WINTER 2024/2025

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.

COVER STORY: Beatrix (Laming), VACTERL, the inspiration behind amazing donations to TOFS from the MJL Charity Golf day. Read a little more about Beatrix, and what this charity event means for TOFS on page 4.

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

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From the Editor

Welcome to your Winter edition of *Chew*. We're starting 2025 with a jam-packed magazine thanks to your wonderful contributions and the amazing work of our editorial team in the run-up to Christmas. There are hugely inspirational accounts throughout the magazine, from eight-month-old baby Willow's mum, Bryony, on page 5, to the contributions from Adult TOFs, Susanna (VACTERL) on the opposite page, and Mark (OA/TOF) on page 23. Beautiful Beatrix, on our cover, is the inspiration behind an amazing £10k donation from the MJL charity golf day, bringing the total donations received from these golf events to an incredible £30k. Read more about it on page 4.

It was great to meet those who came to the OA/TOF seminar in Warrington in November and we report back on some of the presentations on pages 10 – 17. Videos from many of the presentations will be released on our YouTube channel in the forthcoming weeks and planning is well underway for the next seminar in Bristol in March. See advert on page 20.

Read about some recent medical conferences we've attended on pages 18, 20 and 21.

As we start the new year, we're curious to know if you work for an organisation that supports charities by adopting a 'charity of the year'. If you do, would you please consider nominating TOFS? We'd gladly help put a proposal to your employer. Read about Blackhawk Network (BHN) Europe who did just that and have donated an astonishing £22,500 to date! (page 7).

As always, we have more wonderful fundraising stories throughout the magazine. We're so grateful for your continued support and amazed by your ingenuity when it comes to raising money for our charity, regardless of the amount. Huge kudos to the remarkable 2024 Great North Run runners, page 6. Could you join team TOFS for 2025?

We've another busy year ahead as we prepare for our OA/TOF Awareness Week at the end of February (which coincides with Rare Disease Day) and our AGM (page 24) in April. Keep an eye on our social media channels for full details over the coming weeks.

Wishing you a happy and healthy 2025.

Diane

Diane Stephens, *Chew* editor

CONTENTS

This magazine contains references to OA/TOF surgery and content that some readers may find emotionally challenging. If you need support, please contact the TOFS office, or reach out to your local contact volunteer.

Born with VACTERL, Susanna is forging her own path

I'm Susanna Bannister, I am 28 years old and was born with VACTERL syndrome. I have all the letters which impact me all at different levels, which often made me feel really lonely. I knew people who had some, or one, but meeting people with VACTERL to a similar degree felt impossible growing up. It's only recently that I've been able not to feel shame or guilt with my birth story. The reason I felt like that was because of the trauma I felt I had caused my parents.

There was no sign of my VACTERL until I was born and my little radial club hand was there in everyone's faces. When my mum was feeding me, I kept choking and went blue which brought attention to my oesophagus, requiring a fistula repair at two days old. Then, as I got older, I had a distinctive run and walk which children loved to pick out. It was from that young age I learnt that the catwalk world wouldn't be right for me. I had duplex kidney and Atonic bladder, I had anal anomalies, so I now have sacral nerve stimulation and a colostomy bag.

As a child the spotlight shone on my radial club hand; I was a "medical pioneer" like so many of us with VACTERL back in the 1990s! I had a fixator, plates, lots of things to lengthen and straighten my arm. My oesophagus was also constantly giving me stickies and uncomfortable situations. As I have gotten older my oesophagus has stayed a pain, meaning I will eventually need a PEG, but I am putting it off and using antibiotics to help with the swallowing as well as dilations. My oesophagus motility has slowed down a lot, but it doesn't stop me shoving a kebab down it on a night out (or waking up with the worst acid reflux)!

Although my anus and bladder were major problems for me, they weren't major to the doctors. When I started to be able to advocate for myself, that's when I pushed and pushed until a specialist listened to me; it was about seeing who heard me. It was very impactful having doctors who took the time and validated what I was going through and believed my symptoms. I had an amazing colorectal surgeon who saw life was about quality rather quantity. In the NHS we have great things to support people going through acute illnesses but a lot of the time it felt like chronic, or life-long illnesses in our case, didn't matter so much. Being able to find my voice in a system that often didn't believe me feels amazing; to be able to say I have a group of professionals who are there for me has changed my outlook.

As a child I always felt very avoidant of others, I had friends but never felt truly understood.

As a teenager I used Facebook to find a group of people who were like me. The VACTERL teens and adults Facebook group was so helpful, and this is where I built friendships and a love for myself. I found talking and getting advice online to be super helpful.

As I got older, I realised my mental health was slipping due to my physical appearance and the things I had to go through daily, like having accidents, self-catheterising, food stickies and so much more. I managed to go for 18 months of mentalisation-based therapy, both group and individual therapy. I learnt how my relationship with my mum was different as she was also my carer. I longed to be independent, but also knew I had to depend on her as she was the only one who knew my medical history and my body better than anyone else.

With therapy I learnt so much about healthy attachment; it taught me how to ask for my needs to be met. It was also great guidance and made me reflect on my mum's experience with me. This put me in great stead to support myself and her. A lot of my relationships with my family often felt one-sided as I struggled to be independent despite going to university.

The thing I learnt with VACTERL is that it is a boat that is easily capsized, so I often have to consider how it is going to impact different things. For example, how is me walking downhill with my spinal issues going to impact how tired I feel? That's normally a reason I am more likely to get something stuck; because all my muscles are tired, and I won't chew my food properly. If I eat late, my stoma is more likely to leak at night and I will get awful acid reflux. Often small actions like these will impact me, even if they aren't something that other people normally need to consider.

I have found navigating working to be really hard. At school you have so many things in place; you have teachers, SEN staff, you have your parents being informed - sometimes overly informed - but still, safety. Whereas at work, it's all on you it's on you to take care of your body. It's hard because I will never work full time as I have too many appointments and procedures that keep my body in check.

However, that doesn't mean I sit on my bum and let society roll me over. I decided I am going to work with companies that target disabled people, because they are more likely to be able to make reasonable adjustments or I will work where there are lots of employees with disabilities. I am sick of being told you're the first disabled employee or we can't make those adjustments, and the alternative isn't anything like occupational health said. Nowadays, integration is so fundamental to society that we forget how to support our individual needs. I have lots of friends with disabilities, I take part in a lot of disability sports and advocate a lot for sports to be more inclusive. I have friends who don't have disabilities but honestly, I can only mask for so long. I put so much effort into trying not to moan about my physical health when I am with able-bodied people that my mental health takes a dive. My mum always said I was disabled in an able-bodied world, now I am able in a disabled-bodied world. It has bought me great peace knowing that I am okay with my body and knowing that I don't have to do everything the same. I, too, can create a path that I can proudly go down!

Susie, advocating that sport in adulthood needs to be more disability-inclusive

Another hole in one for TOFS!

Cover Story

Did you know that TOFS doesn't get a penny in government funding? We are incredibly fortunate for our wonderful members and their families who make a real difference to the support we offer by fundraising for us.

One such family is Amy Laming and her sister Mandy Larner, whom you may recall reading about in a previous edition of *Chew*. Mandy Larner is the chairperson of a Southampton-based company called Inert Recycling. She has been the inspiration behind several golf days, which have raised a lot of money for various charities that Mandy cares about. Winchester Hospice has benefitted significantly, for example.

Mandy's sister, Amy, is mum to Beatrix who was born with VACTERL. Beatrix is featured on our front cover, following a recent stretch and gastro check-up. She is six years old, enjoys life to the full and doesn't let much stand in her way. We're delighted to hear that she's doing well at school and has recently received a special award for being such a positive member of the class, always aiming high and helping others. Beatrix is also progressing well with her swimming and will soon take her first ballet exam.

Because of her niece and the TOFS connection, Mandy decided that some of the money raised in the 2023 Golf Day would go to TOFS, and we were delighted to hear that she intended to do the same in 2024.


Beatrix

Mandy, the chair of Inert Recycling, organises the annual MJL Charity Golf Day alongside her husband, Keith, and fundraisers Paul and Annette Jones. Paul is a now-retired professional footballer who used to keep goals for Wales, Southampton and several other clubs. Many sportspeople and other celebrities attended the event which took place at the Remedy Oak Gold Club near Ringwood in Dorset. It featured a substantial auction with major money-can't-buy prizes and a black-tie evening dinner.

l-r Organisers Paul and Annette with Mandy and Keith

The day raised an impressive sum for several charities, with £10,000 being donated to TOFS. This generous contribution brings Mandy's total fundraising for us to an astounding £30,000; a truly significant amount that makes a tremendous difference for a small charity like ours. Last year, Mandy's donation enabled us to host our in-person "Improving Care in OA/TOFs" seminar.

TOFS CEO, Diane Stephens, attended the evening event to express our gratitude in person and to help raise awareness of the charity. Diane said, "We are incredibly grateful to Mandy, Keith, Paul and Annette, as well as to everyone who participated and supported the event. £10,000 is an extraordinary donation that will significantly help us to continue providing lifelong support for those born unable to swallow."

Recognition award for courageous four-year old!

George started school last year, a transition that can be difficult for any child, but especially for one born with OA/ TOF.

However, George was able to share what difficulties he had and was very open about his condition, happily talking to others at school about the challenges he faced. He also shared with everybody the video he made for TOFS, where he talks about what his condition is and what it means for him *(https://www.youtube.com/shorts/DuzbPJk1IBU)*. In recognition of this, his school put him forward for the Courageous Advocacy Award which is awarded by the Diocese of Ely.

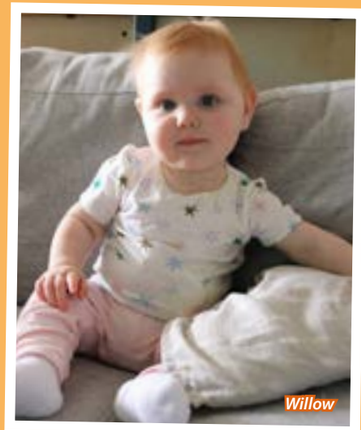
He was presented with a certificate and trophy in front of the whole school by Revd Mandy Flaherty at the end of his first year, although George was a little disappointed that he had to hand back the trophy!

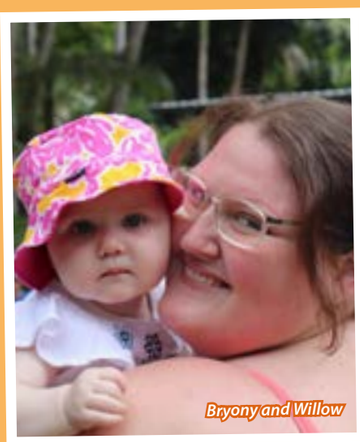
Ed's note: Congratulations to George and thanks to his dad, Stephen, for sharing this fabulous news. So lovely to see George being recognised in this way.
Amazing awareness for OA/TOF too! Read the article on the Diocese's website:
https://elydiocese.org/schools/school-news/georges-story

Our Story

by Bryony Rowlands

Bryony tells us about wonderful Willow and her own journey as a supporter for other OA/TOF families.


Willow


Bryony and Willow

In February 2024, I gave birth to my and Michael's wonderful OA/TOF daughter, Willow. We never planned for an additional needs child. We did all the pre-natal tests and scans and everything said we were having a perfectly (if a little big) healthy baby girl. Fast forward to the day Willow was born. She came into this world at 1.28a.m. and was quickly rushed to the NICU (Neo-natal Intensive Care Unit) and put onto a ventilator. Within half an hour, my partner returned with tears in his eyes as the NICU doctor explained what was wrong with our baby; tracheo-oesophageal fistula and oesophageal atresia.

In that moment, our world was turned upside down. Willow, however, was nothing short of amazing, having her repair done at 34 hours old due to having short-gap. Her surgeon said he was thankful to be operating on a big full-term baby, as he was able to do her repair laparoscopically. After five weeks in hospital, we were sent home and had daily visits from nurses for four weeks. The day after we were fully discharged, Willow's tracheomalacia reared its ugly head and led to Willow needing CPR. Back to hospital for more scopes, scans and surgeries.

Willow quickly learnt that she loved the hospital. She made the nurses smile and loved to watch them all day. After the choking incident, we were informed of the need for an aortopexy. We agreed as we wanted to avoid an incident like that if we could. We had the procedure done and she recovered amazingly…for six days. We went straight back with a different form of choking and it turned out this time it was reflux. One fundoplication and a gastrostomy button insertion later, we finally went home. All through this, Willow was the funniest, sweetest baby ever. We had one nurse very sad the day we were discharged but also relieved for us as it had been a long few weeks.

Throughout this time, I had found the TOFS Facebook group and, in turn the TOFS website, and was so thankful to learn there were other parents like me all around the world asking themselves the same questions. Is this normal? Can we do this? Can we do that? I started to realise I wanted to meet someone in person, either a TOF or another TOF mum. I chatted with Sarah from TOFS and discussed my plan to organise an Australian TOF meet-up in my city.

As the information went out for the event, the nerves kicked in. Am I the right person to be running this? I've only been doing this for eight months. But I thought, "You know what? Maybe someone is only on day one of this, and you can be what you needed on day one." So, on November 3rd, I got up, my partner Michael got Willow ready and we headed into the city to meet some more TOFS. We had two families come and, even though it was small, our smiles could have lit up the night. Each of our little ones did a TOF cough which made us smile and sigh in the relief of them sounding the same and not getting strange looks. I had been talking with these mothers over the previous weeks and we discovered all of our children had the same amazing surgeon and we laughed about what he had said during appointments or reactions our children have to him. Although some people could not make it to this meet up, I had many messages of support, thanking me for organising something for Queensland and telling me they would be there for the next one. So for any Queensland TOF families, there is more to come!

Willow is eight-months-old, and it has been both the longest and quickest time of my life. She is speed-crawling and trying to climb onto everything and trying to eat the cats. I could not be more thankful for how much Willow has progressed and how happy she always is. The days we have can still be dark with worry and guilt but we get through them as a family. Michael and I definitely take our strength from Willow who absolutely does not let anything hold her back.

We have a family saying, "If you don't laugh, you'll cry". Many of Willow's health team know this about us and know it is normal for us to call Willow "WeeWo" because it sounds like the ambulance we had to call four times, or make a joke about a free coffee every time we get into emergency as we are frequent flyers. Trust me, there are still tears but more often than not they are tears of pride and relief. We are so excited to see where this crazy adventure takes us and hope that I can be a support for Queensland families also on this adventure.


Mum, Dad & Willow in hospital

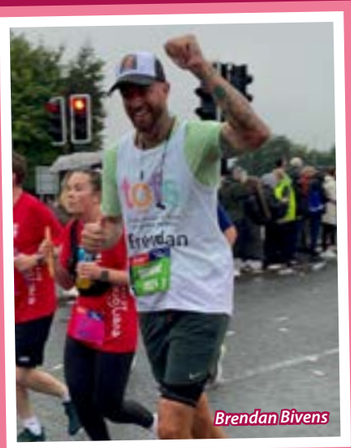
A record-breaking Great North Run!

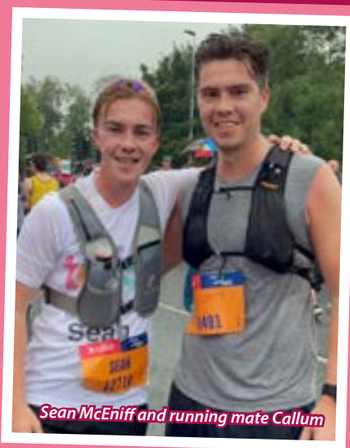
Congratulations to our incredible Great North Run team, who braved wind and rain to complete the challenging 13.1-mile course in support of TOFS. Their collective effort raised a staggering £6,242 - our highest total ever for this event!

A massive shoutout to Brendan, Paul, Sarah, Sean and Victoria for their amazing achievement. Thanks also go to Clare, Sophie, Neil and Sammy for managing the 'Cheering Station' and making sure everyone knew TOFS was there. You're all superstars!

Feeling inspired? Why not join Team TOFS for the 2025 Great North Run? At time of writing, we have one place remaining, so apply quickly at *tofs.org.uk/event/great-north-run-2025* or see all our events at *tofs.org.uk/support-tofs/join-a-fundraising-event/*

Let's keep breaking records together!


Brendan Bivens


Sean McEniff and running mate Callum


Clare Sophie Neil and Sammy at the TOFS cheering station


Paul Shepherd


Victoria Porter


Runner Sarah with Clare at the TOFS cheering point

Fundraising Heroes!

Name: Sarah Winspear

Inspiration: My amazing little cousin, Isobel. Born with OA/TOF and has just turned 18 years old!

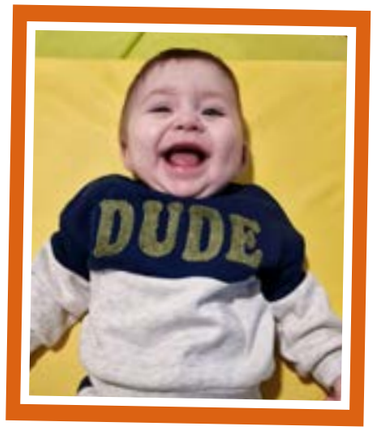
Event: Great North Run 2024

TOFS charity has helped support Issy and my family understand the condition throughout her life. Also, being part of the charity as the Membership, Communications and Events officer, I see behind-the-scenes what important work it takes to provide this support to parents and adults born with OA/TOF. Meeting so many parents, children and adults in the TOFS community everyday gave me the inspiration to run – some of whose names you can see on my vest!

Cold, wet and windy – that was before we even started the race! It was a mental challenge, but it was worth the reward at the end. I would encourage anyone to give any sort of challenge a go and doing it for such a great cause gives you that boost to the finish.

Amount raised: £704.25


Sarah Winspear



Fundraising Heroes!

Name: St. Paul's Youth Forum

Inspiration: Myles Clabby OA/TOF

Event: Annual football match

When Myles Clabby sadly passed away, his brother Jayden and friends came together to remember and celebrate Myles by creating the annual Myles Clabby Memorial Cup alongside local youth club St Paul's Youth Forum (SPYF). Together, we created an annual football match with Jayden and his friends representing the 'young team' and the team at SPYF alongside partners of the organisation and friends and family of the Clabby's representing the 'auld team'. The game was hosted locally thanks to the generosity of St Roch's FC donating their facilities which meant the community could come out in the hundreds to support the event and help to raise as much money as possible for TOFS. We were then hosted by Verde for the post-match celebrations. The day was hugely successful with so many people coming out to celebrate baby Myles.

Amount Raised: £3,005.87

Fundraising Heroes!

Thank you to everyone at Blackhawk Network (BHN) Europe for their incredible £9,640.75 in September and £2,500 in December donation to TOFS. This brings a total of four donations from the company in the last 3 years taking their total support to over £22,500!

TOFS was originally nominated by Jo Fleet-Chapman, a Blackhawk Network employee and TOFS' member, via BlackHawk' CSR/ benefits programme. Jo submitted a request to the board of directors asking them to consider TOFS as a beneficiary for the programme.

Jo is mum to Lara, born with OA/TOF. Read more about Lara's OA/TOF story in the Winter '23/24 edition of *Chew*.

We're incredibly grateful to Jo for nominating us. Does your employer do anything similar?
Why not check if you can nominate TOFS for any charitable donation scheme that your company might have.
For more information, please visit
tofs.org.uk/support-tofs/corporate-partnerships/

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.

Hannah Chandler, from Hawick
– Imogen, born 13 June 2024, VACTERL

Gabriella Johnson, from Shepshed
– Oscar, born 4 August 2023

Paul Woodley-Johnson, from Bridlington
– Bethany, born 11 February 2023, OA/TOF

Ed Snaith, from Clitheroe
– Benjamin, born 3 July 2024, OA/TOF

Leah Kornbluh, from USA
– Avrumy, born 11 October 2023, VACTERL

Leigh Marsh, from Australia
– Apollo, born 14 January 2024, VACTERL

Roscoe Passant, from Swindon
– Adult TOF

Mary Humphrey, from Bedfordshire
– TOF family member

Stacey Mason, from Stoke on Trent
– Alfie, born 15 May 2023, VACTERL

Beverley Gutcher, from Redcar
– Albie, born 25 April 2023, OA/TOF

Natasha Murray, from Bury St. Edmunds
– Arthur, born 16 August 2024, OA/TOF

Katie Chambers, from Derby
– Samuel, born 23 October 2023, VACTE

Megan Wilson, from Lincoln
– Bodhi, born 14 May 2024, OA/TOF

Charlotte Fairhurst, from Wigan
– Rory, born 12 August 2024, OA

Nina Benouaich, from London
– Matteo, born 25 August 2024, OA/TOF

Angela Angus, from Australia
– TOF family member

Gerry Duffy, from Wishaw
– TOF family member

Mike Brooks, from Hertfordshire
– Adult TOF

Kristie Kadavy, from the USA
– Adult TOF

Lauren Douglas-Holt, from Greater Manchester
– Alfie, born 9 August 2024, OA/TOF

Lewis Walters, from Bolton
– Adult TOF

Lynda Phillips, from Leeds
– Oban, born 21 September 2023, OA/TOF

Michell Shotton, from Redcar
– Albie, born 25 April 2023, OA/TOF

Lisa Robinson, from Birmingham
– Adult TOF

Deepali Chopra, from Abu Dhabi
– Yunay, born3 January 2024, OA

John Edwards, from Liverpool
– Adult TOF

Laura Martin, from Oxford
– Adult TOF

Ciara Elliott, from Wallington
– Henry, born 4 September 2024, OA/TOF

Luke Harris, from Ross-on-Wye
– Adult TOF

Craig Sanders, from Waterlooville
– Oscar, born 16 October 2024, OA/TOF

Katie Walters, from Birmingham
– Thea, born 7 September 2024, VACTERL

Mark Lynch, from Derry and Strabane
– Scarlett, born 10 August 2023, OA/TOF

Professionals

Helen Kelly
– Early Years Professional

Name: Sadie Beer

Inspiration: My son, Sonnie, who was born with OA/TOF

Event: Cardiff Half Marathon

I have raised money for TOFS which is a charity very close to my heart. My son, Sonnie, was born with OA/TOF which is a rare congenital condition affecting the oesophagus (food pipe) and trachea (windpipe). Sonnie was born with his food pipe attached to his windpipe meaning he was unable to feed as any fluid would have gone straight into his lungs. Sonnie needed urgent surgery at one day old to detach the food pipe from his windpipe and then further surgery at three days old to re-attach his food pipe to his stomach. Thanks to the amazing surgical team at Cardiff Heath Hospital, this was a success. Sonnie's condition was not picked up during my pregnancy, so it came as a huge shock to us and, being a rare condition, there is very little support or information out there so the TOFS charity has been an amazing support unit for us since his birth.

Although Sonnie is doing really well now, those born with OA/TOF continue to have lifelong issues with eating and breathing for which the TOFS charity offers continued support and information. TOFS receives no government funding and relies completely on donations in order to operate and support those born with OA/TOF and their families.

I have never taken part in anything like this before. I am not a runner but wanted to raise money for TOFS, so I decided to enter last year and threw myself into running. It was an amazing day that I will never forget. I am so grateful for all the support and funding raised.

Amount raised: £1,230.00

I-r Daniel, pictured with Maisie OA/TOF and Joseph

Name: Joseph Wharton and Daniel Kewley

Inspiration: Maisie Wharton, Joseph's sister and Daniel's cousin

Event: Ten-mile Tough Mudder (Northwest)

Maisie has shown so much courage over the years. She's had two fundoplications and thirty-seven dilatations.

Amount raised: £540

Name: Thomas Burke

Inspiration: Our son, Thomas

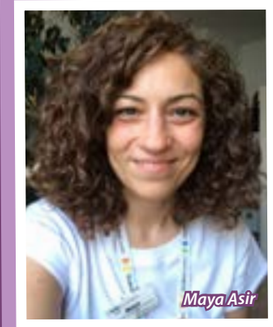
Event: Hillsborough Festival 10k for TOFS

Thomas was born on the 5th of April 2015 in Belfast, Ireland with OA/TOF. He has undergone numerous surgeries and countless hospital visits throughout his life. The TOFS charity has been a great help and support outlet for Thomas and his family over the past nine years and no doubt will continue to do the same in the years to come. In gratitude, we wanted to raise money for this amazing charity. Thomas' daddy, along with family and friends, set out to complete "10k for TOF" at Hillsborough Forest Park in Ireland.

Amount raised: £1,288.75

Conversations around feeding, reflux and oral aversion

As babies born with OA/TOF grow, there comes the exciting (yet sometimes daunting!) part of introducing them to new foods. Inevitably, this may trigger a lot of questions. Members have recently joined together for our online events, which have been themed around providing answers to some of these questions and sharing top tips to manage this new stage of their babies' journey.



At the recent Talk with TLC: 'Reflux Management' event, To'neill Bala, TLC for South Manchester and Naomi Webborn, TLC for South Wales, shared their own experiences and top tips from those experiences; from how to manage reflux, how to recognise potential strictures, to what worked when their own children started weaning. Other parents also shared their own stories, asked questions and supported each other.

Maya Asir, Speech and Language Therapist at Evelina Children's Hospital London, also spoke to members at our last Q&A session about 'Feeding experiences and oral aversion'. She answered a range of questions; from how to overcome long-term food aversion, how to introduce new food/textures, and how to get your baby to use cutlery. Do watch the recording of the Q&A on our YouTube channel to see if Maya gives you any useful advice for either now, or in the future! *https://www.youtube.com/@TOFS/videos*

If you would like to chat, do reach out. Our TLCs are here to listen and to support you. You can find their details on the membership site. *https://members.tofs.org.uk/login.aspx*

In Loving Memory

Many of you will have been shocked to learn of the sudden passing of one of our most valued and esteemed volunteers, Gary Spiers. Gary was an amazing husband, father, son and brother. We extend our deepest condolences to the family circle.

Gary lived an amazing life and contributed so much back, be it in his involvement with TOFS, his conservation work with The Joshua Tree Conservation Trust, his pioneering work for NASA/JPL or judging archery at a national level.

He was an esteemed member of our Adult TOF working group, and colleagues in the group took some time to pay tribute to him and reflect in their September meeting. Adult TOF and group member Alan French wrote the following tribute.

In Memory of Gary Spiers 1963 - 2024

We take this moment to remember Gary. Although our time with him may have been a virtual one, the loss of one of us TOFs makes his passing somewhat unique to us in this group.

Our first thoughts are of course with his wife, family and friends to whom we send our words of support and thankfulness for Gary's work within the OA/TOF community.

Gary was born in Ipswich, UK in the winter of 1963 before moving to Berkshire and Wales. He attended Essex University and then Heriot-Watt University, Edinburgh. Whilst presenting at a conference in Munich, a career in jet propulsion engines was offered. This took him to Alabama, USA. A decade later Gary took up a role with NASA in Pasadena, California.

Gary was a valuable member of our Adult TOF working group. He also sat on the EAT board (A global alliance for organisations that support and educate about living with OA/TOF).

When I first read Gary's introduction piece in the *Chew* Summer 2022 edition, I was somewhat taken aback. Space shuttles, the International Space station, athletic cycling, archery trainer and individual champion; conservation work in the Mojave Desert and a renowned amateur photographer whose pictures were used in publications, and he was an official Olympic time trial judge! And my intro was to follow him!

Meeting Gary virtually for the first time I thought how he reminded me of a professor. He had a confident air about him and whilst his words were few, they were very intuitive.

The era of using and associating with others virtually means we can have a sense of confusion as to what to feel when an individual is taken from us. We have so much respect for his commitment, knowing that the Gary Spiers we knew was having to log in at 7am in California to be with us in attending the Adult TOF Working Group.

Gary shared in his introduction article for *Chew* magazine his motto for life: "Make the most of your life because we only get one go at it". So, whether or not you have a faith or belief, one thing can surely be certain, Gary was never found lacking.

My own personal reflection is that Gary was one of a kind. He was born with a long-gap oesophageal atresia, and not only did he survive the condition, but he gave back to the future generations of individuals who may be born with OA/TOF.
Thank you, Gary, it was a pleasure to have known you. May you rest in peace knowing all you have achieved.

Wonderful OA/TOF seminar in Warrington

2024 Warrington Seminar

In November 2024, we made a return visit to The Engine Rooms in Warrington for a TOFS-organised information seminar for families, adults and interested health professionals. The afternoon is designed to give families and adults the opportunity to meet up and share experiences and hear from healthcare professionals who support patients born with OA/TOF. We had a fantastic turnout of 90 attendees who came from across the country for the afternoon.

The busy programme included presentations on working towards a tissue-engineered oesophagus, respiratory management in paediatrics, ongoing gastrointestinal issues/complications (paediatrics) and adult care developments in the Netherlands. We're very grateful to the speakers, Natalie Durkin, Professor Rebecca Thursfield, Nick Lansdale and Chantal Ten Kate for giving their time freely to present and respond to individual members' questions.

Trustee Kate Tyler with support from Dr Caroline Love and Alan French represented two important organisations for conditions that may impact those born with OA/TOF: Max's Trust, which provides support to those with Anorectal Malformations, and VACTERL Association, supporting those born with VACTERL anomalies.

A huge thank you to everyone who attended on the day; volunteers who helped plan and make the day run so smoothly, and attendees who asked such great questions and shared their own stories. It was lovely to see members make new connections. A big thank you to those who bought raffles tickets as we raised more than £300 for TOFS.

Don't worry if you missed the event, there will be an opportunity to watch the session online as we upload them to our YouTube channel. You can also join us at our next in-person event, on Saturday 1 March 2025 in Bristol. See more on page 20.

Progress in care for OA/TOF adults in the Netherlands

2024 Warrington Seminar

Presentation by Chantal ten Kate, postdoctoral researcher and surgical trainee at Eramus MC, Rotterdam

Report by Jenny Byrne

In 2022 Chantal presented her thesis, *"The Optimization of Healthcare throughout the life of a patient born with OA"*. Her aim was to study the whole circle of life but concentrating on the transition to adult healthcare and the problems adults born with the condition encounter; gastrointestinal, pulmonary, endoscopic surveillance and a little on genetics. Paediatric follow up of OA patients in the Netherlands has been very organised for the last 25 years, children between the ages of four months and 17 years are seen by a multidisciplinary clinic, including a psychologist, physiotherapist and a pulmonologist.

For a long time, there was no follow up for adults in the Netherlands, however, in 2013 a screening and surveillance programme for adults was initiated. They started by investigating the health needs of adults born with the condition, the problems they encounter, what the patients thought about their problems and what was important to them. This was done by organising two separate focus groups; one consisting of those born with OA and a second for their families. The interviews were transcribed and coded, organised into themes and thematic analysis used to look for similarities. The team discovered that gastrointestinal and pulmonary problems are experienced daily, they include problems with dysphagia, reflux, coughing and frequent pulmonary infections. Mental health is also a big topic, emotional distress, and anxiety for medical procedures due to experiences in childhood.

Some adults have problems with how, or even, if, they are going to tell people that they were born with the condition. Some have difficulties coping at lunchtimes or getting time off for appointments and concerns over whether it will affect their career progression. Patients said it was important that there was one physician coordinating their healthcare and said that GPs know too little about their condition to be able to effectively help.


Chantal Ten Kate

Specialists, including gastroenterologists and pulmonologists are essential to improve follow up, as is addressing the patient's emotional distress and other issues that influence the quality of their life. The 'SQEA Questionnaire' (Specific Quality of Life of OA Adults) is used as a tool prior to a consultation with a specialist in the Netherlands, making the appointment more efficient, but also making it easier for patients to discuss other aspects of their life, such as psychological problems.

This questionnaire is being translated and validated in the hope it will be used across the rest of Europe, including the UK. Follow up from this needs to be coordinated by one physician or one dedicated team.

Follow up by gastroenterologists to treat physical complaints also needs to include the risk of Barrett's Oesophagus (hereafter referred to as Barrett's). Ten years ago, Floor Vergouwe researched and reported on the prevalence of Barrett's and Oesophageal Carcinoma in patients born with OA, compared with the general population, with patients presented in this study at a much younger age. This led to a screening and surveillance programme in 2013. In this programme, every patient undergoes a gastroscopy every three to five years. Depending on age and potential outcomes of earlier endoscopies, these are conducted to a standardised protocol. The first eight years of the surveillance programme have been published. Patients were between the ages of 15 and 68 years old and out of 400 endoscopies performed on 271 patients, over 100 had a second or third endoscopy. Nineteen patients had Barrett's. Four developed it during the follow up, and two developed Oesophageal Carcinoma. The surveillance programme has been adapted because of the results. Screening now starts at 20- years-old. Up to the age of 40, patients are offered an endoscopy every ten years, over the age of 40 this takes place every 5 years.

Several PhD theses over the last ten years have researched why there is a higher prevalence of Barrett's in the OA population. Multiple genetic variations and syndromes have been associated with its development. The DNA of these patients was compared with the DNA of those with Barrett's, taking biopsies of patients born with OA who have developed Barrett's and those born healthy who have Barrett's. The DNA extracted from the biopsies showed a higher predisposition associated with the development of Barrett's for those born with OA. Genes involved with inflammatory responses, stress responses and oncological processes were also more frequently disturbed in development. Research was done using the skin cells of the epithelium and fibroblasts. There was an overlap between the results of the biopsies and those of the fibroblasts. At this moment, the higher prevalence of Barrett's in the OA population is thought to be caused by multiple factors.

In 2019, a centre for congenital and perinatal pulmonary disease was founded to treat multiple conditions, including OA. There have been 277 OA patients attend for pulmonary follow up. Ideally, these visits start at the age of 17 and patients undergo a lung function test, CT scan and have a consultation with a pulmonologist. The results of the first 180 patients are due to be published soon by Stephanie Wintels, a PHD student in Chantal's department. The results show that over half of the patients have at least one respiratory complaint eg wheezing or coughing of sputum. One quarter still have the typical barking cough. Over 17% of patients had abnormal lung function results, 40 had impaired lung function and in 50% they had narrowing of the airways. Notably, all of the patients had abnormalities in their CT scans, varying in severity:

32% diverticula, 11% bronchiectasis, 20% anatomic variations and part of a lung missing in one patient. Depending on the results of the lung function, CT scan and consultation, an individual follow up programme is established, this can vary between follow up after three months or five years.

In conclusion, it is important for healthcare professionals to realise that many adults born with OA experience gastrointestinal and pulmonary problems daily. A multidisciplinary programme is necessary, with one coordinating physician. Follow up should not just pay attention to the physical problems, but also mental health, socioeconomic and the problems of daily living. Endoscopic surveillance for the detection of Barrett's oesophagus at an early stage is important.

Ed's note: **Chantal's e-book, referenced in this summary is available from this link:**
https://tofs.org.uk/2022/09/oa-tof-doesnt-end-with-closure/

OA/TOF and the lungs

Presentation by Professor Rebecca Thursfield, Paediatric Respiratory Consultant, Alder Hey Children's Hospital and Honorary Clinical Associate Professor, University of Liverpool

Report by Sarah Baron

2024 Warrington Seminar

Professor Thursfield's talk highlighted the significant respiratory challenges children with OA/TOF experience and the importance of early intervention and specialised care.

Professor Thursfield began by discussing the prevalence of respiratory symptoms in the general population. Nearly one-third of children are reported to wheeze, 17% are diagnosed with asthma, and almost one-fifth frequently catch colds. Given the high incidence of respiratory issues in children, it can be especially difficult for parents and caregivers of children with OA/TOF to distinguish between a typical childhood illness and a symptom specific to OA/TOF. Additionally, when seeking help from primary care, these symptoms are not always recognised as being related to OA/TOF, which can delay proper diagnosis and treatment. This underscores the importance of involving specialist teams who can make that differentiation.

A key component of Professor Thursfield's presentation was Alder Hey's interim analysis data, which examines the hospital's 20-year experience with OA/TOF patients, specifically those born between April 2004 and July 2024. While the dataset is still being updated as historical data is reviewed, the findings thus far provide valuable insights into the complexities of managing OA/TOF.

Professor Rebecca Thursfield presenting

Over the past two decades, Alder Hey has managed over 200 children born with OA/TOF. Among these patients, nine were diagnosed with an H-type fistula (a condition without OA), and 33 children had long-gap OA. The number of dilatations needed by each child varies greatly, with some requiring far more than others (between 0 and 24), highlighting the individualised care these children require.

Thirty-one of the children analysed in the database were diagnosed with tracheomalacia (a condition in which the windpipe becomes weakened or floppy), and eight of them required surgical intervention to address this condition. Finally, the audit highlighted a significant reduction in lung function among children born with OA/TOF. Initial analyses showed that lung function is typically at 83% in these children, but it drops to 68% in those with long-gap OA, pointing to the ongoing challenges in maintaining respiratory health for this group. These findings reinforce the importance of individualised care for children born with OA/TOF, as their respiratory health can be complex and varied. Alder Hey's data underscores the need for continued research and dedicated clinical teams to support these children throughout their journey, providing the necessary interventions to optimise their health and quality of life.

Respiratory challenges and management

Professor Thursfield provided detailed insights into the specific respiratory challenges commonly faced by children born with oesophageal atresia and tracheoesophageal fistula (OA/TOF), as well as the associated symptoms and management strategies. These children are often affected by a range of respiratory issues that require individualised care and management to improve their health outcomes.

One of the most prevalent respiratory issues in children with OA/TOF is tracheomalacia. Tracheomalacia refers to a condition where the trachea, or windpipe, becomes weakened and floppy due to insufficient cartilage support. In children born with OA/TOF, this condition occurs because the trachea lacks cartilage at the site of the fistula, which causes a malacic, or floppy, segment. This weakness leads to collapse in the front and back walls of the trachea, particularly when pressure is applied, making it more difficult for these children to breathe properly.

Tracheomalacia is very common in children with OA/TOF, with studies reporting that up to 83% of these patients also have some degree of the condition. The symptoms of tracheomalacia can range from mild to severe. Mild cases often present with the characteristic "TOF cough," which produces a distinctive barking sound when the floppy section of the trachea closes slightly during a forceful cough. These children may also have difficulty clearing respiratory secretions and experience delays in recovering from respiratory infections. In more severe cases, the symptoms can be much more concerning, including cyanotic episodes, where the child's skin turns blue due to a lack of oxygen, difficulty weaning off a ventilator after surgery, or even the need for ongoing ventilation support.

For children with severe tracheomalacia, surgical management may be necessary. Several surgical interventions are available, including aortopexy, which involves attaching the aortic arch to the sternum to help keep the trachea open. Another option is tracheopexy, where the front of the tracheal wall is suspended from the back of the sternum to support the airway. In more extreme cases, a tracheostomy, a breathing tube inserted into the trachea through the neck, may be required to help the child breathe. Additionally, airway stenting, which involves inserting a hollow tube or stent into the airway, can also be used to maintain an open airway.

In less severe cases of tracheomalacia, medical management may be sufficient. This includes measures such as physiotherapy, antibiotics to prevent or treat infections, and non-invasive mask ventilation support to keep the airways as healthy as possible. For more information about tracheomalacia and its management, families and healthcare professionals can refer to resources like the TOFS website (*www.TOFS.org.uk*).

Aspiration is another major issue in children with OA/TOF. Aspiration occurs when food, liquid, or secretions enter the airway instead of the stomach. The body's response to this is to produce extra fluids and cells to try to clear the substances from the airway, which often results in a characteristic rattling or wet cough. Aspiration can be caused by both anatomical and functional issues. Anatomical causes include conditions such as strictures (narrowing of the oesophagus), vocal cord paralysis, laryngeal cleft, recurrent or missed fistula and broncho-oesophageal fistula (an abnormal connection between the bronchus and oesophagus). Functional causes include reflux, swallowing defects, dysmotility (a condition where the oesophagus has difficulty moving food) and bolus obstruction (difficulty swallowing larger food particles).

Children with OA/TOF are also more susceptible to respiratory infections for several reasons. The weakened tracheal cartilage, less effective cough, tracheal pouch, disrupted cilia at the scar site and reduced ability to clear particles from the airway make these children more prone to viral infections. Furthermore, secondary bacterial infections are common, often developing on top of the viral infections.

The goal of respiratory management for children with OA/TOF is to identify the underlying causes of respiratory issues, alleviate daily symptoms, and reduce long-term health impacts. Any management plan should be individualised to meet the specific needs of each child. Effective management of respiratory secretions is essential, which includes techniques like good airway clearance, chest physiotherapy and the use of nebulisers to thin the secretions. Managing respiratory infections involves maintaining clear airways, using antibiotics to treat secondary bacterial infections and, in some cases, using prophylactic antibiotics to prevent future infections.

In summary, children with OA/TOF face a range of respiratory challenges, from tracheomalacia and aspiration to frequent infections. Specialised care, including both medical and surgical interventions, is crucial for managing these complex conditions. Early diagnosis, tailored management plans and ongoing support from healthcare professionals are essential in optimising the respiratory health and quality of life for these children.

Ongoing Gastrointestinal issues and complications of those born with OA/TOF

Presentation by Mr Nick Lansdale, Consultant Paediatrician Surgeon, Royal Manchester Children's Hospital

Report by Sue Lewis-Jones

2024 Warrington Seminar


Nick Lansdale

Mr Lansdale started his presentation by saying that back in the 1950s and 1960s when OA/TOF surgery was still in its infancy, the focus was very much on survival. Nowadays, it is very much about the ongoing quality of life. He covered the key areas of swallowing difficulties and gastro-oesophageal reflux, along with the long-term issues of the use of Proton Pump Inhibitors (PPI's) and Barrett's oesophagus.

Swallowing difficulties - why do we get them after OA repair?

Strictures occur in the scar tissue at the site of the join and are one of the main anatomical reasons why food gets stuck there or fails to pass down to the stomach. During the initial repair operation, the tissues are often stretched to bring the two ends of the oesophagus together, attaching a thinner lower tube to a bigger upper pouch. The blood supply and resulting tension can be problematic, causing the scar to shrink and narrow, affecting the ability to feed.

The motility of the oesophagus does not work efficiently in those born with OA/TOF. It should be like that of a snake swallowing, with rhythmical muscle contractions pushing food along but is in fact much weaker.

Second strictures can also occur below that of the original join. Reflux can cause a narrowing although these strictures are seen less frequently now with appropriate reflux medication. Congenital oesophageal stenosis are, however, more common than previously thought and are often missed in the original diagnosis. Formed during development, rings of cartilage (which are normally found in the trachea) can be found in the oesophagus and these need removing - but two joins can be problematic. Mr Lansdale feels that all TOF babies should have an oesophagram to rule out the possibility of this type of stricture and to inform surgical options.

Things to look for:

- New babies often develop significant stricture. They might start to choke when feeding, or take longer on the bottle or breast.
- They might bring milk back up, or down through the nose, or froth at the mouth.
- In toddlers, food refusal can be a sign of a stickie.

What does research tell us?

One study of 50 patients born with OA/TOF aged 18 - 63 years, showed that 82% continued to have a swallowing dysfunction throughout life. While 75% needed to take sips of drink when eating, this didn't affect their quality of life.

Ability to swallow hard foods was worst, with foods with skins like apples, sausages, things with seeds, as well as bread being a problem.

What can we do to help?

- At home, encouraging chewing of foods and taking sips of drink can help.
- Medicinally, the reduction of acid in reflux is an important part of treating stricture.
- Balloon dilatation is the most common method of dilation.
- Very problematic strictures can be injected with steroids.
- Occasionally strictures that are very difficult have to be removed, which necessitates a bigger surgery again.

Reflux - why and what to look for

There are mechanical and anatomical reasons why reflux continues to be a problem for those born with OA/TOF. In the initial repair, the stomach will have been pulled up a little (or a lot) causing reflux to flow up from the stomach more easily. Reflux can cause chest infections, swallowing difficulty, regurgitation/vomiting, impaired growth, heartburn, an acid taste in the mouth, unsettled pain, spitting up blood, cough, hoarseness and reluctance to feed.

The muscles in the TOF oesophagus don't work as well as they should, causing dysmotility as well as intra-oesophageal reflux, where fluids and foods move up and down inside the oesophagus.

Untreated reflux can affect the lungs and airways as well as the oesophagus. Complications of reflux include oesophagitis, strictures, silent aspiration, aspiration pneumonia, chronic lung disease, airway reactivity, worsening tracheomalacia and eventually, Barrett's oesophagus.

Managing Reflux

- Coping with reflux can include changing milk, adding thickeners eg carobel, feeding slowly, keeping upright and avoiding certain foods.
- Beds can be propped up.
- PPIs, eg omeprazole, lansoprazole are important. Gaviscon in addition can help too (but not alone).
- Sometimes reflux can be managed by feeding by a different route eg gastrostomy tube, jejunal tube etc.
- Fundoplication remains the mainstay of surgical options for reflux and up to a quarter of those born with OA/TOF will need this operation.
- Famotidine is not easy to get hold of and can have real benefits

In special cases where the oesophagus has been replaced eg gastric pull up: 47% can have anaemia, 25% dumping syndrome, and 29% need supplementary feeds as they have a lower BMI.

Proton Pump Inhibitors (PPIs)

There is a wealth of conflicting literature on the safety of PPIs with two big research studies with millions of people involved across the general population. It is difficult to separate association and causation, in that taking PPIs doesn't necessarily cause a problem. Mr Lansdale used the analogy of both ice cream sales and shark attacks peaking in summer - but we know one does not cause the other! We don't know that PPI use causes the problems they are associated with, but we do know that based on evidence, risks are very low. When PPIs are required due to ongoing symptoms or complications of reflux, the benefit of PPIs will outweigh potential risks. However, it is important to keep these under regular review and when they are not necessary, they can be stopped.

Barrett's oesophagus

Barrett's oesophagus is a pre-cancerous condition caused by repeated exposure of chronic acid reflux, which changes the normal cell lining of the oesophagus to that of the stomach and the intestines. It carries the risk of gastro metaplasia, although the risk of progression to malignancy is low. Diagnosed with endoscopies and biopsies, there is a high risk of Barrett's in the TOF population, 5-7% in some studies.

The UK is behind on follow-up compared to the Netherlands but at the very least, there should be screening before transition, and preferably at the age of 11 and again at transition, so that any evidence of cell change can be highlighted to adult services.

A recent study across several countries into the prevalence of Barrett's oesophagus in adolescents and young adults with OA/TOF included 6,282 patients in long-term follow up; 317 of those had Barrett's and the average age of detection was at 13.8 years.

While for some adults the OA/TOF condition has had an impact, many lead a normal life with education, work and families of their own.

Introduction to TOFS by Diane Stephens, CEO, TOFS

2024 Warrington Seminar

TOFS Chief Executive Diane Stephens made a short presentation about the work of the TOFS charity.

She gave a timeline of the history of the surgery for OA/TOF. The first successful surgery to repair OA/TOF was performed by Mr Cameron Haight in the United States in 1941. The first successful surgery in Europe followed in 1947 by surgeon Mr Richard (Dick) Franklin.

In the absence of an official OA/TOF registry of births, TOFS estimates that there are currently just over 7,700 adults and 3,000 children in the UK born with OA/TOF.

Survival rates for babies born with OA/TOF are now much higher at over 95%, unless there are co-existing cardiac anomalies and there is now an improved awareness of the lifelong implications of being born with OA/TOF. Diane gave an overview of the support and information TOFS provides and explained that the overall aim is to empower parents and adults so that they feel less isolated and better equipped to advocate for themselves or their children.

Diane talked about TOFS' long-term vision for anyone born with OA/TOF – that they should live life unlimited. She acknowledged there is much to be done and part of TOFS' drive to engage with relevant healthcare bodies is ultimately aimed at seeking improvements in care for the OA/TOF community. Diane touched on some of the work that TOFS is doing to support this long-term aim and there was a plea for volunteers to help TOFS continue this valuable work.

Ed's note: Could you play a role in helping TOFS drive their mission forward? If you would like to become a trustee or a volunteer please get in touch, email diane@tofs.org.uk


Natalie Durkin


Drew Bailey

2024 Warrington Seminar


Some of our amazing volunteers, adults born with OA/TOF


Peter (staff), TLC Carolyn & Jayne (staff), on the raffle stall

All speakers kindly took questions from the audience after their talk

We summarise below some of the questions put to Prof Rebecca Thursfield and her responses...

2024 Warrington Seminar

Q **Is the long-gap reduction in lung function due to the type of replacement surgeries, such as those in the stomach and chest, or is it more related to the risks associated with reflux and other complications that could lead to a reduction in lung function?**

A **Professor Thursfield:**

It's a great question and one that we don't yet have a definitive answer to. It's interesting that we have seen a difference in the data and I believe it is likely a combination of factors. My sense is that it is probably developmental. I would like to conduct further studies to understand more about what the lungs and airways look like in these children. When I've performed CT scans on children with significantly reduced lung function, there is often no evidence of scarring or lung damage. This suggests that the issue might be related to the way the child developed; specifically, smaller lungs and airways, rather than damage from surgery or complications. Of course, we're looking at a paediatric population here, so it may be different when studying adults. This is something I plan to investigate further. We are getting a new MRI scanner at Alder Hey, which will enable us to explore this in greater detail.

Q **Q. Why do babies born with OA/TOF that experience cyanotic episodes seem to grow out of it? Will cyanotic episodes re-occur later in childhood or adulthood?**

A **A. Professor Thursfield:**

Malacia is one of those conditions that often improves as a child grows. Think about a tiny baby, their trachea is very small, so when it flops down, it can completely block the airway. As a child grows, their trachea gets larger and the cartilage strengthens, so the impact of malacia becomes less severe. For instance, while babies may experience cyanotic episodes, older children tend to have longer recovery times from infections and may experience breathlessness rather than full airway collapse. I wouldn't expect these cyanotic episodes to reoccur later in childhood, but studies suggest that some issues can emerge later in life. I believe there's a "honeymoon period" in the late teens and early twenties, after which the condition may start to affect airway function as people reach their forties. This could involve issues such as infections or swallowing difficulties, but I wouldn't expect cyanotic episodes to return.

Q **Q. GPs are reluctant to prescribe antibiotics for bacterial infections in children and adults with OA/TOF when they have difficulty coughing anything up. Often, they are sent home with a diagnosis of a viral infection, only to become increasingly unwell a few days later. Is there something they can say to the GP to help secure antibiotics more quickly and avoid getting worse?**

A **A. Professor Thursfield:**

This is a difficult situation because GPs may only see one or two patients with OA/TOF in their careers, so they may not be as familiar with the condition. It's important to build a relationship with your primary care physician so that they become more knowledgeable about OA/TOF. Secretion clearance is crucial in managing respiratory issues. If a child or adult is having trouble clearing secretions, chest physiotherapy can be very helpful for improving airway clearance. It's also important to seek a referral to a respiratory physiotherapist if you haven't already. We want to minimise unnecessary exposure to antibiotics, so when you first notice an increase in secretions, try increasing chest physiotherapy to two or three times a day. If that doesn't help, then it's important to see a healthcare professional again and explain the steps you have already taken to manage the symptoms. This will help ensure the GP understands the need for further action and may lead to a quicker prescription of antibiotics if necessary.


Chantal ten Kate, Rebecca Thursfield, Nick Lansdale - l-r

Members meet up - from the UK to Oz!

TOFS has members in more than 70 countries around the world and it's great to hear about our members meeting up, sharing experiences and making new friends. We're delighted to report that in October and November, in both the UK and in Australia, families and adults have been doing just that.

TOFS member, Bryony Rowlands was the organiser of the Australian meet up in October. Two other families attended and met on the beautiful beach in Queensland, where the children could play in the sand and sunshine, and parents could connect and share stories. Read more about Bryony's own story with her daughter Willow, and the meet up on page 5.


Children playing Christmas games at Merseyside

We're incredibly fortunate to have had various informal meet ups organised by our TOFS Local Contact Volunteers (TLCs). Carrie Semark, pastoral support working group volunteer and Laura Bell, (TLC for London/ Kent) organised a meet up at Ronald Macdonald House in London in November. Eight families travelled from across London, and from Brighton and Hertfordshire. Children and adults born with OA/TOF, aged from just nine weeks to 30 years old, connected and enjoyed the afternoon.


TLCs Carolyn & Alan with families in Merseyside

Liverpool-based TLCs Alan and Carolyn Seeley met with four families in Merseyside for a Christmas get together. Children and siblings had lots of fun doing crafts, playing party games, toasting marshmallows, and getting to know each other.

Turn to page 20 to see upcoming meet ups organised by our other TLCs across the country. If you are interested in hosting a meet up in your area, do let the office know so we can put you in touch with your local TLC and help advertise your event to members.

Max's Trust

- providing support and information for the UK Anorectal Malformation Community

In the spring of 2024 Cassie and Jon Finnigan, the founders of Max's Trust, decided it was time to step down from the charity they founded in 2019. A new chair, Lauren Stahly, has been appointed and three new trustees, Kate MacFarlane, Deepti Grover and I, Kate Tyler, have joined the team.

During our annual conference in September, we all took a moment to reflect on the journey Cassie and Jon have travelled to enable children, parents, adults and medical professionals to come together and raise awareness of Anorectal Malformation. We at Max's Trust will be forever grateful for their inspiration and determination to create the first UK ARM charity.

We were very fortunate to be supported by paediatric colorectal specialists including Joe Curry, Bala Eradi, Kathryn Ford, Govind Murthi and Jonathon Sutcliffe. They shared valuable information which helps parents better understand the complexities of ARM and gives them invaluable information to share with their local healthcare providers. Specialist colorectal nurses Caroline and Rachel ran breakout sessions exploring EHCP/Nursery plans, bowel management and more.

Some females born with ARM may face problems with periods and pregnancy, so we were delighted to welcome Susie Jacob, a Consultant Gynaecologist from Leeds Hospital. Susie ran a breakout group for parents and spent time listening to some of the challenges faced by adults born with ARM.

Further sessions and presentations included:

Psychological Support for Mums and Dads, all trustees

An overview of ERN eUROGEN Anorectal Malformation Patient Journey, Trustee Kate Tyler

Accepting Anorectal Malformation, Trustee Kate Macfarlane

Me and my ARM(s), Guest speaker, Aled Griffiths

Aled was born with VACTERL Association affecting his bowel, bladder, heart, limbs and vertebrae.

Despite these challenges, Aled has not stopped helping others; spending time giving talks in the hope that, on hearing about his journey, others will be inspired to achieve their own goals and dreams.

Currently he is studying Psychology at university and training with the Paralympic shooting team, a truly inspiring young adult.

Our 2024 conference was never going to be easy without Cassie and Jon but thanks to the wonderful parents and professionals who support us we are planning a 2025 event and will continue to offer support to the ARM community.

***Ed's note:** Are you affected by anorectal malformation? Join Max's Trust community here: https://maxtrust.org/*

"Lost twin" study update

by Charles Shaw-Smith


Charles Shaw-Smith

Many members of TOFS gathered at the information seminar in London in November 2023 to hear about this research project, the goal of which is to try to understand better what causes oesophageal atresia and tracheo-oesophageal fistula.

A number of you very kindly signed up to the study at the event. Further to that meeting, a webinar was presented in February 2024; again very well attended and with a very good response of members wishing to become involved. I have emailed all individuals and families who kindly indicated a wish to participate (either at the meeting in November 2024, or subsequently) and returned preliminary information. This email explains reasons for the delays and advises that I will be back in touch soon.

The process of sample collection has gone well, as has collecting data from you and receiving samples and consent forms back in the post. A massive thank you to all those who showed an interest and participated. There is no doubt in my mind that it will be possible to recruit enough individuals to answer the question: is being a twin a risk factor for OA/TOF? The other aspect of the study is the laboratory analysis and, regrettably, there has been, and continues to be, significant delays based on technical aspects of the laboratory assays.

At this point, I would just like to reassure all those individuals who participated that the silence should not be interpreted as a loss of interest or willingness to see the project through to completion. The project is very much ongoing, and I will be providing further updates in due course. Please bear with me during this time.

Ed's note: If you have expressed interest in the project and have not received the aforementioned email, please get in touch directly with Charles. Likewise, if have not yet expressed interest and want to find out more, please do drop him a note. Email: Charles.shaw-smith@nhs.net

What are the Chances?

As we all know only too well; there are 1 in 3,500 chances of being born a TOF. So it stands to reason that the odds are even greater of finding another TOF family close by, let alone on the other side of the garden fence!

But that's what happened this summer when a lovely new family, Rhianne (Rhi) and Liam Davy, along with Archie, Sofia and Lily, moved in next door to The Webborns.

South Wales TLC and TOF mum Naomi Webborn started chatting to the family over the garden wall and, with the children all close in age, within days the youngsters became inseparable.

One evening while the children played around them, the new neighbours were chatting away, when Rhi noted her daughter Sofia had a little problem with her oesophagus. The words and terms she used resonated with Naomi, so she asked 'is Sofia a TOF?' As you can imagine that took Rhi a little by surprise, but she confirmed that 'yes', her youngest child was, indeed, a TOF.

Overwhelmed with emotion, goosebumps and tears of joy, neither mum could talk quickly enough with so much to discuss and share.

Rhi mentioned that whilst they were aware and supportive of the TOFS charity, the children didn't talk much about Sofia's condition. Naomi's family, on the other hand, are the polar opposite and so the children soon began chatting about the condition. George (13) and Sofia (7) have compared their 'shark bites', had some little chats, have had photos taken together and, with George being that much older, it's great for Sofia to see a kind of role model especially since they are both keen footballers too.

Now a few months in, Sofia is proud of her pillow wedge (just like George), and wears her TOFS t-shirt and cap proudly.

Naomi commented: "It's lovely to have them next door, we can pass on resources that we have collected over the years, support each other and most of all have someone who completely understands what you go through as a TOF family literally on your doorstep, and it's amazingly heart-warming.

"We can't wait to do the toddle together next year and look forward to TOFS' awareness week. We will definitely be doing something together - maybe we will even have a party."

Would the odds be less to win the lottery? Maybe the new neighbours should buy a joint ticket just in case!

Do you have a fellow TOF living close by? Share your story with us for the next edition of *CHEW*.


Sofia and George

Report on the 56th meeting of ESPGHAN

In May 2024, Dr Caroline Love and Vanessa Johnson travelled to Milan to represent TOFS and EAT (Esophageal Atresia Global Support Groups) at the 56th Annual Meeting of the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN). Here, they write about their experience.

This was a valuable opportunity to meet with other charities and experts in Oesophageal Atresia (OA) and with representatives from ESPGHAN to discuss the common problems and goals that patient support groups share. Together, we discussed the importance of good transition from paediatrics to adult care and ongoing adult care, how to build better communications and relationships between doctors and patients/families and how to create more involvement for Patient Advocacy Groups (PAGs) with ESPGHAN. We also met separately with the European Refence Network for rare Inherited and Congenital (digestive and gastrointestinal) Anomalies (ERNICA) to promote good transitional care across European OA/TOF specialists.

We attended a range of presentations on the latest developments in OA/TOF and associated conditions. These included an exploration by Dr Auer about whether people born with OA/TOF with swallowing problems continue to experience these issues in the long term, and the underlying causes of these difficulties. These can include problems with the anatomy of the oesophagus such as strictures, ongoing structural blockages we were born with and blockages due to fundoplication which can affect some patients. Dr Auer looked at the causes of swelling and irritation in the oesophagus that can affect swallowing such as Eosinophilic Oesophagitis and reflux. She explored how children and adults born with OA/TOF develop ways of coping with dysphagia (swallowing issues) and how many patients are not even aware that they have any differences in their swallow.

Vanessa and Caroline


Vanessa and Caroline with Professor René Wijnen

We attended a very interesting session by Ulrich Baumann (Germany), Julie A. Lanigan (UK), Hania Szajewska (Poland), Jan De Laffolie (Germany) and Giulia Fiore (Italy) about the impact that Artificial Intelligence (AI) will soon make on every area of medicine. It was stated that 50 years from now, medical practice will look entirely different in every way creating "a new ecosystem for health". The opportunities and risks were considered and the research required to create reliability, transparency and accountability. The participants discussed how AI presents an important opportunity for greater patient empowerment. To engage in these significant developments, the patient community needs to understand how AI is developing and the potential that exists so that they can participate in these processes from the beginning and influence how they develop. AI has the potential to create more individualised care and better predict which patients would benefit from preventative treatment. Doctors will be able to identify high risk patients more easily before they develop symptoms and select the most appropriate therapy more effectively.

Mr Lacher presented some exciting developments of less invasive ways to investigate and treat OA, including a new form of real-time MRI that can allow parents to go into the MRI with their baby and avoid the radiation that can come with some other investigations. He also discussed using surgical robots to perform repair surgery, which may allow surgery to be done on very small babies that currently isn't possible with non-robotic surgery. Lastly, he mentioned a new non-surgical technique for repairing recurrent TOF with a chemical to "glue" the fistula shut. These new methods are not widely available yet but certainly look promising for the future.

We also attended ESPGHAN'S latest guidelines for Eosinophilic Oesophagitis (EoE) by Jorge Amil Dias, Alexandra Papadopoulou (Greece), Salvatore Oliva (Italy), Noam Zevit (Israel) and Carolina Gutierrez (Junquera, Spain). This was an interactive session with an opportunity to televote, the results of which highlighted the current potential variation in clinical management of EoE. AI is already impacting on this area and Salvatore Oliva stated that, "eosinophils are not the main target anymore." Attention is now focused on the earlier stage before symptoms develop, Noam Zevit suggests, calling it, "pre-symptomatic EoE" or "Stage 0 EoE". AI provides the opportunity to create a multimodal assessment focused on inflammation and remodelling "to predict the disease and apply the treat-to target approach."

Neonatal Nurses Association conference

When TOFS was invited to have a presence at the annual conference for the Neonatal Nurses Association (NNA) we jumped at the opportunity to raise the profile of both the charity and the conditions we support.

We know how important the neonatal experience is for new parents and we wanted to ensure practitioners were aware of the resources available to support them - both the expressed breastmilk (EBM) guide written by Kate Yardley, a midwife and mum of a baby born with OA/TOF, and the parent packs, which are available for new parents.


Rhiannon, Diane and Fiona

Neonatal units already have copies of the *OA/TOF book* and now know that free PDFs of our books are available for their use and that our wonderful local contacts (TLCs) will happily support new parents.

CEO Diane Stephens represented us at the event, which took place at Derby Conference Centre in November. There were three charities exhibiting, ourselves, Bliss and APAN.


Róisín McKeon-Carter and Diane Stephens

We took along a banner which emphasised that OA/TOF is a lifelong condition. It was good to meet up with Rhiannon Jones, National Neonatal Surgical Interest Group, who is spearheading a 'Best Practice' framework (reported in the last edition of *Chew*) to guide units to provide best care for OA/TOF babies.

The two-day conference was attended by approximately 200 nursing staff and included many advanced neonatal nursing practitioners.

TOFS lottery winner Tony!

Celebrating survival, support and an unexpected jackpot by Tony's daughter, Carla Grice

My dad and I have been doing the TOFS charity lottery for about three years. We feel it's a very good cause and very close to our hearts.

My son, Leo, was born in November 2018 at James Paget hospital, Gorleston with short gap OA/TOF. He was full term and arrived exactly on his due date. Soon after his birth, it became apparent that something was wrong, and we were quickly transferred to Norfolk and Norwich University Hospital. The consultant, Mr. Ram, was absolutely amazing and explained everything about OA/TOF, as it was something we had never heard of before. Leo had his repair done on the second day of his life, and after five hours in theatre, we were told that everything had gone as well as it could have.

Leo was only in the hospital for two weeks, as he went from strength to strength. It was nerve-racking bringing him home, as we still didn't know much about what life with a baby born with OA/TOF would be like.

That's when we found the charity TOFS. It has been a lifeline for us; just being able to ask people's advice at any time has helped us get over any hurdles we have encountered. It's comforting to know we're not alone going through this. Leo also has a reflux in his ureter (the tube that carries urine from the kidney to the bladder) which is monitored every year.

When we started to wean Leo, we realised how difficult his life was going to be. He didn't manage solids very well at all and was on puréed food until he was 18 months old. Leo is now about to turn 6 and has come a long way since those worrying early days. Although he still struggles with some foods, he eats a fairly normal diet. We still get stickies from time-to-time, but Leo has learnt to deal with these and take it all in his stride. Luckily it doesn't put him off his food!

We are so grateful to Mr. Ram for saving our little Leo's life and for the amazing care he received at Norfolk and Norwich Hospital. We are also grateful to TOFS for guiding us through the hard times. My dad, Tony, received a phone call in October to say he'd won the jackpot on the lotto of £1,000 and that he was the second TOFS player to do so. It was great news to receive - thank you, TOFS.

Ed's note: Do you want to be in with a chance of winning the lottery? Sign up here: *https://tofs.org.uk/support-tofs/play-tofs-charity-lottery/*

Lottery winner Tony with Leo and Carla

Leo, then...

...and Leo, now

In Loving Memory

In Memory of Myles

My son Myles was born 28.01.22 with OA/TOF. Myles spent nine months of his life in the Queen Elizabeth Hospital in Glasgow and had multiple surgeries. Myles coped very well with eating food and enjoyed it. We got Myles home in October 2022, but sadly my son passed away in March 2023 due to Sudden Infant Death Syndrome.

This broke us as a family, and we all miss him dearly. His big brother Jayden has been there for everyone during this time, and I can't thank him enough.

The local youth club and community have been amazing, helping with the charity match and we, as a family, would like to say a big thank you to them all.

Growing up with a disability

Mark Stokes lives in Romsey and works as a print and bindery technician at Hampshire County Council. Here, Mark tells us about his life and achievements despite the challenges he lives with.

I was born with a tracheo-oesophageal fistula, and as a baby I had reconstruction surgery to address the issue. This took many operations to fix but was finally achieved. Unfortunately, there were other complications that occur from being a TOF baby including abnormal size organs and skeletal issues. This meant for me that my right lung didn't develop properly due to scoliosis of the spine. This means the curvature of the spine compresses the rib cage and minimises growth of the lungs. As a child, I often got repeated chest infections as well as other issues, but that was a normal part of my life.

Growing up, my spine curvature worsened. Over the years this was addressed by wearing a body brace for sixteen hours a day, every day. Unfortunately, the curve was too severe, and the decision was made to have a spinal operation with a high fusion Harrington rod inserted. This stayed in until my teenage years as, once the operation was complete, I would no longer have any growth of my torso area. This would have an effect on my overall height but, without this operation, the likelihood was I would be wheelchair-bound, so when looking at those options the operation was a no-brainer for me. However, the operation has left me with limitations on movement and constant pain.

Throughout my childhood, I spent a lot of time off school due to illness and operations. This affected my learning and grades, whilst also dealing with the school bullying that I'm sure most children have experienced at one time or another. I was lucky to have such a supportive mother but also a good network of friends who helped me to deal with my struggles.

When it came to sitting my exams, my grades were low as expected, due to limited attendance. However, I wasn't going to let this stop me from doing my best. I left school and enrolled on a Youth Training Scheme. At that time, this was the best option; I had to try to develop myself and forge a career as I didn't achieve the grades to go to full-time college. This was managed by the Chamber of Commerce where I studied for an RSA Clerical vocational qualification with on-the-job training. Unfortunately, after completing two years, the company I worked for didn't take me on; a common pattern for a lot of people on the course.

I continued working, mostly doing agency work but always trying to do my best with the limitations of my disability. At the age of 23, I was offered a position with a print plant; nothing major, just starting by filling envelopes with instructions. I saw this as an opportunity to make a career for myself, so I then looked at furthering my learning by doing a printing apprenticeship, but unfortunately this was only tailored to 16–21-year-olds at that time.

Nevertheless, I decided to do as much in-house training as possible. My knowledge progressed but, still eager to learn more, I volunteered as a health and safety officer trying to better myself but also to improve the work environment for myself and my colleagues. I later changed company but stayed within the print industry.

I have always had stumbling blocks to deal with, whether that's through my disabilities or through my lack of education and have either found a way around this or dealt with it head-on.

Throughout the years, I have struggled with my health issues and now, as a 51-year-old, that hasn't changed and only gets worse with age, but I make sure I get what help I can, such as reasonable adjustments in the workplace. This obviously doesn't stop me from worrying about my health and how it affects me and my family, but I am determined to make the most of what I have.

My greatest achievement is to have two beautiful girls aged 12 and 10 that I get to watch grow up, and I'm proud to say that I'm their dad. Eboni is 12 and has recently been diagnosed with moderate dyslexia and we are battling to get the support that she needs at school. Skyla is 10 and suffers with constipation. I'm struggling to get further investigation for Skyla even though I explained about my problems and bowel issues, concerned that it might be genetic. Skyla's paediatrician is dismissive that there is any connection, and I have asked for a second opinion with another consultant. I'm also trying to get genetic testing for myself as the original consultant advised to do that before they would look at investigating further into Skyla's problems.

My other achievement is that within the last year or so, I have gained my certificate as a print technician at Level 3 (with distinction) which took almost three years to achieve, so only goes to show that resilience, drive and determination can pay off and you're never too old to learn.

As I get older, I struggle regularly with acid reflux, aspiration, bronchiectasis and chronic pain, but resilience and my children keep me strong and determined to overcome whatever life throws at me.

Mark and his family

WINTER 2024/ 2025

tofschew

lifelong support for those born unable to swallow

This magazine contains references to OA/TOF surgery and content that some readers may find emotionally challenging. If you need support, please contact the TOFS office, or reach out to your local contact volunteer.

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

In Memory of:

Simon Ryan, dad to Colin OA/TOF - £407 donated by family and friends at his funeral.

Margaret Jackson - £33.83 donation from Hedley Jackson Funeral Directors.

tofs

ANNUAL GENERAL MEETING

Thursday 24th April 2025, 7-8pm

Members and Associates are invited to join us for the 2025 AGM of TOFS.

To register scan the QR code or visit tofs.org.uk/events for more info.

Join us!

For a virtual cuppa & chat with other adults born with OA/TOF.

Led by volunteers, who are also adults born with OA/TOF, and is a relaxed, safe space to share stories and experiences.

Thursday 6th February, 8-9pm

Thursday 6th March, 8-9pm

To register scan the QR code or visit *tofs.org.uk/events* for more info

Fundraising thank yous:

Kevin D'Costa -
£50 donation to TOFS as a birthday wish for Ana Johnson, mum to Jacob OA/TOF.

Nia Sutcliffe TOF Adult -
£50 donation from her husband. Euros Football Sweepstake.

Sharon Hamilton, OA/TOF grandparent -
£20.49 donation.

Horeb Chapel, Penydarren -
£50 donation, charity of the month. Thanks to Estelle Hill, mum to Rhiannon OA/TOF, for putting TOFS name forward.

LDL Components Ltd -
£100 donation. Thanks to the employee who put TOFS name forward.

Blackhawk Network (BHN) EMEA -
£12140.75 donation as part of a Care-4 childcare voucher program.
See more on page 7.

Harriet Hand (OA/TOF) along with friends Martha and Maggie Edge raised £640 by holding a cake sale and games events.

Denise Brook, grandparent to Leo (OA/TOF), for donating her expenses of £66.50 back to TOFS.

Susan Moore, grandparent to Samuel Moore OA/TOF, along with Laura, her daughter and mum to Samuel, raised £1,117.30 by holding coffee mornings. Susan's husband also asked if donations in lieu of birthday gifts should be donated to TOFS.

Those who very kindly made donations through the TOFS Facebook page.
A fantastic £981.79 was raised from 1 April to 29 July 2024