SUMMER/AUTUMN 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.

Archer's Story
page 3

Paediatric care to adult care
page 4

Welcome new members!
pages 6–7

Members meeting up
page 9

Father runs ultramarathon
pages 14-15

Cyclists raise £15,000 for TOFS
pages 16-17

Fundraising Heroes
pages 18-19-20

Meet our Teddy Toddlers
page 21

COVER STORY: Mr Suren Arul, Consultant Paediatric Surgeon and Reuben. Mr Arul discuss the innovative OA/TOF dual-repair training for trainee surgeons recently in Birmingham. See pages 12-13

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

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From the Editor

Hello everyone,

Welcome to your Summer/Autumn 2024 *Chew*. Is it just me or is life slipping by way too fast? So now might be the perfect moment to slow down, have a cuppa and leaf through our wonderful magazine.

Some stories in this edition reflect the international nature of our membership these days. But regardless of where you live, the parents amongst you will identify with mum Lyndsay's account on the opposite page and the dreadful feeling of separation as her newborn son was flown off to the nearest NICU for his OA/TOF repair.

We wish Adult TOF Olivia (in Adelaide) well as she prepares for her fistula repair surgery. Hopefully by the time you read this Olivia will be well on the way to recovery and have this latest TOF-chapter behind her. Read Olivia's story to date on page 11.

We are grateful to Mr Suren Arul, pictured on our cover, who talks about both traditional and keyhole approaches to OA/TOF repair. See pages 12-13. Mr Arul and his colleagues facilitated what he believes is the first dual-method training course in the UK for trainee surgeons to practise both repair techniques on new innovative chest models at Birmingham Children's Hospital.

Volunteers and staff have been busy continuing to raise the profile of OA/TOF with medics. Read about the events we've attended and what we've gleaned on pages 8, 9 and 22.

It was a pleasure to be reminded of the huge contribution that the late Judith Bland made in volunteering for TOFS over the years. Judith was a wonderful lady and helped so many, and it's clear to see when reading her son David's tribute on page 15, she was also a tremendous mum.

Many of you will know of the Jeavons family, who are (to date) our most successful London Marathon fundraisers. Ross, (dad to Corey) has been at it again, except this time he's taken on an ultramarathon in honour of his son and raised a magnificent £8,240 in the process (pages 14-15). We are enormously grateful.

The 2024 RideLondon cyclists smashed all records by raising more than £15k! Wow. See pages 16 and 17. Our runners in the Great North Run will be limbering up for the iconic run just about a week or so after this drops on your mat. We wish them well and will report more in the next edition.

Lots more wonderful fundraising stories on pages 16-21. Thank you all for your contributions. Please keep your wonderful stories coming!

Diane

Diane Stephens, *Chew* editor

CONTENTS

Archer's Story 3
Gary Spiers Obituary 3
New fundraising volunteer 4
Paediatric care to adult care 4
New lungs and airways resource 4
Doctor leads charge for improved OA/TOF care 5
Nothing but the best for OA/TOF babies 6 / 7
Welcome new members 6 / 7
VACTERL Association Support Group annual meeting 8
Members meeting up 9
Raising the profile of OA/TOF 9
Virtual coffee and chat 10
Reconnecting with my beginnings 11
Surgeon discusses first OA course 12 / 13
Father runs ultramarathon for TOFS 14 / 15
In Memoriam - Judith Mary Bland 15
Cyclists raise £15,000 for TOFS 16 / 17
New chair for TOFS Council of Management 17
Fundraising Heroes 18 / 19 / 20
New TLCs for Merseyside 20 / 21
Meet our Teddy Toddlers 21
2024 meeting of the BTS 22
In my own words… Chris Phillips 23
New child-friendly poster 24
Upcoming events 24
Fundraising thank yous 24

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.

Archer's Story by Mum Lyndsay Ralph

Our wee boy, Archer, was born in March this year and diagnosed with OA/TOF shortly after birth. Towards the end of my pregnancy, I was diagnosed with polyhydramnios and it was noted that Archer was small but otherwise no-one seemed too concerned. I had extra monitoring and an induction was planned for 37 weeks. The induction failed to progress, so my waters were broken and Archer's arm and leg dropped down, causing his cord to prolapse and resulting in an emergency caesarean section.

Initially, Archer was not in great shape but he came around within minutes with some assistance.

He was then taken to the Special Care Baby Unit where nurses monitored him and tried to insert a feeding tube. However, as we all know, the feeding tube coiled and therefore OA was suspected. X-rays were ordered and the large out-of-region hospital with a NICU was phoned. You can imagine my shock when I came out of recovery to find out my little baby's oesophagus was not formed correctly and instead in two parts. I remember lying there the first night not wanting to Google anything about it due to sheer fear.

My partner flew with Archer to Wellington that night and I remained stuck at our local hospital for two days before joining them. Those two days were the hardest days of my life at the time. Hearing other mothers on the ward with their babies while I lay there alone wondering if my baby was going to be okay was excruciating. The morning of the surgery came and the surgeon called me to explain the procedure and all of the risks, while I was crying on the other end of the line.

I finally got to the hospital where Archer was while he was still in surgery. He had a Type C short gap which was repaired with no complications. Fast forward a couple of days later and he failed extubation due to increased work of breathing. He was re-intubated for a few more days before failing extubation again. Finally, he was scoped by ENT doctors who saw no abnormalities with his airway so it was put down to tracheomalacia, which will hopefully lessen as he gets bigger and stronger. He was finally extubated successfully and put onto CPAP (Continuous Positive Airway Pressure).

He spent a few days each on CPAP and high flow oxygen. He did well coming off high flow so the surgeon was happy for him to start oral feeds. We spent the final week in NICU working on feeding after Archer ripped out his NG tube (more than once). Archer was an absolute star pupil and even came home exclusively breastfeeding. We made it home five weeks and a few days after he was born. Since then he's been growing (albeit slowly) and figuring out himself and the world around him. His current faves are eating his hands and bath time!

Archer has had a mild stricture that the surgeon has been slowly stretching. He has had four dilatations with at least one more scheduled in the next few weeks. We are going to start weaning in about a month and I have a whole bag of feelings about that as I'm sure did all of the other TOF parents before me. On the one hand, I'm so excited to be able to introduce new things to my baby but on the other I'm absolutely petrified and riddled with anxiety. I have done a lot (and I mean A LOT) of scrolling through TOFS and other support groups online. I have read the good, the bad and the ugly! I've even asked the surgeon if we should live close to the hospital during weaning. At the front of my mind are things like dysmotility and stickies. I'm mentally and physically preparing myself and will hopefully have a SaLT (Speech and Language Therapist) with me the first time I attempt to give him a puree. I'm sure it's nerve wracking weaning a non-TOF, so the added stress of an atypical oesophagus is extremely challenging. I recently connected with a local TOF mum who just told me to make sure I puree the life out of anything at first. I'm thinking I will arm myself with my blender, ricer and a sieve.

I feel like I've just settled into life with my little TOF babe and he's finally settling into habits and routines and now we're about to add in a whole other element with starting solids and what that may bring. I guess it's all part of this crazy ride. I'm excited to start this next journey with Archer even if I am a nervous wreck. I'm so thankful every day for my boy and beyond proud of him and how he's coped with the rough start dealt to him. These TOFlings certainly are some of the strongest out there!

Gary Spiers, 1963 – 2024

It is with shock we learn (as *Chew* is going to press) of the sudden passing of a most valued and esteemed volunteer, Gary Spiers.

Gary, who was featured in the Summer 2022 edition of *Chew*, was an amazing brother, son, husband and father. He was an esteemed member of the Adult TOF working group and a board member of EAT, the association of global support groups. Gary was born with OA/TOF in 1963 and he influenced and inspired many within our community. We will publish a tribute to Gary in the next edition and send our deepest condolences to the family circle.

Gary Spiers, born 1963, OA long-gap, GOSH

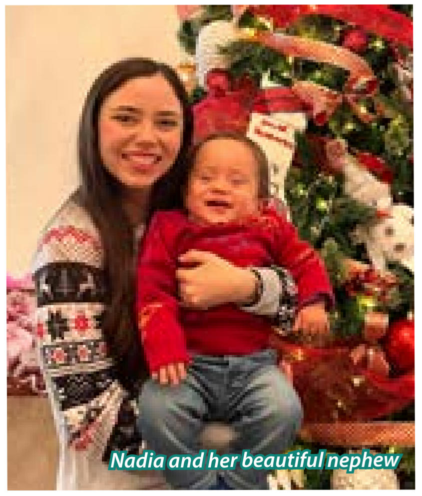
Welcome to Nadia,

new fundraising working group volunteer

My name is Nadia, and I am thrilled to join TOFS as a new fundraising group volunteer. Originally from Mexico, I have been living in the UK since 2022, when I came to pursue my master's degree. Currently, I work in real estate finance in London, where my company encourages us to engage in social causes.

Nadia Guerro Marquez with John Pearce at the London Marathon cheering station

This is how I discovered TOFS, a cause that is personal and means a lot to me. My little nephew was born prematurely at 28 weeks with OA and numerous other complications. The doctors gave my sister very slim chances for his survival on the day he was born. Yet, against all odds, he is now two-years-old and just had his surgery a month ago. He is on the path to a happy life after overcoming many milestones (with still more to come!). His journey has been long and challenging but my family and I are immensely proud of his strength and resilience. We are amazed everyday!



Nadia and her beautiful nephew

I am delighted to be part of TOFS and eager to contribute in any way I can to support families facing similar challenges.

Leaving paediatric care and transitioning to adult care

Moving through school, growing up into teenage years and becoming a young adult is such an important and exciting time. However, some adults born with OA/TOF will agree that leaving behind the familiarity of paediatric care and transitioning into adult services may throw up a few challenges. Members have joined together for our recent online events, which have been themed around providing information and sharing current research around this.

At a recent Talk with TLCs: "Teens and Transition into adult care" event, Bruce Rennie, TLC for Scotland and Tracey Fish, TLC for Leeds, shared their own experiences with their teenage sons who were born with OA/TOF. Other parents and teens born with OA/TOF also shared their own stories, asked questions about what to expect and supported each other.

Dr Una MacFadyen

Dr Una MacFadyen, retired Paediatrician and Neonatologist, also spoke to members at our last Q&A session, "Leaving paediatric care and negotiating adult services". Una shared her current research in which young adults with a chronic condition offer their first experiences as adult hospital patients and how staff might help make this less distressing. She explained the background changes that all teenagers go through when growing into young adults, becoming independent and making their own choices. This highlighted the importance of shared decision making and co-production between the teen, parents and healthcare staff to allow them to feel empowered and advocate for their own care. You can watch the recording of Una's Q&A session on our YouTube channel.

If you wish to share your own experiences with Una, please do get in touch with the office and we can connect you by e-mailing: info@tofs.org.uk

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

Discover our new resource on lungs and airways

As we approach the autumn we're delighted to announce our new resource on lungs and airways developed by the Adult OA/TOF Working Group. This comprehensive guide is designed for individuals born with congenital respiratory conditions and offers valuable insights as well as practical tips to improve respiratory health and quality of life.

The resource includes:

✓ Understanding respiratory conditions
✓ Airway clearance methods
✓ Characteristics of healthy lungs
✓ Managing breathlessness
✓ Breathing techniques
✓ Medical management

https://tofs.org.uk/what-is-oa-tof/common-problems-with-oa-tof/lungs-and-airways/

Dedicated doctor leads charge for improved OA/TOF care

Dr Caroline Love isn't one to sit back and let others do the work. As co-leader of the Dermatology Department at York Teaching Hospital NHS Trust she is on the frontline of a profession that is demanding, under-resourced and challenging. So it would be completely understandable if, in her free time, she liked nothing better than to switch off from all things medical and vocational. Fortunately for all of us who have found ourselves touched in one way or another by OA/TOF, Caroline is an active, dedicated and indefatigable supporter of TOFS.

Caroline has recently been appointed Chair of TOFS' Medical Research Liaison Group subcommittee (MRLG sc) which collaborates and communicates with a multidisciplinary team of experts who have a special interest in OA/TOF.

Caroline is not a newcomer to the work of the MRLG. She has been a key member of this group for several years alongside her voluntary work on the Pastoral Support subcommittee and the Adult TOF working group. She is the author of the Adult Management Handbook and has represented TOFS and given presentations at various medical events.

As a medical professional her expertise is invaluable to TOFS. On top of that, the fact that she, herself, was born with OA/TOF makes her knowledge and understanding of the condition even more indispensable to the future prospects of the MRLG.

Caroline took time out from her busy day to fill us in on her approach to the new role, her own perspective on life as an Adult TOF and the satisfaction she gets from volunteering for TOFS.

Dr Caroline Love

Can you give us a brief summary of what the Medical Research Liaison Group subcommittee (MRLG sc) does?

MRLG is a bridge between members of TOFS and clinicians and researchers, learning about the latest ideas and developments in OA/TOF. The MRLG acts in members' best interests to promote the best health care outcomes for them, as well as translating the information we find out from them in a way non-medics can understand. We are involved in assessing research propositions wanting TOFS' input and attending conferences to spread awareness of OA/TOF and members' issues.

When it comes to being in contact with clinicians and researchers have things changed much in the time that you have been involved with TOFS?

Yes, it has been a massive change! In 2010 when I was first involved, there was little involvement with clinicians and researchers, except as patrons talking at conferences etc. Now, most paediatric surgeons across the UK and Europe are well aware of TOFs and that some have ongoing health problems. We are active participants in research and advocating the needs of our members to clinicians and policy leaders.

Now that you have been appointed chair of the MRLG, going forward, what are your aims and goals in this role?

My aims are twofold; my personal aim is to improve transition from paediatric to adult care and for there to be good adult healthcare for those who need it. My aim for the MLG is for us to "plug the gaps" of what we are missing in our work. Graham Slater and others have had a massive impact in patient driven healthcare but there is still progress to be made. I also want the talents of the other volunteers to be heard and utilised. Examples of this are that we are looking into publishing our own research into trauma influenced care and improving awareness of OA/TOF among midwives and sonographers.

You're a very valuable and extremely busy volunteer, how do you fit everything in?

It has been a bit frantic! At the same time as taking over the MRLG, I also took over clinical lead at work and my sister and sister-in-law have both had baby boys in the last three months! But I'm finding my feet now.

As an adult born with OA/TOF how has your health influenced what you want to do in this role?

My parents were told I was fixed at birth but I've always had chest problems. However, these were dismissed as not being related to having been born with OA/TOF. As a medical student, I asked a paediatric surgeon and again was told, "TOFs don't have health issues". This led me to stop seeking help. It wasn't until I was 30 that I was properly investigated and sorted out. Now, I'm lucky as I know what is wrong with me and who to get help from and I get listened to because I'm a doctor. However, I know that isn't true for many Adult TOFs and parents of TOFs.

What is the most exciting thing and also the most rewarding thing about being involved with TOFS in this capacity?

The most exciting thing is seeing the improvements made since 2010 in both paediatric and adult care for ongoing health issues and playing my part in that. There is still room for improvement but we are working hard on it!

Nothing but the best for our OA/TOF babies

Anyone who has spent time in a special care baby unit, sitting by an incubator in which a tiny scrap of humanity is fighting to survive, will know how important the skill, dedication and kindness of a neonatal nurse is.

Rhiannon Jones is just such a person. An advanced nurse practitioner, specialising in surgical neonates, Rhiannon has been working at Great Ormond Street Hospital for nine years and has been in her current role on the Neonatal Unit since 2018.

But that's not all that she does. In her spare time, Rhiannon works with the National Neonatal Surgical Interest Group (NNSIG), an innovative and dynamic group of nurses, dedicated to the delivery of high-quality care for infants with congenital conditions requiring specialist neonatal surgical management.

Which brings us to a meeting of the ways. Because Rhiannon is currently working on a framework to improve the care of babies born with OA/TOF that will benefit our members past, present and future. Rhiannon took time out of her busy life to tell us about the project.

Hi Rhiannon, can you tell us a little about yourself?

I have always liked looking after and caring for people and I like working with younger people so that's why I trained to be a paediatric nurse. One of my rotations, when I was newly qualified, was in neonatal surgery at the Royal London Hosptial. I just fell in love with working with surgical neonates and that's what I've done now for nearly 20 years. I have worked in several London hospitals, undertaken my master's to become an Advanced Nurse Practitioner and build up the knowledge and skills to look after this unique group of patients and their families.

Why did you get involved with the NNSIG?

The NNSIG was set up in 2003 by neonatal nurses who specialise in surgery. At the time, no one really worked together. Then the teams at Leeds and Newcastle got together to form the group and then they invited more and more services to join them. And it was just something that, as I got into neonatal surgery, I thought was an excellent opportunity to work together. We had so many questions in our own unit about what other people did, so joining the group was a perfect opportunity to see what everybody else did, but also show what we do. We have representation from every neonatal surgical unit or unit that looks after surgical neonates everywhere in the country. Plus we link in with the dieticians and other allied health members. It's expanding into not just the surgical units but all the local units that take these babies back for their ongoing care. It's been a very exciting last two years as the NNSIG have become a speciality group for the Neonatal Nurses Association.

And it must be so much easier now with all the communications and virtual connections we have?

Yes, before COVID we did all our meetings and education face-to-face. We used to have a meeting twice a year rotating between the units in the group. Now, having that ability, that some people join face-to-face and some people attend virtually, it really links us all together. We use the availability of online meetings to set up working groups and run education and teaching days. It is so much cheaper to run these and allows more people to attend and participate.

You must have so much to talk about when you all get together

Yes, friendships have been built up over the years and between the meetings we're always emailing asking questions, sharing ideas and discussing what is new. We're working together more, as we are on this OA/TOF project and if anyone has a question you just send it in and you get responses. And it's not now just the neonatal side or the surgical side. Besides the dieticians we're also linking in with the British Association of Perinatal Medicine (BAPM) and the British Association of Paediatric Surgeons (BAPS) and having that rapport with everyone and building up the groups is an excellent opportunity to be able to share what we all do together.

Has there been any resistance from the surgeons to working with the groups?

No, both BAPM (British Association of Perinatal Medicine) and BAPS (British Association of Paediatric Surgeons) have been very appreciative of the connection and our input. Obviously, every unit works slightly differently but there's never been any animosity between us. We always have a teaching session or update session by a surgeon when we meet. We ask them to speak on our educational days and they are always actively involved in helping write our best practice frameworks.

How will this project influence the way neonatal units treat and care for babies born with OA/TOF?

The first stage of this project is to write what we call a "Best Practice" framework. That is, trying to pull everything that's in the literature that is being done here and around the world into a document. Not saying you have to do this, it's not a protocol or a guideline, but it's saying, "this is what's out there and this is what seems to work" and "this is what has been published," then people can adapt it to their area. The whole idea of it is to guide units, whether they're surgical or non-surgical, to provide the best care that we can for the OA/TOF babies and their families. There will be different sections covering the whole neonatal periods including an antenatal diagnosis covering what should be expected on units or services. Then what you should expect on delivery of your baby. But then also what happens on delivery and post-delivery if you get a diagnosis that you weren't expecting.

The second part is very much the neonatal period from initial surgery towards going home; bringing in multi-disciplinary teams (MDTs), dieticians, speech and language, physios, parents, anyone who needs to be involved working through that whole process.

Once you've been discharged from hospital, the next big thing is to work on the "what happens if?"

We're just focussing initially on the neonatal period but our plan eventually is to publish something together that will go from antenatal care through to transition to adult care. That is my long-term plan but I think that's two or three years down the line. We thought we'd start in the area that we're obviously all in and understand and then we can work with paediatric teams on stages such as weaning, going to nursery and going to school.

What do you hope that the benefits will be for the babies and also for their families?

It's to standardise the care we give to these babies and what should be offered to these families. If you have an antenatal suspicion of OA/TOF we should be offering parents the opportunity to meet surgeons, to come to the meetings where the baby will be born but also to where these babies will go to from a surgical point of view.

Every surgeon and every unit will work differently but best practice will mean that wherever you are in the country you will have the same kind of treatment and link you in with whoever you need to be with. It's not telling people exactly what to do but hopefully guiding them in the direction of what they should do and have. And part of that is getting these families linked in with the TOFS charity earlier for people who have questions so they can then be in touch with other families.

What is the most important thing about this framework that you're producing?

Well, surgical neonates are a very small and a very unique group of patients in the NHS so being able to bring nurses together to give everyone the opportunity to see what we should be doing for these babies and their families is I think, one of the most important things.

Have you been impressed by the resilience of these tiny babies?

Babies and children are more resilient than adults. What they and their parents go through, how they cope with everything day to day, especially if there are other associated conditions, is amazing. So often it's not just that you get fixed, go home and everything's fine, it's often a lifelong condition for some of these families. The knowledge they have is very different from the knowledge we have. We can obviously see one side of it and we can say all this but they're the ones who then have to go home and live it. That's why it's so nice being able to link in with everyone associated with TOFS.

To have some parents helping us and having the ability to work with TOFS and the parents you support is invaluable. Twenty years ago we didn't listen to parents, we didn't talk to them and now from day one we've invited parents to join us in this best practice group and it's an honour to have them with us.


Rhiannon Jones

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.**

Abbie Carter, from Camberley
– Betty, born 22 February 2024, OA/TOF

Eva Lauerbach, from London
– Konstantin, born 21 August 2023, TOF

Jessica Reynolds, from Essex
– Ethan, born 12 April 2024, OA/TOF

Khloe Hodgkinson, from Stoke-on-Trent
– Marnie-Rae, born 18 June 2023, OA/TOF

Marie Anderson, from Canada
– Adult TOF

Marivic Ambon, from Saudi Arabia
– Pierre, born 17 July 2023, OA/TOF

Mark Stokes, from Romsey
– Adult TOF

Megan Longden, from Australia
– Thomas, born 16 March 2024, OA/TOF

Nadia Guerrero, from London
– TOF relative

Nova Floyd-Simpson, from Accrington
– TOF relative

Sharon Baker, from Melton Mowbray
– Adult TOF

Shloima Lax, from London
– Shia, born 19 June 2022, OA/TOF

Kaselyn Gibbs, from USA
– Macauley, born 8 August 2023, OA/TOF

Marianna Kornilaki, from London
– Emmanouil, born 17 July 2013, OA/TOF

Lyndsay Ralph, from New Zealand
– Archer, born 7 March 2024, OA/TOF

Jenna Young, from West Kilbride
– Forest, born 4 November 2023, TOF

Sophie Hughes, from Chelmsford
– Austin, born 27 May 2024, OA/TOF

Jennifer Majer, from Long Eaton
– Finley, born 14 April 2024, VACTERL

Ross O'Driscoll, from County Kildare
– Hugo, born 7 September 2023, VACTERL

Johanna Meere, from London
– Kyrie, born 1 November 2023, VACTERL

James Morris, from Hertford
– Harri, born 27 June 2024, VACTERL

Val Longley, from Northampton
– TOF relative

Flora Jarvis, from Swadlincote
– Alora, born 12 December 2023, TOF

Steph Whyte, from Midlothian
– Ruaridh, born 10 January 2024, VACTERL

Bryony Rowlands, from Australia
– Willow, born 7 February 2024, OA/TOF

Natalie Vickers, from Cheshire
– Isabelle, born 6 November 2023, OA/TOF

Rhianydd Lewis, from the Isle of Man
– Asher, born 16 July 2024, OA/TOF

Professionals

Charlotte Morgan
– Neonatal Surgical Specialist Nurse,
Manchester University Hospital
Foundation Trust.

VACTERL Association Support Group annual meeting

by **Kate Tyler**, Trustee and ATWG Chair

On 29 June Alan (French) and I joined the VACTERL Association Support Group for their annual event. It was good to meet with friends old and new and hear of the group's plans since we last met in October 2023.

This is a very exciting time for their organisation as they have recently applied to become a registered charity. This process should be finalised in the next few weeks. We at TOFS wish them every success.

Patient advocacy groups, like TOFS and VACTERL Association Support Group provide an essential role for rare disease patients and their families. Helping people to find their voice, to express their views and wishes, so that their opinions are heard, understood and valued. These groups provide a sense of community and help all involved to navigate the challenges and uncertainties of living with a rare disease, together demonstrating how multiple anomalies impact each other, sharing solutions to help everyone achieve better health outcomes.

This year's event provided an opportunity for families to meet and chat, young adults to connect and for everyone to be supported and to realise they are not alone with these rare anomalies. Part of the morning's programme included hearing from guest speaker Gail Fitzpatrick, Clinical Nurse Specialist in stoma and bowel care at Birmingham Children's Hospital. Gail gave a very interesting presentation about Anorectal Malformation (ARM).

She discussed the different types of ARM, which occur in male and female infants and how the malformation affects bowel functioning. She also provided some very helpful tips to manage constipation in young children.

Gail's talk was followed by Aled Griffiths who spoke about the practicalities of bowel care, including advice on how to manage complex continence challenges. His willingness to talk about his condition and to reach out to others is inspiring.

Aled's determination to make a difference is one of the reasons the Adult TOF Working Group invited him and his partner Kodi to work with us to write a document around medical trauma. Together we have looked at the definitions of medical trauma and how this can have an effect on our physical and emotional wellbeing. We have included information about the things that can trigger a trauma response. For example, having blood taken, physical examinations, feeling a loss of control, things done without our consent and of not being listened to or valued.

To help those who have experienced medical trauma we provide suggestions to help prior to and during appointments and procedures. For example, having a trauma card which you can hand to your health care professional so they understand your anxieties. Taking an advocate with you to appointments, having music or puzzles to distract you.

The VACTERL Association event was an opportunity for Alan and Aled to present some of the key points in the medical trauma document.* They did this through a PowerPoint presentation and discussion with the audience. This was a thought-provoking talk with parents chatting to us afterwards about their personal experiences and that of their child when faced with medical treatments, examinations and hospitalisation.

It is clear that the different organisations that support those born with rare and complex anomalies share many other topics besides medical trauma. These include accessing medical records, support with disabilities, accessing the most appropriate medical devices and prosthetics; enabling everyone to live their best life. Alan and I, on behalf of the Adult TOF Working Group, look forward to further collaboration with the VACTERL Association Support Group.

*This is in draft form and should be available on TOFS website later in the year.

Ed's note:

Thanks to Kate and Alan for their important work at this event. It is really valued – as evidenced by a recent note received by Kate: "Hi there, thank you so much. I just found it so insightful to see you and the work that you complete. When our son was born, almost 20 years ago, I was told that his condition could be life-limiting. Having you and Alan join the group is sure testament that it is not."

Members meeting up

Members of TOFS stretch across the UK and internationally, so it has been great to see some members creating their own local communities and support networks. In May and June, members have been meeting up across the country to connect, share experiences and support each other.

TLC Naomi Webborn organised a coffee morning for members in South Wales at Ronald McDonald House in Cardiff. Eight families attended including parents, siblings and other children born with OA/TOF and shared stories over a cuppa and cake.

TOFS Celebrity Ambassador, Charlotte Fisher, Ana Johnson and TLC Laura Bell, met with three other families from London at Clapham Common for a picnic in the park. Despite dodging the rain, the families popped a few bubbles and have created a great community for the area.

TLC To'neill Bala also organised a coffee morning for members in Manchester/Stockport. Three families attended and had fun getting to know each other in the sunshine.

Turn to page 24 to see the upcoming meet ups organised by our other TLCs across the country. If you want to host a meetup in your area, do let the office know so we can put you in touch with your local TLC and help you advertise your event to members.

TLC To'neill and members meet up in Stockport

Charlotte, Ana, TLC Laura & members meet up at Clapham Common, London

TLC Naomi and members meet up at Ronald McDonald House Cardiff

Raising the profile of OA/TOF with sonographers and neo-natal staff

Our volunteers have been busy representing us at various medical conferences over recent months. In addition to the BTS event (page 22) and ESPGHAN we also attended the annual conference of the Northern Ireland branch of the Neonatal Nurses Association at the Dunsilly Hotel in April. This was made possible by the support of Claire Burnside, our local contact volunteer (TLC) in Northern Ireland. Details of your Northern Ireland TLC can be found on the members only section of the TOFS website.

We were also represented for the first time by a medical liaison sub-committee volunteer at the Expert Imaging in Obstetrics and Gynaecology conference in London in March.

We are very grateful to these volunteers for their time and support in representing TOFS at these important events.

TLC for Northern Ireland, Claire Burnside

Cuppa and chat (virtually)

with OA/TOF adults – a safe space to listen and share

Are you an adult born with OA/TOF? Are you interested in joining an online get-together to meet other people like you? Then these virtual meet-ups may be just what you are looking for!

They aim to:

- connect adults born with OA/TOF in the UK and across the world.
- provide an informal, relaxing space where the adult OA/TOF community can come together to chat.
- support members to share their personal stories and to ask questions.

The meet-ups are led by four volunteers who are also adults born with OA/TOF. It's a relaxed, safe space to share stories and experiences with others who understand. So come along and grab a cuppa!

Meet the volunteers

- Alison, born 1967, OA/TOF (long gap). Had a colonic interposition repair at 2 and a half years old at Manchester Children's Hospital (Pendlebury).
- Kate, born 1957, OA/TOF (short gap) and associated anomalies
- Michael, born 1952, OA/TOF (short gap) with various interventions.
- Alan, OA/TOF with surgery at John Radcliffe Hospital, Oxfordshire in 1969 and VACTERL anomalies.

This valuable resource has grown from an idea Alison had in 2022. Recently, Alison, Kate, Michael and Alan felt they wanted to plan for the future. To move forward, they needed to reflect on what had already been achieved. They met with TOFS CEO Diane Stephens to discuss how they could take this forward. There were lots of suggestions to work through, including working with other TOF organisations and gathering their views.

Below, we hear from our four volunteers about how these online meetings work, including what members can expect and what has come up during some of these chats.

At the start of each meeting we introduce ourselves, share ground rules and reassure members that what is discussed remains confidential. If necessary, issues raised during these chats can be discussed with CEO Diane Stephens, but only with members' consent. There is no fixed agenda, no session is the same. Topics are based on what the members want to talk about. We share personal and confidential information about what is important to us.

It is important to state we are not medical experts - we are here to listen, to support and to share our own OA/TOF experiences as required. We understand that over the decades, you will have had different experiences of healthcare. Some will have had excellent transition to adult services, others not so good.

In an OA/TOF-orientated environment we all have days when our health is distressing or is challenging. If someone coughs loudly, is wheezy or has to take a little longer to speak, everyone understands - we are all connected. We respect that everyone's experience is unique to them.

Some members have symptoms which may be related to their TOF - in this chat they realise they are not alone. They have lived with these challenges, these difficulties are the norm for them and they know no different. When they describe symptoms and others in the chat recognise the symptoms and can advise them, they feel understood, believed and validated.


Alison


Alan

There are others who recognise the impact of childhood medical trauma and can provide advice on how to approach a GP for support. They can advise how to seek help to cope when facing further treatments, investigations and hospitalisation.

Hearing others describe the plans they put in place before eating out, before going to bed and travelling away from home is very interesting and reassuring. Sharing advice on how to manage "stickies", a troublesome cough, reflux and other aspects of our daily routine validates all of our experiences and helps us find solutions when sometimes we thought we had exhausted them all.

For various reasons, some adults are unable to attend organised events in person. Online meetings provide the opportunity to connect with others and make new friends. This can have a positive knock-on effect when it comes to face-to-face events, as people are already familiar with each other - so it is not as daunting as walking into a room full of strangers!

We also provide information. For example, we can signpost to other organisations that may be able to help, using the chat or articles on the TOFS website. Some members have not accessed the TOFS website where a lot of information can be found. To help everyone navigate the website we drew up a list of the articles, which members may find beneficial. We are able to put the link into the chat and signpost them to the different relevant website articles.

With consent from members, we recently wrote two articles for CHEW Spring 2024 edition – "TOFs Top Tips" and "A Journey to Recover Medical Records". Already we have had feedback from a member who was told by the hospital where she had her TOF surgery that her notes had been destroyed. She has persevered, asked her GP for help and now has the records in her possession.

In these chats, different perspectives are valued, individual narratives are cherished. By listening and sharing our experiences, we hope to prevent or reduce some of the health issues, which have occurred in the older TOF community. Knowledge is empowering and our meetings can help Adult TOFS advocate for themselves and help others on a similar pathway.

Interested? You can find out about upcoming virtual meetings (they happen about once a month) on the TOFS website at *https://tofs.org.uk/events/*


Kate


Michael

Reconnecting with my TOF beginnings

by Olivia Stead

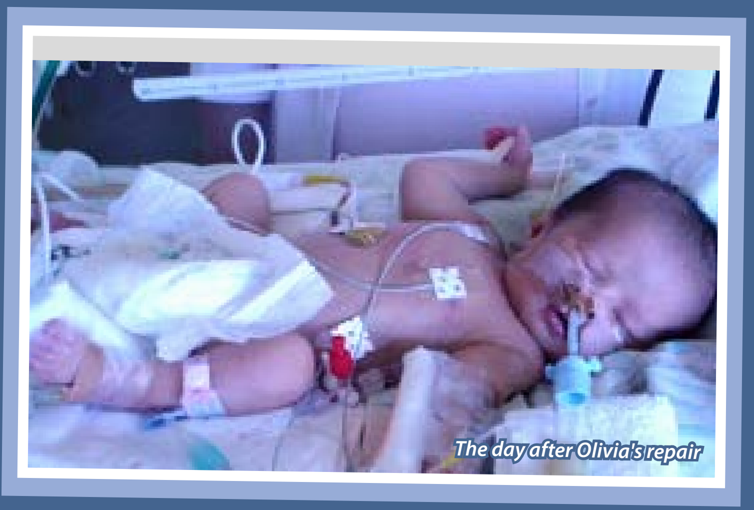
I can't remember a time in my childhood where my swallowing didn't bother me. Aspiration (inhaling liquids into my lungs) was just there in the background. But as far as I understood, my aspiration was not abnormal. And as far as I knew, all my birth defects were fixed at birth.

I was born in 2005 with tracheoesophageal fistula, oesophageal atresia (type B) and a type 2 laryngeal cleft. After my OA/TOF repair at six hours old, I had complications including an anastomotic leak and a collapsed lung. I don't remember much of that time except from looking at old photos, reading my medical records and speaking to my parents. I was also gastrostomy fed until I was 3-years-old.

As I got older, I noticed that I was increasingly choking when drinking liquids. At 15-years-old, I mentioned it to a doctor and was told that I was simply not paying enough attention when drinking water. I did not know what was wrong, but inside I knew that it was something more than that. Eventually, the aspirations were happening every day. I saw another doctor and a speech pathologist, who determined that it was unsafe for me to have any oral fluids, even heavily thickened. I was diagnosed with a recurrent laryngeal cleft by my ENT. A laryngeal cleft is an abnormal connection between the airway and food pipe where they are meant to separate in the throat. I had this repaired as a baby, however it had grown back. I underwent a few procedures to temporarily close the cleft. During this time, my team and I decided I would receive all my fluids through a nasogastric tube. This made my daily life much simpler, as I didn't need to worry about aspirating or keeping hydrated. In April of 2022, after my 18th birthday, I underwent a stitched repair to permanently close my cleft.

After my final cleft repair, I still had some aspirations. I convinced myself that these were "the normal amount," however I was still aspirating regularly. Aspiration from my cleft felt high up in my throat which would feel wet before I started coughing. This new type of aspiration was different, it felt deeper in my chest. A barium swallow suggested there could be a TOF at collar bone height, however no one was truly sure. After a bronchoscopy to investigate, they were able to identify a TOF, which was larger than my surgeons had expected. Unfortunately, too large to be fixed by methods such as ablation (surgical removal of body tissue) as my surgeons had previously planned.

According to them, this TOF has been there from birth and is separate from my original repair site and my laryngeal cleft repair.


The day after Olivia's repair

I have an open repair scheduled for August in Adelaide, South Australia (close to where I live) so by the time you read this it should have taken place. The repair will be done through my neck, removing half of my thyroid to access the TOF. It felt like the most unexpected news, but at the same time, it made an overwhelming amount of sense with the symptoms I had been experiencing.

If I could give any advice, I would say to trust your instincts. Finding your voice to advocate for yourself or your child can be very challenging, especially if you do not feel listened too. But it is so important and can be empowering too.

Like many TOFs, I have related ongoing conditions. I have gastro-oesophageal reflux disease (GORD), gastroparesis, tracheomalacia and restrictive lung disease. Gastroparesis means that my stomach is partially paralysed and holds onto food much longer than normal.

I now have a PEGJ feeding tube which allows me to bypass my (problematic) stomach to receive fluids and feeds. I currently have a PICC line device, which I hope can be removed after my TOF repair in August. I also have Postural Orthostatic Tachycardia Syndrome (POTS) which is a lifelong condition where my body cannot adequately control my blood pressure and heart rate when standing up.

I am currently studying nursing at university with the goal of becoming a nurse practitioner. I understand what a profound impact healthcare staff can have on patients' experiences and wellbeing. I hope to use these experiences to make a positive impact in this area.

I feel that my health conditions give me a greater perspective on life. I am reminded to value things that may seem small and not to stress over inconsequential things. I am still growing as a person and learning to accept the journey that I am on. However, I am grateful for the life I have right now, even if it challenges me.

My parents and younger brother have given me infinite support, my friends have been incredible and my medical team has been and continues to be remarkable. My thoracic surgeon is the reason I am alive today, and an incredible practitioner. My ENT, PEG nurse, paediatric respiratory specialist and adult gastroenterologist are full of compassion, empathy and expertise.

“Would you allow a pilot to fly a jet plane without training on a simulator?”

by **Mr Suren Arul**,
Consultant Paediatric Surgeon, Birmingham Children’s Hospital

Cover Story


Fig. 1 Marnie age 12 years

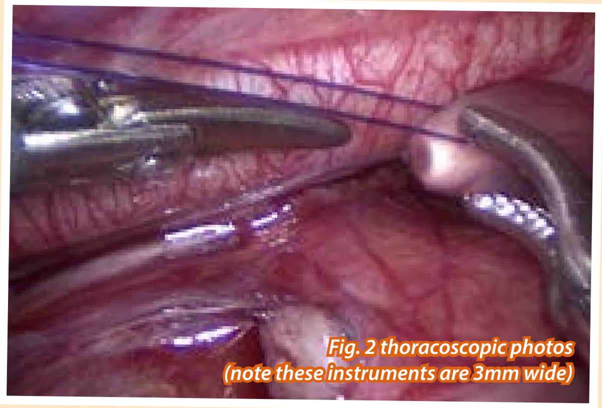


Fig. 2 thoracoscopic photos (note these instruments are 3mm wide)


Fig 3a. Reuben (age 3) in Mr Arul’s clinic; he had thoracoscopic surgery

Historically, most children with oesophageal atresia (OA) and a trachea-oesophageal fistula (TOF) have had a right-sided thoracotomy as described on the TOF website *https://tofs.org.uk/what-is-oa-tof/surgery-for-oa-tof/*. In this operation, the lower oesophageal component is separated from the trachea and then sewn to the upper oesophagus with tiny sutures. This may sound straightforward, but it remains one of the most technically challenging operations in paediatric surgery.

I was trained to do my first oesophageal atresia surgery in Bristol in 1998 under Mr Richard Spicer (see *Chew* Spring 2022). In those days, surgery was an apprenticeship in which you would be taken through the stages of an operation by an experienced surgeon.

Marni (figure 1) was one of my patients with OA/TOF treated at Birmingham Children’s Hospital, one Christmas many years ago with the traditional open thoracotomy. I saw her recently in the clinic, and she is a healthy teenager now who eats and drinks normally.

The first attempt to do OA/TOF surgery with keyhole instruments (thoracoscopy) was described in 1999 and slowly gained acceptance around the world. The equipment has evolved, and surgeons have gained the necessary skills. We now have 3mm diameter instruments that we can use inside the chest of a newborn baby to repair the oesophagus. Excellent cameras and high-definition screens help both the surgeon and trainees with great visualisation (see figure 2). The chest scars are smaller, and if everything goes to plan, feeding by mouth starts earlier and discharge from hospital is sooner.

Reuben (figure 3), is one of my patients who had his OA/TOF repaired by thoracoscopic surgery. He is now 3-years-old and has no problems with feeding or swallowing. As you can see from the photo in figure 3b (which he proudly showed me), he has a virtually scarless chest.

So why, you may ask, doesn’t every surgeon use thoracoscopy? Well, both procedures have pros and cons. An important factor is how the baby tolerates the anaesthetic. A consultant anaesthetist with their team will keep the baby asleep well-oxygenated, and safely monitored throughout the operation. This task is made significantly more difficult if the baby is very premature, small in size, or has other congenital abnormalities or pre-existing problems with the lungs. If the baby is too small or too fragile, then it simply is not safe to attempt keyhole surgery.

That is what happened to little Lilah-Rose (Figure 4). We started the operation by keyhole surgery, but because there were difficulties with ventilation, we converted to an open thoracotomy. Lilah-Rose is now 2 and has no trouble feeding or swallowing.

Not all UK centres offer the thoracoscopic approach because differences in training, surgeon experience and equipment availability need to be considered. However, keyhole surgery is here to stay. After all, if you can have the same results with less pain, quicker discharge from the hospital and virtually no scars, isn’t that the purpose of modern medicine? However, as we have shown, it is not appropriate for every patient, so future paediatric surgeons will have to be experts in both open and keyhole surgery for oesophageal atresia.

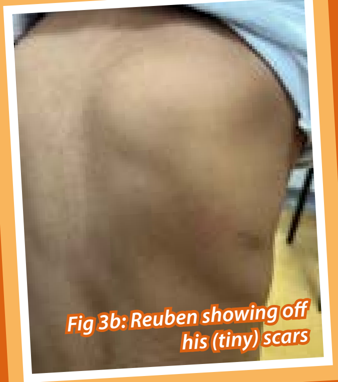


Fig 3b: Reuben showing off his (tiny) scars


Fig 4. Lilah-Rose age 2 had her thoracoscopic surgery converted to open thoracotomy because of problems with ventilation


OA TOF
SIMULATION SURGERY
Master Class
Open and Thoracoscopic Models
Expert Trainers
Birmingham Children’s Hospital
12th April, 2024. £200

Fig 5. The first OA TOF simulation course that combined training for both open and thoracoscopic surgery


Fig 6. The Symulus model of oesophageal atresia for thoracoscopic repair


Fig 7. Mr Lander teaching


Fig. 8. Omer practising the open approach

So, how should we teach our young surgeons this technically challenging operation? If we look at how the RAF train fast jet pilots, they start with basic skills and knowledge and then use a simulator before learning to fly small planes that are easier to manoeuvre. Once pilots pass early stages, they can train on the fast jet simulator. Only after they have proven their competence on the simulator are they allowed to fly a fast jet and then under the watchful eye of an instructor.

On 12 April 2024, we ran the first *Oesophageal Atresia Course* in Birmingham (figure 5), aiming to recreate the equivalent of the flying simulator of a fast jet for oesophageal atresia for both the open and thoracoscopic approaches.

Since 2008, the British Association of Paediatric Surgeons (BAPS) has run a series of international courses that teach a variety of open newborn operations, including oesophageal atresia repair. The BAPS course uses pig and chick tissue to create a model of an OA/TOF. The model is placed inside a box to recreate the experience of operating inside a baby’s chest. Importantly the model has the same “feel” as human tissue when the surgeons are cutting and suturing.

Many surgeons have attempted to simulate the thoracoscopic operation of oesophageal atresia. While putting a plastic tube in a box and then getting trainees to suture the tubes together is relatively simple, creating a realistic model of the trachea and oesophagus is much more challenging. A team from the University of Otago, in Christchurch, New Zealand, worked with an engineering company (Symulus) and used an MRI scan of a baby to make a replica of the chest, trachea and oesophagus of a baby with an OA/TOF (figure 6). Currently, these models are expensive as they are imported from New Zealand, so we are very grateful to Mr Andy Robb and the West Midlands Deanery for providing a grant to purchase the first models. Our 3mm keyhole instruments were provided by Charles Goudie from Karl Storz.

Previous courses have only taught one technique or the other. However, we believe that surgeons must be competent in both techniques, so we devised our course to teach both approaches on the same day. We advertised our course through the British Association of Paediatric Surgeons website, and all 16 places were filled within an hour of opening registration!

Trainee surgeons needed to be confident in basic keyhole techniques. They then studied pre-course material before attending. All 16 candidates did an open repair (figure 7 & 8) and a thoracoscopic repair (figure 9). Both repairs covered all the essential stages of a successful operation - the steps are dividing the fistula, separating the trachea and oesophagus and then suturing the upper and lower parts of the oesophagus together within the tight space of a baby’s chest. Each practical session lasted two and a half hours, making the course one long but enjoyable day for all.

Simulated operations were assessed to see if trainees reached the standard required for an actual operation on a baby. This was our first dual course, and here are some comments from the course feedback:

“Absolutely awesome, superb models and great hands-on individual teaching.”

“Excellent session, clear teaching, felt like you were really being mentored.”

“The models were excellent. It was a great chance to perform a stress-free OA/TOF repair and practice a wide range of skills that I didn’t have a chance to use in real life yet!”

“Really well-done guys, thank you. I’ve told everyone about it, I’ve never used such great surgical models.”

We believe that this way of teaching has an essential role in surgical training.

I would like to thank Anthony Lander, Hetal Patel and Elmarie Van der Merwe for making the animal tissue models and teaching the open operations and Ingo Jester, Mike Singh and Giampiero Soccorso and Max Pachl, who helped develop the keyhole approach in our department and for teaching on the thoracoscopic part of the course.


Fig. 9 Ben practising on the thoracoscopic model


Fig 10. Suren Arul with Joshua and Olivia and their mothers (Rachel and Kirsten). These were two babies with long gap oesophageal atresia we successfully treated with thoracoscopic surgery in 2019

Father runs ultramarathon for TOFS in honour of son's resilience, raising £8,240

It's tough running a marathon. Those who manage it merit admiration and should rightly enjoy a well-deserved feeling of pride. So how about signing up for two and a half marathons – to be completed all at once?

If the idea of attempting to run 100 gruelling kilometres in one go causes you to lie down in a darkened room with a comforting cup of tea and a packet of biscuits, then the Race to the King is not for you.

Fortunately for TOFS, Ross Jeavons thought otherwise. And though he may have questioned his own sanity in doing so, he stepped up to the challenge and took on the iconic royal trail. In reliving his experience, Ross tells us about a not so relaxing summer holiday, his new found aversion to flapjacks and the real reason he decided to run an ultramarathon.

Nearly 15 hours and 100k later - the wonderful Jeavons family

Having run the London Marathon for TOFS in 2022, I always felt that to take on another challenge event for the charity would require something a little different to entice the same friends, family and contacts to donate again.

Then I stumbled across Race to the King, a 100km ultramarathon through the South Downs and Sussex coast. Whilst I've always enjoyed running and had taken on marathons on four previous occasions, the prospect of running two and a half of them in a single day terrified me. One or two friends advised against jumping straight up to the 100km distance, but it was also that doubt (verging on fear) that attracted me to the race. Ultimately, I wanted to prove something to myself, but more so to my two boys, Callum and Corey.

Corey, born in 2022 with long gap OA and who required gastric pull up surgery, has already had to show levels of fight, determination and resilience that most children will never have to draw upon. In my mind, if I am to continuously encourage him to break down his own barriers, I have to take on some of my own.

Given our last fundraising push for TOFS was only two years previously, we made a concerted effort to share as much of Corey's story as possible to evidence why people's support was still so important. Between my wife, Katie and I, we tried to cover a variety of topics on our social media channels, linking them to updates on my training runs. We were open about everything from tube feeding to the challenges of brushing the teeth of a child who has oral aversion, as well as details of how TOFS support children like Corey. Both of us dipped into our work contacts and extended families, asking people to share our blogs and updates far and wide. You'd be amazed where donations come in from.

The training itself was a sizeable time commitment. Some of my Sunday long runs would take upwards of five hours, whilst a slightly ill-timed holiday saw me running continuous laps of an all-inclusive resort in Turkey, a month before the race!

And so I found myself on the start line at 7am on a typical English summer's day - hood up as I sheltered from gale force winds and torrential rain. The terrain was gruelling; from rocky hills to overgrown paths and muddy trails but there was a fantastic spirit amongst the runners. I found it more of a mental challenge than physical, having to keep positive for hours on end and trying not to contemplate the miles that lay ahead. That said, the nausea took me somewhat by surprise as I attempted to take on the recommended level of 900 grams of carbohydrates during the run. I never want to see an energy gel or a flapjack again in my life, thank you.

Just before 10pm, with the last etches of daylight on the horizon, I finally crossed the finish line. Fourteen hours and 51 minutes after the starter's gun went it was finally over and despite it being well past their bed times, Callum and Corey joined me for the final 50 metres! I was in truth too tired to be elated, but in the coming days was so proud of our collective effort. Katie and the boys had sacrificed so much over the previous months to allow me to train and the three of them met me numerous times on the race route to cheer me on and supply drinks and snacks. As the parent of any TOF child knows, it's a team effort that gets you through.

I would recommend the experience to anyone. Race to the King offers a 50km version, as well as the option to run 100km over two days and camp overnight. People perceive ultra running as an event for the elite but in truth you see a huge variety of people there on the day. Whether you want to walk, run, or a bit of both, with some preparation and determination I firmly believe it's a challenge that anyone could take on.

Ross Jeavons Team effort with top supporters, Callum and Corey

Ross' top tips for running an ultramarathon to fundraise for TOFS

- It is easy to be lost in the world of information you read online but I'd recommend finding a good coach who will create a bespoke training plan for you to stick to. It's super helpful to have someone tailor a plan to your own needs and time constraints.
- Pick a race that has good reviews and is well organised. Race to the King was so well stocked with numerous food and aid stations, I had little to worry about.
- When taking on anything over a half marathon, do some research on what to eat before and during the race. It makes a real difference and it's important to practice in advance.
- I'm very much a solo runner, but when taking on a challenge that lasted a whole day (and was quite rural), I certainly could have done with some company. Take it on with a friend if you can.
- If it's your first long distance race don't have a time goal. Just aim to finish and enjoy it.
- Put a fundraising plan together and stick to it. People engage with emotive stories and sometimes it takes a good few posts, e-mails or general nudges to get those donations over the line.
- Never forget the "why". When training is hard, when the rain is pouring down always have in your mind why you're doing it in the first place.

Much-needed hugs for ultra-marathon runner, Ross

In Memoriam - Judith Mary Bland

19 Feb 1937 – 10 June 2023

There are some people who, when faced with a challenge, pave the way for the rest of us. Judith Bland was one such pioneer. At a time when a successful outcome for babies born with OA/TOF was still uncertain, Judith raised her son, David, to understand the problems he was born with and, in doing so, to overcome them and live life to the full. But she was just as encouraging to and supportive of so many other TOF families as they struggled to come to terms with lives turned upside down.

For many years, Judith dedicated much of her free time to TOFS, not least as a proofreader for *Chew* but also as a telephone-support volunteer, a vital role in those pre-social media days, when the only way to connect with others in the same situation was by letter or via a landline. She was always there to help where she could and was a reassuring and welcoming presence at the early conferences and informal get-togethers.

When Judith's granddaughter, Genevieve, was also born with OA/TOF, a rare instance of history repeating itself, in this reputedly non-hereditary condition, she was a rock for her son, David and his wife, Kaye.

Judith will be remembered by her family and friends as a loving mother, wife and grandmother. Someone who was infinitely kind, who had a sense of fair play, who was loyal to her friends and who could be relied upon to fight any justified cause.

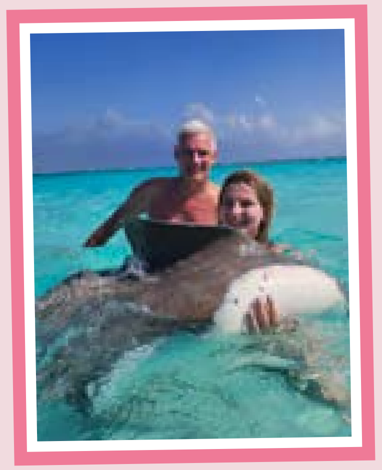
Here at TOFS we are proud to celebrate her life and, in doing so, remember her for the passionate support she gave to our charity right to the end. For not only did Judith bequeath a generous gift to TOFS in her will (of £3,822), but it was quintessentially thoughtful of her to ask that anyone who wished to make a donation at her funeral in lieu of flowers, might do so in aid of TOFS.

This is David Bland's story and tribute to his mother, Judith.

I was born in 1966 when OA/TOF was hardly known about and not many babies had been successfully operated on. The stress for Mum and Dad at that time must have been immense. I know how bad it was for me with Gen (my daughter who was also born with OA/TOF) and we had all the information and support possible.

Mum had to deal with all the choking, passing out and stress, as well as the decisions over whether to have more operations to stretch or not, all on her own. How she managed is beyond me.

I'm not exactly sure when she discovered TOFS as an organisation, but I know it was too late for her. But in her typical giving-sharing style she was determined to do what she could to help others in the situation she had been in.



I know that as she became more involved she realised how 'lucky' she and I had been in that my version of TOF was not too bad. There are so many more complicated outcomes.

That said, she must get the most credit for never treating me or raising me to "be any different". This is key to everything - the result being that, as soon as I was of an age where I understood to always have a drink to "wash things down", I was able to just get on with things. Mum had always gone to great lengths to educate me about what OA/TOF was and to take on board all of the medical information so I understood, could deal with it and work things out.

Fast forward to 2004 and my daughter Genevieve was born. When the doctors were trying to clear the fluid out of her lungs, unsuccessfully, I knew straight away what the problem was. Why? Because my mum had brought me up to understand my condition.

Sure enough, Gen was born with exactly the same condition as me and my poor mum had to go through the emotional wringer all over again. It must have brought back some heavy memories of hard times but she never once reflected on that. She was there to help and support me, supplying answers to all my questions about what I had been like.

Most of all, the way she had brought me up to believe that I was not a victim or sick or different, meant I had the ability to do the same for Genevieve.

The proof? Gen is now 20-years-old and a top athlete, playing water polo (literally the toughest of sports) at the highest level, (NCAA Div.1) at university in New York!

Cyclists raise £15,000 for TOFS

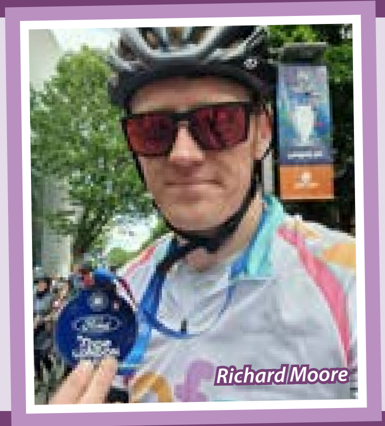
A team of cyclists hit the road as part of a mass participation event and raised more than £15,000 for TOFS. RideLondon-Essex challenges riders to cycle either 100 miles or 60 miles on routes that wind through the Essex countryside as well as navigating the urban landmarks of central London.

Please join us in congratulating Andrew Wasley, Bhaskar O'Shea, Ioannis Koletakis, John Jarrett, Mark Russell, Richard Moore, Ricky Roberts and Ross O'Driscoll who took part in the ride on Sunday 26 May.

Together they cycled a combined distance of over 680 miles and raised an amazing £15,441 for TOFS! Well done guys! Read what some of them have to say about it below.

Think you could take on RideLondon in 2025? Head over to the challenge page on our website to sign up:

tofs.org.uk/support-tofs/join-a-fundraising-event/


Richard Moore

Name: Richard Moore

Inspiration: Our wonderful daughter, Lily, who was born with OA/TOF and, now 11, is absolutely thriving. No small part of her success was down to the TOFS community and support.

Event: People born with OA/TOF have so much to deal with, so I wanted something "hard" too, and this felt just right. On the event day, it was great to meet with some of the team and riders. And along the 100-mile route I chatted with one about their experiences too. It reminded me that we're stronger together and that gave me a real boost when the headwinds kicked in and we were in the final miles. With a combination of the motivation of the event and the memories of what my wife Jess and I went through, it pushed me to get a 5 hours 58 minutes and 5 seconds finishing time (not including stops for snacks!). Thanks to all involved and well done TOFS – we smashed our fundraising target!

Amount raised: £2,198.82 (220% of my personal target)


John Jarrett - Sportograf


Ross O_Driscoll


Mark Russell - Sportograf

Name: Mark Russell

Inspiration: Caleb, my 2-year-old son who has OA/TOF

Event: 2024 Ride London 100

Being selected by TOFS to represent it at this year's Ride London 100 came as a very pleasant surprise. It was also the kick I needed to get back on the saddle as, before my boys were born, I spent most of my free time on a bike.

This would be the second event I had raised money from in the previous 12 months and the first was very successful. I set an ambitious target in my head for fundraising and within a few weeks I was already well over it. People's generosity was incredible.

I was fortunate enough to stay at my brother-in-law's the night before the event as I live up in County Durham. Hearing the rain lashing against the window the night before the event didn't fill me with joy! The previous evening we enjoyed a meal out whilst talking all things OA/TOF and cycling.

After a decent sleep, I made my way to the start and before I knew it, I was heading through Limehouse Tunnel. The weather was cool and overcast but dry. There was a fantastic atmosphere with an incredible amount of support, especially in the smaller Essex villages. Being cheered on really helps to keep you motivated. I had a quick stop at the TOFS cheering point in both directions. It was something I looked forward to as I was pedalling along.

Due to the distance from home, I didn't have anyone to cheer me along, but I had tied a photo keyring of Caleb to my frame bag. When my legs started to feel tired I simply looked down, remembered what that tiny lad went through and powered on. These little TOFs are so strong and resilient.

I bumped into someone I knew at about the halfway point and we both got a proper soaking due to an impressive downpour. But it wasn't long before the sun came out and I dried off.

I managed to tag onto two brilliant cyclists for the last ten miles or so and between us we took turns pushing for the finish. The atmosphere going over Tower Bridge was electric! I'll freely admit to having a few tears after crossing, knowing that I'd done my bit for TOFS and Caleb.

The whole event will live with me for many years to come.

Amount raised: £3,611


Ricky Roberts - Sportograf

Name: Ricky Roberts

Inspiration: My son Chester, who was born with OA/TOF in December 2020, but is a larger-than-life personality and loves bikes more than anything in the world.

Event: RideLondon-Essex 100!

I loved every minute of RideLondon-Essex 100, from leaving the hotel at 5am in the worst rain imaginable, to crossing Tower Bridge in glorious sunshine. On the ride, I had some mechanicals and a puncture, but managed the 100 miles in 5 hours 13 minutes. My family supported me amazingly over the weekend and I couldn't wait to see them after the finish.

I chatted with some great people on the route, all of whom were hearing of OA and TOF for the first time. There was a real sense of camaraderie amongst the riders.

The whole TOFS team were amazing, and we all supported one another over the WhatsApp group before the ride and congratulated one another afterwards. I still see some of their activities on Strava (a social network and fitness tracking app).

Thank you TOFS for allowing me to be part of this amazing event and raise some money for a charity, which is so close to our hearts.

Amount raised: £911.00


Andrew Wasley


Bhaskar O_Shea


Ioannis Koletakis

New chair for TOFS Council of Management

The days are long gone when, to fulfil your duty of sitting on the board of trustees of a charity, all you had to do was swan up to a nice hotel once or twice a year, enjoy a few sandwiches and put your hand up to vote - usually for someone else to do all the work.

These days, trustees are rightfully subject to scrutiny by the Charity Commission.

TOFS' board of trustees, called the Council of Management (CoM), is responsible for the governance of TOFS. The CoM is made up of ten trustees, who are also directors of the charity. They have overall responsibility for ensuring that we deliver our charitable mission (ie we do what we say we are going to do) and that we spend our money wisely. This is important because they are accountable and legally responsible for our work and that we comply with current legislation.

The trustees, who receive no payment for their time and effort, are from diverse backgrounds in the public and private sector and bring a wealth of experience to running our charity. They all have a personal connection with the condition, either as parents, grandparents, or adults born with OA/TOF.

CoM typically meets four times a year and delegates to several sub-committees and working groups. But being a trustee is about much more than just attending board meetings. Trustees add value in many different ways, helping to bring different perspectives as well as their professional expertise and experience of the OA/TOF condition.

And we are delighted to say that is exactly what Drew Bailey, who has recently been appointed the new Chair of TOFS' Board of Trustees, is able to bring to the honorary post.

Drew's first child was born in 2004 with OA/TOF, following a difficult pregnancy during which his mum was diagnosed with Hodgkin lymphoma at 12 weeks. Drew's son has had multiple surgeries, most recently to address scoliosis through fusing 18 vertebrae with rods and screws, with procedures carried out at Queen's Medical Centre in Nottingham and Great Ormond Street in London. He is currently studying English Literature at Nottingham Trent University, although keeping his distance from the hospital!


Drew

Drew is a Chartered Accountant and a Chartered Tax Advisor, having had a 25-year career in the Big 4 accountancy firms, the last 10 years as a partner. He retired as a partner in 2021 and now runs his own international tax practice.

Drew originally became a TOFS trustee in 2006 for a brief period before taking a break to focus on his family. He joined the finance sub-committee in 2013 and became a trustee again in April 2023.

Besides his membership of the finance sub-committee, he has provided ad hoc support and guidance to TOFS over this period, to varying degrees depending on our needs and his availability. His principal objective as Chair is to facilitate the smooth running, success and succession of the organisation.

As well as TOFS and Tax, Drew is a keen rower, as well as being a bit of a petrolhead. He lives with his wife and two other children near Lichfield, Staffordshire.

Fundraising Heroes!

Name: Norwood Park Golf Centre, Southwell, Notts

Inspiration: Frederick Foster OA/TOF (Freddie now 7-years-old)

Event: Throughout the last golfing year, the captains Paddy Whur & Jane Parks held lots of fundraising events, including raffles, quizzes, golf competitions and charity climbs including Kilimanjaro.

Just over £28k was raised, this was donated to different charities; £17k for Beaumond House Hospice Care, Newark; £10k for Lincs & Notts Air Ambulance; £1k to TOFS and some going to the Norwood Junior Development Fund.

Amount raised: £1,000

Fundraising Heroes!

Name: David Loughran

Inspiration: My youngest son Odhrán who was born with OA/TOF in March 2023

Event: I decided to take on a challenge of running 5 kilometres a day for 25 consecutive days, from Monday 26 February (the start of TOFS awareness week in the UK) until Thursday 21 March, Odhrán's first birthday. We celebrated Odhrán and his achievements to date with a final run/walk in our home town of Armagh in Northern Ireland, surrounded by our family and friends.

Gorgeous in red
- Begw Morys born with OA/TOF.
£100 was donated by Begw's grandfather
John Williams who recently passed away

Until Odhrán was born it wasn't a condition I had ever heard of. I figured there's likely a lot of my family and friends who were in exactly the same situation, so if I could raise awareness and some money for the TOFS Charity and educate people in the process, it would be all the more worthwhile.

The TOFS Charity have provided us with so much support and advice over the past 16 months. We couldn't have got to where we are today without the invaluable help and support of both the charity and the fantastic fellow parents we have encountered along the way.

Amount raised: £13,120

Ed's note:

Wow!. What a wonderful achievement, and to raise such an enormous amount is just inspiring.

Thank you so much.

David and his inspiration
- Odhrán

The Loughran family on
Odhrán's first birthday

Name: Chris Baker

Inspiration: My little boy, James, who was born with OA/TOF in April 2023

Event: The day was amazing and surreal. If I didn't have the photographs to prove that it happened, then it would feel as if it was a dream. Running through central London, past such iconic landmarks and with so much support along the way. Nothing can quite prepare you for the emotion of witnessing so many people taking on such a huge challenge, many of them for such personal reasons.

I was cheered on to the finish line by my amazing wife, Jade, and our two children, Penny (aged 5) and James (aged 1), who stationed themselves at mile 19, alongside our friends, who kindly put us up for the weekend.

An absolute bucket list experience that I'll remember for the rest of my life.

Fundraising Heroes!

Name: Chelsea Topley

Inspiration: My niece Aria

Event: Southampton Half Marathon

In April I took part in the Southampton Half Marathon to raise money for TOFS, after my niece Aria was born in March 2023 with the condition. This charity has been amazing from the day my sister gave birth; it has helped her learn to cope with Aria's condition. I really wanted to give back to the charity and I am so proud to say I raised £1,727.50 in total. This was for our warrior Aria, still battling every day, and for all the TOFS families out there.

Amount raised: £1,727.50

Fundraising Heroes!

Name: Gavin Mountford

Inspiration: My son Freddie, born with OA/TOF

Event: London Marathon

Running the London Marathon in support of TOFS has been one of the biggest achievements of my life.

Don't get me wrong, the training was tough, really tough. But that sense of achievement after each training run, backed up by seeing donations rolling in, gave me such a high throughout the process.

The day itself was a mixture of anticipation, nervousness, adrenalin, pain, joy, relief and accomplishment all rolled into one. But I wouldn't have changed a minute of it and having my family and friends there to support me, with their TOFS hats, T-shirts and flags on show, gave me the boosts of energy I so needed.

I'm certainly no long-distance runner and have had a few serious injuries in the past. But I was craving a challenge to push my boundaries and knew I wanted to do something to support TOFS. Being able to repay in a small way the support they had given to us and our son Freddie, who was born with OA/TOF, meant so much to me.

Nothing I could have done would have compared to the strength Freddie has shown throughout his life so far, but I can't wait to share my stories of the London Marathon with him when he grows up.

Now I'm just wondering what the next challenge will be....

Amount Raised: £4,202

Fundraising Heroes!

Gavin Mountford

Name: Alice Longshaw

Inspiration: Alice was inspired by another fundraiser on Facebook who had held a raffle at her local supermarket for TOFS

Event: Bake sale

Alice wanted to raise money for the charity that supports her condition and to increase awareness amongst children and staff at her school (Alma Park Primary School, Levenshulme, Manchester). Alice often feels OA/TOF is invisible and wants people to understand the regular struggles with chewing, swallowing and reflux that she faces.

Alice and her three friends, Elektra, Lyra and Freya (all aged 9 and in year 4) organised the whole initiative; first approaching their class teacher and then the headteacher. They coordinated publicity, creating banners, a parent mail message and an animation to share on social media. They also did huge amounts of baking, from coffee cake to brownies, cupcakes, gingerbread and flapjacks. On the last day of the summer term, they held a sale in the school playground, supported by their amazing teachers, serving customers, explaining the cause and working out prices and costs.

Over the course of this experience, Alice became more confident at explaining OA/TOF and its impact (a huge step for her). When banking the takings at our local post office, she even convinced the postmaster to make a donation!

Amount raised: £275

Fundraising Heroes!

Alice, Elektra, Freya and Lyra

Name: Kelsey & Thomas Crump, along with Jo, Aimee, Ryan, Alex, Charlotte and Adam

Inspiration: Our beautiful daughter, Peyton Riley Crump who was born with OA/TOF on 16/10/23 and sadly passed away on 18/10/2023

Event: St Albans Half Marathon #icelollyrun

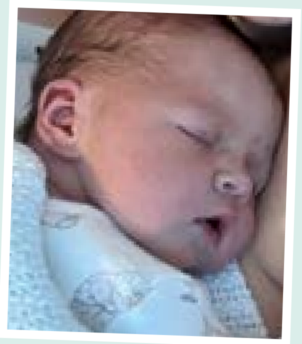
We had no prior knowledge of the condition until Peyton was diagnosed just a few hours after her birth. She was immediately transferred to the NICU at the Rosie Hospital in Cambridge, where she bravely underwent surgery at two days old. Despite the best efforts of her medical team, Peyton passed away during the operation.

In her memory, and to raise awareness of OA/TOF, we embarked on a heartfelt journey to honour Peyton's brief but impactful life. We challenged ourselves to run a half marathon. Together, we completed the race, experiencing moments of joy and tears along the way. Through this endeavour, we raised much-needed funds for a wonderful charity (TOFS).

Peyton's spirit inspired us every step of the way and she will forever remain in our hearts. Her legacy continues to drive us to make a difference, ensuring that her memory lives on and that other families receive the help and support they need.

Amount raised: £6,341.25

Fundraising Heroes!



Name: Christine Leeman

Inspiration: Granddaughter, Bailey Leeman

Event: Raffle and tombola

Fundraising Heroes!

I contacted our local supermarket, Morrisons, to ask if I could hold a tombola in store to raise funds for TOFS. Up until that point, they had never heard of the condition.

Then I contacted Tom Bright, TOFS' newest celebrity ambassador, who kindly agreed to come along once we had sorted a convenient date.

I raised £140 in cash and then decided to raffle off a fabulous prize of a Pamper Hamper that raised another £150. On top of that, the tombola itself raised £320.

I'm really happy that Tom met my gorgeous little tofling granddaughter Bailey and her mummy Beckie and I'd like to thank my friend, Linda Shilito, who came along and helped me. All in all, it was a fabulous day.

Amount Raised: £610

Meet our Teddy Toddlers!

We invited members to join us in putting the fun back into fundraising and get the whole family involved to walk, run or even skip 5K for TOFS.

A huge thank you to everyone who took part in our 2024 Teddy Toddle, which took place between 8 and 16 June. Together they have raised an incredible £4,358 to support TOFS!

We are very grateful to our Teddy Toddlers: Alicia Edge, Amy Potts, Anthony Kelly, Ashleigh Jones, Charlotte Mcginlay, Elizabeth Wise, Georgia Cowie, Jade Carrington, Julie Goddard, Lesley Chapman, Lou Vessey, Matt Gomm, Micheala Venner, Naomi Webborn, Natalie Hillman, Nicola Baldock, Rebecca Head, Susan Dutch and To'neill Bala.

Please take a bow - you all were amazing. Thanks for joining in and getting your friends and family involved too!

New TLCs for Merseyside

Hi, we are Carolyn & Alan Seeley, parents to Adult TOF, Andrew. We have both recently retired and feel that we would like to volunteer our time to raise awareness and support TOF families in Merseyside. We live within walking distance of Alder Hey Hospital (which was a blessing whilst Andrew was a child), so we can pop along and help any new parents and those parents from outside of Merseyside who may be staying there.

During my pregnancy we were unaware that there was a problem, I had all the tell-tale signs, but nobody had joined the dots. Andrew was born in the September of 1989 and operated on, at Alder Hey, at four-hours-old. He was discharged at two-weeks-old but was re-admitted when he contracted bronchiolitis at eight-weeks-old. Andrew was doing really well, and the hospital were so pleased with him that they discharged him at two-years-old. Not knowing anything about TOFS (it was the days before the internet) and the long-term related conditions, we were really pleased and thought it was all over. Then the chest problems started.

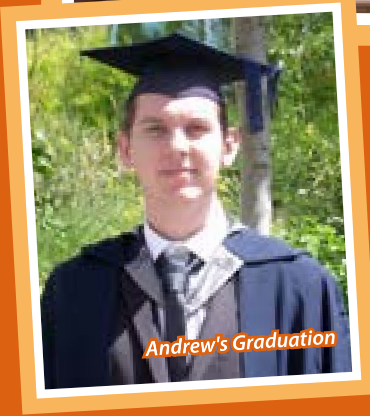
Andrew was given inhalers and steroids in ever increasing doses and seemed to have constant chest infections. Eventually, when he was 6, he was referred to an asthma specialist, who on examination said, "He doesn't have asthma, he wheezes on the way out, not on the way in." All asthma medication was then stopped but the chest infections continued. A few weeks later, we ended up back at Alder Hey because Andrew's lung had collapsed. This resulted in a follow-up appointment with a consultant who introduced us to a new clinic Alder Hey was setting up just for TOFs. It was marvellous, we got all the support and information we needed, we discovered that there were other TOF families around and found out about the TOFS charity.

We are pleased to say that Andrew has gone from strength to strength, he has been to university, has a full-time job and is planning to leave home soon. He does still have many chest infections and the occasional choking episode but leads a full and active life.

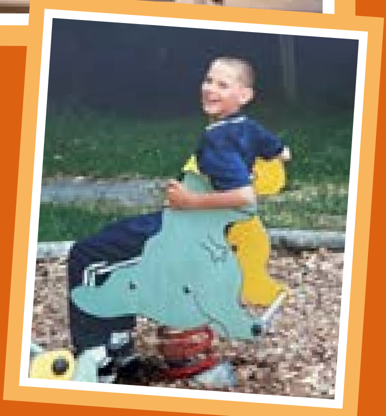
We want to be TLCs because we don't want any parents to feel as alone and afraid as we were, and we now feel we have the time available to do this. So, if you live in the Merseyside area, please feel free to contact us, anytime. We are meeting with other families at Strawberry Field, Liverpool on Saturday 21 September 1-4pm, so do feel free to get in touch and join us.

Andrew in hospital as a baby

Alan, Carolyn, Andrew & his sister



Andrew's Graduation



TOFS attend the Summer 2024 meeting of the British Thoracic Society

by Dr Caroline Love

I represented TOFS along with Trustee Kate Tyler and digital lead Peter Browne at the British Thoracic Society Summer meeting in Manchester in July. We made some helpful contacts with another (bigger) charity, Asthma and Lung, and we hope to work with them and use their experience with working with Government to advocate for the needs of people born with OA/TOF. We discussed the respiratory issues some people born with OA/TOF have in adulthood with respiratory doctors, physiotherapists and other health care professionals, as well as attending an unrelated but fascinating talk on the long-term health problems caused by vaping. There was a very interesting session about the new statement paper produced by a consortium of expert doctors in chronic cough about recommended management strategies, which are summarised below.

Treatable traits in chronic cough

Dr Peter Cho (King's College Hospital) looked at the three main areas that trigger chronic cough; problems with the airways, reflux and nerve triggers for coughing. Those born with OA/TOF may have their cough provoked by any of these.

Airways

A problem from the nose to lungs in the airways can result in chronic cough. This could be as simple as sensitivity to smoke or perfume which irritate the airways. Problems with the nose, sinuses and throat can cause chronic cough, not just lung problems. From an OA/TOF perspective, irritating chemicals can trigger cough for us as for anyone else and we are more prone to nose and sinus problems due to reflux. Our floppy airways (tracheomalacia) may be another big issue. We can also have different airway diseases that cause cough, either as part of the long-term effects of OA/TOF in some people or unrelated to it.

Reflux

Reflux entering the back of the throat and airways, either as liquid, solid or gas, can stimulate chronic cough. Those with OA/TOF are at increased risk of this due to our ongoing swallowing problems (dysphagia) and reflux, and this is particularly true if there has been a gastric pull-up where the stomach has been pulled up into the chest to repair the OA. Reflux can also cause irritated nose and sinus airways which can also worsen coughing. Obviously unrelated to OA/TOF, obesity, is another big cause of reflux.

Neuronal (nerve) causes of chronic cough

The nerves in the airways can also cause a cough. Some medications can cause this (usually one used to treat high blood pressure). It can be worsened by mental health problems (anxiety and depression) and most relevant to OA/TOF patients is a condition called cough hypersensitivity. This is where a small area of the throat is on a "hair trigger" to cough and the outside world can easily set this off, such as temperature changes, perfume or cleaning products. One can also get a tickle or constant throat sensation that makes one want to cough. Another very relevant area to those born with OA/TOF is that food in the oesophagus can trigger the nerves there by stretching it, which then can send information back to the brain to cough.

Treatment of chronic cough

Dr Jacky Smith (Professor of Respiratory Medicine at the University of Manchester) looked at the treatments available. A new area I hadn't heard about, was using specialist speech and language therapists to train people not to cough, teaching people to keep the throat moist, resist the sensation to cough or change the way they use their voice to avoid triggering a cough.

There are also some new medications being produced for coughs caused by nerve factors - a medication called gefapixant is now available privately but not on the NHS yet and there are others in the pipeline.

She also addressed the common problem of incontinence associated with chronic cough. This is very common in adult women with chronic cough (especially those who have had children) and some medications such as duloxetine (Lyfnua), usually used as an antidepressant, can help both the cough and incontinence.

Some other drugs can be helpful; morphine, a very strong painkiller, also calms cough, as can another pain drug called gabapentin. However, this is more for adult patients and may cause severe drowsiness or constipation.

A group discussion also advocated the need for proper assessment of swallowing by speech and language therapists, by putting a camera into the throat to assess swallowing and looking to see if there is any issue there to trigger coughing.

Peter Browne

In my own words … Chris Phillips

(adult born with OA/TOF)

Hi I'm Chris a 43-year-old TOF. I live in Worcestershire with my wife and two children. I was born at home in Walsall in August 1980. As the youngest of five children, I think my parents were expecting a simple easy home birth but my arrival scuppered all those plans! I was born with TOF and VACTERL and those combined resulted in me spending a large portion of my childhood in and out of Birmingham Children's Hospital.

Although my TOF surgery was a success, feeding and choking were a real issue for the first two years and my parents were one of the few we knew who carried out dilatation at home. As the youngest of five, the famous plastic tube had to be kept in the top cupboard to stop any of my siblings trying to be helpful and assist with the plastic tube!

My family had contact with TOFS in the 1980s when my parents (Alan & Val) were supported and then got involved with committees and offering support to other families. The support they offered others involved talking over the phone and in-person where my parents would share their experiences, especially on topics like feeding. They continued to support until I reached an age where I wanted to feel "normal" and not be involved. I'm now at the stage in life where I feel my experiences would help and also as my own children are now older, I have the time to help support and that is why I joined the Adult Working Group in April 2024.

How being a TOF has impacted my Life

Childhood

I'm sure I was an expensive child as I always needed a drink with food, but I also have memories of using my condition to scare the dinner ladies at primary school by pretending to choke, just to see them sprint from one end of the dinner hall to the other.

The one highlight of long hospital stays was meeting some real A Listers – including Cannon and Ball and The Andrex Puppy. My older sister arranged for the seven dwarfs to visit the ward when it became apparent one Christmas I would miss the panto.

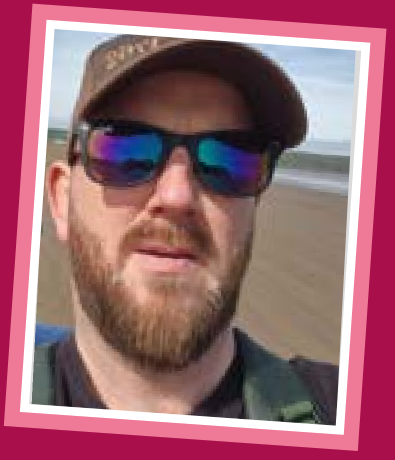
One of the best pieces of advice my parents were given to help support my recovery was to go swimming, this is something that I took to and despite initial struggles (swimming in circles as my one side was so weak), I successfully completed my mile badge at the age of 6. This was something that was recognised by the local paper as the, "Brave Schoolboy" (not my words but the words of the front page of the Birmingham Evening Mail Newspaper) who swam a mile.

The constant check-ups and other surgery for my VACTERL (one major surgery had to be completed twice to correct the first surgery) resulted in a fear of needles, something that still impacts me today.

Adulthood

Still after 43 years I have to be careful when I eat but I also have an internal sense of pride when I do something that others may feel is nothing, like eating a whole bag of crisps without needing a drink or finishing a whole meal with just one drink rather than the normal two or three I normally need (this can be expensive in the pub!!).

I have a few foods that I class as my nemesis. Roast dinners are always a challenge. I make an amazing Roast/Christmas dinner (even though I say so myself) but all my hard work always leads to a little worry as I tackle the roast beef and this can still lead to choking. I also struggle with steak but over the years I have learnt to cope and the process of dealing with a blockage is now just normal to me. My wife is great at spotting the signs when I just disappear and then return to the table a few minutes later and finish my dinner as if nothing has happened.



A milestone for Chris

Newspaper article of Chris from 1987

As a Parent

When we were expecting our son, my biggest worry was that he would experience the same issues as I had and it was a huge relief when he was born and the checks were done to confirm he was ok. This, however, has still not stopped me having to learn not to treat him as a TOF. As he grew up he had to keep reminding me he didn't need a drink with every piece of food! This projection of my issues still happens even though he is now 14!

Overall

Being a TOF is just normal to me as it is all I have ever known and I feel lucky. Longer term I still only have two main impacts from being a TOF:

- Occasional choking incidents.
- The fear of anything medical not just for me but I also hate taking the kids for any sort of treatment, as I think that in my mind I associate doctors/tests/needles with not going home, as they always seemed to be linked to staying in hospital (although these experiences are linked to my VACTERL and TOF).

I think the support we can give each other is invaluable. Until I joined the AWG, I don't think I had ever met another Adult TOF (in all the years of me explaining my condition to people nobody ever said snap or oh that's just like my dad/son/friend etc) and it has been really interesting to start to learn about others and how they have coped with their own journey and how hopefully I can help in a small way to support moving forward.

Chris in hospital when he was born

SUMMER/AUTUMN 2024

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

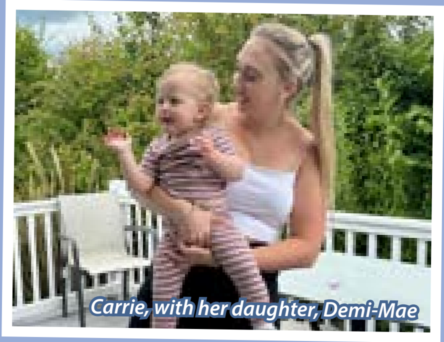
New child friendly poster helps explain OA/TOF

The idea of a child friendly poster for hospitals and schools was suggested by parent, Carrie Semark, a valued volunteer on TOFS' Pastoral Support sub-committee. She often visits the hospital with her daughter and took inspiration from a number of posters displayed in the children's ward, aimed at children and explaining their different conditions.

In consultation with the other parents on the sub-committee, she designed a poster for parents to share with their child born with OA/TOF, to help them understand their condition and explain it to their friends.

The poster is available to download for free on the TOFS website or you can order a physical copy to put up at home, in schools or hospitals.

https://tofs.org.uk/product/child-friendly-poster-for-hospitals-and-schools/



Carrie, with her daughter, Demi-Mae

Join us!

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

Thursday 10 October 7pm (UK)

tofs

Talk with TLCs!

Reflux Management

TLC To'neill

TLC Naomi

Tuesday 1 October 8-9pm

tofs

Merseyside Meet Up!

Join TLCs Alan & Carolyn in Liverpool and meet other OA/TOF families.

Saturday 21 September 1-4pm

Strawberry Field
Beaconsfield Road, Liverpool,
L25 6EJ

We're almost fully booked for our OA/TOF Seminar at Warrington so please book soon if you would like to attend: https://tofs.org.uk/event/adult-family-information-seminar

Fundraising thank yous:

Claire Burnside, mum to Olivia born with OA – £18.18 expenses donated back to TOFS.

Ye Olde Wells Lodge 6541 - £300 donation. Thanks to Ken Hillman, grandfather to Callum Hillman (OA/TOF), for putting TOFS' name forward.

Dechra Pharmaceutical - £1,000.

Easyfundraising - £52.14 donation.

Kate Clayton, grandmother to Joe Styles, born with OA/TOF - £25 donation.

Steve and Maureen Darby, parents to Alistair, born with OA - £50 donation.

Kevin Pretious, uncle to James (VACTERL), took part in a Jurassic Coast Ultra Challenge and raised £453.

Rhiannon Sullivan, mum to Llewyn (OA/TOF), raised £592.40 by holding an open afternoon fundraiser.

James Kennedy, dad to Aiden (OA/TOF), raised £810.90 by taking part in the Sheffield Half Marathon.

Nicole Pretorious, along with her friend Alex, took part in the Stockholm Marathon and raised £1,407 in support of their friend whose daughter, Isabelle, was born with OA/TOF.

To'neill Bala, mum to Eli, born with OA - £17.20 expenses donated back to TOFS.

Trustees who donated their expenses back to TOFS.

Those who kindly made donations via BOPP through our website, raising £605 between 1 April and 29 July 2024.

In memory of

Michael Faulkner, grandfather to Alexander (OA/TOF) - £400 donation.

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