

tofs chew

Autumn 2010

Support for families of children born unable to swallow

TOFS (Tracheo-Oesophageal Fistula Support), the charity that supports families of children with Tracheo-Oesophageal Fistula and associated conditions

Pictured: Pictured: Freya Rowley all dressed up for her christening! Read more about Freya and her family's fundraising support on p2.

Inside

- Find out about TOFS Awareness Week
- Final call for our TOF adult conference!
- A chat with our new medical Patron
- More pictures from the TOFS Children's party

...and much more!



Want to make a difference? Fundraise for TOFS.

Please call us on 0115 961 3092

From the editor...

Welcome to your Autumn issue of *Chew*!

Autumn already! How did that happen? Thank you for all your letters and emails. It sounds like you've had a busy summer! In this issue, we share lots of great fundraising stories, plus news from our TOF families. We tell you all about TOFS Awareness Week which is just around the corner! You'll also find our final call for bookings for our first conference for adult TOFs. If you want a place, please contact us to book your place now! Also inside you can read a fond farewell from ex-Chairman of TOFS, Gren Shepherd! Plus we talk to surgeon and new TOFS patron, Mr Edward Kiely.

Please keep in touch and send us your photos (in digital format please!). We love hearing from you and sharing your news.

Camilla Zajac, Chew Editor

WELCOME

A warm welcome to new members!

- Bernhard Warner and Cristina Duranti from Rome - Teodora born 04/09/09
- Faye Salisbury and Colin Blackmore from Stockport - George born 13/05/10
- Kimberley and Daniel Smith from Bridlington - Hugo born 11/05/08
- Sharon and Thomas Robertson from Renfrew - Madison born 07/02/09
- Sarah and Simon Mayes from Suffolk - Maggie born 18/11/09
- Kelly Sweeney and Michael Hobbs from Aylesbury - Harry born 11/05/10
- Kellie Woodvine and Damien Campbell from Crewe - Chloe born 05/04/10
- Barbara and John Payne from Leeds - Charles born 08/01/92
- Heledd and Iwan Davies from Cardiff - Efa born 02/03/07
- Catherine and Daniel Cobden from Worthing - Oliver born 14/07/09
- Kathleen and David Thomas from Nottingham - Kai born 19/04/10
- Blanche and Colin Bowen from Basildon - Amber born 24/02/10
- Belinda and Simon Webb from Reading - Chloe born 03/06/10
- Zoe and Damian Moran from Mid Glamorgan - Ruby born 06/09/06
- Graham Lewis From Ceredigion, Wales - Grandparent

Chew cover story: Freya Rowley

Pictured on the front of this issue is Freya Jenner Rowley on her christening day on 10 July! The christening took place at St Nicholas' Church in Harpenden and Freya's mum and dad, Rachael and Dominic, kindly asked their guests to consider making donations to TOFS and/or Great Ormond Street Hospital instead of presents. They raised £145 for TOFS!

Freya was born on 2 January 2010 at Luton & Dunstable Hospital and was diagnosed with TOF/OA shortly afterwards. Her mum and dad tell us:

"Freya is a very determined and alert young lady, who was crawling at seven months old. This was particularly memorable as it was on the first day of a family holiday in France with her grandparents. She has an award-winning smile and the most delightful happy personality. We are so incredibly proud of her.

She has never taken much milk, but is very adventurous with lots of different stage one solids. We are slowly progressing with some more challenging textures, learning which foods to avoid, aided by advice on the TOFS forum, website and publications."



Fun for Freya and family on her christening day!

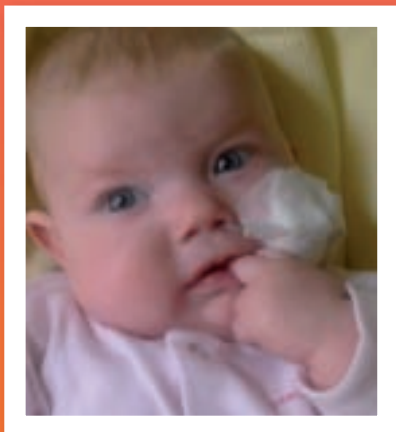
Family Update

Andrew Iveson writes from Hull:

Lavinia was born on 21 December 2009 with a long gap OA with no fistula. They kept her in NICU with a relogal tube until she was three months old when they did a colonic interposition (see p10 for definitions) which was performed by a wonderful surgeon (Miss Besarovic). Lavinia was intubated for a week until they tried to extubate her, but this was unsuccessful as she now had a narrowing of the upper part of her airway. She was then transferred to Mr Crabbe in Leeds who tried three times, but couldn't get her off the ventilator. Eventually she was successfully extubated. After a week we went back to Hull and after a further two weeks Lavinia came home. She lasted two days and had to go back in for another week as she needed a dilatation. This was all successful and Lavinia finally came home properly at five and half months old.

Lavinia is fed through her jejeunostomy and her medication is given to her through a gastrostomy tube. She is on a monitor to check her saturation levels and we have a suction machine at home. This may sound a pain to some, but is reassuring to us! Lavinia still has lots of hurdles to overcome, but we have found if you look at all of the problems she has or could have then you go crazy, so for the minute we are delighted that her OA repair has been done, that she has no tracheostomy tube in and that she is home and smiling!

We have had the natural thoughts of "Why us?", "What is a TOF?" etc which is where TOFS really has helped and we have made some friends who have helped us so much too! My only suggestion is that you consider creating a booklet that is a record for parents that they can refer to and to give to people who treat their child. Every TOF is so different and we have had to explain Lavinia's problems to so many people that we have lost count and lots don't understand just what she has been through when she is looking well.



Lavinia who is "home and smiling" according to her dad!



Rowan, his mum and dad's "absolute pride and joy".

Caring for a child with Down Syndrome and TOF/OA

We recently heard from Lauren Flambard, mum to Rowan. She would like to make contact with other parents of children born with TOF/OA and Down Syndrome. If you'd like to talk to Lauren, please contact her via the TOFS Office on 0115 961 3092 or by email at office@tofs.org.uk.

Rowan James Flambard was born on 13 June 2009 in Jersey, after an uneventful pregnancy. We were surprised by how small Rowan was (5lb 9oz) and he seemed quite floppy, but apart from that we didn't notice anything strange. He was born early evening, and we tried to feed him several times through the night, but he didn't really take much.

The next day, the doctors told us that they suspected Rowan had Down Syndrome, which was a big shock. He was then taken to the Special Care Unit to be fed through NG tube as they thought that his low muscle tone (one of the signs of DS) was causing the problem with feeding, and at that point they discovered that Rowan had OA and an x-ray showed up TOF as well. We had to fly out to Southampton Hospital the next day, where his OA and TOF were repaired by the wonderful Mr Burge. The diagnosis of Down syndrome was confirmed a few days later.

Thankfully his gap wasn't too big, and a few days after his op, Rowan began to breastfeed which we continued successfully until he was six months old. He coped fine with stage one foods and now we've moved on to stage two foods, with the odd more challenging thing (e.g. toast, bigger lumps and finger foods) thrown in. He's had a couple of "stucks", but has been able to clear them himself by regurgitating them.

Since his difficult start in life, Rowan has amazed us on a daily basis. He has already beaten all our expectations, especially in terms of recovery from his operation, and he is our absolute pride and joy. As you can see from his photo, he is a very happy little boy.

If there are any other members of TOFS out there who have a child with Down Syndrome and OA/TOF, we would love to make contact as we have found that the two issues combined give a slightly different slant to the already complex area of feeding and eating. We would really like to hear how other parents have dealt with the challenges and helped their children to progress.

Happy Birthday

Happy Birthday to all our children who have recently celebrated a birthday! Our birthday fairy has been sending out cards to all of you under the age of six. And congratulations to those of you aged six and over in September, October and November!

Members' birthday in September, October and November – 6 to 16 years

September

Jules Armand 20/09/1994 **Robert Youngs** 10/09/1995 **Carly Campbell** 09/09/1996 **Frazer Earl** 13/09/1996 **Kate Robbins** 15/09/1996 **Daniel Green** 15/09/1996 **Christopher Benjafield** 04/09/1997 **Samuel Riley** 09/09/1997 **Martin McDonnell** 16/09/1997 **Amy Lawton** 26/09/1997 **Bethany Gardner** 09/09/1998 **Jamie Gorman** 25/09/1998 **Phoebe Crabtree** 01/09/1999 **Daniel Turner** 03/09/1999 **Lewis Espley** 04/09/1999 **Megan Byrne** 20/09/2000 **Thomas Spencer** 18/09/2001 **Harry Knighton** 19/09/2001 **Richard Weedon** 21/09/2002 **Rebecca Crowe** 26/09/2002 **Joseph Ng** 14/09/2003 **Joshua Earl** 24/09/2003 **Daniel Jeffreys** 09/09/2004 **Amy Fox** 18/09/2004

October

Trevor Button 15/10/1994 **Matthew Barker** 18/10/1994 **Thomas Clark** 19/10/1994 **Alice Wilsmore** 28/10/1994 **Thomas Larby** 31/10/1994 **Phillip Mainwaring** 21/10/1996 **Annie Mae Doherty** 12/10/1997 **Francis Harrison** 22/10/1997 **Louise Chase** 18/10/1998 **William Matthews-boote** 22/10/1999 **Caitlan McCoy** 26/10/1999 **Bernadette Quinlivan** 05/10/2000 **Corin Astles** 09/10/2000 **Bailey Stark** 13/10/2000 **Bethany Patton** 19/10/2002 **Elliot Anderson** 20/10/2002 **Dylan Baker** 22/10/2003 **Lucas Nixon** 27/10/2003 **Adam Howarth** 31/10/2003 **Louisa Shadlen** 21/10/2004

November

Stephanie Boggis 03/11/1994 **Eleanor Garside** 09/11/1994 **Henry Waterfield** 23/11/1994 **Jaqueline Tilly** 20/11/1995 **Christopher Halsey** 24/11/1995 **Ciara Myton** 09/11/1996 **Liam Viljoen** 08/11/1997 **Eleanore Derham** 18/11/1997 **Max Williams** 23/11/1997 **Kate Remmington** 26/11/1997 **Jodie Kreft** 28/11/1997 **Miles Caven** 19/11/1998 **Adam C Williamson** 17/11/1999 **Maddison Tyrer** 21/11/2000 **Dylan Robinson** 07/11/2001 **Sinead Forde** 08/11/2001 **Antonia Maria McGrath** 18/11/2001 **Elliot Smith** 20/11/2001 **Saffron Corbett** 27/11/2001 **Louis Smith** 28/11/2001 **Morgan Miles** 29/11/2001 **Luke Warburton** 03/11/2002 **Milly Dimelow** 07/11/2002 **Nathan Ayling** 11/11/2002 **George Plapoutas** 14/11/2002 **Benjamin Sims** 27/11/2002 **Matthew Dolan** 28/11/2002 **Isobel Cattle** 19/11/2003 **Elizabeth Mole** 21/11/2003 **Benjamin Bailey** 08/11/2004 **Amy Ansbro** 20/11/2004 **Honey Chapman** 21/11/2004

Fundraising

Donations and fundraising

We'd like to thank:

- Claire and Dominic Stewart - £120 sent in lieu of wedding gifts
- Brownhill's Musical Theatre Company - £25
- Laura Tanter - £50 donation
- Carole James (aunt to Nathan Hill), along with members from a chronic illness course - £240 raised by completing a 2.5km walk
- Dianne Pledger - £20
- Emma Johnson - £140 raised by completing the London 10K along with £1285.38 raised to date through Just Giving
- Mick Brown - £500 raised by taking part in the Edinburgh Marathon
- Thank you to our Trustees who very kindly donate some of their expenses back to TOFS.

Corporate and group donations

- St Augustine's R.C. Primary School - £120
- Arcadia Group Limited, Wallis HR - £96 raised by holding a cake sale
- Longcroft School - £300
- The Freemasons' Grand Charity - £2000

A fundraising family tradition

This serial fundraising family have done it again! We've regularly celebrated the efforts of young TOF, Alice Wilsmore, who has taken part in the seven mile Thurrock Cycle Marathon for TOFS for the past five years. This year, Alice, her mum Ann-Marie and her sister Laura couldn't take part. But Alice's dad, (Ian Wilsmore) and uncle (Andrew Offord) continued the family tradition by taking part and completing 21 miles instead of the usual seven. They did it in under two hours and raised £127 for TOFS into the bargain!



Take part in the TOFS 200 Club

Congratulations to our latest winners:

June - Susan and Clifford Chipperfield
July - Susan Martin

Would you like to be in with the chance to win – and raise money for TOFS at the same time? All you have to do is make a minimum donation of £1 a month for one year to TOFS (£12). We will allocate you a number which will be entered into a monthly draw with a single prize of £50 a month. The lucky winner for the month will receive a cheque! Get your family, friends and colleagues involved too – the 200 Club is open to everyone (and you don't need to be called Susan to win!).

Mum on the run!



Rachel Hadfield, mum to Beatrice, told us she was a little nervous before her recent fundraising effort for TOFS, running the Pennine Lancashire 10km race in July. She said:

"Apart from taking Beatrice for walks I have done no exercise since I found out I was pregnant with her (she has just turned one) so this felt like a HUGE challenge for me!"

We are happy to say that the event was a great success and Rachel and her husband, Mark raised £249.09 for TOFS! Rachel tells us:

"I made it round in one piece! It was quite a windy day, but I managed to finish in a time of 1 hour, 7 minutes and 48 seconds, which is excellent considering the lack of training! Beatrice is doing OK at the moment although we are taking her for dilatation number ten soon."

Strictly fundraising

We are very grateful to TOFS supporters who tell people about us and how we support TOF families. We were delighted to receive a donation from the Charity Drive at Merchant Taylors' School in Northwood, Middlesex. They chose TOFS as the beneficiary of a £1000 donation, thanks to a recommendation from Debrah and Edward Craven-Smith, mum and dad to young TOF Barnaby.

Daniel Edward, the Secretary of the school's Charity Drive, said:

"Each year the Charity Drive committee at Merchant Taylors' School, Northwood selects a variety of charities to support (some local, some national and some international). The Charity Drive has spent the last year organising and running a multitude of fun events to raise money for various charities. Events ranged from a Strictly Charity Dancing event with several professional dancers, including Karen Hardy, to the ever popular Sponge The Teacher! We also had great fun with other events such as the junior school read-a-thon and teacher blind date. We are delighted to be able to support TOFS and hope to do so again in the future!"



Bright sparks

We were pleased to hear again from Zoë Powers who has supported us with lots of great fundraising activities. Zoë's son, Colin, now all grown up, was born with TOF. Following on from Zoë's update in the summer issue of *Chew*, she told us about a bright little fundraiser held as part of a Founders Day event at Hitchin Girls' School where she works. Zoë says:

"Year 7 of Frank House raised £37.97, which included money from selling sunglasses. I had a job lot which I got on eBay a few years ago when Colin wanted some sunglasses. He had a couple of pairs, but there were lots left over (nearly 50!). They came from a warehouse closure and didn't cost much. I had never got round to re-selling them, so donated them to Year 7's stall. We had a sunny day, and they only had three pairs left at the end! I have really enjoyed seeing the efforts of the girls in Frank House raising money for TOFS, and I think they have enjoyed doing it too."



A funky fundraiser

Another fundraising regular whose name you might recognise is TOF mum, Joanne Ansbro. As well as being a proud mum to Amy, Joanne enjoys coming up with fresh fundraising ideas to help raise money for TOFS! The latest event was no exception - a Zumbathon! According to the Zumba website, Zumba is "a fusion of Latin and International music that creates a dynamic, exciting, and effective fitness system". Joanne worked with Zumba instructor Susan Spinks, to organise one of the UK's first Zumbathons and raised £1206 in the process!

Participants enjoyed "Three hours of fabulous Zumba music", according to Susan Spinks. She says:

"We chose TOFS because the daughter of one of our members, Joanne, has TOF/OA and we like to help our members improve their quality of life both in the gym and in their home life. We hope that this money will help towards research and raising awareness about the condition."

Thank you for all your continued support, Joanne!

You can find out more about Zumba by contacting Susan Spinks 01325 360040 or taking a look at www.firststep2fitness.com.



Three cheers for three sisters

For the past four years, the inspiring young Cara Byrne has taken part in the Barking and Dagenham 3km fun run in support of TOFS. This year in June she ran again – accompanied for the first time by her sisters, Hazel and Megan! Cara's mum, Jenny explains:

"TOFS has been a great support for us as a family; Cara's younger sister Megan is a TOF. Megan had major surgery at the beginning of March (partial gastric transposition to a full pull up (see definitions on p10) and a previously undiagnosed fistula repaired), but she couldn't keep to a walk – she was too excited!"

Cara and her sisters managed to raise £230 this year. Cara has raised £551 for TOFS in the three previous years (£206 in 2009, £320 in 2008, £25 in 2007). We are very proud of her and Hazel and Megan are looking forward to running again next year and raising money for TOFS."

Thank you for all your support over the years, Cara, and congratulations to you and your sisters on your achievement!



A special christmas greeting

Reaching the peaks

Nick Darmon and three of his friends bravely scaled the dizzy heights of the Three Peaks Challenge for TOFS! Nick is brother to Louise Fox and proud uncle to four year old TOF, Gabriella Fox. Nick and friends completed the tough challenge in 21 hours and 52 minutes - and raised a fantastic £1322.50!

We know it seems too early to mention Christmas, but it's really not that far away! Just ahead of the festive season, we wanted to mention the generosity of members and others who give donations for TOFS in lieu of Christmas cards. This is very much appreciated and is also better for the environment! We are grateful to members who do this every year and also to Heather Marshall, who got in touch to let us know that she raised £124.36 for us in lieu of Christmas cards last year.

Friday 13th - lucky for TOFS



Ben Radford, Neil Ripley, Suzanne Thorne (with Isla), Karen Lawson, Sofie Baker (with Dylan and Daisy)

front row: Dhivya Puri, Harriet Ripley, Sharon Ripley Kyle Thorne

hope, and far more than the racecourse had expected, given that this was not a very busy day at the racecourse, with a crowd of some 4000.

And that's not all. We were given complimentary "premier" entrance tickets, enabling us all to spend the whole afternoon at the course as guests: so we all had the chance to enjoy (most of) a day at the races, before we got going with the actual collecting towards the end of the afternoon. For most of the TOFS group of 26 people, it was their first time at a horseracing event, so it was both exciting and interesting. A few of us placed bets, but we don't think anyone won much on the horses!

We set up a TOFS information stand in one of the Grandstand entrances at Newbury, so that we could tell racegoers a little about TOFS during the day. We also had a large colour advert about TOFS in the programme for the day (the racecard) again so as to explain ourselves somewhat.

The TOFS contingent included seven TOF families, with six TOFS present. There was of course a lot of chatting going on about living with the TOF condition. TOFS owes a big thank you to our collectors: the Foxes, the Radfords, the Clarkes, the Bakers, the Thornes, Ripleys and the Pearces, especially Alison. The best collectors were all ladies, with several people collecting over £100.

Newbury is a long way from the TOFS office in Nottingham. However I live in South Bucks, only 40 miles from Newbury and, as TOFS Vice Chairman and Trustee, headed up the event for TOFS "on the day".

We owe a huge vote of thanks to Nicola Butler, who is Sales Manager at Newbury Racecourse, and who invited us along. Her

TOFS Vice Chairman, John Pearce, tells us about a very special day out at Newbury Racecourse.

Friday 13th was TOFS's lucky day - we won at the races! Newbury Racecourse had very kindly invited TOFS to be the official charity of the day and to make the exit collection at the Racecourse. The total we collected was an amazing £1310 - far more than we dared

close friend Amy Fox has a TOF son Ethan, and is a member of TOFS. Amy and Ethan could not make it on the day, but Amy's parents Ann and Norman Fox were there. Nicola is now trying to get TOFS an invitation to be the official charity at Newbury's Family fun (horseracing) day in late July 2011. So there's a good chance that there will be another opportunity for TOF families to have a good day out - and do some good for TOFS - next summer. If you think you might be interested in taking part, please email the TOFS office, and we'll add you to the list of people to contact early next year.

Contact, contact!

Do you have a good sporting contact? After our success at Newbury Racecourse, we would like to become the official charity for the day at some other events. You might have a good contact at another racecourse, or with the organisers of some cricket matches, or perhaps Rugby or Football grounds, or maybe something like Polo? Please let the TOFS office know of any contacts which might potentially lead to TOFS being invited to make a collection somewhere else.

Collecting for TOFS

We would love to think that you are all dreaming up ways of raising the profile of TOFS where you live, and/or raising some money for TOFS. One of the most obvious ways to help TOFS raise money is via a collection - like the one we did at Newbury Racecourse. However there are strict laws about making collections in public places. These are quite demanding, and need to be followed in full. If you would like to make a collection for TOFS, the smart thing to do is to get written permission from the owner of a private space of some type: then there are few restrictions as to what you can do. Most indoor shopping centres are private land, as are most sports grounds, for instance. Contact the TOFS office for more information.



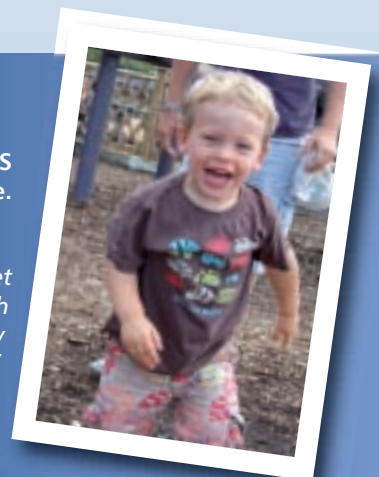
Veronica Radford, Norman Fox, Hannah (with Evie), Evie Clarke, Rory Clarke, Janet Clarke, Rob Pearce, Cherrie Clarke, Ann Fox (Norman and Ann Fox are mum and dad to TOF mum Amy Fox who is friend to Nicola Butler who works at Newbury racecourse.)

Party favours

Amy Fox, mum to Ethan (and part of the Fox family closely involved with the special TOFS day out at Newbury, above), told us about a regular family gathering with a difference. She wrote:

"We have an annual family party a week after Christmas, for my mum's extended family to get together, as my Grandad was one of nine children. The party supports a different charity each year, which relates to somebody within the family. In December 2008 they chose to raise money for a charity on behalf of Ethan and much to our delight, the party raised a huge £150 for TOFS!"

Thank you to you and your family for thinking of us at such a busy time of year, Amy!



11-18 October 2010 –

Take part in TOFS Awareness Week!

Throughout the week of the 11-18 October our members will be organising various local activities and events to help raise awareness and funds for TOFS! This special week culminates in our first conference for adult TOFs (see below)! TOFS Awareness Week is an important way you can help us build our profile amongst families and medical professionals - and support us by raising money to allow us to keep doing the work we do. Thank you so much to all of you who have really got behind TOFS Awareness Week and who already have plans underway to fundraise for TOFS.

We want to hear from you!

Are you planning something special for TOFS Awareness Week? We'd love to hear about it. We can let other members in your area know what's going on and we may be able to give you additional support to help your event go with a swing! If you haven't got in touch already, please email Diane Stephens at diane@tofs.org.uk with details of your event and we'll do our best to get it on the TOFS website!

Tell the world about your efforts!

Tell everyone in your town you're taking part in TOFS Awareness Week with one of our special posters. Just visit our website at www.tofs.org.uk to download your poster or call the office on 0115 961 3092 and we'll post one out to you.

We can create a tailored press release which you can send to local or national newspapers to publicise your story. Please email your child's details to diane@tofs.org.uk.

Our PR successes to date include (and our stars know who they are!): Edinburgh Evening News, Metro, Scottish Sun and Scottish TV, Daily Mail, Huddersfield Examiner and various others. TOF families have also been featured in the in-house magazine of the Passport Office, BT's in-house magazine and the NHS website:

<http://www.nhs.uk/Livewell/twins-and-multiples/Pages/premature-twins.aspx>.

Looking for ideas?

When it comes to fundraising, the possibilities are endless! It's just like the supermarket ad says - "Every little helps". You can do as much or as little as you can manage. It's up to you. We've seen members achieve great success with fundraisers such as:

- Parties
- Non-uniform day
- Collections at work
- Raffles
- Coffee mornings
- Second-hand toy sales
- Bag-packing at local supermarkets
- Sponsored events – not just sporting ones

The list is endless – see the panel on the right for even more inspiration!

Stay in touch!

We want to hear from you ahead of TOFS Awareness Week and we'd love to hear from you afterwards, too! Let us know about your plans and achievements – and send us your pictures (by email preferably). As our financial year ends in November, we would be very, very grateful if you could send in the money you raise by mid-November, but preferably in late October.

We look forward to hearing about your achievements!



What could you do for TOFS Awareness Week?

- Job swap
- Sponsored toddle, silence or tidy up
- Face painting
- Office quiz night
- Lucky dip
- Car boot sale
- Leg shaving
- Slave auction
- Hopping on the spot
- Pub games
- It's a Knockout
- Car wash
- Disco
- Fun run
- Netball tournament
- Aerobic challenge

TOFS Adult conference – your last chance to book!

Saturday 16 October, 2010 – 9.30 – 5pm
The Grimstock Hotel, Coleshill, Warwickshire
[Very close to NEC and Birmingham Airport at M6 / M42 junction]

Are you an adult with TOF/OA, a relative, healthcare professional – or the parent of a TOF teenager soon to make the transition to Adult Care? If so, the first ever adult TOFs conference is for you. But you'll need to book now for a place! Please call the TOFS Office as soon as possible on 0115 960 3092.

This is going to be a very special event, chaired in style by TOFS Patron Miss Leela Kapila! Highlights of the conference include:

- Talks from adult TOFs.
- Talks from medical specialists and others (including John Black, President of the Royal College of Surgeons) on issues such as: changes in surgery, diet, respiratory issues and research into TOF/OA.
- Q&A panel session where you can share your questions with medical and other specialists, chaired by David Drake, past President of the British Association of Paediatric Surgeons.

You'll also have time to meet up with old friends and make some new ones!

We expect to receive funding from Awards For All (part of the Big Lottery Fund) so the cost of booking should be covered. If you have already paid, we expect to be able to offer you the opportunity to convert your payment to a donation, perhaps as an adult subscription to TOFS, or have it refunded.

Last chance to book! For more information or to book your place, please contact the TOFS Office now on 0115 961 3092!

Chairman's farewell

After 25 years of involvement with the TOFS Trustees, it should be easy to think of a few words to say on my departure, but it's not quite that simple. It has been my job for many years now to open the TOFS conference and to introduce the Annual Report at the AGM and the same problem would occur each time, who do you thank for their efforts? And who will be upset if you forget to mention them, so as usual I will start by thanking everyone who has helped us over the years and mentioning a few who have perhaps been closer than most.

The original group of Trustees met in Sheffield to launch the charity where we were hosted by Mr James Dixon the Consultant Paediatric Surgeon at Sheffield Children's Hospital who has maintained close links with us ever since and, along with his wife Jean, has raised thousands of pounds for TOFS through his many fundraising activities.

My great friend David Griffiths, solicitor and runner up in our twenty odd year long squash marathon, wrote our Articles of Association and has remained our legal advisor ever since.

Judith Bland is still producing documents and raising funds for us and attends almost every event we hold. Judy Riley has been a phone contact from the start and so it goes on. Sue Lewis Jones has returned after some time out.

For a few years during the eighties we soldiered on with just a few Trustees keeping us going: Pat Fergusson, Roger Ducat, Graham Bulpitt, Mike Brown, Christine and I kept the ship afloat for a few years until we were joined by Vicky Martin who produced our brilliant book *The TOF Child* and we have progressed from there.

Our main events over the years have, of course, been our conferences and what we have learned from these is that doctors

and surgeons are just "ordinary folks" like the rest of us, but doing an extraordinary job.

Leela Kapila has been brilliant over the years, seeing particularly difficult patients for us and hosting our conferences where all of our Medical Patrons and other speakers have mixed with us, eaten with us, argued with us, diagnosed for us, sat in the bar with us and lowered the barrier that sometimes exists between doctors and patients in a hospital situation. I think that our conferences have become really beneficial to our members and long may it remain so.

I must thank the current Trustees for awarding Christine and I Honorary positions a "Presidents" (which I think means that we will still get to go to the conference) and for being so good that I know that TOFS can only prosper under their guidance. I've just remembered about twenty other people that deserve a mention, including Diane and Jane in the office, but I must end it somewhere, so good luck and best wishes to you all and thanks again to everyone involved. I'm sure you know who you are so forgive me if I missed you!

Gren Shepherd



Gren enjoying some quality time with grandsons Oliver and baby Max and son Tom (who will be speaking at our adult TOFs conference in October)!

Mr Edward Kiely TOFS Patron and Consultant Paediatric Surgeon, Great Ormond Street Hospital



If you attended the 2009 TOFS Conference you will remember Mr Edward Kiely chairing our panel of medical specialists.

We are delighted to say that Mr Kiely has very recently become a TOFS Medical Patron! As a leading Consultant Paediatric Surgeon, Mr Kiely works at Great Ormond Street Hospital for Children. Many of our readers will be aware of the long history between Great Ormond Street Hospital for Children and TOF families and friends. As one of the world's leading children's hospitals, Great Ormond Street has played an important part in helping TOF children. Earlier this year, BBC2 featured a groundbreaking series on the hospital and its doctors and surgeons, including Mr Kiely. He spoke to us about his experience of being involved with Great Ormond Street.

Mr Kiely at the TOFS Conference in October 2009

Filed over the course of a year, Great Ormond Street gave a moving insight into the work of the doctors and the difficult choices they have to make every day. In Mr Kiely's view, the programme "gave a realistic portrait of what goes on and the challenges that have to be faced." As well as the vital medical insight of medical professionals, Mr Kiely feels it is essential to learn from parents' day-to-day experience of their child's condition:

"Information from parents can give us an insight into what is really happening with a child. This provides us with everyday details and gives us a clearer view. Sharing information in this way is amazingly valuable."



Chairing the panel of medical specialists at the end of the TOFS Conference

For Mr Kiely, sharing is the reason that TOFS has a key role in supporting parents and families:

"TOF/OA has a big impact on everyday life. The daily struggles with eating and drinking can make a parent feel very isolated. Sharing experiences with each other through TOFS can be very encouraging and by helping parents and relatives to do this, TOFS provides an invaluable service."

You can read more about the BBC2 programme, Great Ormond Street at: www.bbc.co.uk/programmes/b00s02ct

TOFS at BAPS

The British Association of Paediatric Surgeons held its annual congress in Aberdeen this year. We had a stand at the associated exhibition. The paediatric surgeons as a group have more contact with TOFs than almost any other group of medical professionals. Indeed, most of our medical patrons are paediatric surgeons, and several of them came along to the stand to say hello. Of the surgeons whom we met, almost all the UK-based ones knew of TOFS - however they are somewhat more aware of us now, and (we hope!) much more likely to tell their new patients about TOFS. We did persuade many surgeons to take away copies of our leaflets and poster, asking them to display the poster on a hospital notice board. Interestingly there were many attendees at the conference from less developed nations, and they were a little surprised to see a charitable support group exhibiting amongst the companies offering surgical equipment and the like.

Knowing that the event would not be as large as some we have attended, we sent just one person (John Pearce) and just for the two busiest days of the four day event. We are very grateful to BAPS for allowing us to use otherwise unsold exhibition space for no fee: we could not justify having to pay for this sort of thing. Thanks to a cheap Easyjet flight, the total cost of attendance was really very reasonable. We are proud to say that our stand, whilst not the most impressive at Aberdeen, looked considerably more professional than some of the others there.

We were made welcome at this event, not least by the organiser (Dr Clare Rees of BAPS) and also by the President of BAPS, Mr David Drake. There seems to be ready acceptance that support groups such as ours can be really helpful to patients and their families. Many papers at the conference revolved around outcomes - following up how patients are doing after surgery for whatever - rather than surgical techniques as such. One very interesting paper reported a year-long study (to which TOFS contributed some money several years ago) of current UK practice for treatment of newborn TOFS. From this we learned (amongst many other things) that 184 TOFs were born in the whole of the UK in the year February 08 to March 09, and 21% were diagnosed prenatally. We are hoping that one of the authors of this paper will be able to come to our adult conference in October and perhaps in October 2011 we will be able to invite one of them to speak to our next conference about the one-year-old follow up study that they are doing.



Can you help raise our profile?

When you go to hospital for check-ups or clinics, can you see a TOFS poster anywhere? Please let us know whether you do or don't, and please let us have contact details so that we can send the hospitals some of our posters and information.

Glossary

Definitions of technical and medical terms mentioned in some of our articles and family updates.

Colonic interposition:

in the treatment of babies born with oesophageal atresia, there are occasions when a primary anastomosis (join) of the oesophagus may be an impossibility due to the gap being too wide. In a colonic interposition, a section of colon is taken from its normal position in the gut and transposed, with its blood supply intact, into the chest, where it is joined to the oesophagus above and the stomach below.

Dilatation:

a procedure undertaken to widen a narrowing of the oesophagus (stricture).

Extubate:

to remove a tube from a hollow passageway.

Gastroscopy:

an examination of the inside of the gullet, stomach and duodenum undertaken with a thin, flexible fibre-optic instrument passed through the mouth.

Gastric transposition (or "pull up"):

an operation in which the stomach is used to replace the oesophagus. This involves freeing up the stomach of all its attachments in the abdomen and re-routing it through the inside of the chest into the neck where it is joined to the upper oesophagus (gullet).

Gastrostomy tube:

a specially designed tube through which a baby or child can be fed. It is inserted through the skin directly into the stomach.

Replotal tube:

a small tube is passed through the baby's nose or mouth into the pouch of the oesophagus to suck out any secretions the baby swallows.

Tracheostomy:

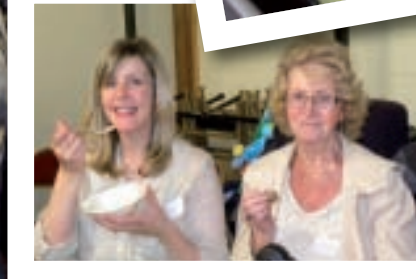
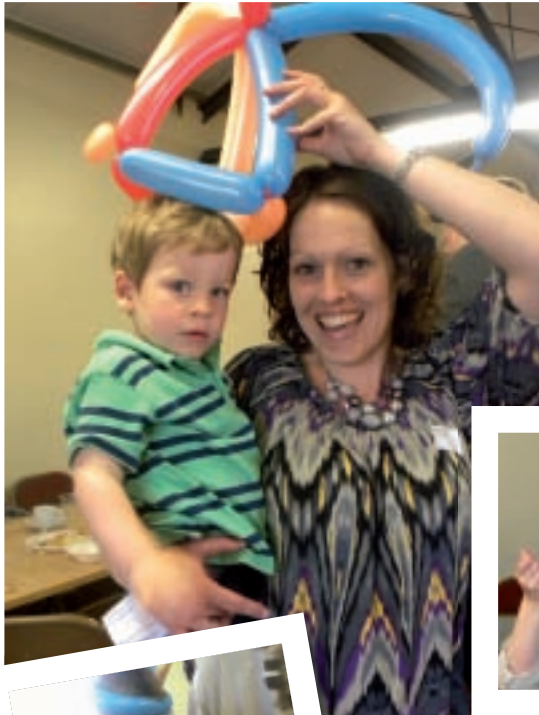
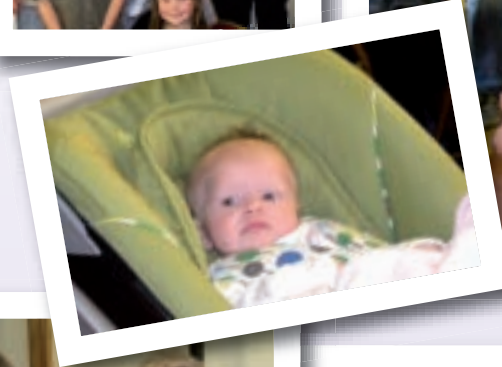
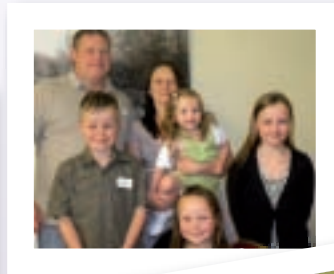
the surgical creation of a connection between the trachea and the skin at the neck, and the insertion of the tube into the trachea to preserve a clear airway.

TOFS Patron, Charles Shaw-Smith takes up new post in Peninsula Medical School, Exeter

TOFS are delighted to extend their best wishes to Charles Shaw-Smith who has accepted a combined clinical/research post at Peninsula Medical School in Exeter. He took up his new post on September 1st, and we are pleased that he will be able to continue with his GOA research project in this permanent position.

More from the TOFS Children's Party 2010!

We had so many great pictures of the fun at this year's TOFS Children's party, we wanted to show you some more! Take a look at our snaps for more of what went on at our annual gathering for TOF youngsters. If you enjoy these pictures, but couldn't make it to our party, why not organise one for your local area as part of TOFS Awareness Week? You'll find details of how we can help publicise your event on p8.



TOFS

Address

TOFS
St George's Centre
91 Victoria Road,
Netherfield,
Nottingham NG4 2NN

Telephone

0115 961 3092

Fax

0115 961 3097

Email

office@tofs.org.uk

Website

www.tofs.org.uk

Registered charity number

327735

Company number

2202260

Medical Patrons

Raymond Buick MB Bch FRCS
James Dickson FRCS FRCSE FRCPC
Bruce Jaffray BMedBiol ChM FRCS
(Glas) FRCS (Paed)
Leela Kapila OBE FRCS
Paul Losty MD FRCS (Paed)
Gordon A MacKinlay FRCSEd FRCS
Sean Marven FRCS (Paed)
Agostino Pierro MD FRCS(Eng) FRCSEd FAAP
Charles Shaw-Smith BM BCh MRCP PhD
Lewis Spitz PhD FRCS
Edward Kiely FRCS FRCSEd FRCPC

Non-Medical Patrons

Richard Briars OBE CBE
Dennis Foxon BA
David Griffiths MA (Oxon)

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Administrative assistant: Jayne Allitt

The views expressed in *Chew* are not necessarily those of the editor or the Council of Management.

TOFS needs YOU!

Are you IT literate and familiar with databases Excel and Access? Do you have regular access to a computer with broadband? Even better, are you within travelling distance of our Nottingham office? Being located near our office isn't essential - but we do URGENTLY need reliable volunteers who can help us fill the gap in our administration systems (working remotely from home if you're not within easy travelling distance).

You'll need to sign a simple volunteering and confidentiality agreement. But we will reimburse your expenses and you'll be making a real contribution to TOFS. Please get in touch with Diane at the office NOW on 0115 961 3092.

TOFS online community

Have you visited the TOFS forum recently? Our online community continues to offer support on a whole mix of issues to new and not so new TOF families! At the time of writing, members of our community are talking about:

- Sharing your child's achievements
- Fundraising news and the announcement of a pregnancy! (Congratulations!)
- Call outs for awareness raising opportunities
- Feedback and thoughts on the TOF adult conference
- Post-op care
- Expressing milk and feeding problems
- Tube weaning

As you can see, there's plenty going in our online community! If you have a question, take a look around the community for a relevant thread - or start a discussion of your own!

www.tofs.org.uk/index.php/forums/

TOFS Events

- TOFS Awareness Week - Monday 11 – Monday 18 October
- TOF Adults Conference - Saturday 16 October

To find out about fundraising and get together events organised by our members, please visit our website at: www.tofs.org.uk

TOFS office staffed:

Monday to Wednesday: 8.30am - 2.30pm
Thursday: 8.30am - 1pm
Friday 8.30am - 12.30pm

Out-of-hours emergency telephone support:

Please call our answerphone on 0115 961 3092 for the number of the volunteer currently providing this service.