

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

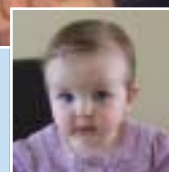


above: Eden with her siblings, brother Ben (aged 10), sister Cora (also aged 10) and sister Lexia aged 5

Eden's journey

Maxine Pollock wrote to us from Coventry to share the story of her daughter, Eden. Eden was born three weeks premature on 5 September 2007 and diagnosed as having TOF/OA. She continued to have reflux and feeding problems and had a Nissen's Fundoplication (see glossary on page 10) in November 2007. Her mum says: "We finally brought Eden home after 19 days in hospital."

Eden's story continues over on page 3



inside:

- Introducing our new logo!
- A TOF parent shares her experience of claiming benefits
- Your news and stories
- An update on the second edition of *The TOF Child*

and much more!

Want to make a difference? Join TOFS.
Please call us on 0115 961 3092

From the editor...

Welcome to the first *Chew* of 2009! In it, we are very proud to introduce the new TOFS logo. As always, it's great to meet new members and hear how much fundraising is going on, even in challenging times like these. We can't always feature your efforts in a full article due to limited space, but they are all very much appreciated. Now, it may be some time until the sunshine gets going properly, but there is plenty to look forward to. Inside you'll find details of the next TOFS Conference, dates for our Nottingham Children's party and an update on the second edition of our publication, *The TOF Child*. It's all go! Have a great spring.

Camilla Zajac,
Chew Editor

What's new?

TOFS 2009 Conference

Work for our biennial conference is well underway. The one-day conference will be held on Saturday 10 October at the Holiday Inn, Newcastle upon Tyne.

Sandra Hawkins, TOFS Honorary Treasurer, is heading the subcommittee responsible for the event.

We are looking forward once again to a really informative conference. With key speakers from paediatric surgery, genetics and child nutrition, 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. We intend to close the conference with a forum where parents will have the opportunity to put their questions to a medical panel. Please write to us at the office or email us NOW if there's a particular topic you'd like to see covered, or if you have any specific questions about TOF/OA or VACTERL.

Please book your place at the conference using the official booking form which you should receive in the post shortly. The cost (subsidised by TOFS) is only £20 per person including lunch and refreshments. Early booking is advisable. Please note the conference sessions may not be suitable for children. We do offer a crèche for children up to 7 years (first child free), however places are limited so we will need your booking as soon as possible.



TOFS launches its new logo

Some of you may have spotted our new-look logo - and for those of you who haven't - get your specs on quick! We are very excited to launch the brand new TOFS logo with the first *Chew* of 2009.

Special thanks go to Alex Marsden from Splash! Creative Design who has put a lot of work into designing a logo for TOFS that reflects exactly what the charity's all about. She shared some of the thought processes behind the new logo:

"We wanted to create a logo that reflects TOFS' role as a national charity. So we worked on developing a friendly, professional look that sends out a clear message about the support TOFS offers to families. The bright colours, the rounded lettering and the uncluttered style are all aimed at expressing TOFS' identity as a community in a clear and positive way. The logo integrates the name of the organisation with the medical condition of TOF. Through all the design process, our aim has been to build on the branding that we have been gradually developing through the TOFS website, *Chew*, other TOFS publications and the exhibition stand."

TOFS Chairman Gren Shepherd said: "We are delighted with the results of all the hard work of Alex and the logo sub committee. Building on our original logo, which has been a central part of TOFS' identity from the beginning, this new look will stand our charity in great stead for the future."

Congratulations Alex, it looks fantastic. Members - let us know what you think.

Research study

There's little research available into the incidence of TOF and Oesophageal Atresia. So TOFS is delighted to be able to help fund a national observational study currently taking place in the UK to assess antenatal diagnoses, associated anomalies and infant outcomes.

Sean Marven FRCS (Paed), consultant paediatric surgeon and a pioneer of keyhole funduplications at Sheffield Children's Hospital has kindly agreed to update us on the study at our conference this autumn.

We are also delighted to report that Mr Marven has agreed to become one of our medical patrons.

Your news and letters



Eden's journey, continued

Eden's Mum continues, "Since coming home Eden had always suffered with bad reflux and feeding problems. She had to have a series of four dilatations because of an oesophageal stricture. Her feeding improved a little, but the vomiting continued. Eden had a Nissen's Fundoplication in November 2007. After the Nissen's, Eden was diagnosed with a severe case of Dumping Syndrome (see glossary on page 10). After lots of communication with Eden's dietician, we now have a new diet and feeding regime. Eden is now fed by pump 16 hours a day. We still feed Eden orally, but a lot of the time she is reluctant to eat as she still occasionally dumps. Eden still retches to vomit which has caused a hernia, but this will be sorted out at a later date if needed. But she is now having good weight gains."

Eden's experiences have been a journey for the whole family:

"Through it all Eden has always been a very happy, contented baby and always has a big smile for everyone. We are truly blessed. Having a TOF baby has taught us so much. We are stronger and we thank God every day that our little TOF baby has come through it all. Eden's siblings have learned so much about her condition and are very involved with her everyday care. The past 16 months have been stressful, but we are very happy to say things are improving for all of us. It took a while to realise: "No more vomit to clean up all day long."

above: Eden just after her birth and inset: Eden celebrates her birthday!

WELCOME!

Welcome

Happy birthday!

Happy birthday to all our children who have celebrated a birthday recently. Our birthday fairies have been sending out cards to all of you under six. And congratulations to those of you aged six and over in April,

HAPPY BIRTHDAY:

Nicola Smith Nathan
Huggins Adam
Tomlinson Peter
Barnett Charlotte
Underwood Caspian
Tyrer Alyssa **Ciambelli**
McCauley Williams
Jack Berry Aden Parker
Megan Evans Daniel
Heath Thomas **Smith**
Rebecca Hadley
Charles Shotton Lucy
Robson Phoebe **Smith**
Heather Leggate
Robert Doward Laura
Thompson James
Soper Joseph Santos
Andrew Day David
Fenton-Smith **Bradley**
Newman Samuel
Mullins Miriam
Holland Cara McKay
Joe Francis Cooper
Kimberley Taylor
Benjamin Egner
Samuel Holleron
Phoebe Cannetti Zijian
Guo Max Swarbrick

Graham Slater: Welcome to the TOFS Council of Management



We've been delighted to welcome several new faces to our Council of Management recently. You met some of them in the last issue of *Chew*. We'd now like to introduce Graham Slater.

"I first heard about TOFS some years ago and was interested in becoming a member because I am an adult TOF. I was treated at Pendlebury Children's Hospital in Greater Manchester and was apparently the first survivor in the north west of England. Though I was born in Lancashire, I now live in Worcestershire with my wife and two adult daughters.

Having been fortunate to have enjoyed a fairly normal life, I decided on reaching 50 (five years ago, now) to celebrate by commencing training to run a full marathon, and raise money for TOFS. After a slight delay caused by the need for surgery (on my knee, nothing more serious!), I fulfilled this ambition in 2007.

I took early retirement recently and I was delighted to become a Trustee of TOFS. As my situation is somewhat different from those of TOF parents and the other Trustees I hope that perhaps I can bring another dimension. I may not be able to identify so easily with the problems faced by TOF parents, but I can identify with our TOFs themselves! I would also be particularly interested to hear from other adult TOFs in case there is more they feel we might do for them."

And a warm welcome to our new members!

- Philippa and Owen Jones of Shipley, West Yorkshire - Isaac born 17/08/08
- Deborah and Darrell Hill of West Haddon, Northants - Nathan born 25/11/08
- Aimee Read and Michael McLarnon from Leicester - Isla born 14/06/08
- Rashidah Owoseni from Manchester - Halimah born 19/04/08
- Linda Fusco from New Jersey, USA - Cheyna born 29/12/06
- Celine and Raymond Murray from Co. Wicklow, Ireland - Aoibheann born 10/03/08
- Jody Margerison-Buckley and Daniel Buckley from Rochdale - Daisy born 23/11/08
- Christine Rafferty and Andrew Roud from Gillingham, Kent - Charlie born 10/10/08
- Kate and John Lovelock from Wallsend, Tyne and Wear - Lily-May born 21/05/08
- Amy Fox and Matthew McAdie from March, Cambridgeshire - Ethan born 08/01/08
- Paula and Steven Hayes from Ingatestone, Essex - George born 31/08/08
- Sarah and Tony Gillette from Woolston, Southampton - Layton (a mini Mr Claus, pictured opposite) born 29/08/08
- Margaret and David Atkinson from Co. Cork, Ireland - Aaron born 03/06/04
- Kay Downham and Gary Leech from Blackburn - Harriet born 22/05/08
- Carol and Craig Johnstone from Alexandria, Dunbartonshire - Reilly born 09/09/08
- Andrea Green and Damian Devlin from Wigan - Rourke born 15/06/08
- Amanda Webber from Doncaster - Samuel born 12/06/08
- Charlotte Croson-Hood and Simon Hood from Rayleigh in Essex - Elisha born 09/10/08
- Jan Bramall and Tom Chapman from Didsbury in Manchester - Amélie born 12/01/08



Your news and letters



Birthday boy

Mum Diane Maskrey from Staines wrote to say that her son Connor was delighted to hear from the TOFS birthday fairy on his big day back in October. She says: "He had a great day playing and watching his new DVDs!"

Here's Harriet!

Thank you to Kay Downham from Blackburn for sending us this great picture of Harriet who was born on 22 May 2008. Harriet had a Nissen's Fundoplication (see glossary on page 10) in January. Kay tells us: "It was an extremely difficult 2008 but a great start to 2009 with Harriet coming home and now we've a wedding to plan as Gary proposed on New Year's Day!"

Congratulations, Kay and Gary – and it's great to hear Harriet is doing well.



above : Connor enjoying his special day - especially opening his presents, and tucking into his cake!

left: little Harriet

Feature: do you benefit?



above: it's snowtime! Brave explorer Laurie surveys his newfound territory

The TOFS website provides information on events and activities, helpful resources and a vital contact point with other TOF families. Our forum is a place for parents like Rachel to share their experiences. To find out more, visit www.tofs.org.uk and go to: TOFS Community.

Rachel's story

My name is Rachel and I'm mummy to Laurie who was born with isolated long gap TOF/OA in January 2007. Mark is my partner, Laurie's daddy, and we have been together for eight years. Laurie was our first child and to say we were shocked at the

news of the TOF diagnosis would be an understatement. Like many others, we had never heard of the condition so we made it our job to find out what we could in order to support Laurie as much as possible.

Many of the forum users reading this will probably have followed our stories over the past year or more and would have been privy to so many of our fears and worries, as well as joys and celebrations. I'm writing this following a request from TOFS asking if I would be willing to help families out there with regards to benefits they are entitled to. I'm not declaring to have all the answers. I'm nothing to do with the HM Revenue and Customs or the Benefits Office so if you know of something I haven't mentioned then please let me know. I'm going to put down everything that I know, or have found out, about the different benefits, and what I'd like to do is pull together a 'one stop shop' for new TOF families so they don't lose out and have the necessary financial support from the start. Many of us have stumbled across our entitlements and as a result, missed out.

Child Benefit: available to parents for all children under the age of 16. See the Bounty pack given by the hospital at the birth or contact the HMRC directly. Coupled with child benefit is the Child Trust Fund - £250 for every child born!

Disability Living Allowance (DLA): applying for this allowance does not necessarily mean your child is 'disabled' or expected to have a visible 'disability'. I dismissed the very mention that Laurie had a 'disability' or 'special needs' at first, but now I understand and accept the term for what it really means. The definition by the DDA (1995) is 'a physical or mental impairment which has a substantial and long term adverse effect on his or her abilities to carry out normal every day activities'.

I feel strongly that every TOF parent out there should be benefiting. All TOFs are different, with differing levels of care requirements, from the very minor to the more severe. The allowance is the government acknowledging that our children require extra time and care - and everything else we cope with. Regardless of the severity of your child's condition, with or without any of the other linked conditions, if you haven't applied - do! You could be awarded the highest for care (£67/wk) to the lowest (£17.75/wk). Every child is different so it is up to you to put your case forward and detail every aspect of 24 hours, looking at 'worst case'. There is an extensive thread on this subject on the TOFS website forum. It is worth reading this before you make your application as it is jam packed with hints and tips on how to complete the application. I am more than happy to provide support, help and advice on submitting your claim.

Once awarded, DLA means you have additional rights in the workplace in respect to 'family friendly' benefits. For example your entitlement to unpaid Parental Leave increases to 18 weeks and extends until the child reaches 18 years of age (as opposed to 13 weeks and age limit of five) and you are entitled to take the leave in ad hoc days rather than week blocks. Likewise, your entitlement and right to apply for Flexible Working extends until the child is 18 years old, as opposed to six years.

DLA is not means tested so you will not lose out if you have savings. Nor will it impact on any other benefits you receive.

Do you benefit? continued

Our TOF children are all remarkable kids. We deserve as much help and support (both financial and emotional) as possible.

Tax Credits: Tax credits are payments administered by the HMRC and available if you're responsible for at least one child. If you work you may also qualify for Working Tax Credit. What you may not be aware of however is the 'disabled' element of child tax credits! If your child is in receipt of DLA you could qualify for the disabled element which is currently worth up to £2,540 per year (increasing in April 09).

If this applies to you, call the DWP and notify them ASAP! If eligible, they should back date up to 93 days (or until DLA was granted if earlier)! They didn't ask for proof of DLA award, just for the date of the letter informing of the award. Tax credits are means tested, hence the 'up to', but depending on family income, you have a good chance of getting something extra!

Carers Allowance (CA): You may be able to get CA if you spend at least 35 hours a week caring specifically for your child who is receiving DLA. I have no personal experience of this benefit; however I am aware that some TOF parents receive it. CA may impact on other benefits you claim and if you work and earn above a certain amount this can also impact on eligibility. For more information about this allowance and its impacts refer to www.direct.gov.uk.

I found a good website which may help you determine what other general benefits your family are entitled to: <http://www.entitledto.com>.

Our TOF children are all remarkable kids; I'm so proud of Laurie and every day he amazes me with his strength to overcome hurdles in respects to food. As such we deserve as much help and support (both financial and emotional) as possible. No one needs to lose out; we are a community of experts and we have an obligation to provide insight to our experiences to every new parent who is exposed to TOF/OA.

Thank you to Rachel for sharing her experience with us - and for offering to support other TOFS parents. We recently heard from a TOF dad who has proven that perseverance really does pay off. The dad, who prefers to remain anonymous, says:



Our son was just about to turn 16 and we had filled in a routine claim renewal form in August. I contacted the TOFS office in December after receiving a devastating letter to say that he was not entitled to DLA at all.

As our son has had a tracheostomy (see glossary on page 10) and other medical problems needing catheterisation and washouts, we felt that possibly as he was older and trying to be fairly independent, that his benefit might be reduced to medium, but receiving the letter stating his entitlement was zero was astounding.

Not to be beaten we contacted ACTS and TOFS, of whom we have been long term members. Both charities gave their support, but we had to go forward with an application to appeal. We also contacted our son's specialist. With the help of his letter and our reasons for the appeal, we are pleased to say that he has now been given his DLA at the High rate.

This is a relief, as he has recently been going on school trips abroad, accompanied by his mother. The extra medical insurance and double travel costs etc are only part of what we use the DLA for, but it is appreciated. We feel sure that like other families, we did not need this extra stress, forms etc when at the end of it all we are back to the original allowance.

above: Rachel's son Laurie recently had his second birthday. Friends Claire and Martyn Cooper-Jones came over with their twin sons, Harrison and Oliver to celebrate.

"How about a short back and sides with plenty of bubbles?" Watched over by Oliver (at the back) Laurie gives Harrison a special bathtime hairdo!

Look out for more on benefits from another TOF parent in your summer issue of Chew.

'The TOF Child'

and May: James Dawes Sandra Lawton Lesley Brown Charles Macknay Cathy Chi Liam Hunt Emma Brown Callum Hillman Charlotte Cooper Bethany Randle Luke Bowron Keren O'Leary Sophie Smith Tudor Morgan-Huggett Michael Webster Steffen Hansen Kristopher Spender Connor Middlehurst Matthew Flynn Jordan Clifford Eilidh Latimer Matilda Smith Stephen-Thomas Gray Victoria Mince Anna Rose Greco Charlie White Layton Smith Zaheemah Sharif Lucy Wilkins Aaron Whittaker Olivia Hellas Charlie Gough Nicole Morley Jonathan Gibbons Matilda Green Matthew Hale Judy Kingham Liam Donaghue Sean Wingrove-Smith Isobel Shorrock Ellie Jenkins Jac Griffiths Alasdair Smith Robert Corbett Lois Gale Mirthiyu Balakrishnan

'The TOF Child' – your contributions required:

Often referred to as "the TOFS book," *The TOF Child* is now ten years old and in need of an update. TOFS patron Charles Shaw-Smith (a consultant clinical geneticist who is investigating possible genetic causes for OA/TOF) has agreed to take on the coordination of a second edition, with the help of his research assistant, Vicki Martin, who produced the current book, (amongst many other much-appreciated activities for TOFS) and is herself an adult TOF. The second edition of *The TOF Child* is due to be published in 2010.

It has been said time and time again that the short quotes and photos from TOF families are what makes the TOFS book so complete. We need your help to make the second edition equally personable! Please take the time to record your experiences with OA/TOF and VACTERL – the sad times, the happy times, the scary times, tips for other parents, experiences in and out of hospital - we need them all! Please don't think that anything might be too mundane or insignificant; new parents can get enormous benefit from reading about the everyday life of other TOF families. Your photographs would be lovely too, though we may not have page space for them all.

We are particularly keen to feature families whose child has a slightly less common feature within the TOFS community (for example, aortopexy, oesophageal replacement surgery, or the various non-TOF parts of VACTERL). We would also like to hear from teenagers or adults who were born with the condition – as well as family

members who have been affected by the birth of a child with OA/TOF or VACTERL.

Please indicate whether you would like names to be taken out so that your contribution is anonymous. To save us having to re-type written contributions, we would appreciate your text by email. Please send it to vicki.martin@adden-brookes.nhs.uk. If you are not able to email information, please send your contributions to the TOFS office, indicating that they are intended for the TOFS book. Please note we may need to edit your contribution so that we can include as wide a range of experiences as possible.

What's new in the second edition?

Some of the topics to be covered in new chapters include:

- keyhole surgery for OA/TOF
- psychological issues
- how speech therapy can benefit TOF children
- the various options for oesophageal replacement surgery, each described by a surgeon who prefers to use that particular procedure.

If there is something you feel that needs to be added to the book and which might get left out, please let us know using the contact information above. Comments about the current book would also be welcome; for example, how do you feel about the size of the publication? Would you like the next edition to have larger pages? Now is your chance to have your say, so please get in touch.

First successful tissue-engineered trachea transplant

Some of you may have watched with interest the news story back in November '08 of the first tissue-engineered trachea transplant. In a pioneering procedure, the bioengineered trachea was successfully transplanted into a patient with a failing airway. Created using the patient's own stem cells, the transplant gave her a normally functioning airway and saved her life.

According to the ScienceDaily.com website the research shows that when combined with

biologically compatible materials, adult stem cells can offer genuine solutions to serious illnesses. They suggest that it is possible to produce a tissue-engineered airway with mechanical properties that permit normal breathing and free from the risk of rejection with conventional transplanted organs. The patient has not developed antibodies to her graft, despite not taking any immunosuppressive drugs. Lung function tests performed two months after the operation were all at the better end of the normal range for a person of her age.

Who knows what this means for future TOFs...

You can find out more at: <http://digbig.com/4yjqgq>.

Glossary

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

Aortopexy: a surgical procedure used to treat severe tracheomalacia in which the aorta (a major artery which lies in front of the trachea) is anchored to the sternum (breast bone). This opens up the trachea.

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

Dumping Syndrome: this occurs as the result of some operations on the stomach. It refers to the symptoms caused when digested food passes too quickly out of the stomach and into the intestine.

Nissen's 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).

Reflux: Reflux or Gastro-Oesophageal Reflux is when the acidic stomach contents pass back into the lower oesophagus, which can cause pain, a reluctance to eat and possible problems in later life.

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. It is used in the management of severe tracheomalacia.

VACTERL: The term 'VACTERL' describes a group of anomalies which can occur together in newborn babies. It is an acronym for: Vertebral (spinal) defects, Anorectal atresia (failure of the anus and lower end of the gut to form), Cardiac (heart) defects, Tracheo-oesophageal fistula with or without Esophageal atresia (American spelling of 'oesophageal'), Renal (kidney) anomalies, Limb defects.

If you're planning an event to raise money for TOFS, send us the details and we'll share them in Chew. Please give us as much notice as possible!

THANK YOU!

Corporate and group donations

- Corus Teesside Beam Hill in Lackenby, Redcar - £400 (TOFS was nominated by employee Chris Winspear in recognition of the support and help given by TOFS to his niece, Isobel Winspear, and her parents, John and Joanne and brother, Dylan.)
- Kelsey Park Sports College in Beckenham - £137.88 raised by a group of Year 10 students through sports events organised for Year 5 and 6 pupils
- Marlow Foods Limited of Stokesley - £448.40 (through a recommendation from Margaret Boanas who is great aunt to Isobel Winspear)
- Harvenna Stores, Bude, Cornwall - £160 raised at their Christmas raffle
- Winifred Eileen Kemp Trust - £1108.31
- The Eccleston Lodge - £250
- The Lodge of St Peter in Essex - £230
- The Garden of England Lodge, Maidstone, Kent - £256.00 raised at a Ladies' Festival
- The Robinson Lodge, Maidstone, Kent - £150
- Employees of Bridgewater College in Somerset and the Charities Committee - £149.50
- Mrs Fenney of Body Matters Holistic Therapy, St Helens - £30
- Eleanor Hodgson of Lincoln, Mini IQ books for children - £75 raised in a book treasure hunt

In loving memory

- Judith Allen - £200 raised on a sponsored walk in memory of her son, Steven, who was tragically killed at work in 2007, aged only 23
- Andrew and Karen Willis - £25 in memory of Mrs Phyllis Pennyfather (grandmother of TOF Eleanore Derham)
- Adam Richardson's Nanny Myra - £25 in memory of Adam's granddad Fred
- De La Rue Currency - £250 in memory of employee, Mrs Pat Wiltshire
- Ron and Judith Bland - £25 in memory of their friend Brian Normington who died in a mid-air collision last year
- In memory of Mrs Patricia Rushton - £8.05
- Elaine Marks-Parker - £100 in addition to previous donations made in memory of her husband, Michael

THANK YOU!

THANK YOU FOR FUNDRAISING!



far left: Joseph counts the pennies donated by his granddad!

middle: Craig Royston celebrates his achievement with his daughter, Charlotte

left: Charlotte O'Donnell (TOF) aged 10 with Laura aged 8 at her first holy communion

Thank you for your donations, especially all those members who keep on working quietly for TOFS year after year. We'd like to thank:

- Joseph Styles - £60 of 20p coins saved up by his granddad, Andrew Clayton
- Felicity Anderton, grandma to Joel Anderton - £80 donation in lieu of Christmas cards
- Friends and family of Joel Anderton - £160 on Joel's naming day
- Mr and Mrs Tomlinson - £125 in lieu of presents for their golden wedding
- Gary Leach and Kay Downham - £25 in lieu of Christmas cards
- Julie and Leslie Logan's family and friends - £80 in lieu of Christmas cards
- Sue and Nara Pandey - £30 in lieu of Christmas presents
- Colin Ryan's grandmother, Joy Howell - £20 in lieu of a Christmas card and gift to her brother and sister-in-law
- Mrs Nellie Hayes - £100
- Patricia Jacobs - £10
- Graham Slater - £80 travel expenses
- Mrs J. Earl - £30
- Margaret Lemon - £50 won through the TOFS 200 Club. Thank you, Margaret
- Joanna Crowe - £150 raised by her TOF daughter Rebecca running the Mini South Run and Joanna herself running the Great South Run, raising £100. Mrs Nickinson and her friends raised a further £50
- Gill, Duncan, Laura and Alec Jackson - £85 raised at their Christmas craft fair
- Diane Maskrey - £20 from the sale of a game given by Connor's granddad Geoff
- Craig Royston - £234 raised by running the Sheffield marathon
- David Lumley - £50 for an honorarium awarded for his role as Speaker Secretary of Newcastle West Probus Club
- The Brockley-Blatt family - £160 raised by selling Christmas cards made by Chris
- Timothy and Angela Mason - £624 raised by selling goods on eBay. (We would like to thank all those who have donated to TOFS through eBay in the past)
- Alison Pressey and Sue Luff - £150 raised by selling Webb Ivory. (Alison and Sue have raised a huge amount over the years in this way, making their total well over £1200! Thank you!)
- Carole Brown - £387.25 raised by doing a parachute jump. (Carole tells us her blood pressure and pulse rate eventually recovered after the jump!)
- Ron and Judith Bland - £100. (Ron did some work for a friend, who made a donation of £60 in lieu of payment, and Judith Bland made this up to £100)
- John O'Donnell - £237.78 raised at a darts tournament

200 Club

The 200 Club replaced our annual prize draw in 2007 and has proved a big hit! Do you want to be in with a 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! You can get your family, friends and colleagues involved too – the 200 Club is open to everyone!

Want to join the club? You can download an application form from our website (just go to the Supporting TOFS page) or request one from the TOFS office.

The latest 200 Club winners are:

November: Tim Rickards
 December: Andrew and Gemma Thompson
 January: Margaret Lemon
 February: Christine Churchward

TOFS

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Company number

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Raymond Buick MB Bch FRCS
James Dickson FRCS FRCSE FRCPC
Bruce Jaffray BMedBiol ChM FRCS
(Glas) FRCS (Paed)
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Paul Losty MD FRCS (Paed)
Gordon A MacKinlay FRCSEd FRCS
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FRCS(Ed) FAAP
Charles Shaw-Smith BM BCh
MRCP PhD
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Hon. Treasurer: Sandra Hawkins
Hon. Secretary: Graham Slater
Christine Shepherd
Sue Lewis-Jones
Dennis Harvey
John Pearce: Co-opted member

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

Goodbye and thank you

It is with regret that we say 'Goodbye and thank you' to Trustee Drew Bailey. We were saddened, although not surprised (he does have two children under four!) when Drew reluctantly resigned from the Council at the start of the year due to family commitments. We're glad to report that we haven't lost him entirely – he's been persuaded to continue to help out with proof reading *Chew* so thanks for that, Drew and hopefully you, Helen and the boys might be able to join us at our Children's Party in May.

TOFS Children's party

Our annual Nottingham Children's party will be held on Saturday 9 May. We will soon be sending out invitations to those of you living within (easy) travelling distance but even if you don't receive one, this doesn't mean you aren't invited. The party will follow our AGM so you are welcome to attend that as well and make a day of it! In fact last year some families made a weekend of it and stayed in a local hotel.

The party is a great opportunity to meet up and share experiences with other TOF families. There'll be entertainment for the children and lots of good (TOF friendly!) food so don't miss it. We usually have face-painting and soft-play for the little ones, but if there's something you think your child would particularly enjoy please email us as soon as possible at info@tofs.org.uk.

This year the party has kindly been funded by a grant from the Winifred Eileen Kemp Trust. Thank you!

Council of Management update

The Council of Management held the first of their quarterly meetings of 2009 on Sunday 11 January. It's fantastic to have these new Trustees on board. As usual, there's much to be discussed, and Drew's resignation means there's a chair to be filled. Could you be just the right person for the job?

Some of the projects undertaken by our Trustees currently include:

- Revival of hospital liaison
- Documenting policies and procedures
- Strategic development of our website

Co-opted member, John Pearce reported back on the NCVO (National Council for Voluntary Organisations) fundraising conference that he kindly attended in November '08 on behalf of TOFS. Speakers included David Sanit, Action Planning, Kevin Ashby, Big Lottery Fund and Gill Raikes, Director of Fundraising with The National Trust.

Just as *Chew* is going to press, Co-opted member John Pearce and office manager Diane Stephens are attending the RCPCH (Royal College of Paediatric Child Health) Spring Meeting in York. This gives TOFS the opportunity to raise the profile of the conditions amongst medical professionals and glean more knowledge from the paediatricians. Presentations of specific interest include 'Assessment of the Young Child with recurrent Respiratory Infection' by Dr David Spencer and 'An evidence base for Gastro-Oesophageal Reflux diagnosis and management: best practice and update' by Dr Mike Thomson.

You will find a full report in the next issue of *Chew*.

Events

AGM (12 noon) and

Nottingham Children's Party (2-4pm)

Sunday 10 May

Council of Management meeting Nottingham

Sunday 12 July 10.30am

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.