SPRING 2024

tofschew

lifelong support for those born unable to swallow

TOFS (Tracheo-Oesophageal Fistula Support), the charity that supports those born with oesophageal atresia, tracheo-oesophageal fistula, and associated conditions.

Photographer: Chiara Ceccaioni

COVER STORY: Interview with singer / songwriter Tom Bright, our newest Celebrity Ambassador! Pages 10 –11

TOFS – started by parents and continues to be run by parents, grandparents and Adult TOFs

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

Telephone number
0115 961 3092 **(see back page for office hours)**

Email
info@tofs.org.uk

Website
www.tofs.org.uk

Registered charity number
327735

Company number
2202260

From the Editor

Welcome to the Spring '24 edition of *Chew*. Lots to read and learn thanks to you kindly sharing your stories – and to our wonderful *Chew* team of volunteers.

We're delighted to have singer/songwriter Tom Bright join us as a celebrity ambassador. He certainly hasn't let OA/TOF get in the way of success and even with his frantic schedule, he found time to talk to fellow TOF, Benedict Welling, on pages 10 and 11. Another inspirational adult, Tracy Wiseman, shares her story on page 12.

Macie's mum, Kirsty tells her story on page 8 and interesting to read the sibling perspective on page 22, from Holly Murphy, whose brother Rory was born with OA/TOF.

At the tail end of 2023, Kate Yardley, registered midwife and parent of Primrose (born with OA/TOF) pitched the idea for a guide to breastfeeding (or more likely, feeding expressed breastmilk) for new OA/TOF parents. A few months later, we're delighted to have launched the (NNA-endorsed) guide during our 2024 Awareness Week. Read Kate's rationale for pitching this idea on the opposite page…

Adult TOF volunteers have been busy compiling a list of top tips for helping others born with OA/TOF – from getting a good night's sleep to outdoor activities. Read about them on pages 13 and 14.

Lots of fundraising stories as usual throughout the magazine. Your fundraising makes such a difference and we're very grateful. If you're interested in finding out more about the difference it makes, just watch the recording of this year's AGM. Short report (including a link to the recording on our website) on page 15.

We're grateful as always to all the local contact volunteers (TLCs) for the work they do and the support they offer. Read TLC Tracey Fish's report on how she managed medicines for her son, James, who was born with OA/TOF on pages 6 and 7. Visit page 16 for the recently produced resource for steps to consider when considering childcare settings by TLC Naomi Webborn. Find out too about TLC-organised talks or local meet ups on page 21.

Have you considered obtaining your health records or for your child born with OA/TOF? Unfortunately, it can be a rather complex process. Read the experiences of some adult TOFs who have tried to do just that on pages 4 and 5.

As always, we love to hear what you think of *Chew*. Please send all comments or ideas for future articles to diane@tofs.org.uk.

Have a great summer.

Diane

Diane Stephens, *Chew* editor

P.S. The next edition of *Chew* will be available in early September. Copy deadline is 31 July. We love to read your stories. Just email for the attention of the *Chew* team at info@tofs.org.uk.

CONTENTS

Kate's OA/TOF inspirational breastfeeding journey

Midwife and OA/TOF parent, Kate Yardley, author of the TOFS Feeding Your Baby Breastmilk resource, writes about why she felt writing the guide was so important.

Primrose

My daughter, Primrose, was born in March 2023 with undiagnosed OA/TOF. This was a HUGE shock for our entire family, particularly as our pregnancy and delivery were so straightforward and 'low risk' (something I prided myself in), coupled with the fact that I am a practising midwife on a busy delivery suite looking after women with 'complex' pregnancies and births every shift – so I would know if something wasn't right, right?

Despite Primrose's diagnosis, I felt passionately that she would have my breastmilk, having previously breastfed our little boy, Ted, for 18 months, and teaching people how to express and breastfeed as part of my role as a midwife every day. I knew the huge number of benefits that breastmilk possesses, not just for babies but for mothers as well, and came to learn many additional advantages, particularly benefiting OA/TOF babies, such as immunity, pain relief, bonding and increased wound healing. But despite this knowledge, my background, my experience and my extremely supportive surgeon and NICU team, I wasn't prepared for the complexities of our feeding journey. Mostly because Primrose didn't exactly make it easy for us, as, although she was born with short-gap OA/TOF, which meant her repair could be carried out when she was a day old, this sprung a huge leak requiring an emergency life-saving second surgery when she was a week old. The result was a 'tight' repair with a particularly stubborn stricture requiring multiple dilations (13 or 14 maybe, we lost count!) over the first eight months of her life. This, however, never dampened our determination to feed breastmilk and eventually progress to breastfeeding, but it was quite the journey, to say the least. For us, it looked like hand expressing, expressing using a pump, buccal feeding, dummy dips, tube feeding, skin-to-skin contact, attempts at the breast, 'emptying' breasts, timing breastfeeds, top-up feeds, engorgement, obsessing over nappies, obsessing over weight, obsessing over milk supply, obsessing over every noise she made when feeding – the list goes on (I could, and may well, write a book)! As a midwife, and as an experienced breastfeeding mom, I had never encountered 90% of these things, which got me thinking – just how would a non-midwife or first-time mom be expected to do this?

Kate with her daughter Primrose

During this time, but particularly once we were discharged home and there wasn't someone there to ask anymore, and Primrose was displaying some pretty terrifying unfamiliar symptoms (which I now know was a severe stricture developing), I searched and searched and found a total absence in any form of literature designed at helping mothers feed breastmilk to their OA/TOF babies. This, coupled with a continuing assumption amongst healthcare professionals and, well, everyone we came across really, that she was formula fed (I mean I get it, just how can you breastfeed a baby born unable to swallow?) set off quite a bee in my bonnet.

This led me to reach out to TOFS and partner with them and other members of the multidisciplinary team to create the 'Feeding Your Baby Breastmilk' resource, the first of its kind (as far as my googling can tell) anywhere in the world; all inspired by our baby Primrose.

I hope to go on to further this work by undertaking a piece of research exploring the breastfeeding experiences of OA/TOF parents, as part of my MSc in Midwifery in September 2024. Currently, there is no research at all into this area and the hope is that this work will inform and update the current TOFS resource, as well as inform the practices of those supporting OA/TOF families to feed breastmilk and breastfeed. Overall, if our experience, this resource or any of my future work goes on to help even just one mother to achieve her feeding breastmilk or breastfeeding goal, that is all that matters.

Primrose has just turned 1, is absolutely thriving, is still breastfeeding and continues to be my inspiration.

Ed's note:

Thanks to the Neonatal Nurses Association (NNA) and the Neonatal Surgical Interest Group (NNSIG) for endorsing the breastfeeding guide. Visit the guide on our website by scanning the accompanying QR code or copy and paste this link into your browser https://tofs.org.uk/oa-tof-information/parents/the-early-days/feeding-your-baby-breastmilk/

Trying to put the pieces together: a journey to recover our medical records

There's nothing quite so frustrating as trying to do a jigsaw puzzle only to discover some of the most important pieces are missing.

For some people born with OA/TOF, trying to chart and understand their early experiences is an emotional journey and one that can be hampered by patchy or even non-existent files.

Different hospitals and health boards have varying regulations surrounding the length of time they keep medical records. So, when it comes to 'matching up scars to procedures', if there are no medical notes to explain the visible clues, it can lead to a feeling of rejection; that being born with OA/TOF is not important enough to warrant preserving the information.

Listening to adults born with OA/TOF who have managed to get copies of their early life hospital records fills us with relief that not all our very important stories have been lost or destroyed. We know there are some adults born with OA/TOF struggling to obtain their notes and this can add to feelings of rejection, an unsettling of emotions when attempts are thwarted each step of the way.

Perhaps our rare and complex condition is not that important in the grand scheme of NHS administration policies.

Adults born with OA/TOF tell us, "We realise the issue is much bigger than approaching a single hospital for our records. Hospitals close down and relocate, and some are demolished, meaning another door is closed to us. When our records are recovered, they are often barely legible, reflecting what the NHS was like then. But our hearts sink when we have a precious document in our hands only to find we can't read it."

Recent GP electronic records are more readily available but sadly there remains a huge gap in our life histories – the paper trail just runs out.

For some, early complicated lives are part of our identity. However, some of us are not ready to connect with this until later in life. Perhaps some adult patients will not have thought about requesting their notes until reading this article where we hope to raise awareness about seeking your records before they are destroyed. Obtaining your information and submitting single-subject access requests for centrally stored notes can take years. The process can involve multiple health boards and GP surgeries and may not be on your list of priorities right now.

We would like to suggest to parents to hold on to any information you have about your TOF children; they are likely to be grateful in years to come. Particularly, as often happens, we meet healthcare professionals who have never heard of the condition and often see us as 'fixed at surgery'. And for young adults, who currently don't have any health issues, think about getting your records now – just in case your repair becomes a little challenging as you age. It is equally important to recognise the emotions triggered when the records of our early lives cannot be recovered, and to advise and support those adults who have been told their files have been destroyed.

Below are some individual accounts from adults born with OA/TOF, as they talk about their despondency at the lack of joined-up thinking, their sadness at the loss of precious information and their hope that, these days, those born with the same condition will have proper access to all the pieces that make up the personal jigsaw of their lives.

CASE 1

"Over the past few years, since trying to recover my medical records, I have learned a great deal about the different policies that hospitals, GP surgeries and health boards follow. One of the main principles of GDPR is that it prohibits the retention of personal data for longer than is necessary and this has significantly impacted my search.

I have discovered that different records are kept for different periods; some are destroyed eight years after the last treatment or when children reach 25 years old. The only way notes can be saved outside this timescale is if the consultant/doctor writes, 'Do not Destroy' on the record and they should then be retained forever.

Sadly, after much searching and disappointment, I realised there is no obligation to inform the patient that their notes will be destroyed. Despite many operations and interventions related to my OA/TOF (long-gap), there are no GP records for me from birth to 38 years old.

A GP surgery replied that I had never been a patient at their practice, despite being registered as a temporary patient each summer for over 20 years.

When I delved deeper, it was revealed that the hospital where I had my initial surgeries destroys all notes once the patient reaches 25 years old. I remain hopeful that having guided my surgeons (via a telephone contact) to operate on me, the surgeon from GOSH will have kept a record of his instructions and that information may still be held in the GOSH archives department. It is the lack of joined-up thinking which, for me, is frustrating and time-consuming. Why can an NHS Trust in the north-east of England find my notes from 24 years ago yet others cannot unearth them?

Unfortunately, my journey has been full of potholes and trip hazards and despite a complaint to NHS England, the end is still not in sight. Suppose someone had advised me to contact PCSE (Primary Care Support England) where notes can be stored centrally or to make an application to access my personal information via a Subject Access Request (SAR) under the Data Protection Act 2018. In that case, my journey may have been a lot less tortuous and, more importantly, successful."

CASE 2

"When I think about my hospital medical records, I am transported back to 1981 and to the basement of Birmingham Children's Hospital, where I nervously held my records. I struggled to read the almost illegible surgeon's handwriting and failed to make the most of this golden opportunity – to read exactly what had happened to my infant self – 24 years earlier. I had been directed to the archive department by the surgeon who had repaired my OA TOF yet, despite his permission, I was reluctant to face my past full on. Yes, I was foolish not to have scribbled down some information from my dusty notes or even stuffed the folder in my bag, something I now regret immensely.

Many years later, when I tried to obtain my hospital records, I was told they had been destroyed, a situation I am still coming to terms with. This may seem odd to some people but I guess my sadness is wrapped up in the loss of all that precious information, denying me a connection with the four operations I had in the first five days of my life, unable to put all the pieces of the jigsaw together – matching my scars to procedures, to the surgical teams who put me back together, who cared for me on that extremely precarious journey at the start of my life. I do recall reading that some of my health issues were 'behavioural' and that I was 'being naughty'. These untruths left me deflated, emotionally fragile and reluctant to read any further, pushing my records back into their allotted slot. It was as if my notes were not a true reflection of me as a child. They were the words of an adult with little or no understanding of what it is like to be born with complex malformations."

CASE 3

" Requesting access to my first few years of health records was fairly straightforward. Although the hospital was no longer a functioning hospital trust, it was responsible for storing the records. My reason for acquiring my early years health records was, as mentioned previously, a sort of 'tale' around what had happened some years previously. The process of making the request took very little time at all. A reply via email the next day to acknowledge my request and then a footnote to say, "Due to staffing issues, the department of Health Records may not meet the 30-day threshold for sending these records." So, I was somewhat surprised when an email dropped into my inbox. I really wasn't prepared... all of a sudden I was a click away from receiving information about the struggles I had faced as a baby/toddler/child. Given the records were from more than half a century ago, I expected to have to decipher various forms of handwriting – a blessing that our digital age relieves us from. As I started to read, I was unprepared for the emotional journey that was about to start. At last, I knew what type of OA/TOF I had. Would I recommend that you request your health records? Yes, absolutely... if you are unsure or confused about what procedures or health conditions you had in the past. Having access to these records could be vital. Whilst causing some initial emotional upset. I have been left feeling empowered with the knowledge I didn't previously have."

CASE 4

"I understand that for many of us, there was no organised transition into adult care; some TOFS like me were discharged from specialist care as young as 5 years old. The public transport challenges my mother endured, plus being accompanied by my younger sibling meant she could not always get me to my appointments. This resulted in me attending local health services, as opposed to the children's hospital where the lifesaving surgery had been carried out. At these local centres, administration lapses may have occurred, my records were not necessarily shared between the different professionals and departments involved in my care. Some families moved around the country with young TOFs visiting many hospitals, this can make sourcing medical records even more challenging. I would like my health records so that I can put times and dates to my treatments, which are sadly fading as time elapses and slips away. Something for my adult kids – for them to appreciate how lucky they are to be here."

Ed's note: Obtaining your health records

You have a legal right to access your personal information. Apply in writing to the hospital records manager at the hospital where you received your treatment.

For more information and useful links regarding access to personal health records go to: https://tofs.org.uk/chat-links/

Name: Holly Jefferies

Inspiration: I was born with OA/TOF 14 and a half years ago. It was a big shock to my parents as it wasn't picked up before I was born. The TOFS charity provided lots of information and resources that really helped my parents get through a difficult time. I wanted to raise awareness of the condition to as many people around me as possible and raise money for the charity so that they can continue to help other families.

Event: I made gingerbread and handed it out during TOFS Awareness Week at school. I also offered it to my family and my dad's work colleagues. I was featured in the school newsletter, which helped tell my story to the whole school community.

Amount raised: £1,780

Managing Medicines

by **Tracey Fish** *(parent and TOFS Local Contact)*

When I was asked to write about the issues I had getting medicines for my OA/TOF son, I struggled to remember what they were. I had plenty, but a combination of brain fog and the passing of time has left the memories faint. Maybe it's a testament to how we, as carers, find a way to get through the challenges and move on. It's also a sign that as time passes, the challenges can get easier and it is possible to reach a more stable lifestyle.

So, what were those challenges? Well, understanding what all of the medicines were was a tough start; there was nothing in the parenting manuals about that. We were presented with feeding, respiratory and toileting issues, and keeping track of which medicine blocked, released or soothed various ailments was a challenge we weren't prepared for. The medical staff were generally patient and empathetic, but trying to understand what we were being told, especially after sleepless nights full of worry, was a huge challenge. My partner, in particular, found this difficult as he was often hearing me relay the information second-hand as we couldn't both be at every appointment.

We found the best way was to make notes, like a little journal, with enough information to allow us to keep track. This became particularly useful when one specialist changed their prescription and we had to watch for the potential knock-on effect. If the bowel specialist wanted to regulate our son's movements, what impact might that have on his feeding? And how might we need to adapt the amount, or even timing, of his other medicines? The notes helped, but essentially keeping an eye on him and watching for signs was still key. I often wondered whether we were too controlling or too quick to worry and rush him to medical care. But as I reflect over the years, I never regret a single precautionary trip to seek help. We realised, over time, that we were the experts in our child's condition because we knew our child better than anyone and could see the warning signs. Prescriptions changed so often that they got out of sync for renewal, and I was visiting the pharmacist multiple times every week. It is worth having a conversation with your GP or prescriber to manage this.

TLC Tracey and her family

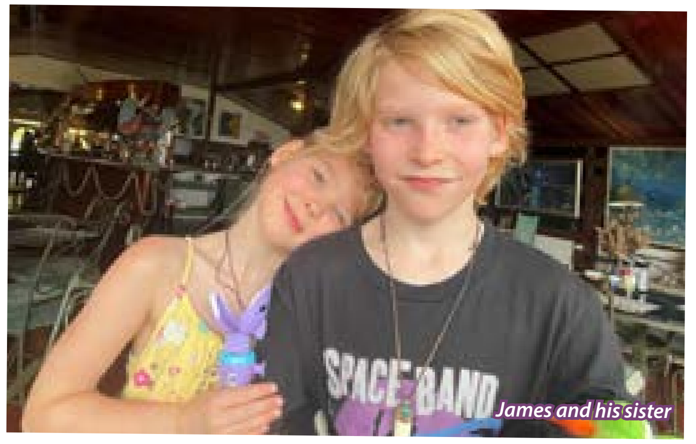
By the time we got to infant school, we'd learned some lessons and ensured that the staff knew the day-to-day processes, what signs to look out for that might indicate an issue, how to manage stocks of medicines and understand that medicines and dosages might change. If we saw signs of a chest infection, we might need them to administer antibiotics for a few days and it was better to agree on this and get paperwork filled out in advance rather than wait until problems arose. Schools and other formal environments don't deal well with ambiguity, and they can't make decisions on children's medical care and medication. However, working with them to find safe boundaries is key to their confidence in managing a child with additional needs in an informed way. This will allow you to relax knowing your child is in a safe environment.

We learned some key lessons about the management of medicine stocks. We were caught out several times by medicines running out, or expiring, at the worst possible times. It always seemed to happen at the start of a bank holiday weekend when the teams we needed would be unavailable for several days. Planning this became a part of our routine. Sometimes we tried to escape on a short break or a holiday and planning for the worst became the norm. Not that we always had issues, but we certainly learned that it was better to be over-prepared than to arrive at a holiday destination and realise that we hadn't brought a backup supply that we suddenly needed. These days we even take two sets of medicines if we're flying – we take enough in our hand luggage to last a few days in case the supplies in our suitcase don't arrive at the destination. Trying to get unusual medicines in foreign pharmacies is an experience we don't want to repeat!

We were able to build a stock of medicines at home in case we needed to start one urgently or to guard against spillages, especially over long weekends. Of course, we all need to be careful not to stockpile too many medicines and to be mindful of expiry dates but having a month's worth in the cupboard came to our rescue many a time; reducing the stress of stocks running low and even helping when the school ran out without any warning.

The main lessons I have learned are:

- Never worry about being too controlling. Nobody will begrudge a concerned carer seeking medical support whenever they are worried and it is better to get help than to run risks
- Try to plan and cater for unexpected problems. It's easier said than done, but having a good stock of medicines, well labelled and monitored for expiry, with notes about what they all do, will reduce your panic moments. And think about how this can transfer into new environments, whether it's nursery, school, a trip to the grandparents, or even a trip abroad
- Have a plan B. Try not to stress but do think through what you would do if there was an issue while you're in an unfamiliar location. Make sure you have key contact information close to hand, and maybe even share those with your support network, so that schools, friends and relatives know how they can help you in an emergency
- Talk regularly to your pharmacist about any potential medicine supply issues – doctors often don't know this, and going back to get a new prescription is very time-consuming
- Talk to your doctor about alternative medicines should your usual one be out of stock. For James' bowel care, we couldn't get his regular medicine and after visiting twenty plus pharmacies, we were told it was out of stock, so we now need to use an alternative
- For nursery/school, check all medication is correctly labelled – the bottle/packet as well as the box
- Speak to somebody. A problem shared is a problem halved and having a good support network is key. Through TOFS you can contact other parents in similar situations and your TOF Local Contact (TLC) will be happy to listen to your issues, suggest ways through your challenges, and can put you in contact with others.



James and his sister

By the time you read this, our fantastic RideLondon team cycle will have completed their 60 or 100-mile cycle for TOFS! They are John Jarrett, Richard Moore, Ricky Roberts, Mark Russell, Andrew Wasley and Ross O'Driscoll along with Bhaskar O'Shea (who was cycling for TOFS with his own place). A huge thank you to them!

We'll report more in the next edition of *Chew*, but you can still read about them and sponsor them here:
https://tofs.org.uk/2024/02/meet-your-2024-ridelondon-team/

A warm welcome to our New Members!

Please note: if you requested that your details be listed in the new members' section and joined after this issue's copy deadline, you will be welcomed in our next newsletter.

Alicia Edge, from Staffordshire
– Nevaeh-Rae, born 19 November 2023, OA

Emma Allez, from Derby
– Ashley, born 28 November 2004, VACTERL

David Cooper, from Letterkenny
– TOF Adult

David Friend, from Christchurch
– TOF Adult

Kate Yardley, from Redmarley
– Primrose, born 26 March 2023, OA/TOF

Irene Burgos Medina, from Spain
– Jorge, born 12 February 2023, OA/TOF

Matthew Wilson, from the USA
– TOF Adult

Shannon Ames, from Bristol
– Alexander, born 4 October 2023, OA/TOF

Simon Edge, from Staffordshire
– TOF Relative

Kylie Plumbridge, from Banbury
– Torvi, born 24 December 2023, OA/TOF

Lynne Hempenstall, from Cheadle
– Lee, born 18 April 1984, TOF

Nicola Deakin, from Bradford
– Olivia, born 20 December 2023, OA/TOF

Mark Wood, from Alnwick
– Daisy, born 30 December 2022, OA/TOF

Annie Shaw, from Tyne and Wear
– Arlo, born 11 September 2023, OA/TOF

Khwaja Nizamuddin, from Blackburn
– Luna, born 9 January 2024, VACTERL

Brionni Pottinger, from Bridgend
– Zephaniah, born 15 October 2023, OA/TOF

Deborah Orr, from Stafford
– TOF Relative

Jane Hunter, from Glasgow
– TOF Relative

Lindsay McGarry, from Dingwall
– Ava, born 27 October 2008, VACTERL

Joanne Nugent, from Tyne and Wear
– George, born 13 September 2017, OA/TOF

Margaret Kushiner, from the USA
– Ari, born 25 July 2021, VACTERL

Peter Smith, from Cwmbran
– Albie, born 3 November 2021, TOF

Stefani Atkins, from the USA
– Landon, born 22 January 2010, VACTERL

Sean McIntyre, from London
– Casey, born 8 January 2024, OA

Adam Shackell, from Trowbridge
– Amelie, born 14 May 2023, OA/TOF

Melissa Kirkman, from Chorley
– Evelyn, born 4 May 2023, VACTERL

Gizem Uslu, from Turkey
– Mert, born 21 November 2023, OA/TOF

Michelle Mitchell, from Sutton in Ashfield
– Harrison, born 18 March 2023, OA

Andrew Coverdale, from Gloucester
– TOF Relative

Thea Langø, from Denmark
– Santiago, born 9 September 2023, TOF

Katie Burrell, from Chelmsford
– TOF Adult

Lisa Smith, from Thurrock
– Jack, born 16 November 1999, VACTERL

Ilias Benjelloun, from London
– Maximillian, born 26 February 2024, OA/TOF

Michaela Hopkinson, from Portsmouth
– TOF Relative

James Key, from Lancashire
– Maximus, born 23 February 2024, OA/TOF

Jack Smith, from Benfleet
– TOF Adult

Mollie-Mae Churcher, from Gosport
– Roman-Ray, born 26 September 2023, OA/TOF

Karolina Bielecka, from Birmingham
– Christopher, born 10 January 2024, OA/TOF

Raphaelle Rex, from London
– Isabelle, born 26 January 2023, VACTERL

Stacey Waite, from Castleford
– Lewis, born 29 October 2023, OA

Timothy Foxx Neal, from Somerset
– TOF Adult

Karina S, from Nottingham
– Alariah, born 30 September 2022, OA/TOF

Amber Jordan, from Cardiff
– Rowan, born 14 February 2024, OA/TOF

Chisom Umeaka, from Edgware
– Munachi, born 2 February 2022, OA/TOF

Paul Dutch, from Essex
– Charlie, born 4 April 2024, TOF

Parrice Bruce, from Essex
– Patsy, born 26 January 2024, OA/TOF

Sammy O'Neill, from Nottingham
– Bailie, born 9 January 2024, TOF

Professionals

Sara Willmott
– Children's Community Nurse, Northamptonshire

Macie's Story

by mum, Kirsty Waring

Finding out you are going to be a mum for the first time at 18 is scary, finding out 20 weeks later that there are medical complications ahead that you cannot comprehend, is even scarier. The first 20 weeks were scary but so exciting! It felt like we spent forever waiting for that first scan, the first kick, finding out the gender so we could buy the first gender-coloured outfit. Finding out we were having a baby girl was a happiness that was soon overshadowed by the uncertainty of the phrase 'stomach bubble'. It worried me, but nothing was certain, we were told to wait for the birth and that surgery might be necessary.

At 37 and a half weeks, my beautiful baby girl was brought into the world early, at 5lb3oz, Macie seemed so small. Still unaware of what condition she had, I was left alone with my baby to give her, her first feed. She quickly turned blue; I was so scared. Shortly after we found out she had long-gap oesophageal atresia – it still didn't sink in. I couldn't comprehend what it all meant. I assumed it would be a quick surgery to correct the problem and then it would be sorted. Two days later, Macie was transferred to Alder Hey Children's Hospital in Liverpool. They told us Macie needed surgery to give her an Oesophagostomy site and to fit a feeding tube. Still, I never thought there would be more, life was crazy, and my Macie blossomed throughout everything. This tiny baby was going through so much, yet it was us who were crying so much.

We spent three long months in the hospital and I have never worked as hard as I did when I was learning how to tube feed, how to use medical equipment and everything I needed to know about the TOF condition. I will forever be grateful that there were two other mums with TOF babies on that ward at the same time I was. At fifteen months old, Macie finally had her surgery, which also involved a gastric pull up. She spent a week heavily sedated recovering and then a further week on the ward. Those two weeks destroyed me, seeing my lovely baby looking so vulnerable. A few weeks later Macie started swallowing and eating. A new fear unlocked in me, it seemed the further along she came, the more scared I was. I had become comfortable with bolus feeding, now, I was terrified of Macie having stickies. I was constantly telling her to chew, chew, chew. She was still using the pump for nightly feeds until she was 5. However, she was now eating like every other child, and we had gradually been lowering the feeds. At 5 she had her tube removed and I could finally breathe! Sadly, the feeding tube site was leaking; we gave it time to heal but it never really did. At the age of 6, Macie had more surgery to remove a section of the bowel – to me, it seemed the older they got the harder the surgeries felt.

Macie with her younger brother

Macie is now almost 11. Between the ages of 6 and 11, she had numerous day procedures to check if she needed a 'stretch'. She has had pneumonia twice, once resulting in a collapsed lung. She has chest infections every single winter. She suffers from stickies and I still tell her to chew, chew, chew. However, she rolls her eyes at me these days; I think my over-worrying is embarrassing to her, but I guess that worry never goes away.

Kirsty with Macie

I look at my baby girl, and even though it's her who is physically scarred, I believe I'm the one who is mentally scarred. She is a wonder; she never lets it get her down, and she never feels sorry for herself – she is my hero!

When Macie was born, my excitement was darkened by fear for her future. But it shouldn't have been because of her strength and the strength I've had to find, I know now nothing will get in our way – there is light in the darkness! Macie starts high school this year, she loves to dance, she is fabulous at trampolining and technology, and she is the best big sister ever to her little brother. If I could go back 11 years and know what I know now, I would not worry so much, because these special children are born ready for their fight! She's my best friend, she makes me so proud, I just hope the years get easier for her. I love you, Macie Mae!

Cytosponge™ trial shows encouraging results

by Tamasine Swan

Ed's note:

Read more about the Cytosponge in the Chew archives on the members-only section of the website. See the Spring '19 and Summer '22 editions

Reflux can affect many individuals born with OA/TOF and can cause a variety of issues, including damage to oesophageal tissue. Over time, this can increase the risk of an individual developing conditions such as Barrett's oesophagus or dysplasia (where pre-cancerous cell changes occur). A webinar event in January 2024, organised by the British Society of Gastroenterologists and reporting on a new technique for monitoring the health of oesophageal tissue, was consequently an event of particular relevance to TOFS and many of its members. The webinar summarised the key findings of a recent trial, funded by NHS England, which sought to evaluate the use of Cytosponge™ (sponge capsule technology) in reflux patients.

Cytosponge™ is an alternative to an endoscopy procedure and requires a patient to swallow a capsule containing a sponge which is attached to a string. The string remains outside the body after the capsule has been swallowed. The capsule casing dissolves in the patient's stomach, allowing the sponge to expand. The sponge is then pulled back up through the oesophagus using the string, collecting oesophageal cells on its surface as it moves upwards. The collected material can then be sent for laboratory analysis once the sponge is retrieved from the mouth. The technique is less invasive than an endoscopy and enables cells to be gathered from the whole length of the oesophagus. The alternative endoscopic technique relies on a visual inspection of the oesophagus using a camera, with biopsies only taken from specific areas.

Over 400 sites across England took part in the trial study with over 8300 Cytosponge™ procedures undertaken between 2021 and 2023. Initially, the trial only involved acid reflux patient referrals, but was later expanded to include monitoring of individuals already diagnosed with Barrett's oesophagus. It sought to assess the Cytosponge™ technique in four separate ways: conclusions regarding the process itself, the patient experience, potential impacts of using the technique and how it would potentially affect existing NHS budgets (known as health economics).

Initial results obtained from this national pilot trial are encouraging. Of those patients who were offered the test as an alternative to an endoscopy, 93% chose to participate, with 95% of those individuals managing to successfully swallow the capsule (mostly at the first attempt). Over 80% were satisfied with the experience, most feeling it to be preferable to the more invasive endoscopy procedure. Feedback also mentioned patients feeling reassured by the fact that cells were more comprehensively gathered compared to an endoscopy (which relies on a doctor visually selecting a small area from which to take a biopsy). No serious adverse effects were reported by patients and no inequalities were identified based on the mixed cohort of individuals involved. Tests tended to be arranged more quickly and results also obtained more promptly than with endoscopy timescales.

Of those completing a Cytosponge™ test, 78% recorded a negative result (no abnormal cell characteristics were observed). Anyone testing positive for specific types of non-standard cell forms, together with a small proportion of the negative group with specific symptoms and/or a higher clinical risk factor, was given an onward referral for an endoscopy. For patients with confirmed Barrett's, interim results suggested that they could be assigned a low, medium or high risk of going on to develop pre-cancerous forms of cell changes (dysplasia). Risk level was dependent on the specific types of cells observed in their Cytosponge™ sample and was subsequently used to prioritise the timing of any follow-up endoscopy (< 6 weeks for high-risk, up to several years for someone in the low-risk category). Someone in the high-risk category is 30 times more likely than a low-risk Barrett's patient to experience further pre-cancerous or cancerous changes to cell characteristics by the time of their scheduled test and there is a high degree of confidence in managing ongoing monitoring using these risk categories. Overall, using the Cytosponge™ appears to provide more detailed information on the biomarkers known to increase dysplasia risk.

The results of the reflux-related cohort have now been published, with results for Barrett's patients awaiting final evaluation. Although trial results have been encouraging, longer-term follow-up is still needed to increase the size of the test cohort and enable comparisons between the accuracy of risk calculated using Cytosponge™ versus alternative testing methods. There is also a need to increase clinician training and exposure to the technique. This should increase confidence in its use amongst medical professionals (with consequent reductions in the use of endoscopy).

Estimates suggest that Cytosponge™ could generate a cost saving in England of between £10 million and £33 million over five years, depending on the percentage of patients using it as an alternative to endoscopy. A saving of approximately £421 per patient per test has been calculated compared with the use of an endoscopy, with a national rollout cost of between £1 million and £12 million. Specialist teams would need to be established and suitable physical space would be required to support the service.

In Lancashire and South Cumbria, using Cytosponge™ helped clear a year-long backlog of Barrett's surveillance cases with a clear cost saving. In parts of Scotland – where the use of Cytosponge™ techniques has also occurred, separate from the NHS England evaluation work – results suggested slightly higher cell change detection rates than with endoscopy alone, with detection of dysplasia at an earlier stage and with more focused endoscopy follow-up with the right specialists and equipment involved. The value of nurses in picking up additional symptoms during conversations with patients was also highlighted in webinar presentations, with this information also feeding into subsequent treatment decisions. Cytosponge™, although appearing to offer benefits as a specific investigative technique, was part of a broader set of available procedures requiring a whole-team approach to clinical decision-making.

The NHS England pilot study funding for Cytosponge™ concluded in April 2024 and alternative funding streams now need to be found if its use is to continue ahead of any future national rollout programme. Individual NHS trusts are now preparing business cases for funding applications, with the trial results being used to inform the content of those applications.

It is hoped that the results of the trial will demonstrate that Cytosponge™ is a technique with the potential to change outcomes for patients. It will, however, require a team approach and a properly costed funding model to be developed before any national rollout will be possible.

The future's looking Bright for our newest Celebrity Ambassador!

Cover Story

There's a busy year ahead for singer/songwriter Tom Bright. He has a new album out and he's playing all the big summer festivals and touring in the UK and abroad. But he still had time to talk to fellow TOF Benedict Welling exclusively for *Chew* magazine. Tom and Benedict share a passion for music, a grasp of their own, different 'normal' and the fun to be had from explaining their scars…

Benedict: What early memories do you have of the condition?

Tom: I have really strong memories of the early days. I remember going back to Great Ormond Street as a 4, 5, 6-year-old. I remember the wards; I remember seeing Professor Spitz after operations and vividly recall how Kings Cross and St Pancras stations used to look coming in on the old train and it would be a proper trip. When I was discharged after my operations and was a bit older, I fell in love with this Japanese restaurant, The Hare and the Tortoise, near Russell Square and my mum would treat me before we got the train back to Derby.

Benedict: What was your experience of growing up with OA/TOF, how did you manage it?

Tom: I accepted that it was me and physically it was always a bit of a struggle, which I probably didn't realise until later in life. I've got a lot of scars all over me; I had my chest opened five times and two ribs taken out. I've got my shark bite scar on my back. I've got puncture wounds, and I was fed through a tube for a long time as well. As a lad growing up, it was a bit difficult to get my head around, but I think I compensated for it because instead of becoming a recluse I was actually the class clown; I always wanted the attention, which is why maybe now I'm a singer/songwriter.

There were traumatic occasions when I'd start choking and my mum would have to get the suction machine, which GOSH had given her to shift whatever it was and then I'd be back at GOSH for a stretch.

In terms of digesting food, it's become a bit of a joke; I'm constantly hungry. I'm a pasta addict. I eat pasta every day of my life – I was destined to marry an Italian, which is what happened! I out-eat everybody. I'm nine and a half stone wet through but I'm an eating machine. Everyone has breakfast, lunch and dinner but for me, that's not enough. I need to be snacking in the day as well or my blood sugar level will drop. It can be so bad that I almost lose the power of speech a little bit. I also have 'dumping syndrome' because my stomach is considerably smaller, and it's been moved up into my upper back. It's like a thick pipe and it functions differently to normal stomachs. But I have a good diet; I find that pasta gives me a lot of slow-burning energy, so always before a gig I'll have a bowl of pasta and that will see me through, and I don't have to worry about my blood sugar level dropping at an awkward time. Because that would be a disaster for me if I'm on a stage and I start feeling dizzy. Ultimately, I just normalise these things because we don't know any different. I don't know what it's like to have a stomach in its normal place.

Benedict: I really relate to you saying it's normalised for us because it's the only thing I've ever known, so you just assume that it's what life is, but other people don't understand that.

Tom: Ever since being invited to be an ambassador for TOFS, it's been mind-blowing. In interviews, when people ask me questions, I see the mystery in their eyes and their jaws dropping. For us it's just normal, isn't it? It's not like I had an accident at the age of 18, it's my whole childhood and my first memories are all of hospital.

Benedict: It's fascinating. I remember once being on holiday and walking down the street with my brother and I wasn't wearing a top. I've got the scars as well, but you forget that it's probably something that people look at and this woman said, "Oh my god what happened to you?" And I said, as a joke, pointing at my brother, "It was him with a sword, we were having a fight." She looked genuinely afraid and scurried off!

Photographer: Chiara Ceccaioni

Tom: Yeah, like the shark bite, that would always be my party trick. On a beach, a kid would say, "What happened?" And I'd say, "Look, just put it this way, do not go too far out in that sea!"

Benedict: What advice would you give to someone growing up with the condition?

Tom: Well, knowing what I know now, that you can reach out to the TOFS community and express any concerns, I'd probably be doing that. There are a lot more people out there with OA/TOF than I ever realised. I'd thought that I was one in a million and it's not the case. There were times when I would feel very alone with it all and I thought the only place I could go would be the hospital and talk to the surgeons, like Professor Spitz or my GP. Outside of that, I was very grateful to my parents and my mum, in particular, who obviously knew everything. But I remember going on holiday to Butlin's when I was about 10 and there was a girl there, a couple of years older than me, who had the same scar on her neck that I have, and my mum got chatting with her family and it turned out she was born with the same condition. And that was the first experience I'd ever had of meeting someone like me. It blew my mind. "What do you mean there's another one!" It's bonkers, isn't it?

Benedict: You've talked about being the class clown, when did you first realise you wanted to be a musician?

Tom: Ooh, late. My first dream throughout my whole childhood was to become a comedian. I wanted to write my own comedy series. I guess I've always been a bit of an entertainer. Maybe it comes from being aged 2 and being in a woman's magazine and I just subconsciously got hooked on being in the limelight. At GOSH, all the celebrities came round: Cilla Black, Linford Christie, the real Postman Pat and then, when I was about 12, I remember coming around post-op and S Club 7 was there and I ended up playing on a Play Station with Rachel Stevens!

Benedict: You are now working on album four, what are your career highlights to date?

Tom: There have been loads. The first mind-blowing, pinch-me moment was playing at the Venice Biennale. Mick Jones from the Clash flew me out there. We performed together in Vivaldi's courtyard. I opened the exhibition with a solo set of my own stuff and then he joined me onstage. That was really cool.

I was very blessed to be asked to cover a The The song by Matt Johnson for a film about the band called The Inertia Variations. It was nominated as Q Music Film of the Year in 2017. I did my own version of Love is Stronger than Death, which was filmed, and I went to the film premiere at the ICA in London. There I was on the cinema screen performing and that track is available to listen to on the album and you can stream it on Spotify. Matt Johnson is a genius and that was a real honour.

I'm off to my fourth Glastonbury this summer and they keep getting better and better. Last year was spectacular; I played to 2,500 people and some of that footage was used for The One Show and Sky News. Playing the London Palladium, that was mental. Just being backstage and seeing the names of the acts that had performed there – the Beatles, Sinatra, incredible. It's all just a highlight really. But even if I hadn't had the highlights like that, just being able to go round touring, just gigging in general, performing songs I write in towns that I've never been to before and people actually buying tickets, meeting great new people. I must never lose that gratitude because it's just awesome.

Benedict: What's next in general?

Tom: I'm touring this fourth album at the minute but, following on from this, there may well be something I can't say too much about at the moment…! I'm doing a load of big festivals this summer and I'm off to Germany in May. I'm going to keep on keeping on and getting these tunes into as many ears as I possibly can.

Benedict: Thank you, Tom!

Tom: Thank you, it's an honour mate and it's been a pleasure!

We're virtually coming together over a cup of tea!

by Judy Riley

It's one of those words that could have come from a sci-fi movie. Webinar.

"Houston to Starship OATOF, you have a webinar approaching you at three times the speed of light!"

It's not from a film script of course. But travel back in time 30 years and you won't find 'webinar' in any dictionary – online or print. It's a made-up term, a mish-mash of web and seminar, created by Eric R. Kolb to describe an online meeting that his company developed. And the brilliant thing about it is that anyone, anywhere in the world, can participate in a webinar presentation, lecture or workshop at the click of a mouse – at the same time!

Picture this: you're trying to find out everything there is to know about up-to-date research into the causes of OA/TOF. Or you're desperate for more information that only a cardiothoracic surgeon can provide. In the old days, you'd have to trawl through past copies of The Lancet or hope that you could grab a few precious minutes with a busy consultant – and then promptly forget everything you've been told. Join a webinar and you can sit in your own front room, with a cup of tea and a biscuit, if you like, and hear the latest findings straight from the professional's mouth. You can make notes and you ask questions via the online chat link, which will be answered during a Q&A session. In some webinars, you can even sign up to take part in ongoing research studies.

TOFS has recently hosted two such webinars. Dr Charles Shaw-Smith and Dr Bryn Webb may be on opposite sides of the Atlantic, but they are working together on the hypothesis that OA/TOF could be directly related to the possibility of a 'lost twin'; a pregnancy that started as identical twins but resulted in the loss of one embryo at a very early stage of development. Charles and Bryn gave an update on their study when they presented their current findings in the hour-long webinar to 62 participants from all over the world (and to date, the Lost Twin video has been viewed 244 times on our YouTube channel). It was fascinating and illuminating and a brilliant example of how, through the magic of modern-day technology, we can share this journey that, in one way or another, we are all on and in doing so, no longer feel that we are on our own.

Joel Dunning

Some of you may have joined the recent webinar on 25 April, when cardiothoracic consultant surgeon, Joel Dunning, presented and answered questions on chest wall deformities, a condition that can affect some born with OA/TOF due to repair surgery in infancy and also to those born with VACTERL association.

It's no coincidence that OA/TOF is classed as a rare disease. These issues are not going to be problems that your family GP sees every day. But the value of signing up for a webinar is that you can get up-to-date information and even be in at the start of new research, which may help to answer questions you desperately want to ask.

TOFS is committed to bringing more opportunities to our OA/TOF community by hosting further webinar presentations with professionals who know and understand the problems we face.

Recognising those problems and finding ways to overcome them is no longer the stuff of science fiction – and neither is the new, online means by which we can stay informed – the webinar.

***Ed's note:** You can catch up with these webinars and many more on our YouTube channel: www.youtube.com/@tofs*

My Story

by Tracy Wiseman

I guess I should start at the beginning. I was born in 1964 with an oesophageal atresia with fistula. I was transferred from Colchester to Great Ormond Street Hospital where they did a repair and had yearly checks until I was 16. I have always had a wheezy cough and was diagnosed with asthma as a child. I had frequent chest infections and developed bronchiectasis, a long-term condition where the airways of the lungs become widened, leading to a build-up of excess mucus that can make the lungs more vulnerable to infection. However, that didn't stop me from enjoying myself and later getting married to my husband, Kevin, and having two fantastic boys (now men). It also didn't stop me from going to Queen gigs in many different countries! After a breast cancer diagnosis in 2012, which I am now clear of, life carried on as normal with the usual chest infections cropping up along with wheezing and coughing.


Tracey and her husband Kevin

In 2020, I was called for a yearly CT scan to check on my bronchiectasis. The result was that the consultant could 'see something strange' in my oesophagus. At the time, I was recovering from a double-brain aneurysm (I don't do things by half), so I wasn't too happy about going for more hospital tests. I felt they were possibly looking at scar tissue from my original operation but agreed in the end to go for a swallow test. This proved that liquid was going into my lung via the fistula and that it was probably my original fistula that had re-opened. I had probably lived with this for many years. I have always coughed when drinking and had to have a drink when eating but these were just normal to me. With this diagnosis, I realised I had just adapted over the years but I did need to get this fixed to stop more lung damage. This started a four-year, four-hospital and five-consultant journey to find a way to close the fistula. My local hospital passed me on to Papworth Hospital and to a consultant who had very little knowledge of people with my condition, so he sent me to the lung defence team. I had about a year of going back and forth, monthly blood tests, breathing exercises and home IV antibiotics, but eventually, they conceded that nothing was going to help until I got the fistula repaired. At this point, I knew I needed to get more proactive. I emailed Great Ormond Street Hospital and managed to get copies of my original medical records. These were mostly handwritten, with the odd ones having been done on a typewriter, which made for interesting reading. In the 1960s parents were not told much about their child's condition, so growing up, I had only the very basic knowledge about being a TOF patient. I realised that I most likely have never had asthma; it was just the ever-present 'TOF' cough. I have learned that the food and drink entering my lung through the fistula were a primary cause of my chest infections, as the food and drink would decay causing infection. I also discovered that I had several dilations as a baby to stretch my oesophagus (I have not needed any as an adult). I found 'My People' on Facebook in the Adults and Teens Born with Oesophageal Atresia forum. I honestly can't say how happy I was to find others like me – I was no longer alone!

After just another few months, I was sent back to the consultant, who said I would need to have a repeat of the original operation, but the risks were deemed quite high. However, I was eventually told they could not get a team together to perform it. The consultant knew of an endoscopic surgeon at Addenbrookes who may be able to help with a less invasive procedure, so off I went to hospital number four! They did three endoscopies under sedation and then decided I would be a good candidate for an Ovesco clip (like a tiny hairgrip with teeth that hold the fistula closed). Unfortunately, as soon as I had this done, I was in pain. Lying down, bending forward, twisting and lying on my right side were all painful. I put up with the clip for several months in the hope it would seal the fistula, and then as suddenly as the pain started it stopped. Another CT scan concluded that the clip had come loose and that I had swallowed it! So, what to do next? I started by asking for a referral to Professor Nick Maynard for some advice and I had a lovely chat with him via video. Finally, I had an expert in my condition and it was nice to know he was there.

Luckily, my consultant at Addenbrookes knew of Professor Bu Hayee at King's College Hospital, who specialised in endoscopic stitching and he agreed to try this on my fistula. Mr Maynard agreed it was worth a try and he also said that if it didn't work then his team would possibly be willing to do the full operation, so I had a plan B (or plan E by this time). Professor Hayee cauterised and then stitched up the fistula, trying to avoid the scar tissue and nerves that had caused me the issues with the Ovesco clip. This has now been done and, so far, I am completely pain-free. I am only just starting the 'endoscopic stitching' journey and I need to have another swallow test to check that nothing is leaking into my lung, but I am quietly confident that finally, after four years, I may now have had a procedure that has cured my original birth fistula. If it doesn't work, then at least I know I can go to Professor Maynard.

My advice to anyone with TOF-related issues is that you may sometimes need to do your own research to get the best help. As for me, there are plenty more music gigs I want to go to and I'm planning on being fit enough to enjoy every one of them!

Adult TOFs Top Tips

We don't know what percentage of adults born with OA/TOF have few or no symptoms of their condition, as they are unlikely to seek out a support group. For some, it may be that they haven't joined the dots and don't realise their symptoms are connected.

Sleep

- Sleeping at an angle can reduce reflux episodes and assist breathing
- Reflux and coughing can occur throughout OA/TOF life, but a bed with an adjustable backrest or blocks under the head end can help. When using bed blocks ensure that the bed is secure
- A wedge-shaped pillow or an arrangement of four to six pillows – arrange pillows to meet individual needs. Three or four horizontally, with an additional pillow placed vertically can support shoulders, neck, and spine and prevent a 'closed chest'. (Extra pillows and/or a V-shaped pillow can be useful but could be counterproductive as the neck may be unsupported, shoulders rounded and breathing further hampered)
- A pillow between the knees or a rolled sheet placed lower down the bed, can help prevent sliding down the raised bed during sleep.

Bathroom

- Permanent grab rails for the bath/shower. These can be particularly useful if you tend to get lightheaded during a coughing episode while bathing. A Community Occupational Therapist assessment is needed to obtain these – or a useful handy person!

Kitchen

- A constant supply of fluids to have with snacks and meals to aid swallowing. Sparkling/fizzy drinks may help move a 'stickie'
- Sauces, mayonnaise, gravy, etc, moisten foods for easier chewing and swallowing
- Food blenders can help make foods easier to swallow and make delicious smoothies and soups
- Sips of iced cold water can help soothe the throat after a reflux flare-up
- Warming and lubricating the oesophagus before eating helps with swallowing. Sip cooled boiled water
  (If your swallowing deteriorates, you are advised to ask your GP for a referral)
- A wall-mounted oven can help to reduce reflux and coughing from bending
- Using a spray frying oil helps to reduce fat intake, as can investing in an air fryer
- Some adult TOFs omit dairy foods from their diets, finding that this helps to reduce the stickiness of their secretions, making it easier to cough and clear them. There are many vegan products available.

Swallowing food can be hard for me.
Please help me to enjoy eating safely.

URGENT TOILET REQUEST
– thank you!
Cardholder has medical needs requiring immediate access to a toilet

My noisy cough is normal for me!
Please don't worry!
It doesn't mean I have something infectious.
Thank you for understanding.

Use the TOFS information cards.

These discreet credit-sized cards will fit in your wallet or purse and open out to display further information that you can show for an explanation. Order hard copies from the leaflet section of the TOFS website: *www.tofs.org.uk*

Eating Out

The prospect of eating out can be very daunting for some TOFs – "What if I have a stickie?"

"What if I start coughing and other people are uncomfortable with the sounds I make?"

When eating out with friends or colleagues, tell them that you may need more time to finish your meal. Taking your time to chew and swallow food is important. Take yoghurt or sachets of mayonnaise to soften foods or ask for extra sauces if the food is dry. Having a drink of water close to hand is essential.

Away from home

Please help me have a comfortable trip

The cardholder has medical needs which may require attention

- Trips away from home can be difficult, particularly if you are visiting unfamiliar places. Trips overseas require extra attention, and it may be worth checking where the nearest hospital is in case a problem arises.
  You may need a letter from your GP confirming your health needs and listing your medication. OA/TOF words in other languages can be found on the TOFS website
- Keep medication and essential feeding equipment with you at all times in a cabin bag, as losing them in lost luggage could be challenging
- Medication and nutritional supplements may need refrigeration. Keep them in a cool bag in transit
- Items we have in our homes need to be in smaller, portable versions, sometimes with recharging devices
- Portable suction rails for bathroom use. Exercise caution as they have been known to lose suction and come away from the wall
- TOFs who are fed via nasogastric, gastrostomy or jejunostomy devices will have to think about supplies including syringes, spare tubes, feed pump and enough feed to last the duration of their stay
- Pack a TOFS first aid kit – including reflux medication and a drink.

Outdoor activities

- Don't be afraid to try anything. Exercise is good for lung health, overall fitness and wellbeing
- Know your limits. You set the pace and ask your companions to follow
- Walking, cycling, swimming, even caving – stop, rest, catch your breath as necessary. Relax and enjoy the activities and views.

Continued on next page

Accessible toilets - not all disabilities are visible

The Equalities Act requires public eateries to have designated accessible toilet facilities.

Disability Radar Key Scheme – privacy, space, and handwashing facilities to:

- Manage tube feeding
- Additional health difficulties affecting bladder and/or bowel function. This may be Dumping Syndrome and other conditions associated with OA/TOF, Anorectal Malformation or changing a stoma bag
- Mental wellbeing: Anxiety, PTSD.

Dental care

Some adults may find a trip to the dentist daunting as the experience can trigger unpleasant memories of other oral treatments and/or investigations from childhood

- Providing the dentist with information from the TOFS website can be very beneficial – not all practitioners will have come across OA/TOF before
- Having OA/TOF-related reflux can have a significant impact on teeth, but your dentist can teach you the best ways to care for and protect your teeth and gums
- Strong teeth will help when chewing foods – an important part of preventing a 'stickie'.

Awareness Week 2024!

This year's TOFS Awareness week ran from 26 February to 3 March and it was heartening to witness so many stories being shared across social media and in various publications. We extend our heartfelt gratitude to everyone who participated.

We kicked off the week in style with the wonderful news of singer/songwriter Tom Bright joining us as our latest celebrity ambassador. Tom shared his inspiring journey with Sky News, BBC Radio London, and of course, TOFS. You can watch some of these in the video section of the website.

Throughout the week, we encouraged members to share our resources to help raise awareness of the conditions and engage with political representatives and medical professionals. Several members also had their stories featured in local newspapers, showcasing the diverse ways in which OA/TOF impacts lives.

Did you see our TLC video? If not, check it out here: https://tofs.org.uk/get-support/.

During the week we also took the opportunity to celebrate the invaluable contributions of our volunteers, including our TLCs (TOFS Local Contacts) – our UK-wide support network of parents of children born with OA/TOF who generously offer their time and expertise to support fellow members. Please take a minute to watch their video on the website and reach out if you need their support.

Rare Disease Day, falling on 29 February, served as a poignant reminder of the global community of 300 million individuals living with rare diseases. Once again, we encouraged members to join the #LightUpForRare campaign, illuminating the importance of equal access to diagnosis, treatment, care and social opportunities for all affected.

Fundraising activities flourished during the week, with many new initiatives launched. These include our new challenge events, located across the country. If you haven't signed up for one yet, head over to our fundraising challenges page and get involved.

We also took some time to spotlight our collaborations with UK and international partners – a collective effort aimed at raising awareness and providing support for related conditions.

Awareness week may now be over but, of course, raising awareness of OA/TOF remains an ongoing fight. With your support, we know we can work towards a world in which those born with OA/TOF live long and healthy lives, unconstrained by the impact of being born with these conditions.

TOFS
27 February

TLC Naomi Webborn has been busy dropping off our Parent Packs at hospitals and other locations in South Wales this week. The packs are designed to give much needed information and reassurance to new parents/carers of babies born with #OA / #TOF and direct them towards the support available from their TOFS Local Contact, the charity and the wider OA/TOF community.

Read more about Naomi's story at: https://www.[illegible]/.../swansea-mum-launches.../...
See more

What links Dr Who with Britain's first successful OA surgeon?

by Jeni Savory *(the first successful survivor of OA surgery in the UK!)*

The actor, Richard Franklin, who died recently, was well-known for his parts in Dr Who in the 1970s. His fans loved his character, Captain Mike Yates. He also appeared as Denis Rigg, a ruthless businessman in Emmerdale in the 1980s. The link with OA is that he was the son of Richard Harrington Franklin (known as Dick) who carried out the first successful OA surgery outside the USA at Hammersmith Hospital in London in 1947.

I was the baby who was lucky enough to survive that surgery and I have been eternally grateful to the surgeon, Richard Franklin, who saved my life. I always knew him as Mr Franklin and had no idea of his first name so was never able to find out more about his professional life, although as he kept in touch, I knew that his son was an actor. As soon as I read about the death of the actor Richard Franklin, I googled his father, the surgeon, and managed to find out more about his life.

Richard Harrington Franklin or 'Dick', as he was known, was born in London in 1906. He studied medicine at St Thomas' Hospital in London and qualified in 1930. In 1935, a new British Postgraduate Medical School was created at Hammersmith Hospital under Professor Grey Turner. Richard Franklin was appointed as his first assistant and senior lecturer. According to the Royal College of Surgeons of England, "Dick's world reputation is soundly based on his pioneering contributions to oesophageal surgery."

During the Second World War, Richard Franklin joined the Emergency Medical Service and helped to manage the casualties from the bombs falling on London while keeping the hospital open.

In January 1947, he performed the first successful repair (outside the USA) of congenital atresia of the oesophagus. Until then, the prime cause of death was the separation of sutures and he demonstrated that healing was "best achieved by full-thickness interrupted silk sutures." In his time, oesophageal surgery changed from being an occasional success to being a routine, safe procedure. In 1953, he published a monograph, 'Surgery of the Oesophagus', which is still available in a used copy on Amazon US for $50.

I remember Mr Franklin as a very kind man who always took an interest in my life. In the 1970s, when I was 27, he invited me to dinner and to stay the night at his home in Twickenham. He offered some health advice, which I'm afraid I didn't follow (like having a cold bath every morning!). He also told me if I ever needed surgery, I should get in touch with him.

After retirement, Richard Franklin moved from Twickenham to Aldeburgh, where he enjoyed sailing and swimming in the sea. He died in 1991.

Thanks to the Royal College of Surgeons for biographical information on Richard Franklin.

TOFS 2024 AGM

TOFS' Annual General Meeting (AGM) took place on Thursday 18 April at 7 pm, over the online platform, Zoom. All members and associates were invited to attend. Apologies were received from Drew Bailey, Pat Fergusson and Christine and Gren Shepherd. The minutes of the 2023 AGM were approved, and TOFS Chair, Duncan Jackson, set out the format for the meeting. Duncan explained that the accounts (and the report) had been examined by our external accountants and approved by the Directors/Trustees at their Council meeting on 16 April 2024.

CEO Diane Stephens thanked staff and volunteers for their input and work in 2023, summarised the key developments in pastoral support throughout the year and reported on membership growth.

Trustee Graham Slater shared developments in medical liaison and collaboration with medical professionals, researchers and other support groups in 2023.

Treasurer John Pearce presented the financial position and the highlights from the year-end accounts. He recommended that Lemans be retained as our accountants. Trustee Clare Johns reported on the successes and challenges of our ongoing fundraising efforts

Trustees Duncan Jackson and Graham Slater had offered themselves for re-election and were unanimously re-elected. Duncan advised that John Pearce and Trace Loffman were resigning as trustees, and he thanked them for their contributions over the years. John had been a trustee for TOFS for over 16 years, and Trace for over eight years. Julia Faulkner was elected unanimously as an additional trustee.

Ed's note: Did you miss the AGM?

Watch the recording here:

www.tofs.org.uk/oa-tof-information/oa-tof-videos/tofs-agm/

Please note that the Annual Report for 2023 will be available once it has been lodged with Companies House and the Charity Commission.

Can you help us bag a great prize?

We're on the lookout for some fantastic prizes for our big raffle later this year. We're already speaking to businesses across the country to source them, but we could do with more.

Can your company or employer help? Many businesses will donate prizes for charities their staff support. Can you check if yours will?

If you think you can help, or need more information on what to ask for, please reach out to Clare Johns (TOFS Trustee) via clare.johns@tofs.org.uk

Steps to consider when looking at any childcare settings for your child (childminder, nursery or school)

by Naomi Webborn *(parent and TOFS Local Contact)*


TLC Naomi with her son

☑ Contact the setting to arrange to meet with the nominated person/people to discuss your child's needs. (This may be with a specific childminder, the head teacher, class teacher, special educational needs coordinator (SENCo), additional learning needs coordinator (ALNCo) and/or pastoral support). It is best to be prepared and initiate this contact well in advance of any intended start date

☑ At the meeting, be prepared and share the information below. This will help to build your child's health care plan with the school

☑ Evidence, videos, or scenarios are important to show staff. This will help them to understand what happens in worse-case scenarios

☑ Download these TOFS guidance sheets (or order hard copies for free from TOFS):

- **About OA/TOF/VACTERL:**
  https://tofs.org.uk/product/about-oa-tof-and-vacterl-booklet/
- **Key points for early years staff:**
  https://tofs.org.uk/product/oa-tof-key-points-for-early-years-staff/
- **GP fact card:**
  https://tofs.org.uk/product/gp-fact-card/

☑ Your child's medical history

☑ Letters from any of your healthcare team/consultants

☑ List safe/unsafe foods for your child and drinks they use in emergencies

☑ Make the school staff aware that not all 'choking' needs action. It is important to make them aware of the difference. Some appear to choke because of a 'stickie' (food lodged in the oesophagus) but can still breathe. Some appear to choke due to unsafe swallow or aspiration – would your child need to calm down, take a sip of a drink until it passes or need physical intervention? Clearly, if a child is unable to breathe, then physical intervention is necessary. Sharing evidence, videos and scenarios will help with this

☑ Suggest training on choking for school staff, including the kitchen team, with first aid information posters placed in key areas. (This advice may be different for children who have had stomach pull ups)

☑ St John Ambulance – choking child guidance
https://www.sja.org.uk/get-advice/first-aid-advice/choking/

☑ When settled, and where relevant, make the class aware of your child's condition. Your child's peers will, in time, become their army of support when needed

☑ Remember that you are your child's advocate and their voice in the early years, so do speak up, share information, and ask questions, so that you feel confident leaving them in that childcare setting

☑ As your child's healthcare plan will need updating annually, resend updated guidance and information from TOFS every year. Offer to meet with new staff to explain your child's condition and needs

☑ If ever in doubt, contact TOFS Facebook groups, TOFS Local Contacts and your team of health care professionals.

Ed's note:

Find a downloadable version of this information on our website through the link below
https://tofs.org.uk/wp-content/uploads/2024/04/Steps-to-consider-when-looking-at-childcare-settings-for-your-child.pdf

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Thanks for the memories!

by John Pearce

It's always sad when someone passes on, but families are increasingly trying to turn that in some small way into something positive by asking for donations to charity (rather than flowers) at funerals. And what better charity than TOFS?


The late Judith Bland, pictured with her husband, Ron, in 2009. Read more about Judith in the next edition

I've recently been reviewing the TOFS 2023 accounts. During the year, TOFS received In-Memoriam donations totalling nearly £7000. These were in honour of 12 people who had sadly passed on. The amounts involved ranged from £30 to nearly £2000. Included in the total was the first part of a will gift (legacy) left to TOFS by long-standing TOFS volunteer Judith Bland. We'll publish full details of this legacy, along with a tribute to Judith in the next edition of *Chew*.

The Trustees are so grateful to Judith and her family, and also to the families of Alan Brock; BJ Griffiths; Dylan Findlay; John Armstrong; June Giles; Kath Saunders; Liz Dignan; Peter Halliday; Ray Draper; Theo-John Mcaleese and Wendy Procter.

The 2023 total was substantially larger than TOFS had received in 2022, which had seen some seven people remembered with a gift to TOFS, totalling £1700. In contrast, 2021 had seen TOFS receive the fantastic £71,000 legacy from June Martin's will. We are most grateful to her and her daughter Vicki, who was born with OA and is a long-standing TOFS volunteer, former Trustee and co-editor of ***The TOF Book***. That major will gift enabled TOFS to massively improve the TOFS website and other online presence and make what TOFS has to offer easier to access remotely. The other 2021 In-Memoriam donations added up to just over £5000 and were in memory of 14 people who had sadly passed on. Thanks to all of you who decided to remember a loved one via a gift to TOFS.

Ask your employer, please!

by John Pearce

TOFS receives a number of donations from companies every year. And it is almost always because a TOFS member works there and has nominated TOFS for a charitable donation. What about nominating TOFS to any charitable donations scheme that your company might have? If the nomination forms are at all complex, we can help at the TOFS office (info@tofs.org.uk)

In 2023, TOFS received nearly £9000 in such donations.

In this respect, we are grateful to:

1 Blackhawk Network - donation of £2500 - nominated by Joanne Hastings
2 Dechra Pharmaceuticals - a donation of £1000
3 BooHoo.com - £1000 donation - a matching donation for Laura Dooley's little boy's birthday
4 Castings plc - £860 donation - nominated by Kevin Smith
5 Marchwood Ltd - £ 500 donation - nominated by Daniel Ford
6 HSBC - £500 donation – employer donation for Clare John's volunteering hours
7 Pavlova a Charity - £200 donation
8 Instruments Direct - £200 donation - nominated by Olivia Tattersall
9 Brae Alpha Welfare Fund - £200 donation - nominated by Dominic Stewart

Impressively, several of these companies have donated to TOFS before: Blackhawk; Dechra; Castings; HSBC; and Instruments Direct.

If you are a member of a club or society that has a charity of the year or similar, please have a go at nominating TOFS. The biggest donation we received from a club or society in 2023 was £2000 from the Etruscan Masonic Lodge. Thanks so much! And it's right to say that the Freemasons, as a group, have supported TOFS to a greater extent than any other club or society over the years.

On the streets at the London Marathon

by John Pearce

Every year, we ask members to raise a lot of money for TOFS by making the sacrifice of preparing for and running the London Marathon, the world's largest fundraising event – and TOFS' biggest one too!

It seems only right that we should be there to offer our runners some support 'on the day'. We have been using the same cheering station location for several years. It's a great place as the runners pass it twice, just over halfway into the Marathon and a bit over three-quarters of the way as well. It's reasonably accessible by the overground / DLR and has cafes/toilets nearby, plus an underpass to cross the road.

Despite showing up at 7 am, a group of supporters from Tommy's had beaten me to the very best spot, but fortunately, there was some barrier space left for the TOFS flags and banners.

We have been chatting to our runners and they have been swapping training notes, etc – on a WhatsApp group for a couple of months before the Marathon – all part of the support from TOFS.

All the TOFS runners finished, with times ranging from 2hrs 51 minutes to 7hrs 05! We have had lots of 'tired but elated' messages, and I'm glad to say that no one has reported any injuries.

Best of all, the total raised by this group was a brilliant £19,600 including gift aid (as of a week after the event). Our leading fundraiser was Gavin with an excellent £4177 (including gift aid). Over the years, only a handful of TOFS runners have beaten that. Emma and Kimberly both raised more than £3000, and Callum's total is very close to that, so a great achievement all round. The fastest runner was Tom, who ran in 2hrs 51!

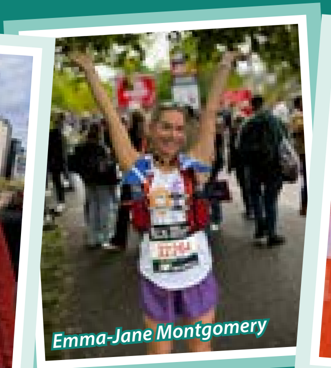
Well done and thanks to everybody!


Our fastest runner, Tom Coe-Hales

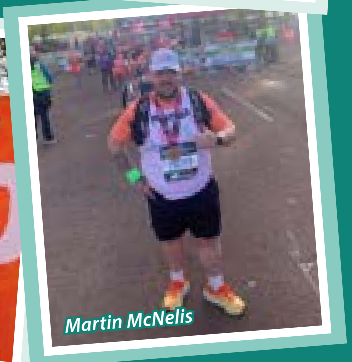

Zoe Sutton


Callum Hillman


Chris Baker


Emma-Jane Montgomery


Gavin Mountford


Martin McNelis

The Big Splash Swimathon 2024

This year has a lot of exciting events that you can get involved in as well as putting in place your own ideas to raise money for TOFS!

The end of March saw our members raising money for TOFS at our first Big Splash Swimathon. What an event we had. Our supporters took on a mini splash with their families and even had the opportunity to take part in the individual 10km mega splash! Several participants joined the WhatsApp community group for this event so that they could connect, talk about the event and share stories. We saw supporters get straight into the event on the first day right through to the last challenging lap. We were thrilled to see the combined fundraising total of £4437 plus gift aid (at the time of writing) for their hard work and efforts, which was rewarded with their very own TOFS Swimathon medal. A big thank you to those who were involved.

If you are interested in supporting us in other ways, please take a look at our website under the 'Support us' section to find out lots of interesting ways to do this.

The Big Splash medal


Gwyneth Robinson


Hayley Ramm


Jasmine Featherstone


Nicola Turnham


Sophie Adamson

Fundraising Heroes!

Name: George Croxall, with parents Katherine and Stephen and younger sister Harriet

Inspiration: To raise awareness and funding for TOFS. George started school this year and TOFS has helped immensely in guiding us and the school to ensure that he has the right support in place.

Event: George's mini triathlon

We set George the challenge of walking 5km, cycling 5km and swimming 10m unaided over a weekend – no mean feat for a 4-year-old! Starting on Saturday 9 March, the walk up the local hill got extended to over 6km (mainly due to the inclusion of three snack stops and a trip to the play park). After lunch, it was time for the bike ride, adding another 6km to the total and getting home just before the rain started.

Sunday brought the swim, which would be the most challenging part for George. In true style, he kept going and completed three widths (15m) – all under his own steam – before going on to complete the rest of his lesson!

We would like to say a huge thank you for the generosity of all our friends and family who donated, but especially, to the staff and parents at George's school for their donations and support.

Amount raised: £755

Fundraising Heroes!

Name: Kerry Bamford

Inspiration: My grandson, who was born unable to swallow

My grandson was born prematurely, unable to swallow and was struggling with other difficulties too. However, with the help of TOFS, other charities and the Sheffield Children's Hospital, he has come on in leaps and bounds. Although he continues to have stretches, he likes most foods. His smile is outstanding and never fails to bring a smile to those who spend time with him. He is a very strong little boy who is now trying to walk. He has the most amazing parents who have remained strong throughout.

Event: I decided to do the 10K Rother Valley Run; I am not a runner; however, I did this with pride.

Amount raised: £215

Fundraising Heroes!

Name: Tracey Fish

Inspiration: TOFS has been supporting me and my family since my son, James, was born in July 2013. When I told my work colleagues about TOFS, we decided that we wanted to give something back. So, on a very warm and sunny Saturday in May 2023, a team of seven of us, plus one dog, decided to hike the Surrey Three Peaks. It was a fantastic day, starting at Denbies Vineyard and taking in the sights of the three highest points in Surrey: Box Hill, Holmbury Hill and Leith Hill. We walked the 39.3km (53,659 steps), got lost about three times, consumed lots of jelly babies and managed to hike up the same peak twice. It was a fabulous day and has inspired us to attempt the Yorkshire Three Peaks this summer.

Event: Surrey Three Peaks Challenge

Amount raised: £500

Can you take on a challenge for TOFS?

Did you know we have a wide range of challenge events happening throughout the year? Everything from inflatable fun runs to ultra marathons. So, whether you're an adrenaline junkie or simply looking for a fun way to get involved, you will find an event for you.

Plus, thanks to our collaboration with Run for Charity, we now have access to over 350 challenge events across the country! So, wherever you are in the UK, you are bound to find something happening close to you.

Sign up today and help us raise vital funds, spread awareness, and support the OA/TOF community.

Featured Events:

15 Jun – Race to the King – Ultra Trail Run (South Downs)

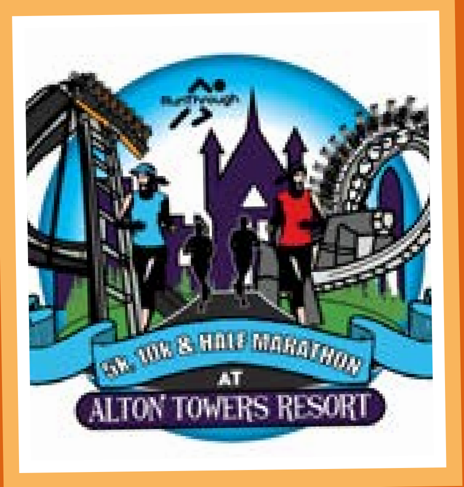
29 Sep – Robin Hood Half Marathon (Nottingham)

13 Oct – Royal Parks Half Marathon (London)

16 Nov – Run Alton Towers (5K,10K & Half Marathon)

AJBell great manchester run

Interested in joining the TOFS team? Find out more about all the events at *https://tofs.org.uk/support-tofs/*



Meet your new TLCs

Meet Catherine, our new TOFS Local Contact (TLC) for the north-east of England, the Royal Victoria Infirmary and the Great North Children's Hospital. Catherine's daughter, Daisy, was born in December 2022 with OA/TOF (long-gap) and has had several dilatations and experiences reflux. She also had severe tracheomalacia requiring a tracheostomy and CPAP.

Also, meet Alan and Carolyn, our new TLCs for Merseyside. Their son was born with OA/TOF in 1989. They live in Liverpool and are happy to support any current and new OA/TOF families in the Merseyside area and those staying at the Alder Hey Hospital.

Our TLCs are there to provide support to parents and carers. If you wish to get in touch with Catherine, Alan and Carolyn, or your own local TLC, you can find their contact details below and on the membership website.

catherinearchbold@hotmail.co.uk

carolynseeley77@gmail.com

Alan.seeley@outlook.com


Catherine


Alan and Carolyn

Would you like to volunteer for us?

We currently have vacancies for the regions listed below. Please do get in touch with the TOFS office if you want to get involved or email info@tofs.org.uk

- North Scotland – Aberdeen
- Glasgow and Scottish Borders
- Northern Ireland – L'Derry
- Hull
- West Sussex
- Southampton
- Leicester & Nottingham
- Birmingham
- North Wales

Brazilian Portuguese Translations of TOFS Resources

by Sarah Winspear

Last year, one of the members from a Brazilian Facebook group for parents with OA/TOF children (GAAE – Grupo de Apoio Atresia de Esofago) reached out and asked us for permission to translate some of our TOFS resources into Brazilian Portuguese to share with parents in the Brazilian and other Portuguese speaking communities.


Atresia de esôfago com Fístula traqueo-esofágica

Pontos-chave para médicos

"Seguimento para toda a vida é essencial"


Sobre AE, FTE e VACTERL

We would like to say a big thank you to the members of the GAAE for translating six resources and our disclaimer, and to all the volunteers who reviewed and verified the translations.

If you would like access to any of the translated resources which include: Pontos chave para educação pré-escolar (early years postcard), Para mais informações (emergency card), Informação para medicos sobre AE, FTE e VACTERL (GP leaflet), Pontos-chave para médicos (GP postcard), Introduzindo sólidos após reparo de AE (Introductions to solids leaflet) and Sobre AE, FTE e VACTERL (OA/TOF & VACTERL leaflet), you will find them on our website in the resources section *https://tofs.org.uk/oa-tof-information/resources/oa-tof-leaflets-in-portuguese/*

Join us for our upcoming events!

Adult 'Coffee & Chat' dates

Meet other adults born with OA/TOF for our virtual coffee and chats! This is an informal, safe and supportive space to share or listen to experiences. A number of our volunteers, who are also adults born with OA/TOF, facilitate and support the space and can signpost to some of our resources. You are welcome to drop in at any time! Find the registration link on our website events page. The next coffee and chat dates are:

- Thursday 6 June 7-8 pm
- Thursday 1 August 7-8 pm

Talk with TLCs – 'Teens and Transition'

Do you have a child born with OA/TOF who is becoming a teenager? Join our 'Talk with TLCs' session to speak to other parents and share experiences on Tuesday 2 July, 7.30-8.30 pm.

The session will be held via Zoom and hosted by two of our TOFS Local Contacts (TLCs), Bruce Rennie and Tracey Fish – both are volunteers and parents of children born with OA/TOF.

Pre-booking is essential, so please register on our website events page.

Informal meet ups

Do feel free to drop in and visit! Further details of our meet ups can be found on our website and socials.


North West Meet Up!

Join TLC To'neill in Stockport and meet other OA/TOF families.

Friday 2nd August, 10.30am


TOFS LONDON GET TOGETHER

Bring your own nibbles and tipples and join us for a

PICNIC IN THE PARK

Saturday 15th June

2pm onwards

CLAPHAM COMMON

(enclosed area next to the Bandstand)


North East Meet Up!

Join TLC Catherine in Newcastle and meet other OA/TOF families.

Saturday 17th August, 10-12pm

Leazes Park, Newcastle

Rory's Story – Growing up with a sibling with OA/TOF

by Holly Murphy

My brother, Rory, was born on 10 January 2016. I was extremely excited to meet my second brother and he was brought home that same day. My mum had explained that she was a little concerned with the noises he was making during feeding and how he couldn't keep anything down. She took him back to the hospital the next day where they reassured her that everything was okay and sent them both home. By day six, these concerns only grew, so she took him back to the hospital and was not taking no for an answer this time. The TAT tube that was put down into his throat coiled in the oesophagus, which confirmed Rory's OA diagnosis. I remember Mum calling saying that she was waiting for an ambulance from either GOSH or Addenbrookes for specialised treatment.

Rory was transferred to Addenbrookes Hospital, where he was placed in the Intensive Care Unit and treated for sepsis. My mum was informed that Rory might not make it through the night. I was 8 years old at the time and was not told until later in my life the severity of Rory's condition. Fast forward to day ten, he had had a successful repair surgery, which had taken approximately five hours. He grew stronger and stronger as the weeks passed and eventually returned home. We were all a family again after a few months of separation.

When he was diagnosed with Oesophageal Atresia and Tracheo-oesophageal Fistula, I had no idea what this was, and I even struggled to pronounce the conditions! However, as I grew older, I researched these conditions so I could be more understanding of what he was going through and widen my knowledge to support him. We were provided with support from our local council, enabling me to be registered as a young carer for him. The nurses who were with Rory at the time would explain to my sister and me that Rory was unwell and that the nurses were doing everything that they could to ensure that he got better. I remember sitting next to him, drawing and painting him, as I was happy to see him again after months. I had been attending school carrying a teddy bear around to reassure me that everything was going to be okay. The school I attended at the time, the same one Rory is attending now, were nothing but supportive and ensured that I was all right during this stressful period of my life.


Holly and her brother Rory


Rory completing TOFS Teddy Toddle

At first, my mum ran through some steps to take for him in case he had a medical emergency during mealtimes. I remember witnessing him choking for the first time – it was difficult to watch and extremely distressing for me. I was upset knowing it was a painful experience for him and that I couldn't just stop it for him. In public, people would shame our family, telling us we were bad people for allowing him to choke when we were just trying to support him through these incidences.

My vocation to study medicine began after witnessing first-hand how my brother's life was saved by clinicians. His condition has had an enormous effect on our whole family, and we have had to learn, adapt and make changes for him as he grows. He has recently had his fifth stretch. Rory continues to amaze me every day. Being his young carer has helped form the person I am and has allowed me to grow as an individual, to be understanding, and patient, and to be able to deal with situations, no matter how difficult they may seem. With his resilience and witty sense of humour, I am proud to have him as my little brother.

You are invited to… our 2024 TOFS face to face Seminar!

We invite you to register for our in-person event on the afternoon of Saturday 16 November 2024, at The Engine Rooms at Birchwood Park, Warrington, WA3 6YN.

We will have a range of speakers from a variety of healthcare professionals who work with OA/TOF patients. Confirmed speakers include Chantal Ten Kate, who is coming all the way from the Netherlands to discuss Adult Care for OA/TOF patients; and Nick Lansdale, who is a Consultant Paediatric and Neonatal Surgeon in Manchester.

It is also a great opportunity to meet and chat with other members and the TOFS team.

Historically, our TOFS seminars have been great successes with amazing feedback from members who attend again and again. The last time we were at The Engine Rooms in Warrington was 2019, when we had a full conference, with 140 attendees and brilliant speakers!

Please keep an eye to our website and social channels for further details. Bookings for the event will open at the end of June.


TOFS conference 2019 at Warrington


TOFS conference 2019 at Warrington

Fundraising Heroes!

Name: Peter Moffatt

Inspiration: My son Caden, who is a TOF, and all others born with OA/TOF

Event: Cardiff Half Marathon.

Amount raised: £740

Above: Photo of my son, Caden, wearing my medal.

Fundraising Heroes!


Jack, Julie Crossley's grandson.
Julie raised £100 from a mini Christmas cake sale

SPRING 2024

tofschew

lifelong support for those born unable to swallow

TOFS office:

The TOFS office is open:
Monday, Wednesday and Thursday 8.30 – 2.30pm

Tel: 0115 961 3092

Emails to info@tofs.org.uk are monitored daily.

Glossary

Please refer to the website www.tofs.org.uk for a glossary of all OA/TOF related terms used in *Chew*.

TOFS is a member of:

geneticalliance.org.uk
raredisease.org.uk
we-are-eat.org

Play the TOFS lottery for your chance to win!

£1,000 Weekly jackpot prize!

Up to £10,000 rollover prize to be won every week

plus 80 weekly prizes of £10

SIGN UP FOR A YEAR TO CLAIM YOUR EXCLUSIVE TOFS BEAR!

play from just £1 a week

tofs.org.uk/support-tofs

GambleAware
BeGambleAware.org

It's back!

Teddy Toddle

Can you walk 5K in a week to support TOFS?

8 - 16 June 2024

Find out more at tofs.org.uk/event/teddy-toddle-2024/

Fundraising thank yous:

Marchwood Power Ltd – £500 donation (nominated by employee Daniel Ford, dad to Lara born OA/TOF).

The staff at Instruments Direct (Services) Ltd – £200 donation instead of sending company Christmas cards. One of their staff members (Olivia Tattersall) has a daughter born with OA/TOF.

Christine Shepherd, mum to Tom (VACTERL) – £50 expenses donated back to TOFS.

Denise Brook, grandparent to Leo (OA/TOF) – £134.20 expenses donated back to TOFS.

Easyfundraising – £94.38 donation.

Barrie and Sandra Williams – £75 donation.

Antony Owens, work colleague of Neil Johns (parent to Samuel, born OA/TOF) – £100 donation, winnings from works sports & social Christmas raffle.

Sue & Philip Richardson, parents to Adam (OA/TOF) – £105 donation.

Chris and John Layne, grandparents to Benjamin Baily – £100 donation.

Nikos Papanikolaou, dad to Stavros (OA/TOF) – £60 donation.

Ungerer Ltd – £50 donation (nominated by one of their employees).

IACF (International Antique & Collectors Fairs) donated £1000 to TOFS. Thanks to grandparent Keith Harris for putting TOFS' name forward.

Andrew Muzika, Adult TOF – £150 donation.

Fusion 21 – £3000 donation. Thanks to Jessica Rodriguez, mum to Ruben (OA/TOF) for putting our name forward.

Trustees who donated their expenses back to TOFS.

Those who kindly made donations via BOPP through our website, raising £779 between 1 May 2023 and 1 April 2024.

David Loughran, dad to Odhrán born OA/TOF, raised an amazing £13,210 by completing a '5k a day' which started on 26 February (during TOFS Awareness week). Amazingly he continued every day until Odhrán's first birthday on 21 March!

Those who very kindly made donations through the TOFS Facebook page. A fantastic £769.24 was raised from 1 November 2023 to 1 April 2024.