tell us about it and we can feature it in the Newsletter.

Please send any donations to the TCFSG Treasurer
Tony Dixon, 31 Parnell Close, Chafford Hundred, Grays
RM16 6BO

**The Treacher Collins
Family Support Group**

Chairman

Alan Hird, 3 Thornton Road,
Bury St Edmunds IP33 2EF
☎ 01284 706101

Secretary

Sue Moore, 114 Vincent Road
Norwich NR1 4HH
☎ 01603 433736

Treasurer

Tony Dixon, 31 Parnell Close
Chafford Hundred, Grays RM16 6BQ
☎ 01375 483638

CONVALESCENT FUND

Need a break?

You can apply for a grant of up to £200 to help with the cost of convalescence.

A letter of recommendation will be required from a medical professional.

To apply contact:

Sue Moore, 114 Vincent Road, Norwich NR1 4HH.
Tel. 01603 433736. Email sue@treachercollins.net

Please send all letters, articles, pictures or anything else
for inclusion in the TCFSG NEWS to
Neil Moore, 114 Vincent Road, Norwich NR1 4HH
Or mail@treachercollins.net

The Puzzler

Well Done to Mark Ellis of Oulton Broad, Suffolk, who won the £10 gift voucher from the last Puzzler as he was able to explain why Winston Churchill had more than the average number of legs!

“Because in any sample there should be at least one person with only one leg the average will always be less than 2.

Winston Churchill had 2 legs therefore he had more than the average number of legs.”

Now for this Puzzler...

For a chance to win a £10 gift voucher all you have to do is answer these three questions:-

1. Name the 78 year old British comedy writer/performer who wears glasses without glass!
2. Why does he wear them?
3. Name his latest film appearance and the actress who stars in it.

All correct entries received by the closing date of **15th November 2001** will be put into a random draw.

Contact Register

If you want help, information or just someone to talk to the contacts on this page will be happy to hear from you

**Louise Ritchie, 14 Glamis Avenue,
Newton Mearns, Glasgow G77 5NZ**

"Our daughter Lucy was born with TCS in March 1996. Choanal Atresia was the first complication that Lucy had to deal with. Stents were put into both nostrils for about three months after she was born, however to date her nose remains 'blocked and snotty'. The Choanal Atresia made feeding a big problem and Lucy was fed orogastrically until a PEG was inserted at two and a half. I never gave up trying her with different foods and drinks, and now Lucy eats well. Following very scary breath holding episodes Lucy had her jaw distracted when two and a half. At the time of the surgery a BAHA was fitted."

**Lynda Campbell, 51 Cluny Road,
Dingwall, Ross-shire IV15 9NS**

"I am a YOUNG middle aged mum with Treacher Collins and have two children who also have the same condition. They are Carla who is 25years old and George who is 23 years old. I am very happy to be contacted by anyone who wishes advice, information about Treacher Collins and I am also happy to meet or visit families who would like some moral support."

**Yvonne Gough, 7 Islington Close,
Newport, Shropshire TF10 7TT**

**Mike & Helen Wilson, 41 Mary
Vale Road, Bournville,
Birmingham B30 2DP**

"We have three children. Rachel (aged 10) is the youngest and has fairly mild TCS (spontaneous as far as we know). It was diagnosed at birth by a young registrar who was very much on the ball. She has a moderate hearing loss and went through behind the ear and in the ear hearing aids with limited success, before getting a BAHA almost 3 years ago. She has had one or two problems with the BAHA that we weren't warned about by the hospital which we could share. Rachel is a patient at Birmingham Children's Hospital. Her ENT consultant is Mr Proops and her craniofacial consultant is Mr Wake. We live about 4 miles from the BCH and so would be in a convenient place for anyone who came here for an operation. Often it is good just to get away from the hospital environment. We would like to feel that if anyone wanted just to talk we could be at the end of the phone."

**Liz & Lexi Brown, 91 Whitehouse Park,
Newtownabbey, Co. Antrim BT37 9SH**

"Looking back over the past nine years we have dealt with a trachy for 3 years, a NG tube followed by a PEG tube and recurrent reflux, removal of the PEG tube despite ongoing feeding problems and early experience of the bone expansion technique on the lower jaw. Lots of experience at dealing with schools, speech therapists etc. etc. And of course lots of experience at living life with a child with an unusual appearance and all that it involves!"

**Diane Mifflin, 2 Saltwells
Drive, Muxton, Telford,
Shropshire TF2 8RJ**

"My particular experience is with hearing problems and the use of a Bone Anchored Hearing Aid. My own daughter was just four years old when her BAHA was fitted and if I could be of any support to a family with a young child contemplating this procedure I would be happy to do so. I have myself appreciated support from members of the Group in the past and know that to share a problem can be a great encouragement."

**Sue Dunham, 39 Duke Street,
Abertillery, Gwent NP3 1BE**

**Julia Ziomek,
26 Napier
Street,
Mountain Ash,
South Wales
CF45 3HW**

**Dawn Liddle, 2 Westcombe
Road, Templecombe,
Somerset BA8 0LH**

**Chris & June Chambers, Flat 10, Carlton Dene, 21 Stourwood Avenue,
Bournemouth BH6 3PW**

"We have a daughter who has TCS. She is now in her early 30s so we have experienced struggles before the advent of the Family Support Group when we were completely on our own. We still remember the problems experienced particularly in baby and early toddler stage which, given our present knowledge, we could have overcome more easily. We have guided her through primary and secondary education, teenager-hood and then on through University and her professional qualifications. During this time we have experienced both successful surgical operations and those which were a complete flop or where later complications set in. We have learned that you must, on occasion, fight for the medical services that you know your child needs without regard to upsetting "learned" professionals. We have struggled with earlier bone conduction hearing aids and enjoyed the success of the BAHA. We would be happy to talk over any problems with TC families who are experiencing difficulties or with those who just want to talk."

**Sandra & Mark Ellis, 21
Beverly Close, Oulton Broad,
Lowestoft NR33 8QQ**

Hazel was diagnosed soon after birth as having Treacher Collins Syndrome - which we had never even heard of. We then entered a period of coming to terms with the news. (After consultation with a geneticist, my husband was 'diagnosed' as having the syndrome in a very mild form.) At the age of about 6 months Hazel was issued with a Bone Conductive Head Band. A Teacher of the Deaf visited Hazel regularly during her pre-school years. At the age of 7, at the Norfolk & Norwich Hospital, Hazel had the 2-stage operation for a Bone Anchored Hearing Aid, which was fitted in May 1999. Hazel has had surgery to close a nick in a lower eyelid and to help correct a drooping upper eyelid.