

Summer 2009

tofs chew

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



Special tofs annual report edition!

From the editor..

Welcome to your special annual report issue of *Chew*! In the centre of this issue you'll find your very own 'pull out and keep' TOFS summary annual report for 2007-2008. With the annual report and everything else we've got to share with you, we're springing into summer with a jam-packed issue of *Chew*. It's reaching you a little earlier than usual to make sure you know about our Extraordinary General Meeting on Sunday 12 July at our Netherfield office. We'd love to see you there. Also in this summer *Chew* - pictures from our 2009 children's party, a special section for adult TOFs, family updates and much more.

Have a great summer.

Camilla Zajac, Chew Editor

P.S. The TOFS Conference is fast approaching. So if you'd like to join us on October 10th, now is the time to complete and send in your booking form!

Important notice for all members

Following on from our announcement at the AGM on 10 May, an Extraordinary General Meeting of TOFS has been convened for Sunday 12 July at 10.30am. The meeting will take place at the Company's registered office - St. George's Centre, 91 Victoria Road, Netherfield, Nottingham. NG4 2NN.

At the meeting the following resolution will be proposed:

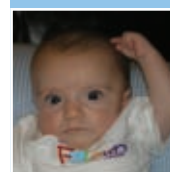
Acceptance of the revised Memorandum and Articles of Association.

A full copy of the Articles is available on our website: www.tofs.org.uk. You can also request a copy from our Nottingham office by phoning 0115 961 3092



Pretty in pink

Here's young Daisy Blossom Buckley looking resplendent in one of her favourite outfits! Daisy became one of our youngest fundraisers at her recent christening, raising a fantastic £2,375 for TOFS thanks to the generosity of friends and family. You can read more about Daisy on page 6.



inside:

Summary Annual Report 2007-2008

TOFS Children's Party 2009

Updates from adult TOFs

New TOFS badges

and much more!

Welcome

A warm welcome to our new members!

- Victoria and Mark Johnston from Meppershall - Luke born 29/03/08
- Emma Gibbs and Patrick Keating from Portsmouth - Milo born 05/08/08
- Emma-Lee Philpott and Andrew Evesden from Epping - Aiden born 18/11/08
- Kathryn and David Winstanley from Chichester - Hebe born 30/01/09
- Samantha Butler, a registered nurse from Boscombe, also an adult TOF
- Melanie Powell from Hailsham, an adult TOF
- Mrs A Tomsett, Children's Community Nurse from Banbury

We'd like to thank

- Lisa Davies - £70 family donation
- Bernadette Poole - £25
- Amanda Ash - £315 in lieu of presents for her 30th birthday
- Joanne and Robert Okley - £20
- Bernadette Poole - £25 through the South West Charitable Giving Scheme
- Sandra Hawkins - £120 donation of travel expenses
- Dennis Harvey - £604 donation of travel expenses
- Diane Maskrey - £20 raised by Connor's grandad from the sale of two DVDs on ebay

In loving memory

- Christina Meek - £105 in lieu of flowers at the funeral of her late mother, Mrs Mavis Meek
- Lyn and Stuart Grayson - £100 in lieu of flowers at the funeral of Irene Bransom (their son Lee's grandmother).
- Penny Derham - £200 in memory of Phyllis Pennyfather, grandmother of TOF Eleanor Derham. Mrs Pennyfather had specially asked for donations to be made to TOFS in lieu of flowers Friends and family of Phyllis Pennyfather - £205
Mr William Longhurst and friends from Belgrade - £160

Corporate and group donations

- The Dental Practice, Devizes - £78 from the team in lieu of Christmas cards. Colleagues Elaine Willis and Nicholas Flindall both have TOF children.

TOFS at the Royal College of Paediatrics and Child Health

As reported in the last *Chew*, Diane Stephens and I recently attended the 13th Annual Spring Meeting of the Royal College of Paediatrics and Child Health at the University of York. We attended for just one day, mainly to run a stand at the exhibition area. Abstracts from the presentations of the conference are available from the TOFS office.

It was a useful exercise in raising awareness of our support group. Our thanks to the conference organisers at RCPCH who granted us exhibition space free of charge where we displayed photographs of our members. This attracted much attention from the paediatric specialists attending the conference. We distributed leaflets and posters which we hope will be displayed in hospitals around the country and more importantly, we were able to speak directly with many clinicians who come into contact with our TOF children.

John Pearce, TOFS Trustee

Volunteers needed!

One of the aims of our hospital liaison project is to have a TOFS poster in every neo-natal unit in the UK, so that parents of children born unable to swallow can access immediate emotional support. When you next attend a routine hospital appointment (and we know that can be fairly frequently!) perhaps you could ask if a poster could be displayed in the neo-natal unit of your hospital?

We would also appreciate it if you could gather contact details for us, as we are trying to update our database of hospitals with these units. We need to know the up-to-date names and addresses of the units/wards, names and addresses of the Sisters/Ward clerks, and their phone numbers/email addresses. We can mail the posters directly to you or to the hospital, if you prefer. For more information, please contact the TOFS office on 0115 961 3092.

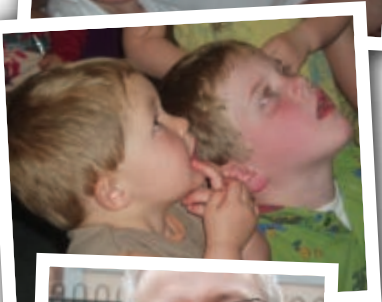
AGM Report

All members were invited to attend the TOFS Annual General Meeting which was held on Sunday 10 May. Chairman Gren Shepherd thanked all those involved with TOFS for their efforts during the accounting period December 2007 to November 2008. He paid particular tribute to the work carried out by the members of the Council of Management and those volunteers who fundraised or offered support on the forum or by telephone, and those who helped continue the work of TOFS in any way.

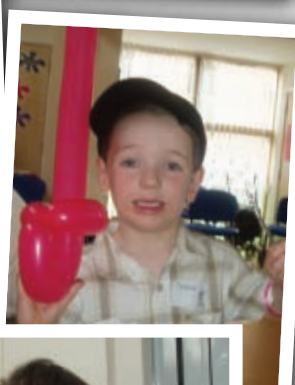
Sandra Hawkins, Treasurer, presented the Accounts for the year and these were subsequently approved. (Full copy available from the TOFS office) Two members retiring by rotation were re-elected and we are pleased to welcome previously co-opted member John Pearce on board as a Trustee.

Birthday wishes to Trustee Dennis Harvey who sent his apologies for Sunday's meeting. Dennis had a good excuse for his non-attendance - he was celebrating his 70th birthday! Many happy returns from all at TOFS.

TOFS Children's Party 2009



Our 2009 children's party was a big success! TOF friends and family had a great time catching up and taking some time out together. Thank you to all those who joined us. We hope you enjoyed Mary Fairy and Pirate Jules! Congratulations to those of you who won family tickets to Twycross Zoo and a Storyshaper party. We raised £144.44 from the raffle and donations for TOFS merchandise. See you next year!



Have you got any other great pictures of your time at this year's TOFS kids' party? We'd love to share them in Chew and on our website so please send them in!

all pictures: having a good time at this year's TOFS children's party! See if you can spot yourself!



Your news and letters



Andy Roud and Christine Rafferty write from Gillingham in Kent:

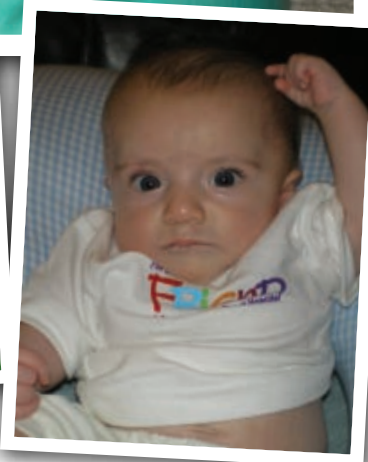
Our son Charlie, who was born on 10 October 2008, is doing really well. His hole in the heart has closed and there are no kidney problems. We are taking him to East Grinstead to see what can be done for his hand. He has had no blues since his operation on Boxing Day and now weighs 13lbs. We are really lucky to have a young GP who is really keen. We are vocal in getting the treatment and care Charlie needs.

alongside: "doing really well" - young Charlie enjoys himself

Tia-Mae in the Telegraph

In March the Daily Telegraph featured the story of a TOF child. The article shared the experiences of Tia-Mae in its article *Girl of 10 eats food for the first time*. Tia-Mae's mum, Sue McCarthy from Bournemouth, explained how Tia-Mae had started wanting to try food after surgery. You can read the article by following the link: <http://digbig.com/4yrak>

Have you or your child been featured in the press? We'd love to share your news with our members.



Happy birthday!

Happy birthday to all our children who have celebrated a birthday recently. 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 June:

Rosie Cadogan Gemma Bradshaw Helen Evans Steven Sutherland
Jasmine Nicholls Michael Flaxington Joseph Holmes Julian Canales Samuel Dobson Sean Taggart Jordan Stretton Lauren Reed Ronan O'Connor Sean Findlay Daniel Bennett Cameron Robb Lewis Millard Oliver Maddern Toni Earl Joseph Currie Madeleine Clarke Imogen Allison Leah Brine Chloe French Oliver Piggott Nadia Botha Rhys Speers Navada Haggart Joshua Ayres Michael Clement

and July: Richard Leckie

Michael Lockett Josie Llewellyn Craig McAuley Findlay Izzett Kimberley Buxton Natalie Frost Shannon Fraser Connor Langridge Alessandro Ingrosso Lewis Walters Shannon Piggott Oliver Fry Susanna Bannister Marta Aumente Blasco James Rothwell Stephen Neill Rory Clarke Henry Turnell Matthew Jones Alfie Ellice Lewis Jones Joseph Griffiths Micha Sloman Hannah Stanger-France Anna Webster James Bedell Sean Walsh James McCormick Musfirah Shariff Harry Coope Louie McConville Kayleigh Banyard Zachary Goggin Joseph Styles Adam Crofts Davies Gregory Maller Andreas Fragias Tyler Henry Christian Brandon Kristen Kohler Jack Strange Dylan Walsh Logan Stowell Alex Lever Thomas Tanswell Alex Cox Ben Barker Jacob Gary Madeleine Hornibrook Jenna Roach Abdur-Rahman Khan

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tofs

Support for families
of children born unable to swallow

TOFS Tracheo-Oesophageal Fistula Support

annual report 2007-08

“... enjoying a healthy life”

About TOFS

Approximately one in every 3,500 babies is born with a TOF/OA related condition. Tracheo-oesophageal fistula and oesophageal atresia (OA) are rare congenital conditions of the oesophagus (food pipe) and/or trachea (airway) that affect newborn babies. Babies with TOF/OA need to have intensive neo-natal care prior to corrective surgery, normally within days of birth. Some children have to undergo additional surgical interventions later on in their lives.

Since it was established in 1982, TOFS has worked with the primary aim of providing mutual support and information to parents of children born with tracheo-oesophageal fistula and oesophageal atresia. A registered charity since 1987, TOFS exists to provide support and information to its members, to those affected by TOF/OA and VACTERL, and to others with an interest in these conditions.

Our core work is focused around the provision of direct family support, and ensuring that families and interested professionals are informed about the care of children with TOF/OA. We depend on support through membership fees, voluntary donations and other sources of charitable income to fund our activities. Many of our organisational, pastoral and management activities are undertaken on a voluntary basis by our members and trustees.

Membership of TOFS is open to all those who care for children born with TOF/OA, VACTERL or any oesophageal condition, to adults born with these conditions and to interested medical professionals.

Organisational structure

The overall direction and management of TOFS is overseen by the Trustees who form the Council of Management (COM) and

Family support

Achievements: December 2007 – November 2008

- We increased our membership from 1058 to 1136.
- We supported parents on a personal level and provided emotional support and advice where appropriate.
- We put plans in place for our biennial conference where families will meet up and learn more about the condition, its cause, treatment and ongoing management.
- We increased our volunteering support with five long awaited new members on our Council of Management and almost doubled our volunteer team of telephone support with four new volunteers.
- We organised social events where families met up and forged friendships.
- We continued to employ our administrative assistant, Jayne Allitt at 20 hours per week and we appointed an Office Manager, Diane Stephens in June 2008 also on a part-time basis. Our staff stagger their hours so that the office is usually open for enquiries daily from Monday to Friday.

Information and resources

Achievements: December 2007 - November 2008

- We supplied information to families in the form of leaflets, brochures, *The TOF Child* book, and our quarterly newsletter, *Chew*.
- We supplied information and advice over the telephone.
- We continued to develop our website to ensure it offers up to date information to visitors.
- The community forum on our website played a big part in our activity over the year with members offering each other emotional support. We carefully monitored the forum to



the Trustees who form the Council of Management (COM), and who are also Directors of the Company. This Council is accountable and legally responsible for the work of the organisation and for ensuring that all aspects of the management and work comply with current legislation. The Council is supported by administrative staff headed by the Office Manager, and by volunteers.

Policies and documentation

Appropriate policies and procedures are in place to support the effective operation of TOFS. These include, but are not limited to: Health & Safety; Protection of Vulnerable Children; Financial Management, Personnel, Guidance & Training; IT & Data Protection and Communications.

For making it happen - thank you:

- to our volunteer phone contacts who provide one-to-one support to parents and carers and to our volunteer birthday and hospital "fairies" who send out cards to children with TOF/OA,
- to the parents, families, friends, relatives and communities of children with TOF/OA who work so hard to raise funds and increase public awareness,
- to all the community fundraisers, corporate sponsors and others whose generous support has allowed us to help the families of children with TOF/OA,
- to those who have provided free advice and support on benefits available to TOFS members,
- to those who have offered advice and support through our website forum,
- to all members who have shared their experience and insights in Chew,
- to anybody who has given their time to TOFS in any way.



front picture: 'miles of smiles' - what a line up! Young TOF Liberty Davies (far right) poses with her brothers and sisters, Jerome (13), Quinley (6) and Peaches (1). Born in January 1993, Liberty needed surgery to repair her trachea-oesophageal fistula. She is now doing very well. He dad, Mark, says: "Liberty leads a perfectly normal and healthy life. In her early years, we really appreciated the support and information TOFS provides."

pictures on this page: out and about and having fun - TOFS children, friends and family.

emotional support. We carefully monitored the forum to help us identify what members need from TOFS, and where possible, we met those needs. We offered advice to members about the benefits they are entitled to.

- We commissioned a new 'child-friendly' TOFS logo which sends out a clear message about the support we offer to families.
- Work started on the second edition of *The TOF Child* book with revised articles and new topics.
- We disseminated information to practitioners from health, education and social care.
- A hospital liaison sub-committee put plans in place to develop relationships with the big teaching hospitals to raise awareness of the group and the ongoing problems our families face.

Research

TOFS is primarily a parent support group. However we do occasionally also provide funds to support scientific research into the causes, effects and implications of TOF/OA and VACTERL.

Achievements: December 2007 - November 2008

- Increased information provision on research to our members through updates and articles in our newsletter, *Chew*.
- As always, we aim to respond to developments in medical research and techniques by keeping families and other interested individuals and organisations accurately and impartially informed.



www.tofs.org.uk

Fundraising

Achievements: December 2007 - November 2008

- We supported our members in their fundraising efforts by providing TOFS sponsorship packs
- We promoted members' fundraising work by sharing their efforts on our website and in *Chew*.

Finance

Full accounts and the Treasurer's report are available on request.

2009 Conference

Our biennial conference will be held on Saturday 10 October at the Holiday Inn in Newcastle upon Tyne. This one-day event will feature key speakers from paediatric surgery, genetics and child nutrition. As always, the conference offers parents and carers the chance to learn first hand from specialists about surgical and medical advances in TOF/OA and VACTERL. There will also be workshops and many opportunities for parents to get to know each other and share experiences. The TOFS Conference is also open to professional members with an interest in this area.

Goodbye and thank you

Pat Furlley Thank you to Pat Furlley who joined us a Trustee in 2005.

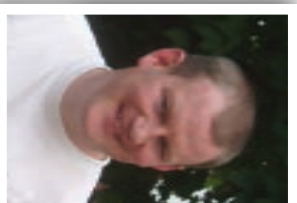
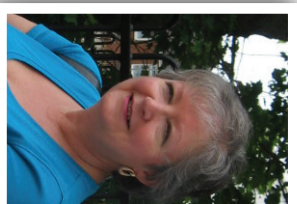
Roger Ducat first joined the Council of Management in 1993. He was our Treasurer for many years and then became Vice-Chairman of the Council.

Pat Fergusson joined the Council of Management in 1992 and has been central to its development from a family support group to a national charity.

Jenny Strickland Thank you to Jenny for her fundraising efforts.

Hello and welcome

We are delighted to welcome a number of new Council of Management members:



above, from left to right: **John Pearce** - co-opted member, **Graham Slater** - Trustee, **Sue Lewis Jones** - Trustee, **Dennis Harvey** - Trustee and **Drew Bailey** - Trustee.

General information

correct as at 30/11/08. Please see back page of *Chew* for current list.

Company registration number 22022260
Charity registration number 327735

Registered office/administrative office

St George's Centre, 91 Victoria Road,
Netherfield
Nottingham NG4 2NN
Telephone 0115 961 3092
Fax 0115 961 3097
Email info@tofs.org.uk
Website www.tofs.org.uk

Council of Management

Hon. Chair: Gren Shepherd
Hon. Vice Chair: Roger Ducat
Hon. Treasurer: Sandra Hawkins
Hon. Secretary: Duncan Jackson
Christine Shepherd
Pat Fergusson
Dennis Harvey
Sue Lewis-Jones
Graham Slater
Drew Bailey
Co-opted member: John Pearce

Staff

Jayne Allitt, Administrative Assistant
Diane Stephens, Office Manager

Bankers: Lloyds Bank Plc, Bristol Road South, Northfield, Birmingham B31 2NP
Accountants: Lemans, 29 Arboretum Street, Nottingham, NG1 4JA

Solicitor: Mr D Griffiths, Edwards Geldard, 44 The Ropewalk, Nottingham NG1 5EL

Patrons

We were delighted to be joined by two new medical patrons during this period: Professor Agostino Pierro and Dr Charles Shaw-Smith. Thank you to all our patrons for their continued interest and support throughout the year.

TOFS' non-medical patrons include:

- Richard Briers, CBE, OBE
- David Scott
- David Griffiths
- Dennis Foxon

Our medical patrons include:

- Raymond Buick, MB BCH FRCS, Consultant Paediatric Surgeon, Birmingham Children's Hospital NHS Trust
- James AS Dickson, FRCS FRCS FRCPCH, previously Consultant at Sheffield Children's NHS Trust
- Bruce Jaffray, Bmed Biol CHN FRCS (Glas) FRCS (Paed), Consultant Paediatric Surgeon, Royal Victoria Infirmary, Newcastle
- Leela Kapila, OBE FRCS, past Vice-President of the Royal College of Surgeons of England and a past President of the British Association of Paediatric Surgeons
- Paul Losty, MD FRCS, Professor of Paediatric Surgery, Royal Liverpool Children's Hospital (Alder Hey) and the University of Liverpool
- Gordon Mackinlay, FRCSed FRCS, Senior Lecturer in Paediatric Surgery, University of Edinburgh and Consultant Surgeon, The Royal Hospital for Sick Children, Edinburgh
- Professor Agostino Pierro (Nuffield Professor of Paediatric Surgery and the Head of Surgery Unit at Great Ormond Street Hospital for Children NHS Trust and UCL Institute of Child Health)
- Dr Charles Shaw-Smith (Wellcome Trust Intermediate Clinical Fellow, Wellcome Trust Sanger Institute/Honorary Consultant in Clinical Genetics, Addenbrooke's Hospital, Cambridge)
- Lewis Spitz, PhD FRCS, Nuffield Professor of Paediatric Surgery, Institute of Child Health, University of London and Consultant Paediatric Surgeon, Great Ormond Street Hospital for Children.

Glossary

Atrial Septal Defect (ASD): a heart problem in which there is a hole between the top chambers. Due to the higher pressure in the left side of the heart, this allows oxygenated blood to flow through the hole from the left to the right side of the heart, and back to the lungs, in addition to the normal flow.

Dilatation: a procedure undertaken to widen a narrowing (oesophageal stricture).

Hip dysplasia: a congenital or acquired deformation or misalignment of the hip joint.

Long Segment Congenital Tracheal Stenosis: a rare but life threatening condition in which, instead of being C-shaped, the rings in the trachea are O-shaped. The airway becomes very narrow and as activity increases through feeding or exercise, breathing becomes extremely difficult and sometimes impossible, requiring urgent treatment.

Nissens Fundoplication: this procedure is commonly used to reduce Gastro-Oesophageal Reflex (GOR). The lower oesophagus is freed up and the top part of the stomach (known as the "fundus") is wrapped around the lower oesophagus to make a valve at the junction of the oesophagus and stomach. The hole in the diaphragm through which the oesophagus passes may also be tightened.

Oesophageal stricture: a narrowing of the oesophagus (food pipe).

Pulmonary atresia: a congenital malformation of the pulmonary valve in which the valve opening fails to develop. The valve is completely closed, blocking the flow of blood from the heart to the lungs.

Slide tracheoplasty: an operation to widen the airway and reduce the breathing problems associated with tracheal stenosis. It uses the body's own tissues, so there is no risk of rejection.

Thickeners for milk and other liquids: children are less likely to vomit if the liquid is thicker consistency. E.g. Carobel, Nestargel, Thixo-D, Thick and Easy

Tracheomalacia: 'floppiness' of the trachea (windpipe).

Tracheostomy: the surgical creation of a connection between the trachea and the skin at the neck, and the insertion of tube into the trachea to preserve a clear airway. Used in the management of severe tracheomalacia.

Ventricular Septal Defect (VSD): a defect in the wall dividing the lower chambers in the heart so that movement of oxygen from the lungs to the tissues is inefficient. The circulation in the lungs is also subject to abnormally high pressures which can be damaging.

Adult TOFS

It's always great to hear from adult TOFS. Please keep on sending us your updates. Here we share news from two grown-up TOFS and also a call for information on a problem experienced by a 'teen' TOF. Don't forget - our 2009 Conference includes a workshop dedicated to the problems that can be experienced by teenage and adult TOFS.

A special occasion

Congratulations to adult TOF Josephine Reading, who celebrated her 50th birthday at the start of this year! She says: "I was born in January 1959 with a trachea-oesophageal fistula and a long-gap oesophageal atresia. It was repaired at the Children's Hospital Birmingham. I spent the first one year and eight months in hospital, making return visit afterwards. I still have problems with feeding, breathing, my weight and mobility. I have written a number of poetry books about my disabilities and life in general.

I thank TOFS for joining in my 50th birthday celebrations. I feel it is truly an achievement to have reached this grand age."

Urgent temporary vacancy

Could you help us produce *Chew*? We need a volunteer to retype information in preparation for it going in our newsletter. Or perhaps you'd be interested in helping out with our telephone support service? Contact Jayne or Diane at the TOFS office for more information.

Life's rosy for Harriet

Harriet Payne leads a busy life as a junior doctor. As an adult TOF, she continues to enjoy reading *Chew* and wanted to share her experiences with our readers. She tells us: "I was born with TOF/OA back in May 1983, along with tracheomalacia, pulmonary atresia, and the cardiac abnormalities Atrial Septal Defect (ASD) and Ventricular Septal Defect (VSD) (see glossary opposite for definitions). The fistula was corrected within a few days of birth, but ensuing problems and the heart conditions meant that I was pretty much a permanent resident of Westminster Children's Hospital for the first years of my life. By the time I started nursery school, I was pretty much healthy but still having problems with swallowing, needing regular dilatations, and having to be wary of 'stodgy' food.

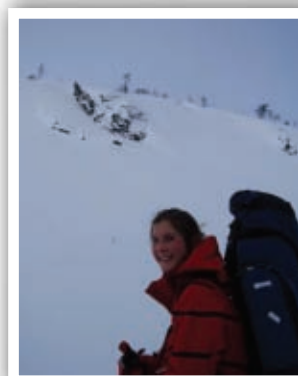
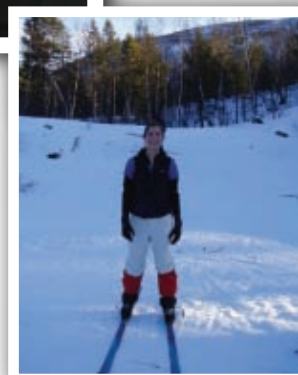
Frustratingly, at about the age of seven or eight I developed severe gastro-oesophageal reflux, which didn't respond to medical management and ended up needing a Nissen Fundoplication (see glossary opposite). The Fundoplication worked wonders, and I've had few problems since. I haven't been sick since I was nine, and only have to be wary of picking up various bugs while travelling. The need for regular dilatations tailed off as I grew up. Apart from still making sure I have water with meals, being more prone to chest infections and a few scars here and there, I don't think you'd be able to tell now at all about my eventful start to life. That's apart from the ubiquitous TOF cough, which still tends to make heads turn.

In terms of impact on my life, of course there were the frequent hospital admissions and time off school, but no long term repercussions - despite my protests. I attended the hospital school when well enough during my longer admissions. Friends were remarkably understanding and school was very supportive. I managed to go on long trips away from home successfully, and eventually ended up at Oxford studying Medicine. I'm now working as a junior doctor, hoping to specialise in A&E. Physically, I'm absolutely fine – sports mad. I represented both school and university in tennis and athletics, ran for my county and club, played netball for school and college and love cycling, climbing and running. I'm pretty much outdoors as much as I can be – exemplified by the fact that I've just got back from a polar medicine course in the Arctic!

What I really hope these words show, is that having TOF/OA as a child does not necessarily limit you in later



left: proud Harriet on graduation day (third from the left), and, below, Harriet likes to get out and about - whether its skiing or exploring the Arctic!



life. It is without doubt a frightening and distressing experience to have a child who is sick and in hospital frequently, but please have faith that there is light at the other end of the tunnel, despite at times it seeming a long and daunting one. Obviously, each child is an individual, and has their own individual problems to face, but please don't lose hope. Things will hopefully get better and TOF, although always being a part of your child and your family's history, will be relegated from the forefront of your everyday life to the background; becoming part of what contributes to the richness and depth of your child's life, rather than defining it.

I'm more than willing to talk to any parents who need a chat or someone to listen."

Thank you for your kind offer of support to TOFS members, Harriet. Readers can contact Harriet through the TOFS office.

captions please

Cyclical Vomiting Syndrome

Can you help a TOF mum with advice on managing Cyclical Vomiting Syndrome? One member's daughter was recently diagnosed with CVS after continued periods of vomiting. She is now being treated with medication which is helping reduce the problems. Her mum has been told that the syndrome has probably due to the start of puberty and the stress this can cause to the body. Has your child experienced CVS? Would you be willing to share your experience with another TOF parent? If so, please contact the TOFS office.



TOFS

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Registered charity number

327735

Company number

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Medical Patrons

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

Non-Medical Patrons

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

Council of Management

Hon. Chair: Gren Shepherd
Hon. Vice Chair: Duncan Jackson
Hon. Treasurer: Sandra Hawkins
Hon. Secretary: Graham Slater
Christine Shepherd
Sue Lewis-Jones
Dennis Harvey
John Pearce

Office personnel

Office manager: Diane Stephens
Administrative assistant: Jayne Allitt

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

Office news

New TOF badges

Members can now get their hands on brilliant TOF badges – absolutely free! Regulars on our online community forum have been asking for TOF badges to send out a clear, positive message at parties, in school and in other settings. Thanks to a

grant from the Winifred Eileen Kemp Trust, these are now

available! As you can see, we have badges with two different designs: 'I have a TOF cough' and 'No food for me, I was born with a TOF'.

If you'd like your own TOF badge please

send us a (preferably stamped) self-addressed envelope

with a note telling us which badge you need.

You can choose a safety pin backing or a child-friendly clip. Just let us know which you'd prefer.



Renewing your TOFS membership

Thank you to everyone who has sent us their subscription renewal forms. It's really important that we hold accurate details on any changes in your child's condition. If you haven't had a chance to send yours in yet, please do so as soon as you can.

We haven't heard from many of you for some time. If your child is older and making great progress, please let us know. If, however, you no longer wish to be a member of TOFS, we would appreciate if you would still return your form in the envelope. Remember, it's Freepost, so there's no need to add a stamp, and we can make sure we remove your details from our database. This will really help us with administration and

postage costs when we send the renewal reminders.

Some of you very kindly sent a substantial donation along with your membership renewal. Thank you very much. We don't list these as individual donations in *Chew* simply because there are so many of them. But please accept our sincere thanks – we couldn't continue our work without you.

TOFS Conference 2009 update

The 2009 TOFS Conference draws ever closer! You should have received your conference booking form by now. If you'd like to join us for what promises to be a great event, please return your form as soon as possible. The sooner you book the better. Priority for free crèche places will be given to members who book early! You can view full details of the conference on our website – but you'll only be able to book your place using our official booking form. If you haven't got yours, please contact the TOFS office on 0115 961 3092.

Events

Extraordinary General Meeting

Sunday 12 July, 10.30am, St George's Centre, Netherfield, Nottingham

All members welcome (see notice on front page)

Council of Management meeting to follow immediately afterwards.

Council of Management meeting

Nottingham, Sunday 27 September, 10.30am

TOFS Conference

Newcastle-on-Tyne, Saturday 10 October

TOFS office staffed:

Monday, Tuesday and Thursday: 8.30am - 2.30pm

Wednesday and Friday: 8.30 - 12 noon

Out-of-hours emergency telephone support:

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