

TOFS

England & Wales · Charity number 327735

Details

Other names	T O F S, TRACHEO-OESOPHAGEAL FISTULA SUPPORT
Status	Registered
Legal form	Charitable company
Company number	02202260
Registered	1988-03-03
Register	View on the Charity Commission register

Contact

Address	St Georges Centre 91 Victoria Road Netherfield Nottingham NG4 2NN
Phone	01159613092
Website	www.tofs.org.uk

Activities

Objects: THE OBJECT FOR WHICH THE ASSOCIATION IS ESTABLISHED IS TO PROVIDE RELIEF TO IN NEED INDIVIDUALS (HEREINAFTER REFERRED TO AS "TOF INDIVIDUALS") SUFFERING FROM TRACHEO OESOPHAGEAL FISTULA, OESOPHAGEAL ATRESIA AND OESOPHAGEAL AND RELATED DISORDERS INCLUDING THE VATER ASSOCIATION (HEREINAFTER COLLECTIVELY REFERRED TO AS "OESOPHAGEAL DISORDERS") AS WELL AS THE PARENTS OR GUARDIANS OF SUCH TOF INDIVIDUALS BY:PROVIDING OR PAYING FOR ITEMS, SERVICES OR FACILITIES WHICH ARE CALCULATED TO ALLEVIATE THE SUFFERING OR ASSIST THE RECOVERY OF TOF INDIVIDUALS WHERE SUCH ITEMS, SERVICES OR FACILITIES ARE NOT READILY AVAILABLE TO THEM FROM OTHER SOURCES;PROMOTING CONTACT BETWEEN THE FAMILIES OF TOF INDIVIDUALS SUFFERING FROM OESOPHAGEAL DISORDERS WITH A VIEW TO SHARING MANAGEMENT PROBLEMS AND SOLUTIONS; ANDCOLLECTING AND DISSEMINATING INFORMATION CONCERNING OESOPHAGEAL DISORDERS IN THE CARE AND TREATMENT THEREOF

Activities: Disseminating information to our membership via leaflets, our TOF Book, periodic newsletters, social media and website. Running conferences and other gatherings where patients and their families can learn about the condition, its causes, treatment and ongoing management. Provision of pastoral support. Liaising and collaborating, where appropriate, with medical professionals and researchers.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£222,536	£189,716	-	-
2023-12-31	£149,765	£171,700	-	-
2022-12-31	£151,779	£183,848	-	-
2021-12-31	£189,481	£131,983	-	-
2020-12-31	£120,038	£92,682	-	-

Trustees

Name	Role	Appointed
Clare Louise Johns		2021-03-20
DUNCAN CARL JACKSON		
Darrell Hill		2015-04-18
Katrina Marie Tyler		2026-05-07
Tamasine Swan		2018-03-24
To'neill Bala		2025-04-24

TOFS

England & Wales - Charity number 327735

Accounts

REGISTERED COMPANY NUMBER: 2202260 (England and Wales)
REGISTERED CHARITY NUMBER: 327735

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2024
FOR
T.O.F.S.

Lemans
29 Arboretum Street
Nottingham
NG1 4JA

T.O.F.S
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FOR THE YEAR ENDED 31 DECEMBER 2024

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T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2024

The Trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 December 2024. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" in preparing the annual report and financial statements of the charity.

The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the Charity's governing document, the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard, applicable in the UK and Republic of Ireland published in October 2019.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

2202260 (England and Wales)

Registered Charity number

327735

Registered office

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

Trustees

Andrew Bailey	Chair (from 9 May 2024)
Duncan Jackson	Chair (until 9 May 2024, Vice-Chair from 9 May 2024)
John Pearce	Vice Chair and Treasurer (resigned 18 April 2024))
Darrell Hill	Treasurer (since 18 April 2024)
Trace Loffman	Secretary (resigned 18 April 2024)
Graham Slater	Secretary (from 18 April 2024)
Clare Johns	
Sue Lewis-Jones	
Tamasine Swan	
Katrina Tyler	

Chief Executive Officer

Diane Stephens

Independent Examiner

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

Bankers

Caf Bank
25 Kings Hill Avenue
Kings Hill
West Malling
Kent
ME19 4JQ

STRUCTURE, GOVERNANCE AND MANAGEMENT

Objectives and aims

The principal objective of T.O.F.S. is to improve the lives of individuals (hereinafter referred to as "TOF individuals" or "TOFs") suffering from tracheo-oesophageal fistula (TOF), oesophageal atresia (OA) and oesophageal and related disorders including the VACTERL Association (hereinafter referred to as "oesophageal disorders"), as well as the families of such TOF individuals.

Oesophageal atresia and tracheo-oesophageal fistula (OA/TOF) are rare congenital conditions of the oesophagus (food pipe) and/or trachea (airway) that affect newborn babies. Babies with OA/TOF need to have intensive neonatal care prior to corrective surgery, normally within days of birth. Some children have to undergo additional surgical interventions later on in their lives. It is now recognised that life-long follow up is essential.

Constitution

T.O.F.S. is a charity which was founded in 1982 and established as a 'Company Limited By Guarantee and not having a Share Capital' on October 20th, 1987. T.O.F.S. is registered both at Companies House and with the Charity Commission.

On May 14th 2016, T.O.F.S. held an Extraordinary General Meeting at which revised Articles of Association were adopted, thus replacing in a single document the original (1987) Memorandum of Association and Articles of Association.

This was done with the agreement of the Charity Commission and the revised Articles were lodged in May 2016 with both the Charity Commission and Companies House.

Organisational Structure

The overall direction and management of T.O.F.S. is overseen by the Council of Management of which all Trustees are members, and who are also Directors of the Company. The Council is accountable and legally responsible for the work of the organisation and for ensuring that all aspects of the management and work comply with current legislation. The Council is supported by four members of staff, headed by the CEO, and also by volunteers.

Governance

The Council meets typically four times per year and - as permitted by the Articles of Association - additionally delegates some detail matters to several sub-committees (see also 'Committee Structure' paragraph below).

T.O.F.S. is bound by its Articles of Association to hold an AGM. In 2024, as noted above, this was held by videoconference. In addition to the standard agenda items, including presentation of the annual accounts and trustee elections, the opportunity was taken to provide further explanation of T.O.F.S. activities by a series of presentations on key topics (pastoral support, medical liaison, plans for the current year and beyond) to those members who attended. This format was well received and will be retained in 2025.

Policies and Documentation

Appropriate policies and procedures are in place to support the effective operation of T.O.F.S. These include, but are not limited to: Governance; Health & Safety; Risk Management; Safeguarding; Financial & Commercial Management; Personnel, Guidance & Training; IT & Data Protection; Communications; Research & Collaboration, Fund-raising.

Risk Management

The Trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud or error.

T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2024

Risks are reviewed and mitigated by:

- An organisational commitment to standards of good management and operational practice.
- Established policies, which commit to compliance with all relevant legislation and good practice.
- Regular review of all policies and procedures.
- Establishing adequate financial reserves.

Committee Structure

Since 2019, T.O.F.S. has operated with a revised set of sub-committees, each of which has written terms of reference and authority as delegated by the Trustees, and as permitted by the Articles of Association (specifically paragraphs 110-112.) These sub-committees are formally minuted, and chaired by either a Trustee or the CEO. Membership of the sub-committees is drawn from the Trustees, members of staff and other 'family' members of the organisation. At present, there are specific sub-committees for: Finance; Strategy & Planning; Staff Management & Recruitment; Pastoral Support; Publications; Conferences & Events; Medical Liaison & Collaboration.

Recruitment and Appointment of Trustees

T.O.F.S. welcomes eligible people who have an interest in helping the organisation achieve its objectives by becoming a Trustee. Whilst TOFS members include parents and grandparents of TOF children and Adults born with OATOF, T.O.F.S welcomes potential trustees from all walks of life.

The Articles of Association state the eligibility of Trustees, which, in summary, state that those eligible must:

- Be over the age of 18.
- Already be or become members of the organisation.
- Not be undischarged bankrupts.
- Not previously have been removed from trusteeship of a charity by a Court or the Charity Commissioners.
- Not be under a disqualification order under the Company Directors' Disqualification Act 1986.
- Not be disqualified by the Charities Act 1993 (Section 72) from acting as a charity trustee.
- Undertake to fulfil their responsibilities and duties as a trustee of T.O.F.S. in good faith and in accordance with the law and within the objectives of T.O.F.S.
- Not have financial interests in conflict with those of T.O.F.S. (either in person or through family or business connections) except where formally notified in a conflict of interest statement.

To ensure Trustees are fully competent, T.O.F.S. will:

- Provide an up-to-date Trustee Induction Pack.
- Support induction, in a manner tailored to the experience of the individual, by the use of a 'buddy' system whereby each new Trustee is guided by an experienced Trustee or recently retired Trustee.
- Provide access to and, where appropriate, cover the costs of induction training.
- Conduct de-briefing of retiring Trustees in order to review, and amend where necessary, the Induction of new Trustees.
- Provide a job description for honorary officers

T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2024

Staff Recruitment

There were no changes to staff roles during 2024. The charity continues to be supported by administrator Jayne Allitt and digital communications lead, Peter Browne, along with Sarah Winspear who joined in late 2023 as membership, communication and events officer. The small staff team are led by CEO Diane Stephens. Three employees work on a full-time basis remote (for the most part) and part-time employee Jayne Allitt is office-based.

Strategic Direction

In 2024, T.O.F.S. continued with its three-pronged approach to its activities and the benefits delivered to its members, namely:

- Near-term benefit: information and pastoral support to members, both families and Adult TOFs.
- Long-term benefit: engagement with relevant healthcare professional bodies, clinicians and researchers.
- Sustainable operational effectiveness.

Delivery of objectives in 2024

Pastoral support and information exchange

Pastoral support and information exchange have traditionally been the core activities of T.O.F.S., and 2024 was no exception. T.O.F.S. continued with a largely digital service model for information events to allow access for as many OA/TOF patients and their families as possible. These were attended by 153 families/adults over the year. (More about these online events in the 'events' section of this report.)

T.O.F.S. organised a face-to-face event in Warrington in November for members to meet up in person and gain information and support, along with hearing from OA/TOF-knowledgeable health professionals. The event was attended by 75 members.

In addition, there were seven local meet-ups organised by five local contact volunteers (TLCs) and three members in their areas: South Wales, London, Stockport, Liverpool, and Australia. These were attended by 30 families in total.

T.O.F.S. continued to supply information and support both to new members and associates, (235 in 2024), and to existing TOF parents/carers, adults born with OA/TOF and health professionals through leaflets, brochures, postcards and digital resources.

The T.O.F.S. website continues to be visited on a frequent basis, with visitors predominantly from the UK but also from all over the world. The new look website had been built in-house in 2022 and designed to be much more intuitive and user-friendly for those seeking information about the consequences of being born with OA/TOF. 2024 saw a small increase in visitors to the website, with 41,593 visitors (40,278 in 2023).

New resources for 2025

The Pastoral Support Sub-Committee (PS s/c) and the Adult TOF Working Group (ATWG) were closely involved in developing and making new resources available throughout the year. Volunteers on these groups have been personally impacted by OA/TOF and this experience shapes the resources that are developed each year.

Members of the ATWG researched and contributed content for a new digital resource relating specifically to post-repair problems with lungs and airways. This resource offered valuable insights as well as practical tips to improve respiratory health and quality of life for OA/TOF patients. Content was endorsed by a professor of Cardiorespiratory studies and a clinical specialist physiotherapist. This resource was viewed 1,081 times in 2024 from time of launch by 346 individuals.

With tremendous support from the OA/TOF community, a successful T.O.F.S. Awareness week was held from 26 February to 3 March, to coincide with Rare Disease Day on 29 February. Members were asked to bring T.O.F.S. and our free provision of digital books to the attention of health professionals. Many members raised the profile of OA/TOF by sharing their stories in regional and national press, and letters were sent to MPs, flagging the need for adequate care at time of transition. Car window stickers were made available for members, along with branded bibs and wristbands.

Singer/songwriter Tom Bright, who is himself an adult born with OA/TOF, joined the organisation as a celebrity ambassador to help raise the profile of OA/TOF. T.O.F.S. produced a video to promote the partnership and explain the impact of the condition which had 625 views throughout the year.

Member and midwife Kate Yardley, (parent of a baby born with OA/TOF) was commissioned to produce content for a resource aimed to help new mums who wanted to breastfeed their OA/TOF baby. The 'Expressed Breast Feeding' resource was endorsed by the Neonatal Nursing Association and added to the website as part of the 2024 Awareness week. It was subsequently viewed 1,145 times during 2024 by 285 people.

A new video to promote the T.O.F.S. Local Contact (TLC) service for members was filmed and viewed 140 times over the year. TLCs are a valued group of volunteers, all of whom are experienced TOF parents. Spread across the UK, TLCs are available to listen, talk and offer support to new TOF parents, organise local informal get-togethers, and take posters and leaflets into hospitals, especially where TOF surgery takes place. Some TLCs have shown further commitment by giving talks on behalf of T.O.F.S. Our TLC for Scotland, Bruce Rennie, represents T.O.F.S. on the Expert Advisory Group of the Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS.) Our TLC for Wales, Naomi Webborn, is a key member of the Pastoral Support sub/committee and has continued to be involved in many support initiatives over 2024. She also represented TOFS during Awareness week at the Rare Disease event at the Welsh Assembly.

With the help of our TLC volunteers, we launched new parent packs for hospitals to share with new parents. 62 packs were distributed over the year to thirteen hospitals via their TLC.

In conjunction with support from the Brazilian Facebook group (GAAE- grupo de Apoio Atresia de Esofago) T.O.F.S. facilitated the translation of some of its resources into Brazilian Portuguese to share with parents in the Brazilian and other Portuguese speaking communities. These resources were made available on the website and have been downloaded 18 times since their launch.

We continued to promote the online digital library for healthcare professionals offering free access to downloadable versions of our books, along with other relevant publications. This service was requested by 62 health professionals across a range of disciplines. The majority of these requests were from the UK (47), and the rest were from health professionals working in various other countries around the world.

All members received three editions of the members' magazine, 'Chew', written and edited by the CEO and volunteers on the Chew editorial board.

Our office staff (working mainly remotely) continued to support members via telephone and email with follow-up support calls and emails made to new members who had given permission for the office to do so.

Child-friendly posters were designed for children's wards at hospitals and schools explaining OA/TOF in child-friendly language, to help children born with OA/TOF to understand their condition and explain it to friends. These posters have been downloaded 24 times since they were added to the website.

Facebook

The T.O.F.S. Facebook group remains a crucial platform for supporting patients and families of those born with OA/TOF. Many members are instrumental in offering the benefit of their experiences to new parents and the Facebook group plays an increasingly supportive and 'real-time' role in the exchange of parents' experiences with their OA/TOF babies and children. The Facebook group gained 234 new members in 2024, bringing its total membership to 5,112, with an average of 1,259 members active each day.

To better support our Adult TOF community, we decided several years ago to endorse a Facebook group specifically for Adult and Teen TOFs, which was and still is, run by one of our members, and now administrated by one of our Trustees and some of our Adult TOF working group members. This provides a very useful forum for our growing number of Adult TOF members, whereby they can share information and experiences on issues that continue to affect them. In 2022, T.O.F.S. officially linked this Adult Group with the T.O.F.S. Facebook page making a visible connection between the charity and the Facebook Group. At 31 December 2024, the total membership of this group stood at 893, with an average of 103 members active each day.

Online events to support members

The series of online events giving members the opportunity to hear from leading clinicians and healthcare professionals and have their questions put to them, continued via Zoom. There were five such events, hosted by one or both of TOFS Chair Drew Bailey and Vice Chair Duncan Jackson, along with the CEO. Topics covered were the Lost Twin Hypothesis, Chest Wall Deformities, Leaving paediatric care and negotiating adult services, Feeding experiences and oral aversion. We are very grateful to the expert speakers who gave their time freely. In total these were attended by 100 members mainly from the UK, but also UK, Belgium, Germany, Sweden, Canada, New Zealand, Ireland, Switzerland, Kenya, Mauritius, Denmark, Australia, France and the Netherlands. In addition, all the information sessions were recorded, edited and subtitled and subsequently added to the YouTube channel.

The informal online 'Cuppa & Chat' meet-ups for adults continued and TOFS volunteers facilitated 10 of these virtual meet-ups with 21 adults attending over the year.

TLC volunteers facilitated five 'Talk with TLCs' events during the year. These 'Talk with TLC' sessions offer members the opportunity to engage with each other virtually, in discussion with their peers about various aspects of the OA/TOF condition. Subjects covered included Starting Nursery, Pre-School & School; Managing VACTERL anomalies; Teens & Transition; and Reflux Management. In total, 32 families were supported by these events. An outcome from the Starting Nursery talk was the development of a 'Steps to consider when looking at childcare settings' resource which was subsequently added to the website and downloaded 29 times over 2024.

Two TLC volunteers also organised informal meet-ups online which supported five families.

Volunteers

Volunteers continue to play an increasingly important role in the support that T.O.F.S. offers new parents, carers and adults. We continue to benefit from the improved co-ordination of our volunteers and the associated support activities, and welcomed seven new volunteers, either as TLCs, Facebook moderators or on sub-committees or working groups. We would not be the organisation we are without the valuable support from our volunteers, whether their role is in advising members with DLA/PIP applications, TLC support, writing for *Chew*, sending out birthday cards, taking part in committees, moderating Facebook or helping with fundraising.

There are currently three T.O.F.S. Overseas Contacts (TOCs) one in Jordan, one in Canada and one in New Zealand. All are active in offering support to TOF families within their own country and they share T.O.F.S. knowledge when applicable. This has been mutually beneficial, resulting in translations of some T.O.F.S. leaflets into Arabic. (It should be noted that these Overseas Contacts do not in any legal sense represent T.O.F.S. in these countries; they are - as the name implies - purely our contacts in these countries.)

'*The TOF Book*', published in November 2016, continues to sell, although understandably not quite at the level of prior years. Nonetheless, there is evidence that a significant proportion of the new members who joined in the year purchased the book, including overseas members. The fully illustrated '*Soft Food Recipe book*', published in December 2020, continued to provide a useful addition to our publications. We continued to make the facility for both books to be purchased directly from ourselves via our website.

Merchandise

Introduced in 2023, T.O.F.S. branded merchandise continued to be made available for members to buy from the online shop. These items are supplied by a third party and T.O.F.S. does not seek material financial gains from this addition but instead, meet demand by the community and raise the profile of OA/TOF.

Use of Information Technology (IT)

The use of IT continues to be a powerful tool in support of our operations. Facebook remains a very significant means by which members and non-members communicate on OA/TOF matters, and we have increasingly used this form of social media to augment communication with our members. T.O.F.S. has made significant strides in leveraging technology to enhance member benefits and streamline operations. Highlights include:

Dedicated Digital Lead: TOFS has appointed a dedicated Digital Lead to drive technology adoption within the organisation. This strategic move aims to maximise the advantages of digital solutions for our members.

Enhanced Website: TOFS has invested in a new, faster website that not only provides essential information but also includes an online shop. Members can now conveniently order leaflets and books through the website, resulting in a more efficient process for administrative staff.

Hybrid Working Model: Embracing technology, TOFS has adopted a hybrid working model. This approach allows flexibility and widens the talent pool during recruitment. Employees can work both remotely and in-office, optimising productivity for members.

Video Conferencing for Member Engagement: TOFS utilises video conferencing systems to offer live Q&A sessions with medical experts. Members can participate from anywhere, fostering knowledge sharing and support. Additionally, virtual meetups provide a valuable channel for volunteers to connect direct with members who need support.

Active Presence on Other Social Media Channels: TOFS extends its reach beyond Facebook. We maintain an active presence on Instagram, Twitter, Threads, and even TikTok, engaging with our community and sharing valuable content.

Exploring AI: TOFS is currently testing and investigating the use of artificial intelligence (AI) within its operations. Whilst in the early stages, we anticipate that AI could enhance efficiency, improve decision-making, and provide personalised experiences for our members. We will closely monitor its impact and adapt accordingly in the future.

TOFS continues to evolve its technological landscape, ensuring that our members receive the best possible support and resources.

Altido Group Ltd of Cheltenham remain our primary bespoke IT service provider and we hereby note our gratitude for their provision of these services at a discounted or free of charge basis. (We note for reasons of transparency that the late Dennis Harvey (who retired as a Trustee during 2022) was the father-in-law of the Altido Managing Director.)

Liaison with the medical profession and with the NHS

We continued in our commitment to disseminating information to practitioners from health, education and social care. We continue to be assisted by members in distributing posters to hospitals to display in their local neo-natal wards to increase awareness of T.O.F.S. when new parents and carers most need help.

T.O.F.S. continues in its efforts to increase its profile within the medical community. Since 2016, we have had a Medical Advisory Group, which is intended to provide us with a leading group of medical professionals across all relevant disciplines, who can provide advice and guidance, and support our publications with medically approved input. Its Research sub-group continues to support and guide T.O.F.S.' engagement with research studies.

The involvement of T.O.F.S. in research programmes into OA (Oesophageal Atresia) reflects the almost mandatory requirement for relevant patient group support to be given to such projects and where relevant for "the patient voice" and patient perspective to be built into the study's terms of reference. In some instances, this support is characterised purely by endorsement of its relevance and priority to OA patients. In other cases, support may also involve some funding contribution, whilst a research activity may be characterised by more active involvement and/or collaboration with T.O.F.S.

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Projects underway or completed and/or published in 2024 that T.O.F.S. is currently supporting and/or endorsing include:

- The GOSH/ICH (Great Ormond Street Children's Hospital/Institute of Child Health) tissue-engineering project (this is investigating the use of stem cells to develop an oesophagus);
- A study into the feeding issues for patients up to the age of 12 months (which is the subject of a PhD degree);
- A major randomised controlled trial (Treating Oesophageal Atresia to prevent Stricture, TOAST) to investigate whether or not the general use of antacid medicines with all OA babies would be helpful;
- A study (Oesophageal atresia Core outcomes LongTerm, OCELOT) to develop a lifelong relevant 'core outcome set' for OA.
- A study (CSOR - Children's Surgical Outcome Reporting) to compare the outcomes (notably parent-reported outcomes) of babies born with congenital malformations including those born with OA.

In the latter three studies, T.O.F.S. has membership of the study steering group. We also note that since January 2021 T.O.F.S. Trustee Graham Slater has been a Patient & Public Voice partner to the NHS England Clinical Reference Group on Specialised Surgery in Children.

TOFS representatives also attended the following UK medical conferences:

- Expert imaging in Obstetrics and Gynaecology (EIOG). EIOG is a new initiative, aiming to disperse information about OA/TOF to obstetric and paediatric medical professionals
- British Thoracic Society Summer Meeting
- Neonatal Nurses Association and ANNP Annual Conference
- Northern Ireland Neonatal Nurses Association Conference

Co-operation with other organisations

During 2024, T.O.F.S. continued its engagement with other UK patient organisations to start collaborative action concerning care for adult patients suffering ongoing morbidity as a result of being born with congenital malformations such as OA, and/or other rare conditions acquired in childhood. Efforts are ongoing, to jointly approach relevant medical societies and policy-makers in the NHS to address the absence of specialist care - an issue of growing concern as the number of adult patients requiring such care increases each year. A jointly signed letter with seven other UK patient groups was submitted to a number of institutions including the Royal Colleges, the NHS and the Dept. of Health & Social Care. This letter has been acknowledged by its addressees and an initial meeting with representatives of the NHS England Specialist Commissioning Team was held in December where the issues raised were acknowledged. However, ongoing advocacy and engagement with the NHS will be required in order to make effective progress.

We also increased our engagement with organisations which support other conditions in the VACTERL spectrum which OA/TOF patients can also suffer from. We attended and presented at associated conferences such as that run by Max's Trust and the VACTERL Association Family Event.

T.O.F.S. also continued to play a leading role in EAT (Esophageal ATresia Global Support Groups e.V.). This organisation now has member associations in fourteen countries. EAT is a German-registered association, and its involvement is much sought by various international medical working groups, especially those supported by EU funding. As a result, via EAT, T.O.F.S. continues to be actively involved in European collaborative healthcare programmes, with INoEA (International Network on Esophageal Atresia) and other relevant international initiatives.

Through our membership of EAT, T.O.F.S.:

- is actively participating in the European Reference Network (ERN) known as ERNICA (ERN for Inherited and Congenital Anomalies) and ERN-eUROGEN. The latter reflects our increased efforts to support our VACTERL patients which also included our active participation in the annual meeting of AIMAR, the Italian anorectal patients support group. Particular projects include the development of 'patient journeys'; Quality of Life/Mental health studies and webinars; patient/parent-friendly versions of guidelines and consensus statements; and Transition & Adult Care.

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- contributed to the development of the programme for the INoEA conference to be held in 2025; the result of this activity was to ensure active participation of EAT representatives (including three from TOFS) as presenters or moderators in most conference sessions.
- contributed to EAT's engagement with EURORDIS (the European Rare Diseases 'umbrella' organisation for rare disease patient support groups), in particular with regard to the EURORDIS Mental Health initiative and the EURORDIS support to patient representatives in the ERNs (European Reference Networks).
- represented EAT (in conjunction with colleagues from other EAT Member Associations) at medical conferences notably:
 - the ESPGHAN (The European Society for Paediatric Gastroenterology Hepatology and Nutrition) conference
 - the EUPSA (The European Paediatric Surgeons Association, of which T.O.F.S. medical patron Prof. Paolo de Coppi is currently President) conference
 - European Respiratory Congress. Our attendance at this congress reflects our increased focus on respiratory morbidity which to some degree affects the majority of OA/TOF patients. TOFS Volunteer Dr Caroline Love attended in her role as a patient advocate for EAT/TOFS representing the European Lung Foundation; a short video about TOFS was played at the patient support group day.

Finally, it is noted that on May 1st, 2024, Dr Caroline Love took over as the Chair of the T.O.F.S. Medical Liaison, Research & Collaboration sub-committee.

Expenditure, Funding, Financial Management and Governance

Expenditure

Total expenditure increased in 2024, from the £171,700 of 2023 to £193,716. The Trustees had planned for 2024 expenditure to be increased with a number of projects planned for the year.

The Trustees concluded some time ago that the most effective way to improve support to members and the general community impacted by OA/TOF was by having staff in place to generate better information, make that more accessible, and generally co-ordinate activity better. Staff costs in all amounted to some 70% of total expenditure in 2024, and the administration element of this remains low. Indeed, we are now conducting a high proportion of our video-editing, information-preparation and layout in-house and have reduced external cash expenditure commensurately.

During the year, we held one conference for members, as explained elsewhere in this report. The charity also continued to offer its members a series of online Question-and-Answer events with medical experts. The external cash cost of these events was just over £3,200 and involved significant staff effort.

The charity adopted virtual meetings in 2020 and – for most of the staff, most of the time - remote working from home via Teams. There does not yet appear to be strong reason to revert to traditional face to face meetings. It is likely that we will continue to use these cost-effective options to a great extent. However, the charity retains its one office as an operating base, from which two staff members work. We have searched without success for a materially cheaper alternative office.

Much of the time spent by T.O.F.S. on engagement with healthcare professionals, their associations and their initiatives is undertaken by volunteers, including some of the Trustees. The volume, impact and importance of this work is far greater than might be inferred from the relatively low sums which the charity has spent on it.

As noted elsewhere in this report, T.O.F.S. attended several UK medical society events in person, with a couple of small exhibition stands. The cost of attending such events can be material, though travel and subsistence is typically the greatest element. However, expenditure in this category was similar to that of 2023.

The cost of magazines and publications was similar to 2023, despite the charity changing supplier.

T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2024

Some years ago, the Trustees decided to designate £20,000 in all to pay for sponsorship of relevant medical research and activities of similar long term "scientific" benefit to the OA/TOF community over several years. The Trustees decided to transfer another £20,000 from general funds to this designated research fund in 2021.

We had expected to pay the last tranche of support for the OCELOT project in 2023, but we were not asked to do so. This was paid in 2024.

Income

The charity has no ongoing committed income such as grants, etc. The public sector makes no contribution to our work other than Gift Aid on donations from UK-based individuals.

Around half of the charity's income arises because of fundraising undertaken by our members and the wider community impacted by OA. Most of the remainder arises because a member has directly donated it in one way or another or most typically encouraged others to do so. This high degree of engagement with members and the OA community is vital to T.O.F.S. and the Trustees are very grateful for it.

In 2024, underlying income reached a record level of £183,323. For reference, underlying income has varied between £111,337 and £142,268 (excluding the exceptional Martin and Pretious legacies and the Forrester Trust donation) over the previous five years. Total income in 2024 included a grant of £23,248 from Stewart Investors in Edinburgh which has been ring fenced for updated editions of *The TOF Book*. We are grateful to TOF parent, Greg Johnston for putting TOFS forward.

The value of donations and grants from companies, clubs and societies such as Rotary clubs, sports clubs, Freemasons' lodges and local faith groups grew significantly in 2024, even excluding the Stewart Investors exceptional donation. In almost every case, such corporate/club donations arise because a member has nominated T.O.F.S. to their employer/club/society.

Our two largest corporate donations in 2024 (excluding the Stewart Investors grant) came from organisations that had already donated to T.O.F.S in 2022 and 2023. Blackhawk Network group of companies donated over £12,000 as part of their CSR/benefits programme. We are grateful to TOF parent Jo Fleet-Chapman for her nomination. For the second year running, we were chosen as a beneficiary from the MGL Golf Day which is organised by Mandy and Keith Lerner. Their donation of £10,000 brings the total donations from this event to £30,000. The Trustees are very grateful to the family for deciding to donate once again some of the net proceeds of their annual charity Golf Day to the charity.

Other significant corporate donations in 2024 include £3,000 from Fusion 21 and a grant from Blackbaud for £4,918.50, to fund a new resource for parents to help with breastfeeding their OA/TOF babies.

T.O.F.S. asks members to make a donation in respect of their membership, and many do so, especially upon joining. A significant number make regular monthly donations, and for this, we are very grateful.

The London Marathon remains the largest fundraising event for T.O.F.S., and in 2024 we had seven people who raised almost £19,000. The leading fundraiser was Gavin Mountford who raised £4,277, including Gift Aid.

The Great North Run has been a fixture on the T.O.F.S. calendar for some time. In 2024, our five entrants raised an excellent combined total of over £6,000 including Gift Aid, which is a record fundraising amount for this event.

For a third year, T.O.F.S. had places in the Ride London-Essex 100 cycle ride. Our cyclists raised an excellent combined total of over £15,000 (including Gift Aid). Sadly, the organisers have made a decision not to run this event in 2025.

Some of our younger members took part with their mums and/or dads in our third annual Teddy Toddle, which raised almost £4,500. 2024 saw the first TOFS-organised Big Splash Swimathon which raised over £5,000.

The Trustees are most grateful to the people who put so much effort into training for and completing all of the above events, and into raising a great deal of money for the charity.

T.O.F.S.
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2024

More traditional fundraising activity, organised by members themselves, raised just over £45,000. The Trustees are especially grateful to members who organise and undertake so many small-scale events and raise so much for T.O.F.S. We continue to offer them support with fundraising packs, items such as T.O.F.S. branded running vests and a fundraising guide with hints and tips. In 2024 we developed a new fundraising postcard.

Fundraisers of note include Ross Jeavons, (the best-ever London Marathon fundraiser), who ran a 100k Ultramarathon in 2024 raising £8,240. Our largest individual fundraiser was David Loughran, whose fundraising challenge for T.O.F.S. during 2024 Awareness week raised £13,210.

The charity continues to take part in "Your Charity Lottery", which is run by a licensed third-party operator, with approximately 160 people playing on a weekly basis to benefit T.O.F.S.

Income from the sale of the two books published by T.O.F.S. has remained at a useful level. The charity's online shop has been expanded to offer the books with relatively little administrative load, and also to allow members to easily order the many free-of-charge leaflets, badges, etc.

Lastly, we note e-cards - TOFS offered members the chance to send one of a range of selected TOFS electronic Christmas Cards – and to donate to TOFS. The amount raised during Winter 2024-2025 rose to approximately £950 and we are hopeful of further growth in future.

Financial Management

The Trustees have delegated most of the charity's financial management to the Treasurer, who works with a Financial Sub-Committee (FSC). The FSC had held its normal half-yearly meetings in 2024, to review expenditure and incomes, to monitor progress against budgets and to recommend budgets for ratification by the whole Council of Management of T.O.F.S.

On a day-to-day basis, the charity uses a commercial bookkeeping system and produces monthly internal updates. The Treasurer and FSC normally produce reports for the Trustees several times per year, typically quarterly. The Fundraising Working Group meets much more frequently than the FSC and reports to the FSC.

Financial Review and Reserves policy

Like other charities, T.O.F.S. requires reserves in order to operate in the short term and to satisfy legal obligations in the event of the end of funding, a major reduction of funding or a delay in further funding becoming available. In the event of having to close the charity, the reserves would enable proper notice to be given to the beneficiaries and staff and for all legally due payments to be made to staff, volunteers and the organisations with which we do business. In view of the great uncertainties arising from the COVID-19 pandemic, in 2020 the Trustees raised the minimum level of reserves to an amount sufficient to cover all normal operating expenses for a full year. The reserves policy has not been changed since. At the end of 2024, T.O.F.S. has significantly more in reserves than our policy demands, however the apparent excess is very likely to reduce as it is expected that expenditure will exceed the income that can reasonably be anticipated for the next couple of years.

Investment policy and objectives:

T.O.F.S. continues to hold current bank accounts with Lloyds Bank Ltd and CAF Bank Ltd (a part of the Charities Aid Foundation.) For accepting payments and donations it also has accounts with PayPal, Facebook, Just Giving, Peoples' Fundraising, BOPP and Givestar. TOFS also has an account with "In memoriam" donations website Much Loved.

The current "investment" policy was adopted in February 2018. This enables (but does not commit) T.O.F.S. to invest up to approximately half of its apparently excess reserves in risky assets – in pursuit of a meaningful return – via vehicles such as charity-specific diversified pooled investment funds with reputable financial institutions. However, in view of the uncertain/troubling investment horizon, the Trustees decided upon the recommendation of the FSC to continue to hold all reserves as cash in FSCS-protected savings accounts. For the whole of 2024, T.O.F.S. has had savings accounts with Cambridge and Counties Bank, Mansfield Building Society, Hampshire Trust Bank, Redwood Bank and Virgin Money.

T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2024

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by order of the Council on 23 March 2025 and signed on its behalf by:



Andrew Ian Bailey (Chair)

INDEPENDENT EXAMINER'S REPORT
TO THE TRUSTEES OF T.O.F.S.

I report to the Charity Trustees on my examination of the accounts of the company, for the year ended 31 December 2024 set out on pages 14 to 22.

Responsibilities and basis of report

As the Charity Trustees of the company, (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your company's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. Accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. The accounts do not accord with those records; or
3. The accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
4. The accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)]

I have no concerns and have come across no other matters in connection with the examinations to which attention should be drawn in this report, in order to enable a proper understanding of the accounts to be reached.

K Mealand

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

21 May 2025

T.O.F.S.
STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2024

		Unrestricted funds		Year Ended 31.12.24	Year Ended 31.12.23
		General fund £	Designated funds £	Total funds £	Total funds £
INCOME AND ENDOWMENTS FROM:	Notes				
Donations and legacies	2	197,020	-	197,020	125,617
Other trading activities	3	15,281	-	15,281	14,846
Investments	4	10,235	-	10,235	9,302
Total income and endowments		222,536	-	222,536	149,765
EXPENDITURE ON:					
Raising funds	5	5,684	-	5,684	1,811
Charitable activities	6	181,066	4,000	185,066	167,080
Other	7	2,966	-	2,966	2,809
Total expenditure		189,716	4,000	193,716	171,700
NET INCOME/(EXPENDITURE)		32,820	(4,000)	28,820	(21,935)
Transfers between funds		(23,248)	23,248	-	-
Net movement in funds		9,572	19,248	28,820	(21,935)
Reconciliation of funds					
TOTAL FUNDS BROUGHT FORWARD		270,813	14,726	285,539	307,474
TOTAL FUNDS CARRIED FORWARD		280,385	33,974	314,359	285,539

The notes form part of these financial statements

		Unrestricted funds		Year Ended 31.12.24	Year Ended 31.12.23
	Notes	General fund £	Designated funds £	Total funds £	Total funds £
FIXED ASSETS					
Tangible assets	12	-	-	-	-
Investments	14	-	-	-	-
		-	-	-	-
CURRENT ASSETS					
Stock		5,104	-	5,104	6,980
Debtors: amounts falling due within one year	13	10,594	-	10,594	13,555
Investments	14	263,801	-	263,801	238,167
Cash at bank		10,498	33,974	44,472	33,492
		289,997	33,974	323,971	292,194
CREDITORS					
Amounts falling due within one year	15	9,612	-	9,612	6,655
NET CURRENT ASSETS					
		280,385	33,974	314,359	285,539
TOTAL ASSETS LESS CURRENT LIABILITIES					
		280,385	33,974	314,359	285,539
NET ASSETS					
		280,385	33,974	314,359	285,539
FUNDS					
General fund	16			280,385	270,813
Designated funds				33,974	14,726
TOTAL FUNDS					
				314,359	285,539

The notes form part of these financial statements

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2023.

The trustees have not required the charitable company to obtain an audit of its financial statements for the year ended 31 December 2023 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

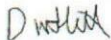
- (a) ensuring that the charitable company keeps accounting records that comply with Section 386 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial period and of its surplus or deficit for each financial period in accordance with the requirements of Section 394 and Section 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies' regime.

The financial statements were approved by the Council of Management on 23 March 2025 and were signed on its behalf by:



A Bailey (Chair) – Trustee



D Hill (Treasurer) – Trustee



G Slater (Company Secretary) - Trustee

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements and assessment of going concern

TOFS is a private charitable company limited by guarantee incorporated in England within the UK. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 1 of these financial statements. The nature of the charity's operations and principal activities are stated on page 2 of these financial statements.

The charity constitutes a public benefit entity as defined by FRS102. The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS102), the Charities Act 2011, the Companies Act 2006 and UK Generally Accepted Practice.

The financial statements are prepared on a going concern basis under the historical cost convention. The financial statements are presented in sterling which is the functional currency of the charity and rounded to the nearest £. The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

Income

Voluntary income is received by way of donation and gifts and is included in full in the Statement of Financial Activities when received. The value of services provided by volunteers has not been included.

Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with the use of resources.

Tangible Fixed Assets

Depreciation is provided at the following annual rate to write off each asset over its estimated useful life:

Office equipment	33% on cost
------------------	-------------

From January 2012, the Trustees decided to write off the cost of office equipment in full in the year of purchase

Stocks

Stock is valued at the lower of cost and estimated selling price.

Current asset investments

The charity holds cash on deposit for investment purposes, in order to obtain a better rate of return, thereby increasing their income enabling them to meet their objects.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Debtors and Creditors

Debtors and Creditors receivable and payable within one year are recorded at transaction price.

Cash at Bank

The charity holds sufficient funds in order to meet its short-term cash commitments as they fall due.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees. Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes. Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2024

2. DONATIONS AND LEGACIES

	2024	2023
Donations:		
Charitable Trusts, Clubs and Corporations	67,452	32,508
Individuals	5,592	2,632
In Memoria	2,534	8,801
Members and Friends	45,049	28,463
London Marathon/Great North Run/Teddy Toddle/Ride London 100/		
Big Splash	44,600	29,717
Other	31,793	23,496
	197,020	125,617

- Other donations and gifts include donations made by members in respect of their membership.
- Members and Friends donations are made as a result of events run by them to raise funds for TOFS.
- London Marathon, Great North Run, Teddy Toddle, Ride London and Big Splash are special cases of fundraising by members for TOFS.

3. INCOME FROM OTHER TRADING ACTIVITIES

	2024	2023
Sale of TOFS goods	5,552	6,027
TOFS fundraisers and raffles	6,129	8,819
TOAST project	3,600	-
	15,281	14,846

4. INVESTMENT INCOME

Interest receivable	10,235	9,302
	10,235	9,302

5. COSTS OF RAISING FUNDS

Opening stock	6,980	4,044
Purchases	1,158	769
Closing stock	(5,104)	(6,980)
	3,034	(2,167)
Just Giving subscription	331	216
London Marathon / Great North Run/ Ride London	2,319	3,762
	5,684	1,811

6. CHARITABLE ACTIVITIES

	2024	2023
Pastoral support and information exchange:		
Newsletters	12,915	7,771
Event costs	3,253	2,859
Telecommunications	1,604	1,860
Printing, postage, stationery, fundraising costs and publicity	9,276	8,331
Support costs (note 8)	112,260	109,700
	139,308	130,521
Medical liaison, research and co-operation:		
Projects - Medics to INoEA / Medical and Hospital Liaison	2,635	3,100
Research costs	4,000	-
Awareness week and other	3,414	70
Support costs	35,450	32,770
Projects European Collaboration / EAT	259	619
	45,758	36,559
	185,066	167,080

7. OTHER COSTS

	2024	2023
Accountancy and professional fees	2,966	2,809

8. SUPPORT COSTS

	Pastoral support & information exchange	Medical liaison research and co-operation	2024 TOTAL	2023 TOTAL
Wages	103,708	32,750	136,458	127,427
Finance	129	41	170	120
Information Technology	2,249	710	2,959	8,682
Office accommodation	4,301	1,358	5,659	5,456
Travel and sundry	1,873	591	2,464	785
	112,260	35,450	147,710	142,470

Support costs have been allocated to the activities based on time spent.

9. NET INCOMING RESOURCES

	2024	2023
Net resources are stated after charging:		
Independent examiner's fees	2,028	1,914
Payroll Administration	535	571

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2024 nor for the year ended 31 December 2023.

Trustees' Expenses

Five (2023 – 6) of the trustees received reimbursed expenses in the period of £2,515 (2023- £4,129). The expense reimbursements were dominated by the cost £1,504 (2023 £2,081) of a new printer, apple watch and travel.

11. STAFF COSTS

The average number of full time equivalent employees during the period was 4 (2023 – 3.59)

No employee received total employee benefits of more than £60,000.

The total staff costs and employee benefits were as follows:

	<u>31.12.24</u>	<u>31.12.23</u>
	£	£
Wages and Salaries	119,687	115,266
Social Security Costs	6,443	5,088
Pension Costs	10,328	7,073
	136,458	127,427

12. TANGIBLE FIXED ASSETS

	<u>Office Equipment</u>
	£
COST	
At 1 January 2024	3,944
Additions/(Disposals)	-
At 31 December 2024	3,944
DEPRECIATION	
At 1 January 2024	3,944
Charge for the year	-
At 31 December 2024	3,944
NET BOOK VALUE	
At 31 December 2024	-
At 31 December 2023	-

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2024

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Prepayments and other debtors	8,723	11,541
Gift Aid	1,871	2,014
	10,594	13,555

14. CASH HELD FOR INVESTMENTS

	2024	2023
Current asset investments	263,801	238,167
Fixed asset investments	-	-
	263,801	238,167

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

Accountancy	2,028	1,914
Social Security & other taxes	2,617	2,831
Accruals	4,967	1,910
	9,612	6,655

16. MOVEMENT IN FUNDS

	<u>At 1.1.24</u>	<u>Net Movement</u>	<u>Transfers</u>	<u>At 31.12.24</u>
	£	<u>in funds</u>	<u>between funds</u>	£
Unrestricted funds				
General Fund	270,813	32,820	(23,248)	280,385
Designated Fund - Medical research	14,726	(4,000)	-	10,726
The Tof Book	-	-	23,248	23,248
TOTAL FUNDS	285,539	28,820	-	314,359

Net movement in funds, included in the above are as follows:

	<u>Incoming</u>	<u>Resources</u>	<u>Gains and</u>	<u>Movement</u>
	<u>resources</u>	<u>expended</u>	<u>losses</u>	<u>in funds</u>
Unrestricted funds				
General Fund	222,536	189,716	-	32,820
Designated Fund – Medical research	-	4,000	-	(4,000)
Projects and resources	-	-	-	-
TOTAL FUNDS	222,536	193,716	-	28,820

16. MOVEMENT IN FUNDS CONTINUED....

	<u>At 1.1.23</u>	<u>Net Movement</u>	<u>Transfers</u>	<u>At 31.12.23</u>
	£	<u>in funds</u>	<u>between funds</u>	£
Unrestricted funds				
General Fund	292,748	(21,935)	-	270,813
Designated Fund – Medical research	14,726	-	-	14,726
Projects & resources	-	-	-	-
TOTAL FUNDS	307,474	(21,935)	-	285,539

Net movement in funds, included in the above are as follows:

	<u>Incoming</u>	<u>Resources</u>	<u>Gains and</u>	<u>Movement</u>
	<u>resources</u>	<u>expended</u>	<u>losses</u>	<u>in funds</u>
Unrestricted funds				
General Fund	149,765	171,700	-	(21,935)
Designated Funds – Medical research	-	-	-	-
Projects and resources	-	-	-	-
TOTAL FUNDS	149,765	171,700	-	(21,935)

The research designated fund was created in 2013. The Trustees added to this in 2014. A total of £40,000 of reserves has now been designated to support relevant medical research work, over several years. In 2019 the Trustees created an additional designated fund for "Projects and Additional Resources" – to cover principally additional staff costs over the subsequent couple of years. The trustees closed this latter fund during 2022. In 2024, the donation of £23,248 received from Stewart Investors was designated for future editions of the Tof Book.

17. RELATED PARTY TRANSACTIONS.

During the year, TOFS has bought IT services amounting to £390 (2023 - £1,228) from Altido (formerly CRM Labs). The managing director of this firm is the son-in-law of the late Dennis Harvey, who served as a Trustee until March 2022.

18. PENSION CONTRIBUTIONS

The charity operates a defined contribution scheme. The assets are managed independently of the charity and contributions are charged to the Statement of Financial Activities in the period they are made. The charge for the year was £10,328 (2023 - £7,073).

T.O.F.S.
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2024

	Year Ended 31.12.2024		Year Ended 31.12.2023	
	£	£	£	£
Donations				
Charitable Trusts, Clubs and Corporations	67,452		32,508	
Individuals	5,592		2,632	
In Memoria	2,534		8,801	
Members and Friends	45,049		28,463	
London Marathon, Great North Run, Teddy Toddle, Ride London 100 and Big Splash	44,600		29,717	
Other	31,793		23,496	
		197,020		125,617
Other income				
Sale of TOFS Goods	5,552		6,027	
Interest	10,235		9,302	
TOFS Fundraisers and raffles	6,129		8,819	
TOAST project	3,600		-	
		25,516		24,148
Total Income		222,536		149,765
Cost of TOFS Goods Sold				
Opening stock	6,980		4,044	
Purchases	1,158		769	
Closing stock	(5,104)		(6,980)	
		3,034		(2,167)
Just Giving subscription		331		216
London Marathon / Great North Run / Ride London		2,319		3,762
		5,684		1,811
Fundraising, Publicity & Co-operation				
Newsletters		12,915		7,771
Printing, postage, stationery, fundraising costs & publicity		9,276		8,331
Cooperation with other organisation		259		619
Liaison with the medical profession		6,049		3,170
		28,499		19,891
Central costs				
Wages, social security & pension costs		136,458		127,427
Accountancy		2,966		2,809
Telecommunications		1,604		1,860
		141,028		132,096

This page does not form part of the statutory financial statements
Page 23

T.O.F.S.
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2024

	Year Ended 31.12.2024		Year Ended 31.12.2023	
	£	£	£	£
Other Operating costs				
Event expense	3,253		2,859	
Travel and meeting	1,737		81	
Rent and Insurance	5,659		5,456	
Research, Recruitment and Sundry	4,727		704	
Computer costs	2,959		8,682	
Bank charges	170		120	
Bad Debts	-		-	
		18,505		17,902
Total Expenditure		193,716		171,700
NET INCOME/(EXPENDITURE)		28,820		(21,935)
Funds brought forward		285,539		307,474
Funds carried forward		314,359		285,539

This page does not form part of the statutory financial statements

TOFS

England & Wales - Charity number 327735

Accounts

REGISTERED COMPANY NUMBER: 2202260 (England and Wales)
REGISTERED CHARITY NUMBER: 327735

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

FOR
T.O.F.S.

Lemans
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Nottingham
NG1 4JA

T.O.F.S
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FOR THE YEAR ENDED 31 DECEMBER 2023

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T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2023

The Trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 December 2023. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" in preparing the annual report and financial statements of the charity.

The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the Charity's governing document, the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard, applicable in the UK and Republic of Ireland published in October 2019.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

2202260 (England and Wales)

Registered Charity number

327735

Registered office

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

Trustees

Duncan Jackson	Chair
John Pearce	Vice-Chair & Treasurer
Drew Bailey	(from 20 April 2023)
Darrell Hill	
Clare Johns	
Sue Lewis-Jones	
Trace Loffman	Secretary
Graham Slater	
Tamasine Swan	
Katrina Tyler	

Chief Executive Officer

Diane Stephens

Independent Examiner

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

Bankers

Caf Bank
25 Kings Hill Avenue
Kings Hill
West Malling
Kent
ME19 4JQ

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STRUCTURE, GOVERNANCE AND MANAGEMENT

Objectives and aims

The principal objective of T.O.F.S. is to improve the lives of individuals (hereinafter referred to as “TOF individuals” or “TOFs”) suffering from tracheo-oesophageal fistula (TOF), oesophageal atresia (OA) and oesophageal and related disorders including the VACTERL Association (hereinafter referred to as “oesophageal disorders”), as well as the families of such TOF individuals.

Oesophageal atresia and tracheo-oesophageal fistula (OA/TOF) are rare congenital conditions of the oesophagus (food pipe) and/or trachea (airway) that affect newborn babies. Babies with OA/TOF need to have intensive neonatal care prior to corrective surgery, normally within days of birth. Some children have to undergo additional surgical interventions later on in their lives. It is now recognised that life-long follow up is essential.

Constitution

T.O.F.S. is a charity which was founded in 1982 and established as a ‘Company Limited By Guarantee and not having a Share Capital’ on October 20th, 1987. T.O.F.S. is registered both at Companies House and with the Charity Commission.

On May 14th 2016, T.O.F.S. held an Extraordinary General Meeting at which revised Articles of Association were adopted, thus replacing in a single document the original (1987) Memorandum of Association and Articles of Association.

This was done with the agreement of the Charity Commission and the revised Articles were lodged in May 2016 with both the Charity Commission and Companies House.

Organisational Structure

The overall direction and management of T.O.F.S. is overseen by the Council of Management of which all Trustees are members, and who are also Directors of the Company. The Council is accountable and legally responsible for the work of the organisation and for ensuring that all aspects of the management and work comply with current legislation. The Council is supported by four members of staff, headed by the CEO, and also by volunteers.

Governance

The Council meets typically four times per year and - as permitted by the Articles of Association - additionally delegates some detail matters to several sub-committees (see also ‘Committee Structure’ paragraph below).

T.O.F.S. is bound by its Articles of Association to hold an AGM. In recent years, as noted above, this was held by videoconference. In addition to the standard agenda items, including presentation of the annual accounts and trustee elections, the opportunity was taken to provide further explanation of T.O.F.S. activities by a series of presentations on key topics (pastoral support, medical liaison, plans for the current year and beyond) to those members who attended. This format was well received and will be retained.

Policies and Documentation

Appropriate policies and procedures are in place to support the effective operation of T.O.F.S. These include, but are not limited to: Governance; Health & Safety; Risk Management; Safeguarding; Financial & Commercial Management; Personnel, Guidance & Training; IT & Data Protection; Communications; Research & Collaboration.

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Risk Management

The Trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud or error.

Risks are reviewed and mitigated by:

- An organisational commitment to standards of good management and operational practice.
- Established policies, which commit to compliance with all relevant legislation and good practice.
- Regular review of all policies and procedures.
- Establishing adequate financial reserves.

Committee Structure

Since 2019, T.O.F.S. has operated with a revised set of sub-committees, each of which has written terms of reference and authority as delegated by the Trustees, and as permitted by the Articles of Association (specifically paragraphs 110-112.) These sub-committees are formally minuted, and chaired by either a Trustee or the CEO. Membership of the sub-committees is drawn from the Trustees, members of staff and other 'family' members of the organisation. At present, there are specific sub-committees and working groups for: Finance; Strategy & Planning; Staff Management & Recruitment; Pastoral Support; Events, Medical Research and Liaison.

Recruitment and Appointment of Trustees

T.O.F.S. welcomes eligible people who have an interest in helping the organisation achieve its objectives by becoming a Trustee. Whilst TOFS members include parents and grandparents of TOF children and Adults born with OA/TOF, T.O.F.S welcomes potential trustees from all walks of life.

The Articles of Association state the eligibility of Trustees, which, in summary, state that those eligible must:

- Be over the age of 18.
- Already be or become members of the organisation.
- Not be undischarged bankrupts.
- Not previously have been removed from trusteeship of a charity by a Court or the Charity Commissioners.
- Not be under a disqualification order under the Company Directors' Disqualification Act 1986.
- Not be disqualified by the Charities Act 1993 (Section 72) from acting as a charity trustee.
- Undertake to fulfil their responsibilities and duties as a trustee of T.O.F.S. in good faith and in accordance with the law and within the objectives of T.O.F.S.
- Not have financial interests in conflict with those of T.O.F.S. (either in person or through family or business connections) except where formally notified in a conflict of interest statement.

To ensure Trustees are fully competent, T.O.F.S. will:

- Provide an up-to-date Trustee Induction Pack.
- Support induction, in a manner tailored to the experience of the individual, by the use of a 'buddy' system whereby each new Trustee is guided by an experienced Trustee or recently retired Trustee.
- Provide access to and, where appropriate, cover the costs of induction training.
- Conduct de-briefing of retiring Trustees in order to review, and amend where necessary, the Induction of new Trustees.
- Provide a job description for honorary officers.

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Staff Recruitment

There was some restructuring of staff roles in the second half of 2023 when T.O.F. S. had vacancies for two part-time positions, previously held by membership support and communications worker Crystal Brook, and event manager and administrator Claire Stewart. Key responsibilities within these part time roles were amalgamated to create one full time position for a membership, communication and events officer. Sarah Winspear (who has a family member born with OA/TOF) was recruited into the role in October 2023.

The charity continues to be supported by administrator Jayne Allitt and digital communications lead, Peter Browne. Out of the small staff team, which includes CEO Diane Stephens, two of the team members have a personal connection with OA/TOF. T.O.F.S. continued to adopt a hybrid working model for employees. This approach allows flexibility and widens the talent pool during recruitment. Employees can work both remotely and in-office, optimising productivity for the benefit of members.

Strategic Direction

In 2023, T.O.F.S. continued with its three-pronged approach to its activities and the benefits delivered to its members, namely:

- Near-term benefit: information and pastoral support to members, both families and Adult TOFs.
- Long-term benefit: engagement with relevant healthcare professional bodies, clinicians and researchers.
- Sustainable operational effectiveness.

Delivery of objectives in 2023

Pastoral support and information exchange

Pastoral support and information exchange have traditionally been the core activities of T.O.F.S., and 2023 was no exception. T.O.F.S. continued with a digital service model for events to allow access for as many OA/TOF patients and their families as possible. For the first time since the pandemic, T.O.F.S also organised two in-person information events over the year, one of which was specifically for the OA/TOF adult community. T.O.F.S. continued to supply information and support both to new members and associates, (220 in 2023), and to existing TOF parents/carers, adults born with OA/TOF and health professionals through leaflets, brochures, and postcards. The Adult TOF Working Group (ATWG) and the Pastoral Support Sub-Committee (PS s/c) were closely involved in developing and adding new resources throughout the year.

The T.O.F.S. website continues to be visited on a frequent basis, predominantly from the UK but also from all over the world. The new look website had been built in-house in 2022 and designed to be much more intuitive and user-friendly for those seeking information about the consequences of being born with OA/TOF. 2023 saw a decrease in visitors to the website, with 40,278 visitors (47,313 in 2022). It should be noted that the website moved from using Universal Analytics to Google Analytics 4 in 2023 and in addition, a cookie control system was implemented on the site to allow users to opt-out from tracking so a true comparison of visitor numbers is difficult.

The ATWG oversaw the development of a new resource for patients with other congenital anomalies in the VACTERL association. This booklet was written and produced to provide information for those born with these rare and complex conditions. It sought to assist healthcare providers understand the additional malformations and how they may impact upon one another. The booklet endorsed the need for multi-disciplinary, collaborative care pathways to improve health outcomes and quality of life (in line with the position paper published by T.OFS in 2021). It was launched at a support and information event that T.O.F.S. ran for the adult OA/TOF community in York in July 2023. The booklet was downloaded 83 times in 2023 and there were 40 requests for hard copies.

The ATWG were also responsible for a medical trauma card which was produced and launched at the GOSH seminar in November. The office distributed 18 of these cards in response to member requests over the last few weeks of 2023.

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T.O.F.S. continued to promote the online digital library for healthcare professionals offering free access to downloadable versions of books, along with other relevant publications. This service was requested by 74 health professionals across a range of disciplines. Most were from the UK (55), with four from Australia, four from Ireland, three from the States, two from Canada and single requests from an additional handful of other countries. All members received a Spring and Summer/Autumn edition of the magazine, 'Chew', written and edited by the CEO and volunteers on the *Chew* Editorial Board. In a change to the *Chew* schedule, the work on the Winter edition was complete by Christmas but wasn't distributed until early 2024.

Office staff continued to signpost and support members via telephone and email with follow-up support calls and emails made to new members who had given permission for the office to do so.

With tremendous support from the OA/TOF community, a successful TOFS Awareness week was held from 26 Feb to 4 March, to coincide with Rare Disease Day.

Seven adults born with OA/TOF submitted their personal story for inclusion in a specially created video resource which was launched and viewed 490 times during Awareness Week and 1616 times over the year. Further videos with full stories of the individuals featured were released in subsequent weeks.

A new digital travel guide was written and made available and downloaded 30 times over the week, and 115 times throughout the year. Members of the ATWG were involved in the publication of a new 'Health passport' resource, urging members to 'Get the facts' about their surgery they had undergone for the condition. There were 91 requests for these during Awareness Week itself and 146 throughout 2023. A fourth little card was produced as part of the 'little card' series, to help support members whilst travelling abroad. There were 64 requests for the little card pack throughout 2023.

Members were asked to bring OA/TOF and our free provision of digital books to the attention of health professionals.

Many members raised the profile of OA/TOF by sharing their stories in regional and national press, and letters were sent to MPs, flagging the need for adequate care at time of transition. OA/TOF-branded car window stickers were made available for members, along with branded bibs and wristbands. There were 109 requests for hard copy resources during 2023 Awareness Week.

Facebook

The T.O.F.S. Facebook group remains a crucial platform for supporting patients and families of those born with OA/TOF. Many members are instrumental in offering the benefit of their experiences to new parents and the Facebook group plays an increasingly supportive and 'real-time' role in the exchange of parents' experiences with their OA/TOF babies and children. The Facebook group gained 294 new members in 2023, bringing its total membership to 4878, with an average of 1401 members active each day.

To better support the Adult TOF community, T.O.F.S. decided several years ago to endorse a Facebook group specifically for Adult and Teen TOFs, which was and still is, run by one of the members of T.O.F.S., and now administrated by one of the Trustees and some of the ATWG members. This provides a useful forum for the growing number of Adult TOF members, whereby they can share information and experiences on issues that continue to affect them. At 31 December 2023, the total membership of this group stood at 829, with an average of 132 members active each day.

Events

T.O.F.S. organised two face-to-face events for members to meet up and gain information and support. The first, in July, was an information seminar specifically for Adults born with OA/TOF and attended by 27 adults. The second, in November, was facilitated by ICH and GOSH, who kindly provided (with no charge) the use of the seminar rooms and refreshments/lunch for attendees. The focus of this information seminar was around improvements in care for OA/TOF patients, and it was attended by 58 members.

The series of online Q&A events giving members the opportunity to hear from leading clinicians and healthcare professionals continued via Zoom. There were five such events, hosted by the Chair of T.O.F.S. Duncan Jackson, along with the CEO or another trustee. Topics covered were mainly paediatric-related: reflux, respiratory, feeding and swallowing issues, physiotherapy in managing respiratory conditions, along with a session for the adult OA/TOF community on GI issues and surgical treatments. T.O.F.S. is very grateful to the expert speakers who gave their

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time freely. These were attended by members mainly from the UK, but also from Australia, USA, South Africa, Argentina, Canada, New Zealand, Italy, States, and Bulgaria. In addition, all of the information sessions were recorded, edited and subtitled and subsequently added to the YouTube channel.

The informal online coffee meet-ups for adults continued and T.O.F.S. facilitated four such meet-ups (in March, April, May and December) with around 29 adults attending over the year.

T.O.F.S. Local Contacts, (TLCs) are a valued group of volunteers, all of whom are experienced TOF parents, who give their valuable time to volunteer for TOFS. In addition to TLC support described below, T.O.F.S. facilitated three 'Talk with TLCs' events during the year. These 'Talk with TLC' sessions offer members the opportunity to engage with each other virtually, in discussion with their peers about various aspects of the OA/TOF condition. Subjects covered included weaning and feeding difficulties, mental health matters and starting nursery, pre-school and school. In total, 30 families were supported by these events, and T.O.F.S. is very grateful to the TLCs who hosted the sessions.

Three TLCs organised local get-togethers in their area, Manchester, South-East of England and Kent. These were attended by 15 families in total. The combination of these events supported a total 260 families and adults over the year.

Finally, all volunteers continue to play an increasingly important role in the support that T.O.F.S. offers new parents, carers and adults. T.O.F.S. continues to benefit from the improved co-ordination of volunteers and the associated support activities, and welcomed five new volunteers, either as TLCs, or on sub-committees or working groups. In addition, some existing volunteers took on new additional roles. T.O.F.S. would not be the organisation it is without the valuable support from TLCs, and volunteer members who assist in many other ways such as contributing to *Chew*, sending out birthday cards, contributing to committees, and helping with fundraising.

As well as supporting via TLC events, some TLCs, are involved in hospital liaison and raise awareness of OA/TOF. Our TLC for Scotland, Bruce Rennie, continued to represent T.O.F.S. on the Expert Advisory Group of the Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS). Naomi Webborn, TLC for South Wales, represented T.O.F.S. at a meeting of the Welsh Diseases Roundtable and at a meeting of the Congenital Anomaly Register and Information Service (CARIS) for Wales in the last quarter of 2023.

There are currently three T.O.F.S. Overseas Contacts (TOCs) one in Jordan, one in Canada and one in New Zealand. All are active in offering support to TOF families within their own country and they share T.O.F.S. knowledge when applicable. This has been mutually beneficial, resulting in translations of some T.O.F.S. leaflets into Arabic. (It should be noted that these Overseas Contacts do not in any legal sense represent T.O.F.S. in these countries; they are - as the name implies - purely our contacts in these countries).

'*The TOF Book*', published in November 2016, continues to sell, although understandably not quite at the level of prior years. Nonetheless, there is evidence that a significant proportion of the new members who joined in the year purchased the book, including overseas members. The fully illustrated '*Soft Food Recipe book*', published in December 2020, continued to provide a useful addition to our publications. We continued to make the facility for both books to be purchased directly from ourselves via our website.

Use of Information Technology (IT)

The use of IT continues to be a powerful tool in support of operations. T.O.F.S. continues to evolve its technological landscape, ensuring that our members receive the best possible support and resources.

T.O.F.S. has made significant strides in leveraging technology to enhance member benefits and streamline operations, and appointed a dedicated Digital Lead staff member in 2021 to drive technology adoption within the charity. This strategic move aims to maximise the advantages of digital solutions for members.

In 2022 T.O.F.S. invested in a new, faster website that provides essential information and now includes an online shop. Members can conveniently order leaflets and books through the website, resulting in a more efficient process for administrative staff.

In the Autumn of 2023, the Digital Development Working Group were responsible for adding the ability for members to purchase T.O.F.S. branded merchandise from the online shop. These items are supplied by a third part supplier.

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T.O.F.S. utilises video conferencing systems to offer live Q&A sessions with medical experts. Members can participate from anywhere, fostering knowledge sharing and support. Additionally, virtual meetups provide a valuable channel for volunteers to connect directly with members who need support.

TOFS extends its reach beyond Facebook and maintains an active presence on Instagram, Twitter, Threads, and TikTok, engaging with community and sharing valuable content.

In 2023 T.O.F.S began testing and investigating the use of artificial intelligence (AI) within its operations. While in the early stages, it's anticipated that AI could enhance efficiency, improve administration and provide personalised experiences for members and T.O.F.S. will closely monitor its impact and adapt accordingly in the future.

Altido Group Ltd of Cheltenham remain our primary bespoke IT service provider and we hereby note our gratitude for their provision of these services at a discounted or free of charge basis. (We note for reasons of transparency that the late Dennis Harvey (who retired as a Trustee during 2022) was the father-in-law of the Altido Managing Director).

Liaison with the medical profession and with the NHS

We continued in our commitment to disseminating information to practitioners from health, education and social care. We continue to be assisted by members in distributing posters to hospitals to display in their local neo-natal wards to increase awareness of T.O.F.S. when new parents and carers most need help.

In 2023, medical conferences were again held in person. T.O.F.S. attended several, including the BSPGHAN (The British Society of Paediatric Gastroenterology, Hepatology and Nutrition) conference, the ESPGHAN conference (The European Society for Paediatric Gastroenterology Hepatology and Nutrition), and the BTS (British Thoracic Society) conference. We attended a paediatric feeding event organised by the Southern Health and Social Trust in Northern Ireland. We were also invited to participate at a joint meeting of AUGIS and the BAPS ChUGS Special Interest Group to consider treatment pathways for adult patients with serious ongoing gastro-intestinal morbidity.

T.O.F.S. continues in its efforts to increase its profile within the medical community. Since 2016, we have had a Medical Advisory Group, which is intended to provide us with a leading group of medical professionals across all relevant disciplines, who can provide advice and guidance, and support our publications with medically approved input. Its Research sub-group continues to support and guide T.O.F.S.' engagement with research studies.

The involvement of T.O.F.S. in research programmes into OA reflects the almost mandatory requirement for relevant patient group support to be given to such projects and where relevant for "the patient voice" and patient perspective to be built into the study's terms of reference. In some instances, this support is characterised purely by endorsement of its relevance and priority to OA patients. In other cases, support may also involve some funding contribution, whilst a research activity may be characterised by more active involvement and/or collaboration with T.O.F.S.

Projects underway or completed and/or published in 2023 that T.O.F.S. is currently supporting and/or endorsing include:

- The GOSH/ICH (Great Ormond Street Children's Hospital/Institute of Child Health) tissue-engineering project (this is investigating the use of stem cells to develop an oesophagus);
- A study into the feeding issues for patients up to the age of 12 months (which is the subject of a PhD degree);
- A PhD research project to research the psychological impact of OA on both patients and their families, and develop some online self-help tools (TaPSOn.) This project is being conducted by a psychologist, who is also an OA survivor;
- A study into the role of social media in support for adults who were born with OA/TOF and their families, which is being led by an academic researcher who was born with the condition;
- A major randomised controlled trial (Treating Oesophageal Atresia to prevent Stricture, TOAST) to investigate whether or not the general use of antacid medicines with all OA babies would be helpful;
- A study (Oesophageal atresia Core outcomes LongTerm, OCELOT) to develop a lifelong relevant 'core outcome set' for OA.

In addition, T.O.F.S. is actively supporting the European Reference Network (ERN) known as ERNICA (ERN for Inherited and Congenital Anomalies) through our membership of EAT (Esophageal Atresia Global Support Groups e.V.) - see also the section below entitled 'Co-operation with other organisations'.

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T.O.F.S. Trustee Graham Slater was until September 2023 a member of the ERNICA Board and of its Coordination Team, and remains a patient representative on the programme's Transition & Adult Care project. Two other members of T.O.F.S. are also engaged in the ERNICA programme.

Finally, we note that since January 2021 T.O.F.S. Trustee Graham Slater has been a Patient & Public Voice partner to the NHS England Clinical Reference Group on Specialised Surgery in Children.

Co-operation with other organisations

During 2023, T.O.F.S. continued its engagement with other UK patient organisations to start collaborative action concerning care for adult patients suffering ongoing morbidity as result of being born with congenital malformations such as OA, and/or other rare conditions acquired in childhood. Efforts are ongoing, to jointly approach relevant medical societies and policy-makers in the NHS to address the absence of specialist care - an issue of growing concern as the number of adult patients requiring such care increases each year.

We also increased our engagement with organisations which support other conditions in the VACTERL spectrum which OA/TOF patients can also suffer from. We attended and presented at associated conferences such as that run by Max's Trust in September and the VACTERL Association Family Event in October.

T.O.F.S. also continued to play a leading role in EAT. This organisation now has member associations in fourteen countries. EAT is a German-registered association, and its involvement is much sought by various international medical working groups, especially those supported by EU funding. As a result, via EAT, T.O.F.S. continues to be actively involved in European collaborative healthcare programmes, and other relevant international initiatives.

EAT's key successes and activities during 2023 were:

- (i) An ongoing and significant commitment to 'ERNICA'.
- (ii) Involvement with EURORDIS (the European Rare Disease organisation), with which T.O.F.S. is indirectly linked by its membership both of EAT and Genetic Alliance (the latter is the umbrella organisation across the UK for all rare disease patient support groups.)
- (iii) Participation in an InoEA (International Network on Esophageal Atresia) study into transition from paediatric to adult care - this study's findings and recommendations were published in 'Nature'.

Expenditure, Funding, Financial Management and Governance

Expenditure

Total expenditure fell a little in 2023, from the £183,848 of 2022 to £171,700. The Trustees had planned for 2023 expenditure to be very similar to 2022, having previously increased greatly from the £131,983 of 2021, and £92,682 of 2020.

The Trustees concluded some time ago that the most effective way to improve support to members and the general community impacted by OA was by having staff in place to generate better information, make that more accessible, and generally co-ordinate activity better. Staff costs in all amounted to some 70% of total expenditure in 2023, and the administration element of this remains low. Indeed, we are now conducting a high proportion of our video-editing, information-preparation and layout in house and have reduced external cash expenditure commensurately. Staff costs turned out a little lower than planned because two staff decided to leave the charity in mid 2023, and their roles were not satisfactorily replaced for approximately three months.

During the year, we held two half-day seminars for members, as explained elsewhere in this report. We are very grateful to Great Ormond Street Hospital / Institute of Child Health who offered their seminar space to T.O.F.S. at no charge for one of these events. The net external cash cost of these seminars was relatively low and the Trustees plan to perpetuate such seminars, partly because of this. However, a great amount of staff and volunteer effort was put into organising and running each. The charity also continued to offer its members a series of online Question-and-Answer events with medical experts. The external cash cost of these events was almost nothing, but each has involved significant staff effort.

The charity adopted virtual meetings in 2020 and – for most of the staff, most of the time - remote working from home via Zoom and Teams. There does not yet appear to be strong reason to revert to traditional face to face meetings. It is likely that we will continue to use these cost-effective options to a great extent. However, the charity retains its one office as an operating base, from which one staff member works. We have searched without success for a materially cheaper alternative office.

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Much of the time spent by T.O.F.S. on engagement with healthcare professionals, their associations and their initiatives is undertaken by volunteers, including some of the Trustees. The volume, impact and importance of this work is far greater than might be inferred from the relatively low sums which the charity has spent on it.

As noted elsewhere in this report, T.O.F.S. attended several UK medical society events in person, with a small exhibition stand. The cost of attending such events can be material, though travel and subsistence is typically the greatest element. However, expenditure in this category was below that of 2022, because the triennial InoEA conference took place in Cincinnati, USA in 2022, and T.O.F.S. had funded several people to attend that.

In 2023, the charity spent some £4,050 on a feasibility study related to a desired T.O.F.S. mobile-phone App for members' use. After considerable staff and volunteer effort, the paid-for initial design resulted in a meaningful costing for development and maintenance. The Trustees stopped the project at this stage, as the projected expense turned out to be substantially higher than initially hoped.

However, the charity spent less in 2023 than in 2022 on newsletters and publications. The biggest impact here was that only two issues of our newsletter *Chew* were paid for in 2023, the costs of the Winter 2023/24 issue having fallen into 2024. Other major new publication resources were added in 2023, but these were made available in soft-copy only and with the preparation work by volunteers and staff at very little external cash cost.

Some years ago, the Trustees decided to designate £20,000 in all to pay for sponsorship of relevant medical research and activities of similar long term "scientific" benefit to the OA/TOF community over several years. The Trustees decided to transfer another £20,000 from general funds to this designated research fund in 2021.

We had expected to pay the last tranche of support for the OCELOT project in 2023, but we were not asked to do so and now anticipate that payment will be made in 2024.

Income

The charity has no ongoing committed income such as grants, etc. The public sector makes no contribution to our work other than Gift Aid on donations from UK-based individuals. Around half of the charity's income arises because of fundraising undertaken by our members and the wider community impacted by OA. Most of the remainder arises because a member has directly donated it in one way or another or most typically encouraged others to do so. This high degree of engagement with members and the OA community is vital to T.O.F.S. and the Trustees are very grateful for it.

The Trustees had feared that the cost-of-living crisis and substantial inflation of 2023 might lead to a reduction in the charity's income. However, underlying income in 2023 ended up very similar to the 2022 level, which has been a pleasant surprise.

In 2023, underlying income reached a record level of £145,943. For reference, underlying income has varied between £111,337 and £142,268 (excluding the exceptional Martin and Pretious legacies and the Forrester Trust donation) over the previous five years. Total income in 2023 included a legacy from the estate of the late Judith Bland, a long-term active supporter and volunteer for T.O.F.S.

The value of donations from companies, clubs and societies such as Rotary clubs, sports clubs, Freemasons' lodges and local faith groups grew significantly in 2023. As a group, the Freemasons are particularly significant supporters of T.O.F.S. In almost every case, such corporate / club donations arise because a member has nominated T.O.F.S. to their employer / club / society.

Several company supporters made donations in 2023 having donated in 2022 or previous years, and the Trustees are very grateful for this. Our most material new supporter was the MJL Golf Day, which donated some £20,000 to T.O.F.S. in 2023, and has promised to donate again in 2024. The Trustees are very grateful to Mandy Lerner for deciding to donate some of the net proceeds of her annual charity Golf Day to the charity.

T.O.F.S. asks members to make a donation in respect of their membership, and many do so, especially upon joining. A significant number make regular monthly donations, and for this, we are very grateful.

The London Marathon remains the largest fundraising event for T.O.F.S., and in 2023 we had seven people raise money for us in this marathon. The leading fundraiser was Ioannis Koletakis who raised a little over £3,000, with four others each raising over £2,000.

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The Great North Run has been a fixture on the T.O.F.S. calendar for some time. In 2023, our five entrants raised an excellent combined total of just over £4,600. For a second year, T.O.F.S. had places in the Ride London-Essex 100 cycle ride. Our three cyclists raised an excellent combined total approaching £3,800.

Many of our younger members took part with their mums and/or dads in our third annual Teddy Toddle, which raised an excellent almost £6,000 in 2023.

The Trustees are most grateful to the people who put so much effort into training for and completing all of the above events, and into raising a great deal of money for the charity.

More traditional fundraising activity, organised by members themselves, raised a little under £30,000. The Trustees are especially grateful to members who organise and undertake so many small-scale events and raise so much for T.O.F.S. We continue to offer them support with fundraising packs, items such as T.O.F.S. branded running vests and a fundraising guide with hints and tips.

The charity continues to take part in "Your Charity Lottery", which is run by a licenced third party operator, with approximately 160 people playing on a weekly basis to benefit T.O.F.S.. We also repeated our self-organised large online raffle which was held close to Easter, using (mostly) donated prizes.

Income from the sale of the two books published by T.O.F.S. has remained at a useful level. The charity's online shop has been expanded to offer the books with relatively little administrative load, and also to allow members to easily order the many free-of-charge leaflets, badges, etc. Late in 2023, the T.O.F.S. online shop started to offer various items of T.O.F.S. branded merchandise via partner company Printfull. It is expected that a small margin will result.

Lastly, we note e-cards. In 2023 for the third time, TOFS offered members the chance to send one of a range of selected TOFS electronic Christmas Cards – and to donate to TOFS. The amount raised during Winter 2023-2024 rose to approximately £1100, we are hopeful of further growth in future.

Financial Management

The Trustees have delegated most of the charity's financial management to the Treasurer, who works with a Financial Sub-Committee (FSC). The FSC had held its normal half-yearly meetings in 2023, to review expenditure and incomes, to monitor progress against budgets and to recommend budgets for ratification by the whole Council of Management of T.O.F.S..

On a day-to-day basis, the charity uses a commercial book-keeping system and produces monthly internal updates. The Treasurer and FSC normally produce reports for the Trustees several times per year, typically quarterly. The Fundraising Working Group meets much more frequently than the FSC and reports to the FSC.

Financial Review and Reserves policy

Like other charities, T.O.F.S. requires reserves in order to operate in the short term and to satisfy legal obligations in the event of the end of funding, a major reduction of funding or a delay in further funding becoming available. In the event of having to close the charity, the reserves would enable proper notice to be given to the beneficiaries and staff and for all legally due payments to be made to staff, volunteers and the organisations with which we do business. In view of the great uncertainties arising from the COVID-19 pandemic, in 2020 the Trustees raised the minimum level of reserves to an amount sufficient to cover all normal operating expenses for a full year. The reserves policy has not been changed since. At the end of 2023, T.O.F.S. has significantly more in reserves than our policy demands, however the apparent excess is very likely to reduce as it is expected that expenditure will exceed the income that can reasonably be anticipated for the next couple of years.

Investment policy and objectives:

T.O.F.S. continues to hold current bank accounts with Lloyds Bank Ltd and CAF Bank Ltd (a part of the Charities Aid Foundation.) For accepting payments and donations it also has accounts with PayPal, Amazon Smile (which closed during 2023), Facebook (which started to make payments to TOFS via Paypal rather than directly during 2023), Just Giving, Peoples' Fundraising, BOPP, and most recently Givestar. TOFS also has an account with "In memoriam" donations website Much Loved.

T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2023

The current “investment” policy was adopted in February 2018. This enables (but does not commit) T.O.F.S. to invest up to approximately half of its apparently-excess reserves in risky assets – in pursuit of a meaningful return – via vehicles such as charity-specific diversified pooled investment funds with reputable financial institutions. However (in view of the uncertain/troubling investment horizon), the Trustees decided upon the recommendation of the FSC to continue to hold all reserves as cash in FSCS-protected savings accounts. For the whole of 2023, T.O.F.S. has had savings accounts with Cambridge and Counties Bank, Mansfield Building Society, Hampshire Trust Bank, Redwood Bank and Virgin Money.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by order of the Council on 18 April 2024 and signed on its behalf by:

D Jackson (Chair)

INDEPENDENT EXAMINER'S REPORT
TO THE TRUSTEES OF T.O.F.S.

I report to the Charity Trustees on my examination of the accounts of the company, for the year ended 31 December 2023 set out on pages 13 to 21.

Responsibilities and basis of report

As the Charity Trustees of the company, (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your company's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. Accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. The accounts do not accord with those records; or
3. The accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
4. The accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)]

I have no concerns and have come across no other matters in connection with the examinations to which attention should be drawn in this report, in order to enable a proper understanding of the accounts to be reached.

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

April 2024

T.O.F.S.
STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2023

		Unrestricted funds		Year Ended 31.12.23	Year Ended 31.12.22
		General fund £	Designated funds £	Total funds £	Total funds £
	Notes				
INCOME AND ENDOWMENTS FROM:					
Donations and legacies	2	125,617	-	125,617	135,789
Other trading activities	3	14,846	-	14,846	13,175
Investments	4	9,302	-	9,302	2,815
Total income and endowments		149,765	-	149,765	151,779
EXPENDITURE ON:					
Raising funds	5	1,811	-	1,811	5,134
Charitable activities	6	167,080	-	167,080	175,938
Other	7	2,809	-	2,809	2,776
Total expenditure		171,700	-	171,700	183,848
NET (EXPENDITURE)		(21,935)	-	(21,935)	(32,069)
Transfers between funds					
		-	-	-	-
Net movement in funds		(21,935)	-	(21,935)	(32,069)
Reconciliation of funds					
TOTAL FUNDS BROUGHT FORWARD		292,748	14,726	307,474	339,543
TOTAL FUNDS CARRIED FORWARD		270,813	14,726	285,539	307,474

The notes form part of these financial statements

T.O.F.S. – COMPANY NUMBER 2202260
BALANCE SHEET
AT 31 DECEMBER 2023

		Unrestricted funds		Year Ended 31.12.23	Year Ended 31.12.22
	Notes	General fund £	Designated funds £	Total funds £	Total funds £
FIXED ASSETS					
Tangible assets	12	-	-	-	-
Investments	14	-	-	-	50,000
		-	-	-	50,000
CURRENT ASSETS					
Stock		6,980	-	6,980	4,044
Debtors: amounts falling due within one year	13	13,555	-	13,555	7,114
Investments	14	238,167	-	238,167	197,051
Cash at bank		18,766	14,726	33,492	53,761
		277,468	14,726	292,194	261,970
CREDITORS					
Amounts falling due within one year	15	6,655	-	6,655	4,496
NET CURRENT ASSETS		270,813	14,726	285,539	257,474
TOTAL ASSETS LESS CURRENT LIABILITIES		270,813	14,726	285,539	307,474
NET ASSETS		270,813	14,726	285,539	307,474
FUNDS	16				
General fund				270,813	292,748
Designated funds				14,726	14,726
TOTAL FUNDS				285,539	307,474

The notes form part of these financial statements

T.O.F.S. – COMPANY NUMBER 2202260
BALANCE SHEET - CONTINUED
AT 31 DECEMBER 2023

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2023.

The trustees have not required the charitable company to obtain an audit of its financial statements for the year ended 31 December 2023 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Section 386 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial period and of its surplus or deficit for each financial period in accordance with the requirements of Section 394 and Section 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies' regime.

The financial statements were approved by the Council of Management on 18 April 2024 and were signed on its behalf by:

D Jackson (Chair) – Trustee

J Pearce (Vice-Chair & Treasurer) – Trustee

T Loffman (Company Secretary) - Trustee

The notes form part of these financial statements

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

1. ACCOUNTING POLICIES

Basis of preparing the financial statements and assessment of going concern

TOFS is a private charitable company limited by guarantee incorporated in England within the UK. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 1 of these financial statements. The nature of the charity's operations and principal activities are stated on page 2 of these financial statements.

The charity constitutes a public benefit entity as defined by FRS102. The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS102), the Charities Act 2011, the Companies Act 2006 and UK Generally Accepted Practice.

The financial statements are prepared on a going concern basis under the historical cost convention. The financial statements are presented in sterling which is the functional currency of the charity and rounded to the nearest £. The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

Income

Voluntary income is received by way of donation and gifts and is included in full in the Statement of Financial Activities when received. The value of services provided by volunteers has not been included.

Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with the use of resources.

Tangible Fixed Assets

Depreciation is provided at the following annual rate to write off each asset over its estimated useful life:

Office equipment	33% on cost
------------------	-------------

From January 2012, the Trustees decided to write off the cost of office equipment in full in the year of purchase

Stocks

Stock is valued at the lower of cost and estimated selling price.

Current asset investments

The charity holds cash on deposit for investment purposes, in order to obtain a better rate of return, thereby increasing their income enabling them to meet their objects.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Debtors and Creditors

Debtors and Creditors receivable and payable within one year are recorded at transaction price.

Cash at Bank

The charity holds sufficient funds in order to meet its short-term cash commitments as they fall due.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees. Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes. Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

2. DONATIONS AND LEGACIES

	2023	2022
Donations:		
Charitable Trusts, Clubs and Corporations	32,508	23,834
Individuals	2,632	8,810
In Memoria	8,801	1,724
Members and Friends	28,463	30,261
London Marathon/Great North Run/Teddy Toddle/Ride London 100	29,717	45,850
Other	23,496	25,310
	125,617	135,789

- Other donations and gifts include donations made by members in respect of their membership.
- Members and Friends donations are made as a result of events run by them to raise funds for TOFS.
- London Marathon, Great North Run, Teddy Toddle and Ride London are special cases of fundraising by members for TOFS.

3. INCOME FROM OTHER TRADING ACTIVITIES

	2023	2022
Sale of TOFS goods	6,027	5,969
TOFS fundraisers and raffles	8,819	7,206
	14,846	13,175

4. INVESTMENT INCOME

Interest receivable	9,302	2,815
	9,302	2,815

5. COSTS OF RAISING FUNDS

Opening stock	4,044	6,182
Purchases	769	-
Closing stock	(6,980)	(4,044)
	(2,167)	2,138
Just Giving subscription	216	216
London Marathon / Great North Run/ Ride London	3,762	2,780
	1,811	5,134

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

6. CHARITABLE ACTIVITIES

	2023	2022
Pastoral support and information exchange:		
Newsletters	7,771	12,091
Gifts and entertaining children	-	785
Event costs	2,859	-
Telecommunications	1,860	1,699
Printing, postage, stationery, fundraising costs and publicity	8,331	7,598
Support costs (note 8)	109,700	111,686
	130,521	133,859
Medical liaison, research and co-operation:		
Projects - Medics to INoEA / Medical and Hospital Liaison	3,100	5,913
Research costs	-	10,249
Awareness week and other	70	326
Support costs	32,770	24,518
Projects European Collaboration / EAT	619	1,073
	36,559	42,079
	167,080	175,938

7. OTHER COSTS

	2023	2022
Accountancy and professional fees	2,809	2,776

8. SUPPORT COSTS

	Pastoral support & information exchange	Medical liaison research and co-operation	2023 TOTAL	2022 TOTAL
Wages	98,119	29,308	127,427	123,085
Finance	91	29	120	243
Information Technology	6,685	1,997	8,682	5,079
Office accommodation	4,201	1,255	5,456	5,398
Travel and sundry	604	181	785	2,399
	109,700	32,770	142,470	136,204

Support costs have been allocated to the activities based on time spent.

9. NET INCOMING RESOURCES

	2023	2022
Net resources are stated after charging:		
Independent examiner's fees	1,914	1,950
Payroll Administration	571	523

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2023 nor for the year ended 31 December 2022.

Trustees' Expenses

Six (2022 – 2) of the trustees received reimbursed expenses in the period of £4,129 (2022- £2,017). The expense reimbursements were dominated by the cost £2,081 (2022 £903) of two computers and associated items purchased by a Trustee for use by our staff. £94 (2022 – £458) of their travel expenses were donated back to TOFS by the Trustees.

11. STAFF COSTS

The average number of full time equivalent employees during the period was 3.59 (2022 – 3.7)

No employee received total employee benefits of more than £60,000.

The total staff costs and employee benefits were as follows:

	<u>31.12.23</u>	<u>31.12.22</u>
	£	£
Wages and Salaries	115,266	112,692
Social Security Costs	5,088	4,921
Pension Costs	7,073	5,472
	127,427	123,085

12. TANGIBLE FIXED ASSETS

	<u>Office Equipment</u>
	£
COST	
At 1 January 2023	3,944
Additions/(Disposals)	-
At 31 December 2023	3,944
DEPRECIATION	
At 1 January 2023	3,944
Charge for the year	-
At 31 December 2023	3,944
NET BOOK VALUE	
At 31 December 2023	-
At 31 December 2022	-

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023	2022
	£	£
Accounts receivable	-	-
Prepayments and other debtors	11,541	4,029
Gift Aid	2,014	3,085
	13,555	7,114

14. CASH HELD FOR INVESTMENTS

	2023	2022
Current asset investments	238,167	197,051
Fixed asset investments	-	50,000
	238,167	247,051

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

Accountancy	1,914	1,950
Social Security & other taxes	2,831	2,347
Accruals	1,910	199
	6,655	4,496

16. MOVEMENT IN FUNDS

	<u>At 1.1.23</u>	<u>Net Movement</u>	<u>Transfers</u>	<u>At 31.12.23</u>
	£	<u>in funds</u>	<u>between funds</u>	£
Unrestricted funds				
General Fund	292,748	(21,935)	-	270,813
Designated Fund - Medical research	14,726	-	-	14,726
Projects & resources	-	-	-	-
TOTAL FUNDS	307,474	(21,935)	-	285,539

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Gains and losses	Movement in funds
Unrestricted funds				
General Fund	149,765	171,700	-	(21,935)
Designated Fund – Medical research	-	-	-	-
Projects and resources	-	-	-	-
TOTAL FUNDS	149,765	171,700	-	(21,935)

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

16. MOVEMENT IN FUNDS CONTINUED....

	<u>At 1.1.22</u>	<u>Net Movement</u>	<u>Transfers</u>	<u>At 31.12.22</u>
	£	<u>in funds</u>	<u>between funds</u>	£
Unrestricted funds				
General Fund	312,629	(19,881)	-	292,748
Designated Fund – Medical research	24,975	(10,249)	-	14,726
Projects & resources	1,939	(1,939)	-	-
TOTAL FUNDS	339,543	(32,069)	-	307,474

Net movement in funds, included in the above are as follows:

	<u>Incoming</u>	<u>Resources</u>	<u>Gains and</u>	<u>Movement</u>
	<u>resources</u>	<u>expended</u>	<u>losses</u>	<u>in funds</u>
Unrestricted funds				
General Fund	151,779	171,660	-	(19,881)
Designated Funds – Medical research	-	10,249	-	(10,249)
Projects and resources	-	1,939	-	(1,939)
TOTAL FUNDS	151,779	183,848	-	(32,069)

The research designated fund was created in 2013. The Trustees added to this in 2014. A total of £40,000 of reserves has now been designated to support relevant medical research work, over several years. In 2019 the Trustees created an additional designated fund for “Projects and Additional Resources” – to cover principally additional staff costs over the subsequent couple of years. The trustees closed this latter fund during 2022.

17. RELATED PARTY TRANSACTIONS.

During the year, TOFS has bought IT services amounting to £1,228 (2022 - £3,059) from Altido (formerly CRM Labs). The managing director of this firm is the son-in-law of the late Dennis Harvey, who served as a Trustee until March 2022.

During this year, some of the expenses reimbursed to Trustees were donated back to the Charity, which totalled £94 (2022 - £458).

18. PENSION CONTRIBUTIONS

The charity operates a defined contribution scheme. The assets are managed independently of the charity and contributions are charged to the Statement of Financial Activities in the period they are made. The charge for the year was £7,073 (2022 - £5,472).

T.O.F.S.
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2023

	Year Ended 31.12.2023		Year Ended 31.12.2022	
	£	£	£	£
Donations				
Charitable Trusts, Clubs and Corporations	32,508		23,834	
Individuals	2,632		8,810	
In Memoria	8,801		1,724	
Members and Friends	28,463		30,261	
London Marathon, Great North Run, Teddy Toddle and Ride London 100	29,717		45,850	
Other	23,496		25,310	
		125,617		135,789
Other income				
Sale of TOFS Goods	6,027		5,969	
Interest	9,302		2,815	
TOFS Fundraisers and raffles	8,819		7,206	
		24,148		15,990
Total Income		149,765		151,779
Cost of TOFS Goods Sold				
Opening stock	4,044		6,182	
Purchases	769		-	
Closing stock	(6,980)		(4,044)	
		(2,167)		2,138
Just Giving subscription		216		216
London Marathon / Great North Run / Ride London		3,762		2,780
		1,811		5,134
Fundraising, Publicity & Co-operation				
Newsletters	7,771		12,091	
Printing, postage, stationery, fundraising costs & publicity	8,331		7,598	
Cooperation with other organisations	619		1,073	
Liaison with the medical profession	3,170		6,239	
		19,891		27,001
Central costs				
Wages, social security & pension costs	127,427		123,085	
Accountancy	2,809		2,776	
Telecommunications	1,860		1,699	
		132,096		127,560

This page does not form part of the statutory financial statements

T.O.F.S.
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2023

	Year Ended 31.12.2023		Year Ended 31.12.2022	
	£	£	£	£
Other Operating costs				
Event expense	2,859		-	
Gifts and entertaining children	-		785	
Travel and meeting	81		1,143	
Rent and Insurance	5,456		5,398	
Research, Recruitment and Sundry	704		11,505	
Computer costs	8,682		5,079	
Bank charges	120		243	
Bad Debts	-		-	
	_____	17,902	_____	24,153
		_____		_____
Total Expenditure		171,700		183,848
		=====		=====
NET (EXPENDITURE)		(21,935)		(32,069)
Funds brought forward		307,474		339,543
		_____		_____
Funds carried forward		285,539		307,474
		=====		=====

TOFS

England & Wales - Charity number 327735

Accounts

REGISTERED COMPANY NUMBER: 2202260 (England and Wales)
REGISTERED CHARITY NUMBER: 327735

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022
FOR
T.O.F.S.

Lemans
29 Arboretum Street
Nottingham
NG1 4JA

T.O.F.S
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FOR THE YEAR ENDED 31 DECEMBER 2022

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T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2022

The Trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 December 2022. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" in preparing the annual report and financial statements of the charity.

The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the Charity's governing document, the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland published in October 2019.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

2202260 (England and Wales)

Registered Charity number

327735

Registered office

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

Trustees

Duncan Jackson	Chair	
John Pearce	Vice-Chair & Treasurer	
Dennis Harvey		(resigned 31 March 2022)
Darrell Hill		
Clare Johns		
Sue Lewis-Jones		
Trace Loffman	Secretary	(appointed 31 March 2022)
Graham Slater	Secretary	(resigned 31 March 2022)
Tamasine Swan		
Katrina Tyler		(appointed 31 March 2022)

Chief Executive Officer

Diane Stephens

Independent Examiner

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

Bankers

Caf Bank
25 Kings Hill Avenue
Kings Hill
West Malling
Kent
ME19 4JQ

T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2022

STRUCTURE, GOVERNANCE AND MANAGEMENT

Objectives and aims

The principal objective of T.O.F.S. is to improve the lives of individuals (hereinafter referred to as "TOF individuals" or "TOFs") suffering from tracheo-oesophageal fistula (TOF), oesophageal atresia (OA) and oesophageal and related disorders including the VACTERL Association (hereinafter referred to as "oesophageal disorders"), as well as the families of such TOF individuals.

Oesophageal atresia and tracheo-oesophageal fistula (OA/TOF) are rare congenital conditions of the oesophagus (food pipe) and/or trachea (airway) that affect newborn babies. Babies with OA/TOF need to have intensive neonatal care prior to corrective surgery, normally within days of birth. Some children have to undergo additional surgical interventions later on in their lives. It is now recognised that life-long follow up is essential.

Constitution

T.O.F.S. is a charity which was founded in 1982 and established as a 'Company Limited By Guarantee and not having a Share Capital' on October 20th, 1987. T.O.F.S. is registered both at Companies House and with the Charity Commission.

On May 14th 2016, T.O.F.S. held an Extraordinary General Meeting at which revised Articles of Association were adopted, thus replacing in a single document the original (1987) Memorandum of Association and Articles of Association. This was done with the agreement of the Charity Commission and the revised Articles were lodged in May 2016 with both the Charity Commission and Companies House.

Organisational Structure

The overall direction and management of T.O.F.S. is overseen by the Council of Management of which all Trustees are members, and who are also Directors of the Company. The Council is accountable and legally responsible for the work of the organisation and for ensuring that all aspects of the management and work comply with current legislation. The Council is supported by four members of staff, headed by the CEO, and also by volunteers.

Governance

The Council meets typically four times per year and - as permitted by the Articles of Association - additionally delegates some detail matters to several sub-committees (see also 'Committee Structure' paragraph below).

T.O.F.S. is bound by its Articles of Association to hold an AGM. In 2022, as noted above, this was held by videoconference. In addition to the standard agenda items, including presentation of the annual accounts and trustee elections, the opportunity was taken to provide further explanation of T.O.F.S. activities by a series of presentations on key topics (pastoral support, medical liaison, plans for the current year and beyond) to those members who attended. This format was well received and will be retained in 2023.

Policies and Documentation

Appropriate policies and procedures are in place to support the effective operation of T.O.F.S. These include, but are not limited to: Governance; Health & Safety; Risk Management; Safeguarding; Financial & Commercial Management; Personnel, Guidance & Training; IT & Data Protection; Communications; Research & Collaboration.

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Risk Management

The Trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud or error.

Risks are reviewed and mitigated by:

- An organisational commitment to standards of good management and operational practice.
- Established policies, which commit to compliance with all relevant legislation and good practice.
- Regular review of all policies and procedures.
- Establishing adequate financial reserves.

Committee Structure

Since 2019, T.O.F.S. has operated with a revised set of sub-committees, each of which has written terms of reference and authority as delegated by the Trustees, and as permitted by the Articles of Association (specifically paragraphs 110-112.) These sub-committees are formally minuted, and chaired by either a Trustee or the CEO. Membership of the sub-committees is drawn from the Trustees, members of staff and other 'family' members of the organisation. At present, there are specific sub-committees for: Finance; Strategy & Planning; Staff Management & Recruitment; Pastoral Support; Publications; Conferences & Events; Medical Liaison & Collaboration.

Recruitment and Appointment of Trustees

T.O.F.S. welcomes eligible people who have an interest in helping the organisation achieve its objectives by becoming a Trustee. Whilst TOFS members include parents and grandparents of TOF children and Adults born with OA/TOF, T.O.F.S welcomes potential trustees from all walks of life.

The Articles of Association state the eligibility of Trustees, which, in summary, state that those eligible must:

- Be over the age of 18.
- Already be or become members of the organisation.
- Not be undischarged bankrupts.
- Not previously have been removed from trusteeship of a charity by a Court or the Charity Commissioners.
- Not be under a disqualification order under the Company Directors' Disqualification Act 1986.
- Not be disqualified by the Charities Act 1993 (Section 72) from acting as a charity trustee.
- Undertake to fulfil their responsibilities and duties as a trustee of T.O.F.S. in good faith and in accordance with the law and within the objectives of T.O.F.S.
- Not have financial interests in conflict with those of T.O.F.S. (either in person or through family or business connections) except where formally notified in a conflict of interest statement.

To ensure Trustees are fully competent, T.O.F.S. will:

- Provide an up-to-date Trustee Induction Pack.
- Support induction, in a manner tailored to the experience of the individual, by the use of a 'buddy' system whereby each new Trustee is guided by an experienced Trustee or recently retired Trustee.
- Provide access to and, where appropriate, cover the costs of induction training.
- Conduct de-briefing of retiring Trustees in order to review, and amend where necessary, the Induction of new Trustees.
- Provide a job description for honorary officers.

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Staff Recruitment

There was some restructuring of staff roles in early 2022 with membership support and communications worker Crystal Brook, taking on additional responsibility for TLCs, T.O.F.S.' largest volunteer local contact project. Claire Stewart, (already a local contact volunteer) joined the staff in February 2022, in an event management and administration role. The charity continues to be supported by administrator Jayne Allitt and digital communications lead, Peter Browne. Out of the small staff team, which includes CEO Diane Stephens, three employees work on a part-time basis, and three are also parents of children born with OA/TOF. Based on the experience of the COVID pandemic we have successfully moved to home-based employment for the majority of our staff.

Strategic Direction

In 2022, T.O.F.S. continued with its three-pronged approach to its activities and the benefits delivered to its members, namely:

- Near-term benefit: information and pastoral support to members, both families and Adult TOFs.
- Long-term benefit: engagement with relevant healthcare professional bodies, clinicians and researchers.
- Sustainable operational effectiveness.

Delivery of objectives in 2022

Pastoral support and information exchange

Pastoral support and information exchange have traditionally been the core activities of T.O.F.S., and 2022 was no exception. The global pandemic created the need for increased support amongst the OA/TOF community, and T.O.F.S. has responded by moving to a digital service model for its events. In addition, we continued to supply information and support both to new members and associates, (262 in 2022), and to existing TOF parents/carers, adults born with OA/TOF and health professionals through leaflets, brochures, and postcards for key points of the OA/TOF journey – such as going to nursery/school.

The Digital Development working group oversaw the launch of a new website in January. Built in-house, it was designed to be much more intuitive and user-friendly for those seeking information about the consequences of being born with OA/TOF. Information was categorised into three distinct sections, so that different visitors might navigate the content more easily and find information specifically relevant to them, whether they be parents, adults or medical professionals. The T.O.F.S. website continues to be visited on a frequent basis, predominantly from the UK but also from all over the world. 2022 saw a 12% increase in visitors to the website from 42,212 in 2021 to 47,313 in 2022.

The Adult TOF working group oversaw the launch of a comprehensive Adult OA/TOF management handbook for health professionals. Written by Dr Caroline Love, herself an Adult TOF, it was peer-reviewed and endorsed by leading OA/TOF-knowledgeable experts. This substantial work highlights issues faced by adults and teens born with OA/TOF and covers respiratory, gastrointestinal, VACTERL, nutritional and dental complications amongst others. The handbook was launched in mid-April at a conference for paediatric gastroenterologists. During the remainder of 2022, it was accessed by 2,172 visitors to the T.O.F.S. website. In addition, a PDF was made available and downloaded 283 times during 2022.

We continued to promote the online digital library for healthcare professionals offering free access to downloadable versions of our books, along with other relevant publications. This service was requested by 77 health professionals across a range of disciplines. Most were from the UK (55), with nine from Australia, three from Ireland, two from Spain and single requests from an additional handful of other countries. All members received a Spring, Summer and Autumn/Winter editions of our newsletter, 'Chew', written and edited by the CEO and volunteers on the Chew Editorial Board.

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Our office staff (working mainly remotely) continued to support members via telephone and email with follow up support calls and emails made to new members who had given permission for the office to do so. A two-phase membership campaign took part in the second half of 2022 and an important new digital health automated facility was developed to enable members to update their own or their child's health records at any time in respect of OA/TOF and related conditions.

With tremendous support from the OA/TOF community, a successful TOFS Awareness week was held from 28 Feb to 6 March, to coincide with Rare Disease Day. Members were asked to bring OA/TOF to the attention of health professionals and especially to our free provision of digital books for health professionals. There were 21 requests from health professionals from various disciplines during the week.

Many members raised the profile of OA/TOF by sharing their stories in regional and national press, and letters were sent to MPs, flagging the need for adequate care at time of transition. New car window stickers were made available for members, along with branded bibs and wristbands. There were 118 requests for hard copy resources during 2022 Awareness Week.

Facebook

The T.O.F.S. Facebook group continues to play a key part in pastoral support. Many members are instrumental in offering the benefit of their experiences to new parents and the Facebook group plays an increasingly supportive and 'real-time' role in the exchange of parents' experiences with their OA/TOF babies and children. The Facebook group gained 265 new members in 2022, bringing its total membership to 4689. To better support our Adult TOF community, we decided several years ago to endorse a Facebook group specifically for Adult and Teen TOFs, which was and still is, run by one of our members, and now administrated by one of our Trustees and some of our Adult TOF working group members. This provides a very useful forum for our growing number of Adult TOF members, whereby they can share information and experiences on issues that continue to affect them. In 2022, TOFS officially linked this Adult Group with the T.O.F.S. Facebook page making a visible connection between the charity and the Facebook Group. At 31 December 2022, the total membership of this group stood at 812, with 47 members having joined during 2022.

Events

In light of the ongoing unpredictability caused by Covid, T.O.F.S. remained cautious about making plans for in-person meetings for members, and plans for a Family and Adult TOF Conference remained on hold. One face-to-face event took place in July with 12 families attending a children's party. The series of online events giving members the opportunity to hear from leading clinicians and healthcare professionals continued via Zoom and we held our first interactive adult virtual event, offering adults the opportunity to hear from speakers and to attend breakout rooms to chat informally with their peers. This was attended by 27 members. Some members attending the meeting were enthusiastic about holding informal online meet-ups and T.O.F.S. facilitated the first of these meet-ups with 11 adults attending. There were two information and support online Q&A events, hosted by T.O.F.S.' Chair, Duncan Jackson, along with Vice-Chair John Pearce or CEO Diane Stephens. Members were offered the opportunity to pose pertinent questions in advance of the sessions. We are very grateful to the expert speakers who gave their time freely, and these sessions supported over 148 families and adults over the year.

The 'Talk with TLCs' initiative continued with three events during the year. TOFS Local Contacts, (TLCs) are a valued group of volunteers, all of whom are experienced TOF parents, who give their valuable time to volunteer for TOFS. These 'Talk with TLC' sessions offer members the opportunity to engage with each other virtually, in discussion with their peers about various aspects of the OA/TOF condition. Subjects covered included weaning and feeding difficulties and starting school. In total, 29 families were supported by these events, and we are very grateful to the TLCs who hosted the sessions.

Finally, all volunteers continue to play an increasingly important role in the support that T.O.F.S. offers new parents, carers and adults. We continue to benefit from the improved co-ordination of our volunteers and the associated support activities, and welcomed nine new volunteers, either as TLCs, or on sub-committees or to take part in a newly created Events working group. In addition, some existing volunteers took on new additional roles. We would not be the organisation we are without the valuable support from especially, our TLCs, and our volunteer members who assist in many other ways such as contributing to *Chew*, sending out birthday cards, taking part in committees, and helping with fundraising.

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Our TLC volunteers are all parents with experience of caring for a TOF child on a day-to-day basis. Spread across the UK, TLCs are available to listen, talk and offer support to new TOF parents, organise local informal get-togethers, and take posters and leaflets into hospitals, especially where TOF surgery takes place. Some TLCs have shown further commitment by giving talks on behalf of T.O.F.S. Our TLC for Scotland, Bruce Rennie, represents T.O.F.S. on the Expert Advisory Group of the Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS.) TLCs are offered information on basic listening and counselling and are given support from the staff team. In 2022, three new TLCs were recruited for Oxford, Brighton and South Manchester. Two TLCs organised informal get-togethers over the summer of 2022.

There are currently three T.O.F.S. Overseas Contacts (TOCs) one in Jordan, one in Canada and one in New Zealand. All are active in offering support to TOF families within their own country and they share T.O.F.S. knowledge when applicable. This has been mutually beneficial, resulting in translations of some T.O.F.S. leaflets into Arabic. (It should be noted that these Overseas Contacts do not in any legal sense represent T.O.F.S. in these countries; they are - as the name implies - purely our contacts in these countries.)

'The TOF Book', published in November 2016, continues to sell, although understandably not quite at the level of prior years. Nonetheless, there is evidence that a significant proportion of the new members who joined in the year purchased the book, including overseas members. The fully illustrated 'Soft Food Recipe book', published in December 2020, continued to provide a useful addition to our publications. We continued to make the facility for both books to be purchased directly from ourselves via our website.

Use of Information Technology (IT)

The use of IT continues to be a powerful tool in support of our operations. Facebook remains a very significant means by which members and non-members communicate on OA/TOF matters, and we have increasingly used this form of social media to augment communication with our members. The T.O.F.S. Facebook group membership currently stands at over 5,000 (including the Adult Facebook group) with a substantial number of members from outside the UK and provides instant self-help support amongst its very active participants.

Altido Group Ltd of Cheltenham remain our primary bespoke IT service provider and we hereby note our gratitude for their provision of these services at a discounted or free of charge basis. (We note for reasons of transparency that the late Dennis Harvey (who retired as a Trustee during 2022) was the father-in-law of the Altido Managing Director.)

Liaison with the medical profession and with the NHS

We continued in our commitment to disseminating information to practitioners from health, education and social care. We continue to be assisted by members in distributing posters to hospitals to display in their local neo-natal wards to increase awareness of T.O.F.S. when new parents and carers most need help.

In 2022, medical conferences were again held in person. T.O.F.S. attended several, including the AUGIS (Association of Upper GI Surgeons) conference, the BTS (British Thoracic Society) conference (both of which provide opportunity to continue our efforts to engage more with adult clinicians), and we were invited for one day at the BAPS conference. We also attended the BSPGHAN conference.

T.O.F.S. continues in its efforts to increase its profile within the medical community. Since 2016, we have had a Medical Advisory Group, which is intended to provide us with a leading group of medical professionals across all relevant disciplines, who can provide advice and guidance, and support our publications with medically approved input. A meeting of the group was held by videoconference in February and again in November. In addition its two sub-groups focused respectively on T.O.F.S.' engagement with research and on engagement with international research initiatives and other collaborative activities such as the International Network on Esophageal Atresia (INoEA.)

The involvement of T.O.F.S. in research programmes into OA reflects the almost mandatory requirement for relevant patient group support to be given to such projects and where relevant for "the patient voice" and patient perspective to be built into the study's terms of reference. In some instances, this support is characterised purely by endorsement of its relevance and priority to OA patients. In other cases, support may also involve some funding contribution, whilst a research activity may be characterised by more active involvement and/or collaboration with T.O.F.S.

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Projects underway or completed and/or published in 2022 that T.O.F.S. is currently supporting and/or endorsing include:

- The GOSH/ICH (Great Ormond Street Children's Hospital/Institute of Child Health) tissue-engineering project (this is investigating the use of stem cells to develop an oesophagus);
- A study into the feeding issues for patients up to the age of 12 months (which is the subject of a PhD degree);
- A PhD research project to research the psychological impact of OA on both patients and their families, and develop some online self-help tools (TaPSOn.) This project is being conducted by a psychologist, who is also an OA survivor;
- A study into the role of social media in support for adults who were born with OA/TOF and their families, which is being led by an academic researcher who was born with the condition;
- A major randomised controlled trial (Treating Oesophageal Atresia to prevent Stricture, TOAST) to investigate whether or not the general use of antacid medicines with all OA babies would be helpful;
- A study (Oesophageal atresia Core outcomes LongTerm, OCELOT) to develop a lifelong relevant 'core outcome set' for OA.

In addition, T.O.F.S. is actively supporting the European Reference Network (ERN) known as ERNICA (ERN for Inherited and Congenital Anomalies) through our membership of EAT (Esophageal ATresia Global Support Groups e.V.) - see also the section below entitled 'Co-operation with other organisations'.

T.O.F.S. Trustee Graham Slater is a member of the ERNICA Board and of its Coordination Team, and a patient representative on the programme's OA related work-packages. Two other members of the TOFS Medical Liaison & Research sub-committee are also engaged in the programme.

Finally, we note that since January 2021 T.O.F.S. Trustee Graham Slater has been a Patient & Public Voice partner to the NHS England Clinical Reference Group on Specialised Surgery in Children.

Co-operation with other organisations

During 2022, T.O.F.S. reached out to other UK patient organisations to start collaborative action concerning care for adult patients suffering ongoing morbidity as result of being born with congenital malformations such as OA, and/or other rare conditions acquired in childhood. Efforts are ongoing, to jointly approach relevant medical societies and policy-makers in the NHS to address the absence of specialist care - an issue of growing concern as the number of adult patients requiring such care increases each year.

T.O.F.S. also continued to play a leading role in EAT. This organisation now has member associations in fourteen countries. EAT is a German-registered association, and its involvement is much sought by various international medical working groups, especially those supported by EU funding. As a result, via EAT, T.O.F.S. continues to be actively involved in European collaborative healthcare programmes, and other relevant international initiatives.

EAT's key successes and activities during 2022 were:

- (i) An ongoing and significant commitment to 'ERNICA'.
- (ii) Involvement with EURORDIS (the European Rare Disease organisation), with which T.O.F.S. is indirectly linked by its membership both of EAT and Genetic Alliance (the latter is the umbrella organisation across the UK for all rare disease patient support groups.)
- (iii) Participation in an INoEA (International Network on Esophageal Atresia) study into transition from paediatric to adult care (also see above.)
- (iv) Participation, including presentations and session moderation, at the 2022 International Congress on Esophageal Atresia. See further comment below.

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The 2022 International Congress on Esophageal Atresia organised by INoEA

This congress is held every three years and is the world's only international, multi-disciplinary event held specifically for OA and associated conditions. Over 600 people (either in person or on-line) attended the 2022 congress which was held in October in Cincinnati, USA. EAT's active participation in these congresses is a key success factor, and T.O.F.S. provided six (including four speakers) of the 17 representatives of EAT. T.O.F.S. also encouraged attendance, abstract submission and acceptance of offers to present at the congress, and provided some limited financial support to three clinicians in order to facilitate their travel. Of particular benefit to T.O.F.S. (and to all member associations of EAT) was the increased focus on Transition and Adult Care, and on Quality of Life and the psychological and emotional impact of OA and its consequences on patients and their families. This congress provides unique opportunity for networking with other members of the EAT federation and with clinicians who have a specific interest in OA. The next congress will be in 2025. T.O.F.S. as part of EAT will continue its commitment to working with INoEA in a joint effort to improve outcomes for OA patients and their families.

Funding, Financial Management and Governance

After two years of pandemic-induced uncertainty, the Trustees of T.O.F.S. were looking forward to a more "normal" year in 2022. These hopes were dashed, principally for reasons originating well away from our base in the UK. During mid-year, we feared that soaring inflation and the cost-of-living crisis would act to reduce donations of most types to T.O.F.S. It is a pleasant surprise to report that income in 2022 was substantially higher than we had budgeted for and was indeed a record on an underlying basis. It appears that this is at least, partially due to the many efforts of our fundraising working group.

This increase in income appears to be part of a multi-year trend, which has seen the charity's income more than double over the past ten years. The Trustees interpret this ongoing increase as a sign that our members and the wider community of those impacted by Oesophageal Atresia appreciate what T.O.F.S. does, would like more of it, and are prepared to help fund it.

In line with our 2018 (revised 2021) strategy, T.O.F.S. had budgeted to increase expenditure in 2022, principally with the intention of improving support to members and the OA community generally.

We envisaged spending considerably more than our anticipated income, using excess reserves to facilitate this. The fact that income surprised positively in 2022 meant that the deficit for the year was not as large as had been anticipated.

In 2022, underlying income reached a record level of £142,269. For reference, underlying income has varied between £111,337 and £120,038 (excluding the exceptional Martin and Pretious legacies and the Forrester Trust donation) over the previous five years. Total income in 2022 included an exceptional corporate donation, substantially larger than previous donations from companies, of £9,510. The Trustees are most grateful for this donation from Blackhawk Network.

The majority of the charity's income (about 56% of the total) arises because of fundraising undertaken by our members and the wider community affected by OA. Most of the remaining 44% arises because a member has directly donated it in one way or another or encouraged others to do so. This high degree of engagement with members and the OA community is vital to T.O.F.S. and the Trustees are very grateful for it.

T.O.F.S. asks members to make a donation in respect of their membership, and many do so, especially upon joining. A significant number make regular monthly donations, and for this, we are very grateful.

The London Marathon remains the largest fundraising event for T.O.F.S. In 2022, this was particularly successful, with income about 50% higher than the previous record. Our best ever fundraiser was Ross Jeavons, who successfully achieved some media presence and raised more than £14,500. Our other runners did very well too, with a further five of them each raising in excess of £3,000 each.

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We continue to offer entries for the Great North Run, and this year our four entrants raised an excellent combined total of almost £4,000. We introduced a new event for members to take part in during 2022: the Ride London-Essex 100. T.O.F.S. had three charity places, and a total of £3,500 was raised by our cyclists - a great result.

The Trustees are most grateful to the people who put so much effort into training for and completing these events, and into raising a great deal of money for T.O.F.S.

Another new activity for 2022 was a large online raffle held at Easter, using mostly donated prizes. More significantly, we continue to take part in "Your Charity Lottery", which is run by a licensed third party operator, with approximately 160 people playing on a weekly basis to benefit T.O.F.S.

More fundraising activity was organised by members themselves and raised over £30,000. The Trustees are especially grateful to members who undertake so many small-scale events, and raise so much for T.O.F.S. We continue to offer them support with fundraising packs, items such as T.O.F.S. branded running vests and a fundraising guide with hints and tips.

The value of donations from companies, clubs and societies such as Rotary clubs, sports clubs, Freemasons' lodges and local faith groups has grown in 2022, even excluding the Blackhawk Network's exceptional donation. In almost every case, such corporate donations arise because a T.O.F.S. member has nominated T.O.F.S. to their employer, club or society. As a group, the Freemasons are particularly significant supporters of T.O.F.S.

Income from the sale of the two books published by T.O.F.S. has remained at a useful level in 2022. These books are now sold direct from the T.O.F.S. office, using our own online shop, our previous relationship with Amazon having been problematic.

Total expenditure increased greatly in 2022, as planned. In 2022, this reached £183,848. This can be contrasted with the £131,983 of 2021, £92,682 of 2020, £97,239 of 2019, and the £101,017 spent in 2018.

The major element of the increase was in terms of employing staff. The Trustees concluded some time ago that the most effective way to improve support to members and the general community impacted by OA was by having staff in place to generate better information, make that more accessible, and generally co-ordinate activity better. Staff costs in all, amount to a little under 70% of total expenditure, and the administration element of this remains low.

We held a substantial children's party-style event for members to attend in mid-year. We had hoped to hold more such events, but decided in the light of experience to focus on online events. There was no traditional T.O.F.S. conference in 2022, but this meant a significant saving.

The charity adopted virtual meetings in 2022 and for most of the staff, most of the time, remote working from home via Zoom and Teams. There does not yet appear to be strong reason to revert to traditional face-to-face meetings. It is likely that we will continue to use these cost-effective options.

In 2022, the charity has been able to fully resume our engagement with relevant medical bodies. We attended several UK events in person, with a small exhibition stand. The cost of attending such events can be material, though travel and subsistence is typically the greatest element. Most notably, the triennial INoEA conference took place in Cincinnati, USA in 2022. T.O.F.S. funded three healthcare professionals to attend, each of whom was taking an active part in the conference. The charity also paid for our CEO and a very active volunteer to attend as patient representatives.

Volunteers, including some of the Trustees, undertake much of the time spent on engagement with healthcare professionals, their associations and their initiatives. The volume, impact and importance of this work is far greater than might be inferred from the relatively low sums that the charity has spent on it.

Some years ago, the Trustees decided to designate £20,000 in all to pay for sponsorship of relevant medical research and activities of similar long term "scientific" benefit to the OA/TOF community over several years. The Trustees decided to transfer another £20,000 from general funds to this designated research fund in 2021.

This designated fund was used in 2022 to pay for TOFS' support to the TaPSOn project, and to pay for TOFS' support to the OCELOT project. The fund also covered the cost of sending healthcare professionals to Cincinnati.

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The Trustees have delegated most of the charity's financial management to the Treasurer, who works with a Financial Sub-Committee (FSC.) The FSC had held its normal half-yearly meetings in 2022, to review expenditure and incomes, to monitor progress against budgets and to recommend budgets for ratification by the whole Council of Management of T.O.F.S.

On a day-to-day basis, the charity uses a commercial bookkeeping system and produces monthly Internal updates. The Treasurer and FSC normally produce reports for the Trustees several times per year, typically quarterly. The Fundraising Working Group reports to the FSC.

Financial Review and Reserves policy

Like other charities, T.O.F.S. requires reserves in order to operate in the short term and to satisfy legal obligations in the event of the end of funding, a major reduction of funding or a delay in further funding becoming available. In the event of having to close the charity, the reserves would enable proper notice to be given to the beneficiaries and staff and for all legally due payments to be made to staff, volunteers and the organisations with which we do business. In view of the great uncertainties arising from the COVID-19 pandemic, in 2020 the Trustees raised the minimum level of reserves to an amount sufficient to cover all normal operating expenses for a full year. The reserves policy has not been changed since. At the end of 2022, T.O.F.S. has significantly more in reserves than our policy demands, however the apparent excess is very likely to reduce as it is expected that expenditure will exceed the income that can reasonably be anticipated for the next couple of years.

Investment policy and objectives:

T.O.F.S. continues to hold current bank accounts with Lloyds Bank Ltd and CAF Bank Ltd (a part of the Charities Aid Foundation.) For accepting payments and donations it also has accounts with PayPal, Amazon Smile, Facebook, Just Giving, Peoples' Fundraising and "In memoriam" donations website Much Loved.

The current "Investment" policy was adopted in February 2018. This enables (but does not commit) T.O.F.S. to invest up to approximately half of its apparently-excess reserves in risky assets – in pursuit of a meaningful return – via vehicles such as charity-specific diversified pooled investment funds with reputable financial institutions. However (in view of the uncertain/troubling investment horizon), the Trustees decided upon the recommendation of the FSC to continue to hold all reserves as cash in FSCS-protected savings accounts. For the whole of 2022, T.O.F.S. has had savings accounts with Cambridge and Counties Bank, Mansfield Building Society, Hampshire Trust Bank, Redwood Bank and Virgin Money.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by order of the Council on 20 April 2023 and signed on its behalf by:

D Jackson (Chair)



INDEPENDENT EXAMINER'S REPORT
TO THE TRUSTEES OF T.O.F.S.

I report to the Charity Trustees on my examination of the accounts of the company, for the year ended 31 December 2022 set out on pages 12 to 20.

Responsibilities and basis of report

As the Charity Trustees of the company, (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your company's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. Accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. The accounts do not accord with those records; or
3. The accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
4. The accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)]

I have no concerns and have come across no other matters in connection with the examinations to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

T.O.F.S.
STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2022

		Unrestricted funds		Year Ended 31.12.22	Year Ended 31.12.21
		General fund £	Designated funds £	Total funds £	Total funds £
	Notes				
INCOME AND ENDOWMENTS FROM:					
Donations and legacies	2	135,789	-	135,789	178,035
Other trading activities	3	13,175	-	13,175	8,954
Investments	4	2,815	-	2,815	2,492
Total income and endowments		151,779	-	151,779	189,481
EXPENDITURE ON:					
Raising funds	5	5,134	-	5,134	7,139
Charitable activities	6	163,750	12,188	175,938	122,244
Other	7	2,776	-	2,776	2,600
Total expenditure		171,660	12,188	183,848	131,983
NET (EXPENDITURE)/INCOME		(19,881)	(12,188)	(32,069)	57,498
Transfers between funds					
		-	-	-	-
Net movement in funds		(19,881)	(12,188)	(32,069)	57,498
Reconciliation of funds					
TOTAL FUNDS BROUGHT FORWARD		312,629	26,914	339,543	282,045
TOTAL FUNDS CARRIED FORWARD		292,748	14,726	307,474	339,543

The notes form part of these financial statements

T.O.F.S. – COMPANY NUMBER 2202260
BALANCE SHEET
AT 31 DECEMBER 2022

		Unrestricted funds		Year Ended 31.12.22	Year Ended 31.12.21
	Notes	General fund £	Designated funds £	Total funds £	Total funds £
FIXED ASSETS					
Tangible assets	12	-	-	-	-
Investments	14	50,000	-	50,000	-
		50,000	-	50,000	-
CURRENT ASSETS					
Stock		4,044	-	4,044	6,182
Debtors: amounts falling due within one year	13	7,114	-	7,114	11,564
Investments	14	197,051	-	197,051	251,182
Cash at bank		39,035	14,726	53,761	74,558
		247,244	14,726	261,970	343,486
CREDITORS					
Amounts falling due within one year	15	4,496	-	4,496	3,943
NET CURRENT ASSETS		242,748	14,726	257,474	339,543
TOTAL ASSETS LESS CURRENT LIABILITIES		292,748	14,726	307,474	339,543
NET ASSETS		292,748	14,726	307,474	339,543
FUNDS	16				
General fund				292,748	312,629
Designated funds				14,726	26,914
TOTAL FUNDS				307,474	339,543

The notes form part of these financial statements

T.O.F.S. – COMPANY NUMBER 2202260
BALANCE SHEET - CONTINUED
AT 31 DECEMBER 2022

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2022.

The trustees have not required the charitable company to obtain an audit of its financial statements for the year ended 31 December 2022 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

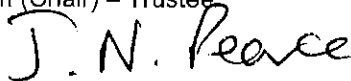
- (a) ensuring that the charitable company keeps accounting records that comply with Section 386 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial period and of its surplus or deficit for each financial period in accordance with the requirements of Section 394 and Section 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies' regime.

The financial statements were approved by the Council of Management on 20 April 2023 and were signed on its behalf by:



D Jackson (Chair) – Trustee



J Pearce (Vice-Chair & Treasurer) – Trustee



T Loffman (Company Secretary) - Trustee

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

1. ACCOUNTING POLICIES

Basis of preparing the financial statements and assessment of going concern

TOFS is a private charitable company limited by guarantee incorporated in England within the UK. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 1 of these financial statements. The nature of the charity's operations and principal activities are stated on page 2 of these financial statements.

The charity constitutes a public benefit entity as defined by FRS102. The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS102), the Charities Act 2011, the Companies Act 2006 and UK Generally Accepted Practice.

The financial statements are prepared on a going concern basis under the historical cost convention. The financial statements are presented in sterling which is the functional currency of the charity and rounded to the nearest £. The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

Income

Voluntary income is received by way of donation and gifts and is included in full in the Statement of Financial Activities when received. The value of services provided by volunteers has not been included.

Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with the use of resources.

Tangible Fixed Assets

Depreciation is provided at the following annual rate to write off each asset over its estimated useful life:

Office equipment	33% on cost
------------------	-------------

From January 2012, the Trustees decided to write off the cost of office equipment in full in the year of purchase

Stocks

Stock is valued at the lower of cost and estimated selling price.

Current asset investments

The charity holds cash on deposit for investment purposes, in order to obtain a better rate of return, thereby increasing their income enabling them to meet their objects.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Debtors and Creditors

Debtors and Creditors receivable and payable within one year are recorded at transaction price.

Cash at Bank

The charity holds sufficient funds in order to meet its short-term cash commitments as they fall due.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees. Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes. Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

2. DONATIONS AND LEGACIES

	2022	2021
Donations:		
Charitable Trusts, Clubs and Corporations	23,834	8,182
Individuals	8,810	6,733
In Memoriam	1,724	77,145
Members and Friends	30,261	25,800
London Marathon/Great North Run/Teddy Toddler/Ride London 100	45,850	33,649
Other	25,310	26,526
	135,789	178,035

- Other donations and gifts include donations made by members in respect of their membership.
- Members and Friends donations are made as a result of events run by them to raise funds for TOFS.
- London Marathon, Great North Run and Teddy Toddler are special cases of fundraising by members for TOFS.

3. INCOME FROM OTHER TRADING ACTIVITIES

	2022	2021
Sale of TOFS goods	5,969	5,911
TOFS fundraisers and raffles	7,206	3,043
	13,175	8,954

4. INVESTMENT INCOME

Interest receivable	2,815	2,492
	2,815	2,492

5. COSTS OF RAISING FUNDS

Opening stock	6,182	7,482
Purchases	-	2,848
Closing stock	(4,044)	(6,182)
	2,138	4,148
Just Giving subscription	216	216
London Marathon / Great North Run	2,780	2,775
	5,134	7,139

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

6. CHARITABLE ACTIVITIES

	2022	2021
Pastoral support and information exchange:		
Newsletters	12,091	10,827
Gifts and entertaining children	785	-
Telecommunications	1,699	1,606
Printing, postage, stationery, fundraising costs and publicity	7,598	6,319
Support costs (note 8)	111,686	83,885
	133,859	102,637
Medical liaison, research and co-operation:		
Projects - Medics to INOEA / Medical and Hospital Liaison	5,913	158
Research costs	10,249	1,940
Awareness week and other	326	329
Support costs	24,518	17,180
Projects European Collaboration / EAT	1,073	-
	42,079	19,607
	175,938	122,244

7. OTHER COSTS

	2022	2021
Accountancy and professional fees	2,776	2,600

8. SUPPORT COSTS

	Pastoral support & information exchange	Medical liaison research and co-operation	2022 TOTAL	2021 TOTAL
Wages	100,930	22,155	123,085	90,396
Finance	198	45	243	217
Information Technology	4,165	914	5,079	4,369
Office accommodation	4,426	972	5,398	4,537
Travel and Sundry	1,967	432	2,399	1,546
	111,686	24,518	136,204	101,065

Support costs have been allocated to the activities based on time spent.

9. NET INCOMING RESOURCES

	2022	2021
Net resources are stated after charging:		
Independent examiner's fees	1,950	1,638
Payroll Administration	523	530

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2022 nor for the year ended 31 December 2021.

Trustees' Expenses

Two (2021 – 3) of the trustees received reimbursed expenses in the period of £2,017 (2021- £3,043). The expense reimbursements were dominated by the cost (some £903) of a computer and associated items purchased by a Trustee for use by our staff. £458 (2021 –£120) of their travel expenses were donated back to TOFS by the Trustees.

11. STAFF COSTS

The average number of full time equivalent employees during the period was 3.7 (2021 – 2.9)

No employee received total employee benefits of more than £60,000.

The total staff costs and employee benefits were as follows:

	<u>31.12.22</u>	<u>31.12.21</u>
	£	£
Wages and Salaries	112,692	85,305
Social Security Costs	4,921	1,794
Pension Costs	5,472	3,297
	123,085	90,396

12. TANGIBLE FIXED ASSETS

	<u>Office Equipment</u>
	£
COST	
At 1 January 2022	3,944
Additions/(Disposals)	-
At 31 December 2022	3,944
DEPRECIATION	
At 1 January 2022	3,944
Charge for the year	-
At 31 December 2022	3,944
NET BOOK VALUE	
At 31 December 2022	-
At 31 December 2021	-

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022	2021
	£	£
Accounts receivable	-	-
Prepayments and other debtors	4,029	2,465
Gift Aid	3,085	9,099
	7,114	11,564

14. CASH HELD FOR INVESTMENTS

	2022	2021
Current asset investments	197,051	251,182
Fixed asset investments	50,000	-
	247,051	251,182

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

Accountancy	1,950	1,638
Social Security & other taxes	2,347	2,051
Accruals	199	254
	4,496	3,943

16. MOVEMENT IN FUNDS

	<u>At 1.1.22</u>	<u>Net Movement</u>	<u>Transfers</u>	<u>At 31.12.22</u>
	£	<u>in funds</u>	<u>between funds</u>	£
Unrestricted funds				
General Fund	312,629	(19,881)	-	292,748
Designated Fund - Medical research	24,975	(10,249)	-	14,726
Projects & resources	1,939	(1,939)	-	-
TOTAL FUNDS	339,543	(32,069)	-	307,474

Net movement in funds, included in the above are as follows:

	Incoming	Resources	Gains and	Movement
	resources	expended	losses	in funds
Unrestricted funds				
General Fund	151,779	171,660	-	(19,881)
Designated Fund – Medical research	-	10,249	-	(10,249)
Projects and resources	-	1,939	-	(1,939)
TOTAL FUNDS	151,779	183,848	-	(32,069)

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

16. MOVEMENT IN FUNDS CONTINUED....

	<u>At 1.1.21</u>	<u>Net Movement</u>	<u>Transfers</u>	<u>At 31.12.21</u>
	£	<u>in funds</u>	<u>between funds</u>	£
Unrestricted funds				
General Fund	235,633	96,996	(20,000)	312,629
Designated Fund – Medical research	6,915	(1,940)	20,000	24,975
Projects & resources	39,497	(37,558)	-	1,939
TOTAL FUNDS	282,045	57,498	-	339,543

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Gains and losses	Movement in funds
Unrestricted funds				
General Fund	189,481	92,485	-	96,996
Designated Funds	-	39,498	-	(39,498)
TOTAL FUNDS	189,481	131,983	-	57,498

The research designated fund was created in 2013. The Trustees added to this in 2014. A total of £40,000 of reserves has now been designated to support relevant medical research work, over several years. In 2019 the Trustees created an additional designated fund for "Projects and Additional Resources" – to cover principally additional staff costs over the subsequent couple of years. The trustees closed this latter fund during 2022.

17. RELATED PARTY TRANSACTIONS.

During the year, TOFS has bought IT services amounting to £3,059 (2021 - £1,541) from Altido (formerly CRM Labs). The managing director of this firm is the son-in-law of the late Dennis Harvey, who served as a Trustee for part of the year.

During this year, some of the expenses reimbursed to Trustees were donated back to the Charity, which totalled £458 (2021 - £120).

18. PENSION CONTRIBUTIONS

The charity operates a defined contribution scheme. The assets are managed independently of the charity and contributions are charged to the Statement of Financial Activities in the period they are made. The charge for the year was £5,472 (2021-£3,297).

T.O.F.S.
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2022

	Year Ended 31.12.2022		Year Ended 31.12.2021	
	£	£	£	£
Donations				
Charitable Trusts	23,834		8,182	
Individuals	8,810		6,733	
In Memoria	1,724		77,145	
Members and Friends	30,261		25,800	
London Marathon, Great North Run, Teddy Toddle and Ride London 100	45,850		33,649	
Other	25,310		26,526	
		135,789		178,035
Other income				
Sale of TOFS Goods	5,969		5,911	
Interest	2,815		2,492	
TOFS Fundraisers and raffles	7,206		3,043	
		15,990		11,446
Total Income		151,779		189,481
Cost of TOFS Goods Sold				
Opening stock	6,182		7,482	
Purchases	-		2,848	
Closing stock	(4,044)		(6,182)	
		2,138		4,148
Just Giving subscription		216		216
London Marathon / Great North Run		2,780		2,775
		5,134		7,139
Fundraising, Publicity & Co-operation				
Newsletters	12,091		10,827	
Printing, postage, stationery, fundraising costs & publicity	7,598		6,319	
Cooperation with other organisations	1,073		-	
Liaison with the medical profession	6,239		487	
		27,001		17,633
Central costs				
Wages, social security & pension costs	123,085		90,396	
Accountancy	2,776		2,600	
Telecommunications	1,699		1,606	
		127,560		94,602

This page does not form part of the statutory financial statements

T.O.F.S.
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2022

	Year Ended 31.12.2022		Year Ended 31.12.2021	
	£	£	£	£
Other Operating costs				
Conference expense	-		-	
Gifts and entertaining children	785		-	
Travel and meeting	1,143		50	
Rent and Insurance	5,398		4,537	
Research, Recruitment and Sundry	11,505		2,470	
Computer costs	5,079		4,369	
Bank charges	243		217	
Bad Debts	-		966	
		24,153		12,609
Total Expenditure		183,848		131,983
NET (EXPENDITURE)/INCOME		(32,069)		57,498
Funds brought forward		339,543		282,045
Funds carried forward		307,474		339,543

TOFS

England & Wales - Charity number 327735

Accounts

REGISTERED COMPANY NUMBER: 2202260 (England and Wales)
REGISTERED CHARITY NUMBER: 327735

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2021
FOR
T.O.F.S.

Lemans
29 Arboretum Street
Nottingham
NG1 4JA

T.O.F.S
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FOR THE YEAR ENDED 31 DECEMBER 2021

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Detailed Statement of Financial Activities	22

T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2021

The Trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 December 2021. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" in preparing the annual report and financial statements of the charity.

The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the Charity's governing document, the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland published in October 2019.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

2202260 (England and Wales)

Registered Charity number

327735

Registered office

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

Trustees

Duncan Jackson	Chair
John Pearce	Vice-Chair & Treasurer
Graham Slater	Secretary
Dennis Harvey	
Darrell Hill	
Clare Johns	(Appointed 20 March 2021)
Sue Lewis-Jones	
Trace Loffman	
Samantha Mann	(Resigned 20 May 2021)
Tamasine Swan	

Chief Executive Officer

Diane Stephens

Independent Examiner

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

Bankers

Caf Bank
25 Kings Hill Avenue
Kings Hill
West Malling
Kent
ME19 4JQ

T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2021

SPECIAL NOTE CONCERNING THE COVID-19 PANDEMIC

Along with the entire voluntary sector, and indeed the country at large, T.O.F.S. activities were for a second year significantly impacted in 2021 by COVID-19.

However, the financial position at year-end was better than anticipated as a result of successful fund-raising initiatives, a large one-off legacy and, as a result of the pandemic, reduced expenditure (see the Financial section of this report for further details). The Trustees remain aware that the ongoing nature of the COVID-19 pandemic, and its consequent impact on the UK's economic climate, has the potential to affect T.O.F.S.'s income in the coming years, and they will continue to monitor the financial position accordingly.

As in 2020 events which T.O.F.S. had planned to operate or attend were cancelled, postponed to 2022, or re-arranged so as to be delivered using technologies such as video-conferencing. More detail on what was achieved in this latter respect is discussed in the relevant section(s) below.

More specifically regarding COVID-19 itself – and particularly as T.O.F.S. supports individuals whose prevailing health condition renders them potentially more vulnerable to corona viruses – we continued to respond by disseminating relevant information to our membership. This was provided either by health professionals on our medical advisory committee or by reference to publicly available sources of COVID-19 information, such as Public Health England.

All internal meetings (including the AGM) were held by video-conference, and staff members worked almost entirely from home. Appropriate risk assessments were carried out. New staff are now joining the charity in home-based roles.

It should also be noted that COVID-19 has had – and indeed continues to exert – an ongoing impact on the work of researchers and collaborative projects with healthcare professionals in which T.O.F.S. is involved or has an interest. Whilst this inevitably has brought some delay to key projects, it is nevertheless re-assuring to state that no projects have actually been cancelled due to resource or financial constraints.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Objectives and aims

The principal objective of T.O.F.S. is to improve the lives of individuals (hereinafter referred to as “TOF individuals” or “TOFs”) suffering from trachea-oesophageal fistula (TOF), oesophageal atresia (OA) and oesophageal and related disorders including the VACTERL Association (hereinafter referred to as “oesophageal disorders”), as well as the families of such TOF individuals.

Oesophageal Atresia and trachea-oesophageal fistula (OA/TOF) are rare congenital conditions of the oesophagus (food pipe) and/or trachea (airway) that affect newborn babies. Babies with OA/TOF need to have intensive neonatal care prior to corrective surgery, normally within days of birth. Some children have to undergo additional surgical interventions later on in their lives. It is now recognised that life-long follow up is essential.

Constitution

T.O.F.S. is a charity which was founded in 1982 and established as a ‘Company Limited By Guarantee and not having a Share Capital’ on October 20th, 1987. T.O.F.S. is registered both at Companies House and with the Charity Commission.

On May 14th, 2016, T.O.F.S. held an Extraordinary General Meeting at which revised Articles of Association were adopted, thus replacing in a single document the original (1987) Memorandum of Association and Articles of Association.

This was done with the agreement of the Charity Commission and the revised Articles were lodged in May 2016 with both the Charity Commission and Companies House.

T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2021

Organisational Structure

The overall direction and management of T.O.F.S. is overseen by the Council of Management of which all Trustees are members, and who are also Directors of the Company. The Council is accountable and legally responsible for the work of the organisation and for ensuring that all aspects of the management and work comply with current legislation. The Council is supported by four members of staff, headed by the CEO, and also by volunteers.

Governance

The Council meets typically four times per year and - as permitted by the Articles of Association - additionally delegates some detail matters to several sub-committees (see also 'Committee Structure' paragraph below).

T.O.F.S. is bound by its Articles of Association to hold an AGM. In 2021, as noted above, this was held by video-conference, where, in addition to the standard agenda items including presentation of the annual accounts and trustee elections, the opportunity was taken to provide further explanation of T.O.F.S. activities by a series of presentations on key topics (pastoral support, medical liaison, plans for the current year and beyond) to those members who attended. This format was well-received and will be retained in 2022.

Policies and Documentation

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

Risk Management

The Trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud or error.

Risks are reviewed and mitigated by:

- An organisational commitment to standards of good management and operational practice
- Established policies which commit to compliance with all relevant legislation and good practice
- Regular review of all policies and procedures
- Establishing adequate financial reserves

Committee Structure

Since 2019 T.O.F.S. has operated with a revised set of sub-committees each of which has written terms of reference and authority as delegated by the Trustees, and as permitted by the Articles of Association (specifically paragraphs 110-112). These sub-committees are formally minuted and chaired by either a Trustee or the CEO and membership of the sub-committees is drawn from the Trustees, members of staff and other 'family' members of the organisation. At present there are specific sub-committees for: Finance; Strategy & Planning; Staff Management & Recruitment; Pastoral Support; Publications; Conferences & Events; Medical Liaison & Collaboration.

Recruitment and Appointment of Trustees

T.O.F.S. welcomes eligible people who have an interest in helping the organisation achieve its objectives by becoming a Trustee. Whilst the majority of TOFS members are parents or grandparents of TOF children, TOFS welcomes potential trustees from all walks of life.

The Articles of Association state the eligibility of Trustees, which, in summary, state that those eligible must:

- be over the age of 18
- already be or become members of the organisation

T.O.F.S
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2021

- not be undischarged bankrupts
- not previously have been removed from trusteeship of a charity by a Court or the Charity Commissioners
- not be under a disqualification order under the Company Directors' Disqualification Act 1986
- not be disqualified by the Charities Act 1993 (Section 72) from acting as a charity trustee
- undertake to fulfil their responsibilities and duties as a trustee of T.O.F.S. in good faith and in accordance with the law and within the objectives of T.O.F.S.
- not have financial interests in conflict with those of T.O.F.S. (either in person or through family or business connections) except where formally notified in a conflict of interest statement

To ensure Trustees are fully competent, T.O.F.S. will:

- Provide an up-to-date Trustee Induction Pack
- Support induction, in a manner tailored to the experience of the individual, by the use of a 'buddy' system whereby each new Trustee is guided by an experienced Trustee or recently retired Trustee
- Provide access to – and where appropriate cover the costs of – induction training
- Conduct de-briefing of retiring Trustees in order to review, and amend where necessary, the Induction of new Trustees
- Provide a job description for honorary officers

Staff Recruitment

In Spring 2021 TOFS started a recruitment drive for a full-time digital and communications specialist to fill a skills gap in the staff team and drive online engagement with our priority areas of work, and TOF parent, Peter Browne, joined the staff team in July, as Digital Communications Lead. One of our objectives in 2021 was a restructuring of the website to give a more intuitive experience for those seeking information about OA/TOF, and a working group was set up to drive this initiative forward. The charity continued to be supported by administrator Jayne Allitt, membership support and communications worker, Crystal Brook and - until September - volunteer and events co-ordinator, Sophie Parkins (all of whom work on a part-time basis). Out of the small staff team (including CEO, Diane Stephens), three employees are also parents of children born with OA/TOF.

Strategic Direction

During 2021 T.O.F.S. carried out a major review of its strategy.

It determined to maintain its three-pronged approach to its activities and the benefits delivered to its members, viz:

- Near-term benefit: information and pastoral support to members – both families and Adult TOFs
- Long-term benefit: engagement with relevant healthcare professional bodies, clinicians and researchers
- Sustainability and improved operational effectiveness: reduce the dependence for certain operational tasks on its Trustees (by extending its network of volunteers and by ensuring operational activities are - wherever possible - carried out by members of staff), and, where possible, streamlining its administrative processes

As 2022 will be the 40th anniversary of T.O.F.S. creation, some specific activities and events were identified for the coming year. The strategy review also developed a vision as to how we ideally would see healthcare for OA/TOF patients being organised in the UK by 2032 and made recommendations on how over the next ten years T.O.F.S. should aim to evolve including what actions T.O.F.S. should undertake in advocating for the necessary changes to UK healthcare.

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As a result of the review, T.O.F.S. revisited its statement of vision, redefining it with an aspiration to 'work towards a world in which those born with OA/TOF live long and healthy lives, unconstrained by the impact of being born with these conditions', Simultaneously, we adopted a minor but significant amend to our strapline to explicitly state our commitment to lifelong support.

Activities and Achievements in 2021

Pastoral support and information exchange

Pastoral support and information exchange have traditionally been the core activities of T.O.F.S., and 2021 was no exception. The global pandemic brought about an even greater need for support for many within the OA/TOF community. We continued to supply information and support both to new members and associates, (271 in 2021), and to existing TOF parents/carers, Adult OA/TOF patients and health professionals with leaflets, brochures, and postcards for key points of the OA/TOF journey – such as going to nursery/school.

Two new information pamphlets were produced during the year, one to coincide with the annual Awareness Week in the Spring, and a new version of the pamphlet for 'Healthcare professionals treating Adults born with OA/TOF' was published in the last quarter of the year.

An online website library was created to offer health professionals free access to downloadable version of our books, along with other relevant publications. All members received a Spring, Summer and Autumn/Winter editions of our newsletter, '*Chew*', written and edited by volunteers on the Chew Editorial Board, along with the CEO.

Our office staff (working mainly remotely) continued to support members via telephone and email with follow up support calls and emails made to new members who had given permission for the office to do so, at time of joining.

2021 Awareness week

With tremendous support from the OA/TOF community, a successful TOFS Awareness week was held from 15 to 21 March, to coincide with the international Swallowing Awareness Day. The over-arching focus this year was mental health support for the OA/TOF community, recognising the often significant impact of OA/TOF on families and adult patients, along with the isolation and challenges brought about by the pandemic. A document signposting members to mental health resources and support was created and shared.

Many members raised the profile of OA/TOF by sharing their stories in regional and national press, and letters were sent to MPs, flagging the need for adequate care at time of transition. 'Introducing solids following repair for OA/TOF' (the pamphlet referred to above) was written by parent and paediatric dietitian, Julia Faulkner, and made available to members to either download or request a hard copy from the office. Branded bibs and wristbands were made available to members. Members were encouraged to download resources from the website, and some members distributed leaflets and information to their GPs and other health professionals.

Members responded generously to an appeal for submissions for a short T.O.F.S. 'movie', featuring patients of all ages talking about different aspects of how the condition affects them. T.O.F.S. member James Currey and family edited and produced the video, and it was widely circulated, with over 400 shares on social media during Awareness week itself. The video remains a valuable resource available on the TOFS website.

In keeping with the mental health theme, a virtual pampering spa event was organised by Sophie Parkins, volunteer and events co-ordinator, raising over £600 for T.O.F.S. Other fundraisers took place around the UK, and with the support of TLCs Bruce Rennie and Laura Bell, T.O.F.S. facilitated a 'Sharing tips/strategies for positive mental health' TLC talk.

Facebook

The T.O.F.S. Facebook group continues to play a key part in pastoral support. Many members are instrumental in offering sound advice and guidance to new parents and the 'Facebook' group plays an increasingly supportive (and 'real-time') role in the exchange of parents' experiences with their OA/TOF babies and children. Three more

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volunteers joined the valuable volunteer moderating team all of whom are experienced TOF parents, to help assist with the administration of running the group. To better support our Adult TOF community, we decided several years ago to endorse a Facebook group specifically for Adult TOFs, (which is run by one of our members, and one of our trustees helps administer). This provides a very useful forum for our growing number of Adult TOF members, whereby they can share information and experiences on issues which continue to affect them.

Events

Due to the ongoing Covid situation, plans for a Family and Adult TOF Conference in October remained on hold. The series of 'online' events using the Zoom platform giving members the opportunity to hear from leading clinicians and healthcare professionals continued, with, this year, additional investment in the Zoom webinar platform. Four of these events were held over the course of the year. They were hosted by T.O.F.S.' Chair, Duncan Jackson, along with Vice-Chair John Pearce, and members were offered the opportunity to pose pertinent questions in advance of the sessions. We are very grateful to the speakers who gave their time freely, and these sessions supported over 150 families/adults over the year.

The 'Talk with TLCs' initiative was launched in 2020 and continued in 2021. TOFS Local Contacts, (TLCs) are a valued group of volunteers, all of whom are experienced TOF parents, who give their valuable time to volunteer for TOFS. This programme offers members the opportunity to engage with each other virtually, in discussion with their peers about various aspects of the OA/TOF condition. In addition to the TLC event on mental health held during Awareness week, three additional events took place, and we are very grateful to the TLCs who hosted the sessions, which supported 50 participants over the course of the year.

Finally, all volunteers continue to play an increasingly important role in the support T.O.F.S. offers new parents, carers and adult patients. We continue to benefit from the improved co-ordination of our volunteers and the associated support activities, and we welcomed eight new volunteers to the team, on sub-committees, moderating Facebook, and to take part in a newly-created Adult TOF working group. In addition, some existing volunteers took on new additional roles. We would not be the organisation we are without the valuable support from, especially, our TLCs, and our volunteer members who assist in many other ways such as contributing to *Chew*, sending out birthday cards, taking part in committees, and helping with fundraising. Our TLC volunteers are all parents with experience of caring for a TOF child on a day-to-day basis. Spread across the UK, TLCs are available to listen, talk and offer support to new TOF parents, organise local informal get togethers, and take posters and leaflets into hospitals, especially where TOF surgery takes place. Some TLCs have shown further commitment by giving talks on behalf of T.O.F.S. Our TLC for Scotland, Bruce Rennie, represents T.O.F.S. on the Expert Advisory Group of the Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS). TLCs are offered information on basic listening and counselling and are given support from the staff team. In 2021 we introduced a TLC and volunteer specific newsletter and celebrated Volunteers Week in June.

There are currently three T.O.F.S Overseas Contacts (TOCs) one in Jordan, one in Canada and one in New Zealand. All are active in offering support to TOF families within their own country and they share T.O.F.S. knowledge when applicable. This has been mutually beneficial, resulting in translations of some T.O.F.S. leaflets into Arabic. [It should be noted that these Overseas Contacts do not in any legal sense represent T.O.F.S in these countries; they are - as the name implies - purely our contacts in these countries.]

'*The TOF Book*', published in November 2016, continues to sell, although understandably not quite at the level of prior years. Nonetheless, there is evidence that a significant proportion of the new members who joined in the year purchased the book, including overseas members. The fully illustrated '*Soft Food Recipe book*', published in December 2020 proved a popular addition to our publications and we enabled the facility for both books to be purchased directly from ourselves with the addition of a shop to our website, eliminating the need to use, and pay Amazon for this service.

Use of Information Technology (IT)

The use of IT continues to be a powerful tool in support of our operations. Facebook remains a very significant means by which members and non-members communicate on OA/TOF matters, and we have increasingly used this form of 'social media' to augment communication with our members. T.O.F.S.' Facebook group membership

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currently stands at approximately 4,000 including a substantial number of members from outside the UK and provides instant self-help support amongst its very active participants.

The T.O.F.S. website continues to be visited on a frequent basis predominantly from the UK but also from all over the world. The Digital Development Working Group met monthly to review the ongoing development of the new site which would be almost complete at the end of 2021 (and subsequently launched to membership in mid-January 2022).

Altido Group Ltd of Cheltenham remain our primary IT service provider and we hereby note our gratitude for their provision of these services at a discounted price. [We note for reasons of transparency that Trustee Dennis Harvey is the father-in-law of the Altido Managing Director.]

Liaison with the medical profession and with the NHS

We continued in our commitment to disseminating information to practitioners from health, education and social care. We continue to be assisted by members in distributing posters to hospitals to display in their local neo-natal wards to increase awareness of T.O.F.S. when new parents and carers most need help.

At the start of 2021, T.O.F.S. had plans in place to attend a number of medical conferences during the year, mainly in order to engage widely with the professionals attending. The Covid-19 restrictions and subsequent 'on-line only' conferences (or complete cancellation) meant that this did not happen.

The involvement of T.O.F.S. in research programmes into OA reflects the almost mandatory requirement for relevant patient group support to be given to such projects and where relevant for "the patient voice" and patient perspective to be built into the study's terms of reference. In some instances, this support is characterised purely by endorsement of its relevance and priority to OA patients. In other cases, support may also involve some funding contribution; on other occasions a research activity may be characterised by more active involvement and/or collaboration with T.O.F.S.

T.O.F.S. continues in its efforts to increase its profile within the medical community. Since 2016 we have had a Medical Advisory Group, which is intended to provide us with a leading group of medical professionals across all relevant disciplines, who can provide advice and guidance, and support our publications with medically approved input. A meeting of the group was held by video-conference in May at which it was agreed to establish two sub-groups, one to focus on our response to requests from researchers for engagement by T.O.F.S. and subsequent monitoring of research projects in which T.O.F.S. is engaged; a second one will focus on engagement with international research initiatives and other collaborative activities such as the International Network on Esophageal Atresia (INoEA).

Projects - underway or planned to commence in 2021 - which T.O.F.S. is currently supporting and/or endorsing include:

- The GOSH (Great Ormond Street Children's Hospital)/ICH tissue-engineering project (this is investigating the use of stem cells to develop an oesophagus - a project featured in the media in August 2018);
- A study into the feeding issues for patients up to the age of 12 months (which is the subject of a PhD degree);
- A Quality of Life PROM (Patient-reported Outcomes Measures) study;
- A PhD research project to research the psychological impact of OA on both patients and their families, and develop some online self-help tools (TaPSOn). This project is being conducted by a psychologist who is also an OA survivor.
- Two smaller higher degree research projects into psychological well-being of adults who were born with OA /TOF, and experiences of transition from paediatric to adult care;
- A study into the role of social media in support for adults who were born with OA/TOF and their families, which is being led by an academic researcher who was born with the condition;
- A study concerning desirable after-care outcomes for OA patients;
- A major randomised controlled trial (**T**reating **O**esophageal **A**tresia to prevent **S**tricture, **TOAST**) to investigate whether or not the general use of antacid medicines with all OA babies would be helpful.
- A study (**O**esophageal atresia **Co**re outcomes **L**ong**T**erm, **OCELOT**) to develop a long-term 'core outcome set' for OA

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In addition, T.O.F.S. is actively supporting the European Reference Network (ERN) known as ERNICA (ERN for Inherited and Congenital Anomalies) through our membership of EAT (The Federation of Esophageal Atresia and Tracheo-esophageal Fistula Support Groups e.V.) - see also the section below entitled 'Co-operation with other organisations'.

T.O.F.S. Trustee Graham Slater is a member of the ERNICA Board and of its Coordination Team, and a patient representative on the programme's OA related work-packages.

Medical professionals and researchers at GOSH (Great Ormond Street Hospital for Children, London) remain committed to ERNICA, even though UK healthcare providers are - as a result of Brexit - no longer able to fully participate in such initiatives.

In 2021 T.O.F.S published its first-ever Position Paper ("TOWARDS A HOLISTIC MODEL FOR THE TREATMENT OF THOSE BORN WITH OESOPHAGEAL ATRESIA (OA) FROM DIAGNOSIS TO TRANSITION AND ADULT CARE") aimed at both relevant medical professionals and the NHS. This paper makes clear recommendations about how healthcare for OA/TOF patients should be delivered - we await further reaction in 2022.

Finally we note that in January 2021 T.O.F.S. Trustee Graham Slater was appointed as a Patient & Public Voice partner to the NHS England Clinical Reference Group on Specialised Surgery in Children.

Co-operation with other organisations

During 2021 T.O.F.S. continued to play a leading role in EAT (the Federation of Esophageal Atresia - Tracheo-oesophageal fistula Support Groups). This organisation now has member associations in fourteen countries.

After ten years in the role Trustee Graham Slater stood down as EAT's Chairman (and as an EAT Board member) in 2021 but will remain as its Special Patient Advisor.

T.O.F.S. member Julia Faulkner (a paediatric dietician who also has first-hand experience as her son is an OA/TOF patient) was elected as an EAT Board member.

EAT is a German-registered association, and its involvement is much sought by various international medical working groups, especially those supported by EU funding. As a result, via EAT, T.O.F.S. continues to be actively involved in European collaborative healthcare programmes, and other relevant international initiatives.

EAT's key successes during 2021 were:

- (i) An ongoing and significant commitment to 'ERNICA' [see also the above paragraph and the above section on 'Liaison with the medical profession']
- (ii) Involvement with EURORDIS (the European Rare Disease organisation), with which TOFS is indirectly linked by its membership both of EAT and Genetic Alliance (the latter is the umbrella organisation across the UK for all rare disease patient support groups).
- (iii) Participation in an INoEA (International Network on Esophageal Atresia) study into transition from paediatric to adult care.

Funding, Financial Management and Governance

At the start of the year, the Trustees of T.O.F.S. agreed a budget which would see 2021 expenditure rise to a level materially above estimated income, something made possible by the Charity's useful reserves position. The main intention – as in 2020 – was to improve near-term pastoral support to our members, by further bolstering our staff resources.

As things turned out, total expenditure in 2021 was £131,983 the charity's highest annual expenditure to date. This can be contrasted with the £92,682 of 2020, £97,239 of 2019, and the £101,017 spent in 2018.

The charity has not made any use at all of the Government's furlough schemes, and indeed has not benefitted at all from any other public-sector pandemic support.

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In February, we received our largest-ever donation, a wonderful gift of some £71,000 from the estate of Mrs June Martin MBE. Her daughter, Vicki Martin (who has been very actively involved in T.O.F.S. in several ways for many years) kindly decided to vary the will to increase the amount left to charities, and T.O.F.S. is just one of the grateful beneficiaries.

This large gift gave the Trustees the confidence to increase expenditure further. In particular, we were able to greatly improve our Digital Communications, recruiting a staff member for this work, which most notably includes a major refresh of the T.O.F.S. website.

We had hoped to run a number of Information events in 2021 (as in pre-pandemic years) for members and their families to attend. But as the year wore on, it became clear that the Covid outlook would make these impossible. And with heavy hearts, we found ourselves unable to run our annual conference, for the second year running. In a typical year, the T.O.F.S. conference constitutes significant expenditure. The substitute members' Q and A sessions on Zoom had a relatively low cost.

Fortunately, we found ourselves able to reinstate full publication of our house magazine *Chew* in 2021, and this was another significant expense.

As in 2020, the charity has adopted virtual meetings and – for most of the staff, most of the time - remote working from home via Zoom and Teams. It is likely that we will continue to use these cost-effective options to a great extent, though some face to face meetings will be reinstated when possible.

In a typical year, we would send some T.O.F.S. representatives along to meetings of relevant professional bodies such as the British Association of Paediatric Surgeons. We have not been able to undertake this activity either, due to the pandemic.

During 2021, some of the charity's leaflets have been updated or reprinted, and the new Adult TOF health issues pamphlet and a new Feeding pamphlet has been published, at a cost of considerable staff time.

Some years ago, the Trustees decided to designate £20,000 in all to pay for sponsorship of relevant medical research and activities of similar long term "scientific" benefit to the OA/TOF community over several years. In 2021, we have continued to use this money mostly for the partial financial support for one PhD research project, which has unfortunately been slowed down in 2021 by the impacts of the pandemic.

In January 2021, in view of a significant number of anticipated research-related initiatives and acknowledging the 2020 year-end financial position of the charity, the Trustees decided to transfer another £20,000 from general funds to this designated research fund.

In late 2019, the Trustees agreed to create another designated fund, called the "Projects and additional resources fund". The £62,000 involved was the same as the sum of the two substantial unanticipated and exceptional income items of preceding years: the 2018 Pretious legacy of £22,000 and the £40,000 Forrester trust donation of 2019. As anticipated, the main use for this has been our now-increased staff resources, specifically those who joined T.O.F.S. as from the start of 2020. The fund was almost completely exhausted by the end of 2021, and the Trustees have decided to close it: the projects and extra resources which it was funding will simply be paid for from ordinary funds going forward.

In 2021, T.O.F.S. recorded total income of £189,481. This was a record, and our underlying income of £118,481 was very close to a record level. This must be judged as a huge success given that underlying income (excluding only the truly exceptional Pretious legacy and the Forrester Trust donation) has varied between £111,337 and £120,038 over the previous 4 years.

It remains the case that the vast majority of the income to T.O.F.S. arises because of fundraising by members or because of a donation from or through a member or some other action a member has taken. The T.O.F.S. Trustees are hugely grateful to them.

A Fundraising Working Group (FRWG) was started in mid 2020. Initially, its aim was to address the significant collapse in income which had been experienced in Spring 2020. Latterly, the FRWG has been trying to build a basis for ongoing increases of T.O.F.S.'s income. During 2021, this group led several fundraising initiatives.

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A repeat of the 2020 Teddy Toddle was hugely successful, raising nearly £14,000.

The charity has teamed with “Your Charity Lottery” to run an ongoing lottery for T.O.F.S. This started at the beginning of 2021 and has raised some £2,500 in 2021 for the charity.

The London Marathon is T.O.F.S.’s highest-profile and largest fundraising activity, as we have purchased Charity “Golden Bond” runners’ entries every year.

In 2021, the Marathon took place in October and all five T.O.F.S. entrants completed the course, raising a great sum in the process. We also had some entrants in the Virtual London Marathon which took place to great fundraising effect on the same day. The Great North Run, the world’s largest half-marathon, happened as scheduled in September. We had obtained Charity places for this, which was also very effective. We are most grateful to the people who put so much effort into training for and completing these events, and into raising a great deal of money for T.O.F.S..

More traditional fundraising activities, organised by members themselves, raised a large proportion of what T.O.F.S. received as Members’ and Friends’ fundraising. The Trustees are especially grateful to members who undertake these events and raise so much for T.O.F.S. We continue to offer them support with fundraising packs, items such as T.O.F.S. branded running vests and a fundraising guide with hints and tips.

Toward the end of 2021, the charity offered its members a service to send T.O.F.S.- branded e-cards, in return for a donation. We had hoped also to offer printed Christmas Cards, but have not yet found a way to offer a quality product at a fair price which we can confidently expect would raise material funds for T.O.F.S.

During 2021, T.O.F.S. has sought to remind members that T.O.F.S. would very much appreciate some more Will gifts. We joined umbrella body “Remember a Charity” to help in this activity.

T.O.F.S. asks members to make a donation in respect of their membership, and many do so, especially upon joining. A significant number make regular monthly donations, and for this, we are very grateful.

The number of donations from companies, clubs and societies such as Rotary clubs, sports clubs, Freemasons’ lodges and local faith groups has continued at a high level in 2021, though two large donations from 2020 were not matched this year. The Trustees regularly ask members to mention T.O.F.S. in the context of their employer’s or club’s charitable efforts, and we believe that this is effective.

Lastly, a significant contributor to income in 2021 (some £6,000) has been the sale of the two books which T.O.F.S. now publishes. These have been available for some time via Amazon. However, it was becoming more and more difficult and expensive to deal with Amazon, and now, T.O.F.S. sell books online directly to members and others from our website.

The Trustees have delegated most of the charity’s financial management to the Treasurer, who works with a Financial Sub-Committee (FSC). The FSC had held quarterly meetings in 2021 (as it did in 2020, though these are normally twice per year) to review expenditure and incomes, to monitor progress against budgets and to recommend budgets for ratification by the whole Council of Management of T.O.F.S. Thus the charity has had three revisions to its budget this year.

On a day-to-day basis, the charity uses a commercial book-keeping system and produces monthly internal updates. The Treasurer and FSC normally produce reports for the Trustees several times per year, typically quarterly.

Public benefit

The Trustees have had due regard to the guidance published by the Charity Commission on public benefit when reviewing the charity’s aims and objectives and in planning future activities.

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FOR THE YEAR ENDED 31 DECEMBER 2021

Financial Review and Reserves policy

Like other charities, T.O.F.S. requires reserves in order to operate in the short term and to satisfy legal obligations in the event of the end of funding, a major reduction of funding or a delay in further funding becoming available. In the event of having to close the charity, the reserves would enable proper notice to be given to the beneficiaries and staff and for all legally due payments to be made to staff, volunteers and the organisations with which we do business. In view of the great uncertainties arising from the COVID-19 pandemic, in 2020 the Trustees raised the minimum level of reserves to an amount sufficient to cover all normal operating expenses for a full year. The reserves policy has not been changed during 2021. At the end of 2021, T.O.F.S. has significantly more in reserves than our policy demands, however some of the apparently excess has been set aside for special projects, as already mentioned.

Investment policy and objectives:

For the whole of 2021, T.O.F.S. has held current bank accounts with Lloyds Bank Ltd and CAF Bank Ltd (a part of the Charities Aid Foundation). For accepting payments and donations it also has accounts with PayPal, Amazon Smile, Facebook, Just Giving, Peoples' Fundraising and Virgin Money Giving. At the end of 2021, Virgin Money Giving closed down, and so TOFS has ceased to use it. During 2021, TOFS started to accept "in memoriam" online donations via Much Loved.

The current "investment" policy was adopted in February 2018. This enables (but does not commit) T.O.F.S. to invest up to approximately half of its apparently-excess reserves in risky assets – in pursuit of a meaningful return – via vehicles such as charity-specific diversified pooled investment funds with reputable financial institutions. However (in view of the uncertain/troubling investment horizon), the Trustees decided upon the recommendation of the FSC to continue to hold all reserves as cash in FSCS-protected savings accounts. The T.O.F.S. savings accounts are with Cambridge and Counties Bank, Mansfield Building Society, Hampshire Trust Bank, Redwood Bank and Virgin Money.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by order of the Council on 31 March 2022 and signed on its behalf by:

D Jackson (Chair)

INDEPENDENT EXAMINER'S REPORT
TO THE TRUSTEES OF T.O.F.S.

I report to the Charity Trustees on my examination of the accounts of the company, for the year ended 31 December 2021 set out on pages 13 to 21.

Responsibilities and basis of report

As the Charity Trustees of the company, (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your company's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. Accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. The accounts do not accord with those records; or
3. The accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
4. The accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)]

I have no concerns and have come across no other matters in connection with the examinations to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

April 2022

T.O.F.S.
STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2021

		Unrestricted funds		Year Ended 31.12.21	Year Ended 31.12.20
		General fund £	Designated funds £	Total funds £	Total funds £
	Notes				
INCOME AND ENDOWMENTS FROM:					
Donations and legacies	2	178,035	-	178,035	113,491
Other trading activities	3	8,954	-	8,954	2,739
Investments	4	2,492	-	2,492	3,808
Total income and endowments		189,481	-	189,481	120,038
EXPENDITURE ON:					
Raising funds	5	7,139	-	7,139	4,523
Charitable activities	6	82,746	39,498	122,244	85,753
Other	7	2,600	-	2,600	2,406
Total expenditure		92,485	39,498	131,983	92,682
NET INCOME/(EXPENDITURE)		96,996	(39,498)	57,498	27,356
Transfers between funds		(20,000)	20,000	-	-
Net movement in funds		76,996	(19,498)	57,498	27,356
Reconciliation of funds					
TOTAL FUNDS BROUGHT FORWARD		235,633	46,412	282,045	254,689
TOTAL FUNDS CARRIED FORWARD		312,629	26,914	339,543	282,045

The notes form part of these financial statements

T.O.F.S. – COMPANY NUMBER 2202260
BALANCE SHEET
AT 31 DECEMBER 2021

		Unrestricted funds		Year Ended 31.12.21	Year Ended 31.12.20
	Notes	General fund £	Designated funds £	Total funds £	Total funds £
FIXED ASSETS					
Tangible assets	12	-	-	-	-
		-	-	-	-
CURRENT ASSETS					
Stock		6,182	-	6,182	7,482
Debtors: amounts falling due within one year	13	11,564	-	11,564	10,006
Investments	14	251,182	-	251,182	213,190
Cash at bank		47,644	26,914	74,558	53,893
		316,572	26,914	343,486	284,571
CREDITORS					
Amounts falling due within one year	15	3,943	-	3,943	2,526
NET CURRENT ASSETS		312,629	26,914	339,543	282,045
TOTAL ASSETS LESS CURRENT LIABILITIES		312,629	26,914	339,543	282,045
NET ASSETS		312,629	26,914	339,543	282,045
FUNDS	16				
General fund				312,629	235,633
Designated funds				26,914	46,412
TOTAL FUNDS				339,543	282,045

The notes form part of these financial statements

T.O.F.S. – COMPANY NUMBER 2202260
BALANCE SHEET - CONTINUED
AT 31 DECEMBER 2021

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2021.

The trustees have not required the charitable company to obtain an audit of its financial statements for the year ended 31 December 2021 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Section 386 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial period and of its surplus or deficit for each financial period in accordance with the requirements of Section 394 and Section 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies' regime.

The financial statements were approved by the Council of Management on 31 March 2022 and were signed on its behalf by:

D Jackson (Chair) – Trustee

J Pearce (Vice-Chair & Treasurer) – Trustee

G Slater (Company Secretary) - Trustee

The notes form part of these financial statements

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2021

1. ACCOUNTING POLICIES

Basis of preparing the financial statements and assessment of going concern

TOFS is a private charitable company limited by guarantee incorporated in England within the UK. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 1 of these financial statements. The nature of the charity's operations and principal activities are stated on page 2 of these financial statements.

The charity constitutes a public benefit entity as defined by FRS102. The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS102), the Charities Act 2011, the Companies Act 2006 and UK Generally Accepted Practice.

The financial statements are prepared on a going concern basis under the historical cost convention. The financial statements are presented in sterling which is the functional currency of the charity and rounded to the nearest £. The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

Income

Voluntary income is received by way of donation and gifts and is included in full in the Statement of Financial Activities when received. The value of services provided by volunteers has not been included.

Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with the use of resources.

Tangible Fixed Assets

Depreciation is provided at the following annual rate to write off each asset over its estimated useful life:

Office equipment	33% on cost
------------------	-------------

From January 2012, the Trustees decided to write off the cost of office equipment in full in the year of purchase

Stocks

Stock is valued at the lower of cost and estimated selling price.

Current asset investments

The charity holds cash on deposit for investment purposes, in order to obtain a better rate of return, thereby increasing their income enabling them to meet their objects.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Debtors and Creditors

Debtors and Creditors receivable and payable within one year are recorded at transaction price.

Cash at Bank

The charity holds sufficient funds in order to meet its short-term cash commitments as they fall due.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees. Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes. Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2021

2. DONATIONS AND LEGACIES

	2021	2020
Donations:		
Charitable Trusts, Clubs and Corporations	8,182	16,075
Individuals	6,733	7,921
In Memoria	77,145	4,406
Members and Friends	25,800	41,520
London Marathon/Great North Run/Teddy Toddle	33,649	21,206
Other	26,526	22,363
	178,035	113,491

- Other donations and gifts include donations made by members in respect of their membership.
- Members and Friends donations are made as a result of events run by them to raise funds for TOFS.
- London Marathon, Great North Run and Teddy Toddle are special cases of fundraising by members for TOFS.

3. INCOME FROM OTHER TRADING ACTIVITIES

	2021	2020
Sale of TOFS goods	5,911	2,659
TOFS fundraisers and raffles	3,043	80
	8,954	2,739

4. INVESTMENT INCOME

Interest receivable	2,492	3,808
	2,492	3,808

5. COSTS OF RAISING FUNDS

Opening stock	7,482	1,381
Purchases	2,848	10,248
Closing stock	(6,182)	(7,482)
	4,148	4,147
Just Giving subscription	216	216
London Marathon / Great North Run	2,775	160
	7,139	4,523

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2021

6. CHARITABLE ACTIVITIES

	2021	2020
Pastoral support and information exchange:		
Newsletters	10,827	6,905
Conference expense	-	1,310
Gifts and entertaining children	-	782
Telecommunications	1,606	791
Printing, postage, stationery, fundraising costs and publicity	6,319	2,674
Support costs (note 8)	83,885	55,235
	102,637	67,697
Medical liaison, research and co-operation:		
Projects - Medics to INOEA / Medical and Hospital Liaison	158	627
Research costs	1,940	3,499
Awareness week and other	329	1,495
Support costs	17,180	12,205
Projects European Collaboration / EAT	-	230
	19,607	18,056
	122,244	85,753

7. OTHER COSTS

	2021	2020
Accountancy and professional fees	2,600	2,406

8. SUPPORT COSTS

	Pastoral support & information exchange	Medical liaison research and co-operation	2021 TOTAL	2020 TOTAL
Wages	75,029	15,367	90,396	58,236
Finance	180	37	217	239
Information Technology	3,626	743	4,369	3,345
Office accommodation	3,766	771	4,537	4,424
Travel and Sundry	1,284	262	1,546	1,196
	83,885	17,180	101,065	67,440

Support costs have been allocated to the activities based on time spent.

9. NET INCOMING RESOURCES

	2021	2020
Net resources are stated after charging:		
Independent examiner's fees	1,638	1,590
Payroll Administration	530	456

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2021

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2021 nor for the year ended 31 December 2020.

Trustees' Expenses

Three of the trustees received reimbursed expenses in the period of £3,043 (2020- £1,268). The expense reimbursements were dominated by the cost (some £2,100) of a computer and associated items purchased by a Trustee for use by our staff. £120 (2020 –NIL) of their travel expenses were donated back to TOFS by the Trustees.

11. STAFF COSTS

The average number of full time equivalent employees during the period was 4.5 (2020 – 3)

No employee received total employee benefits of more than £60,000.

The total staff costs and employee benefits were as follows:

	<u>31.12.21</u>	<u>31.12.20</u>
	£	£
Wages and Salaries	85,305	56,894
Social Security Costs	1,794	-
Pension Costs	3,297	1,342
	90,396	58,236

12. TANGIBLE FIXED ASSETS

	<u>Office Equipment</u>
	£
COST	
At 1 January 2021	3,944
Additions/(Disposals)	-
At 31 December 2021	3,944
DEPRECIATION	
At 1 January 2021	3,944
Charge for the year	-
At 31 December 2021	3,944
NET BOOK VALUE	
At 31 December 2021	-
At 31 December 2020	-

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2021

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>31.12.21</u>	<u>31.12.20</u>
	£	£
Accounts receivable	-	847
Prepayments and other debtors	2,465	4,535
Gift Aid	9,099	4,624
	11,564	10,006
	2021	2020

14. CURRENT ASSET INVESTMENTS

Cash held for investments	251,182	213,190

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

Accountancy	1,638	1,590
Social Security & other taxes	2,051	698
Accruals	254	238
	3,943	2,526

16. MOVEMENT IN FUNDS

	<u>At 1.1.21</u>	<u>Net Movement in funds</u>	<u>Transfers between funds</u>	<u>At 31.12.21</u>
	£	£	£	£
Unrestricted funds				
General Fund	235,633	96,996	(20,000)	312,629
Designated Fund - Medical research	6,915	(1,940)	20,000	24,975
Projects & resources	39,497	(37,558)	-	1,939
TOTAL FUNDS	282,045	57,498	-	339,543

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Gains and losses	Movement in funds
Unrestricted funds				
General Fund	189,481	92,485	-	96,996
Designated Fund – Medical research	-	1,940	-	(1,940)
Projects and resources	-	37,558	-	(37,558)
TOTAL FUNDS	189,481	131,983	-	57,498

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2021

16. MOVEMENT IN FUNDS CONTINUED....

	<u>At 1.1.20</u>	<u>Net Movement</u>	<u>Transfers</u>	<u>At 31.12.20</u>
	£	<u>in funds</u>	<u>between funds</u>	£
Unrestricted funds				
General Fund	182,275	53,358	-	235,633
Designated Fund – Medical research	10,414	(3,499)	-	6,915
Projects & resources	62,000	(22,503)	-	39,497
	=====	=====	=====	=====
TOTAL FUNDS	254,689	27,356	-	282,045
	=====	=====	=====	=====

Net movement in funds, included in the above are as follows:

	<u>Incoming</u>	<u>Resources</u>	<u>Gains and</u>	<u>Movement</u>
	<u>resources</u>	<u>expended</u>	<u>losses</u>	<u>in funds</u>
Unrestricted funds				
General Fund	120,038	66,680	-	53,358
Designated Funds	-	26,002	-	(26,002)
	=====	=====	=====	=====
TOTAL FUNDS	120,038	92,682	-	27,356
	=====	=====	=====	=====

The research designated fund was created in 2013. The Trustees added to this in 2014. A total of £40,000 of reserves has now been designated to support relevant medical research work, over several years. In 2019 the Trustees created an additional designated fund for “Projects and Additional Resources” – to cover principally additional staff costs over the subsequent couple of years. The trustees expect to close this latter fund during 2022.

17. RELATED PARTY TRANSACTIONS.

During the year, TOFS has bought IT services amounting to £1,541 (2020 - £1,416) from Altido (formerly CRM Labs). The managing director of this firm is the son-in-law of Dennis Harvey, one of the Trustees.

During this year, some of the expenses reimbursed to Trustees were donated back to the Charity, which totalled £120 (2020 - £NIL).

18. PENSION CONTRIBUTIONS

The charity operates a defined contribution scheme. The assets are managed independently of the charity and contributions are charged to the Statement of Financial Activities in the period they are made. The charge for the year was £3,297 (2020-£1,342).

T.O.F.S.
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2021

	Year Ended 31.12.2021		Year Ended 31.12.2020	
	£	£	£	£
Donations				
Charitable Trusts	8,182		16,075	
Individuals	6,733		7,921	
In Memoria	77,145		4,406	
Members and Friends	25,800		41,520	
London Marathon, Great North Run and Teddy Toddle	33,649		21,206	
Other	26,526		22,363	
		178,035		113,491
Other income				
Sale of TOFS Goods	5,911		2,659	
Interest	2,492		3,808	
TOFS Fundraisers and raffles	3,043		80	
		11,446		6,547
Total Income		189,481		120,038
Cost of TOFS Goods Sold				
Opening stock	7,482		1,381	
Purchases	2,848		10,248	
Closing stock	(6,182)		(7,482)	
		4,148		4,147
Just Giving subscription		216		216
London Marathon / Great North Run		2,775		160
		7,139		4,523
Fundraising, Publicity & Co-operation				
Newsletters	10,827		6,905	
Printing, postage, stationery, fundraising costs & publicity	6,319		2,674	
Cooperation with other organisations	-		230	
Liaison with the medical profession	487		2,121	
		17,633		11,930
Central costs				
Wages, social security & pension costs	90,396		58,236	
Accountancy	2,600		2,406	
Telecommunications	1,606		791	
		94,602		61,433

This page does not form part of the statutory financial statements

T.O.F.S.
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2021

	Year Ended 31.12.2021		Year Ended 31.12.2020	
	£	£	£	£
Other Operating costs				
Conference expense	-		1,310	
Gifts and entertaining children	-		782	
Travel and meeting	50		388	
Rent and Insurance	4,537		4,424	
Research, Recruitment and Sundry	2,470		4,308	
Computer costs	4,369		3,345	
Bank charges	217		239	
Bad Debts	966		-	
		12,609		14,796
Total Expenditure		131,983		92,682
NET INCOME		57,498		27,356
Funds brought forward		282,045		254,689
Funds carried forward		339,543		282,045

TOFS

England & Wales - Charity number 327735

Accounts

REGISTERED COMPANY NUMBER: 2202260 (England and Wales)
REGISTERED CHARITY NUMBER: 327735

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2020
FOR
T.O.F.S.

Lemans
29 Arboretum Street
Nottingham
NG1 4JA

T.O.F.S.
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FOR THE YEAR ENDED 31 DECEMBER 2020

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T.O.F.S.
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

The Trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 December 2020. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" in preparing the annual report and financial statements of the charity.

The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the Charity's governing document, the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland published in October 2019.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number
2202260 (England and Wales)

Registered Charity number
327735

Registered office
St George's Centre
91 Victoria Road
Netherfield
Nottingham
NG4 2NN

Trustees	
Duncan Jackson	Chair
John Pearce	Vice-Chair & Treasurer
Graham Slater	Secretary
Dennis Harvey	
Darrell Hill	
Sue Lewis-Jones	
Trace Loffman	
Samantha Mann	
Tamasine Swan	

Chief Executive Officer
Diane Stephens

Independent Examiner
K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

Bankers
Caf Bank
25 Kings Hill Avenue
Kings Hill
West Malling
Kent
ME19 4JQ

SPECIAL NOTE CONCERNING THE COVID-19 PANDEMIC

Along with the entire voluntary sector, and indeed the country at large, T.O.F.S. activities were significantly impacted in 2020 by COVID-19.

Whilst the actual financial position at year-end was considerably better than predicted in April (see the Financial section of this report for further details) the Trustees remain aware that the ongoing nature of the COVID-19 pandemic, and its consequent financial impact together with the UK's current economic climate, have the potential to affect T.O.F.S.'s income in the coming years, and they will continue to monitor the financial position accordingly.

From March 2020 onwards, all of the events which T.O.F.S. had planned to operate or attend were cancelled, postponed to 2021, or re-arranged so as to be delivered using technologies such as video-conferencing. More detail on what was achieved in this latter respect is discussed in the relevant section(s) below.

More specifically regarding COVID-19 itself - and particularly as T.O.F.S. supports individuals whose prevailing health condition renders them potentially more vulnerable to corona viruses - we responded by disseminating relevant information to our membership. This was provided either by health professionals on our medical advisory committee or by reference to publicly available sources of COVID-19 information, such as Public Health England.

All internal meetings (including the AGM) subsequent to February were held by video-conference, and staff members worked almost entirely from home. Appropriate risk assessments were carried out. New staff are now joining the charity in home-based roles.

It should also be noted that COVID-19 has had - and indeed continues to exert - an ongoing impact on the work of researchers and collaborative projects with healthcare professionals in which T.O.F.S. is involved or has an interest. Whilst this inevitably has brought some delay to key projects, it is nevertheless re-assuring to state that no projects have actually been cancelled due to resource or financial constraints.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Objectives and aims

The principal objective of T.O.F.S. is to improve the lives of individuals (hereinafter referred to as "TOF individuals" or "TOFs") suffering from tracheo-oesophageal fistula (TOF), oesophageal atresia (OA) and oesophageal and related disorders including the VACTERL Association (hereinafter referred to as "oesophageal disorders"), as well as the families of such TOF individuals.

Oesophageal Atresia and tracheo-oesophageal fistula (OA/TOF) are rare congenital conditions of the oesophagus (food pipe) and/or trachea (airway) that affect newborn babies. Babies with OA/TOF need to have intensive neo-natal care prior to corrective surgery, normally within days of birth. Some children have to undergo additional surgical interventions later on in their lives. It is now recognised that life-long follow up is essential.

Constitution

T.O.F.S. is a charity which was founded in 1982 and established as a 'Company Limited By Guarantee and not having a Share Capital' on October 20th, 1987. T.O.F.S. is registered both at Companies House and with the Charity Commission.

On May 14th, 2016, T.O.F.S. held an Extraordinary General Meeting at which revised Articles of Association were adopted, thus replacing in a single document the original (1987) Memorandum of Association and Articles of Association.

This was done with the agreement of the Charity Commission and the revised Articles were lodged in May 2016 with both the Charity Commission and Companies House.

T.O.F.S.
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

Organisational Structure

The overall direction and management of T.O.F.S. is overseen by the Council of Management of which all Trustees are members, and who are also Directors of the Company. The Council is accountable and legally responsible for the work of the organisation and for ensuring that all aspects of the management and work comply with current legislation. The Council is supported by four members of staff, headed by the CEO, and also by volunteers.

Governance

The Council meets typically four times per year and - as permitted by the Articles of Association - additionally delegates some detail matters to several sub-committees (finance; pastoral support; medical liaison & research; staffing & recruitment; strategy & projects); which are chaired by either a Trustee or the CEO and which, where appropriate, are attended not only by one or more other trustees but also by persons from across the wider T.O.F.S. membership.

T.O.F.S. is bound by its Articles of Association to hold an AGM. In 2020, as noted above, this was held by video-conference, where, in addition to the standard agenda items including presentation of the annual accounts and trustee elections, the opportunity was taken to provide further explanation of T.O.F.S. activities by a series of presentations on key topics (pastoral support, medical liaison, plans for the current year and beyond) to those members who attended. This format was well-received and will be retained in 2021.

Policies and Documentation

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

During 2020 a comprehensive review of all policies was undertaken and, where deemed appropriate, new versions were drafted and subsequently approved by the Council of Management.

In addition, a 'Code of Conduct' (applicable to Trustees, Volunteers and staff), and a Staff Handbook were published.

Risk Management

The Trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud or error.

Risks are reviewed and mitigated by:

- An organisational commitment to standards of good management and operational practice
- Established policies which commit to compliance with all relevant legislation and good practice
- Regular review of all policies and procedures
- Establishing adequate financial reserves

Recruitment and Appointment of Trustees

TOFS welcomes eligible people who have an interest in helping the organisation achieve its objectives by becoming a Trustee. Whilst the majority of TOFS members are parents or grandparents of TOF children, TOFS welcomes potential trustees from all walks of life.

The Articles of Association state the eligibility of Trustees, which, in summary, state that those eligible must:

- be over the age of 18
- already be or become members of the organisation
- not be undischarged bankrupts
- not previously have been removed from trusteeship of a charity by a Court or the Charity Commissioners

T.O.F.S.
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

- not be under a disqualification order under the Company Directors' Disqualification Act 1986
- not be disqualified by the Charities Act 1993 (Section 72) from acting as a charity trustee
- undertake to fulfil their responsibilities and duties as a trustee of T.O.F.S. in good faith and in accordance with the law and within the objectives of T.O.F.S.
- not have financial interests in conflict with those of T.O.F.S. (either in person or through family or business connections) except where formally notified in a conflict of interest statement

To ensure Trustees are fully competent, T.O.F.S. will:

- Provide an up-to-date Trustee Induction Pack
- Support induction, in a manner tailored to the experience of the individual, by the use of a 'buddy' system whereby each new Trustee is guided by an experienced Trustee or recently retired Trustee
- Provide access to – and where appropriate cover the costs of – induction training
- Conduct de-briefing of retiring Trustees in order to review, and amend where necessary, the Induction of new Trustees
- Provide a job description for honorary officers

Staff Recruitment

In order to support the strategy of increasing pastoral support to our growing membership base, the work of the volunteer and events co-ordinator who was recruited in late 2019 continued for much of the year, and a part-time membership communications and support worker was recruited in early 2020.

Strategic Direction

T.O.F.S. carried out a major review of its strategy in the Autumn of 2018 and adopted a three- pronged approach to its activities and the benefits delivered to its members, viz:

- Near-term benefit: increase pastoral support to members – both families and Adult TOFs
- Long-term benefit: raise engagement with relevant healthcare professional bodies, clinicians and researchers
- Sustainability: reduce the excessive dependence for certain operational tasks on its Trustees (by extending its network of volunteers and by ensuring operational activities are - wherever possible - carried out by members of staff)

Activities and Achievements in 2020

Pastoral support and information exchange

Pastoral support and information exchange have traditionally been the core activities of T.O.F.S., and 2020 was no exception. The global pandemic brought about an even greater need for support for many within the OA/TOF community. We continued to supply information and support both to new members, a record number of whom joined throughout the year (378), and to existing TOF parents/carers, Adult TOFs and health professionals with leaflets, brochures, and postcards for key points of the OA/TOF journey – such as going to nursery/school. All members received the Spring edition of our newsletter, 'Chew', published just after the UK went into lockdown. To combat the challenges of printing during lockdowns, and the financial impact of the pandemic, the *Chew* editorial board created an electronic version of *Chew* (instead of the printed version), and this was circulated to members in the Summer and Autumn/Winter. Our office staff (working remotely) continued to support members via telephone and email, with the introduction of follow up support calls and emails to new members who had given permission for the office to do so.

T.O.F.S.
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

2020 Awareness week

With tremendous support from the OA/TOF community, a successful TOFS Awareness week was held in the final week of February, to co-incide with Rare Disease Day. The theme for the week was 'Lifelong follow-up for OA/TOF'. Letters were sent to MPs, flagging the need for adequate transition care, and many members raised the profile of our conditions by sharing their stories in regional and national press. An updated version of the generic 'About TOF, OA and VACTERL' leaflet was published, and copies were sent to all of the main Surgical Centres. Branded bibs and wristbands were produced and made available to members. Members were encouraged to download resources from the website, and there were 260 requests for afore-mentioned wristbands; 70 requests for bibs, and a further 115 requests for printed leaflets, mainly from the UK but also Republic of Ireland, Cyprus, Singapore, Australia and Kuwait.

Many members distributed leaflets and information to their GPs and local hospitals, and Great Ormond Street Hospital had an information afternoon for patients and their families.

With Local Contact volunteer support, a successful information afternoon and children's party brought the week to a close. The event was attended by 25 families and two Adult TOFs, and Mr Sean Marven, medical patron of TOFS, delivered a presentation on oesophageal dysmotility and reflux, along with Speech and Language Therapist, Jane Shaw (both from Sheffield Children's Hospital).

The T.O.F.S. website continues to be visited on a frequent basis predominantly from the UK but also from all over the world.

A comprehensive and regularly-updated Covid-19 section with information pertinent to the community was introduced in the Spring of 2020. Specific advice regarding shielding was sought from relevant health professionals, and published on the site. New Covid-related resources were made available including badges to print out at home, and hidden disability lanyards for those sensitive about being out and about with the 'TOF cough' when restrictions were relaxed.

The T.O.F.S. Facebook group continues to play a key part in pastoral support. Many members are instrumental in offering sound advice and guidance to new parents and the 'Facebook' group plays an increasingly supportive (and 'real-time') role in the exchange of parents' experiences with their OA/TOF babies and children. This year, we introduced two additional volunteer moderators, both of whom are experienced TOF parents, to help assist with the administration of running the group. To better support our Adult TOF community, we made a decision several years ago to endorse a Facebook group specifically for Adult TOFs, (which is run by one of our members, and one of our trustees helps administer). This provides a very useful forum for our growing number of Adult TOF members, whereby they can share information and experiences on issues which continue to affect them.

Plans that were underway for a Family and Adult TOF Conference in October had to be suspended, due to the pandemic. Instead, a series of 'online' events using the Zoom platform gave members the opportunity to hear from leading clinicians and healthcare professionals. These events were hosted by T.O.F.S.' Chair, Duncan Jackson, and members were offered the opportunity to pose pertinent questions in advance of the sessions. We are very grateful to those health professionals who gave their time freely, and these sessions supported over 200 families/adults over the year.

A new initiative launched in 2020, was a programme of events referred to as 'Talk with TLCs'. TLCs (TOFS Local Contacts, are a valued group of volunteers, all of whom are experienced TOF parents, who give their valuable time to volunteer for TOFS). This programme offered members the opportunity to engage with each other virtually, in discussion about various aspects of the OA/TOF condition.

T.O.F.S.
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

Finally, all volunteers continue to play an increasingly important role in the support T.O.F.S. offers new parents and carers. We continue to benefit from the improved co-ordination of our volunteers and the associated support activities, and the volunteer team more than doubled in size during 2020 (from 17 to 42). We would not be the organisation we are without the valuable support from, especially, our TLCs, and our volunteer members who assist in many other ways such as contributing to *Chew*, sending out birthday cards, taking part in committees, helping with fundraising. In 2020, our TLC team grew from five members to 19 members. These volunteers are all parents with experience of caring for a TOF child on a day-to-day basis. Spread across the UK, TLCs are available to listen, talk and offer support to new TOF parents, organise local informal get togethers, and take posters and leaflets into hospitals, especially where TOF surgery takes place. Some TLCs have shown further commitment by giving talks on behalf of T.O.F.S. Our TLC for Scotland, Bruce Rennie, represents T.O.F.S. on the Expert Advisory Group of the Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS). TLCs are offered information on basic listening and counselling and are given support from the volunteer and events co-ordinator and the T.O.F.S. office.

There are currently three T.O.F.S. Overseas Contacts (TOCs) one in Jordan, one in Canada and one in New Zealand. All are active in offering support to TOF families within their own country and they share T.O.F.S. knowledge when applicable. This has been mutually beneficial, resulting in translations of some T.O.F.S. leaflets into Arabic. [It should be noted that these Overseas Contacts do not in any legal sense represent T.O.F.S. in these countries; they are - as the name implies - purely our contacts in these countries.]

'*The TOF Book*', published in November 2016, continues to sell, although understandably not quite at the level of prior years. Nonetheless, there is evidence that a significant proportion of the new members who joined in the year purchased the book. Almost 2000 copies are now in use worldwide.

Finally, a significant achievement was the publication in December 2020 of '*The SOFT Food Recipe Book*'. Our staff and many volunteers contributed to this fully-illustrated book of recipes appropriate for youngsters born with OA. This represents a major addition to T.O.F.S.' publications and thanks are expressed to all those who contributed to it.

Liaison with the medical profession

We continued in our commitment to disseminating information to practitioners from health, education and social care. We continue to be assisted by members in distributing posters to hospitals to display in their local neo-natal wards to increase awareness of T.O.F.S. when new parents and carers most need help.

T.O.F.S. continues in its efforts to increase its profile within the medical community. Since 2016 we have had a Medical Advisory Group, which is intended to provide us with a leading group of medical professionals across all relevant disciplines, who can provide advice and guidance, and support our publications with medically approved input. Due to Covid-19 a formal meeting of this group - originally planned for October - was postponed until early in 2021.

At the start of 2020, T.O.F.S. had plans in place to attend a number of medical conferences during the year, mainly in order to engage widely with the professionals attending. The Covid-19 restrictions meant that we were only able to attend one, the annual meeting of BSPGHAN (British Society of Paediatric Gastroenterology, Hepatology, and Nutrition). T.O.F.S. is now a member of the BSPGHAN Charities Committee, through which we intend to build improved engagement both with other patient groups and with paediatric gastroenterologists and nutritionists, and in particular to pursue a UK response to the 2016 ESPGHAN / NASPGHAN guidelines on the treatment of OA patients.

The involvement of T.O.F.S. in research programmes into OA reflects the almost mandatory requirement for relevant patient group support to be given to such projects and where relevant for "the patient voice" and patient perspective to be built into the study's terms of reference. In some instances, this support is characterised purely by endorsement of its relevance and priority to OA patients. In other cases, support may also involve some funding contribution; on other occasions a research activity may be characterised by more active involvement and/or collaboration with T.O.F.S.

T.O.F.S.
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

Projects - underway or planned to commence in 2021 - which we are currently supporting and/or endorsing include:

- The GOSH (Great Ormond Street Children's Hospital)/ICH tissue-engineering project (this is investigating the use of stem cells to develop an oesophagus - a project featured in the media in August 2018);
- A study into the feeding issues for patients up to the age of 12 months (which is the subject of a PhD degree);
- A Quality of Life PROM (Patient-reported Outcomes Measures) study;
- A PhD research project to research the psychological impact of OA on both patients and their families, and develop some online self-help tools (TaPSOn). This project is being conducted by a psychologist who is also an OA survivor.
- Two smaller higher degree research projects into psychological well-being of adults who were born with OA /TOF, and experiences of transition from paediatric to adult care;
- A study into the role of social media in support for adults who were born with OA/TOF and their families, which is being led by an academic researcher who was born with the condition;
- A study concerning desirable after-care outcomes for OA patients;
- A major randomised controlled trial (Treating Oesophageal Atresia to prevent Stricture, TOAST) to investigate whether or not the general use of antacid medicines with all OA babies would be helpful.

In all, some six separate UK universities are involved in the above projects.

In December 2017, we had also agreed to instigate our own research project entitled '*Should children born with OA/TOF have a mandated transition and adult care pathway?*' This project has subsequently been incorporated into an international study led by INoEA (the International Network on Oesophageal Atresia) which has a multi-disciplinary project team including T.O.F.S. Trustee Graham Slater. Whilst progress on this project has been considerably hampered by Covid-19, the project team aims to publish its findings and recommendations in the Autumn of 2021. Participation in such projects strengthens our collaboration with and recognition by, clinicians both nationally and internationally.

In addition, T.O.F.S. is actively supporting the European Reference Network (ERN) known as ERNICA (ERN for Inherited and Congenital Anomalies) through our membership of EAT (The Federation of Esophageal Atresia and Tracheo-esophageal Fistula Support Groups e.V.) - see also the section below entitled 'Co-operation with other organisations'.

T.O.F.S. Trustee Graham Slater is a member of the ERNICA Board and of its Coordination Team, and a patient representative on the programme's OA related work-packages. In 2020 one of these projects produced a third paper (following two in 2019) to be published in the European Journal of Paediatric Surgery [ERNICA Consensus Conference on the Management of Patients with Long-Gap Esophageal Atresia: Perioperative, Surgical, and Long-Term Management], again in which Trustee Graham Slater was a named co-author.

An ERNICA animation on nutrition and feeding of OA/TOF patients was produced by a team led by T.O.F.S. member Julia Faulkner, who besides being a paediatric dietician also has first-hand experience as her son is an OA/TOF patient.

Medical professionals and researchers at GOSH (Great Ormond Street Hospital for Children, London) remain committed to ERNICA, even though UK healthcare providers are - as a result of Brexit - no longer able to fully participate in such initiatives.

Use of Information Technology (IT)

The use of IT continues to be a powerful tool in support of our operations. Whilst our web-site remains well visited, we note the ever growing use of Facebook as a means by which members and non-members communicate on OA/TOF matters, and we have increasingly used this form of 'social media' to augment communication with our members. T.O.F.S.' Facebook group membership currently stands at approximately 4,000 including a substantial number of members from outside the UK and provides instant self-help support amongst its very active participants.

Altido Group Ltd of Cheltenham remain our primary IT service provider for Email, Web-site and our Data-base, and we hereby note our gratitude for their provision of some enhancements to these services on a discounted or 'free of charge' basis. [We note for reasons of transparency that Trustee Dennis Harvey is the father-in-law of the Altido Managing Director.]

T.O.F.S.

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 DECEMBER 2020**

Co-operation with other organisations

During 2020 we continued to play a leading role in EAT (the Federation of Esophageal Atresia - Tracheo-oesophageal fistula Support Groups). This organisation now has member associations in fourteen countries. T.O.F.S. Trustee Graham Slater was re-elected to the Board of EAT in April 2019 for a further period of two years and continues to be EAT's Chairman.

EAT is a German-registered association, and its involvement is much sought by various international medical working groups, especially those supported by EU funding. As a result, via EAT, T.O.F.S. continues to be actively involved in European collaborative healthcare programmes, and other relevant international initiatives.

EAT's key successes during 2020 were:

- (i) An ongoing and significant commitment to 'ERNICA' [see also the above paragraph and the above section on 'Liaison with the medical profession']
- (ii) Involvement with EURORDIS (the European Rare Disease organisation), with which TOFS is indirectly linked by its membership both of EAT and Genetic Alliance (the latter is the umbrella organisation across the UK for all rare disease patient support groups).
- (iii) Participation in an INoEA (International Network on Esophageal Atresia) study into transition from paediatric to adult care (also see above).
- (iv) Carrying out a PROM (Patient Reported Outcome Measures) study into the impact of COVID-19 on OATOF patients.

Funding, Financial Management and Governance

Most charities, including T.O.F.S., have found their finances have been heavily impacted by the COVID-19 pandemic in 2020, most notably in the Spring. However T.O.F.S.'s finances recovered very substantially late in the year.

The year had started relatively normally, but by the time the London Marathon was postponed in March, it was clear that major organised fundraising events would not happen. This was most concerning for T.O.F.S. as the charity's major source of income is fundraising undertaken by members and their friends. Indeed, the vast majority of the income to T.O.F.S. arises because of fundraising by members or because of a donation from or through a member or some other action a member has taken. The T.O.F.S. Trustees are hugely grateful to them.

The Trustees have delegated most of the charity's financial management to the Treasurer, who works with a Financial Sub-Committee (FSC). The FSC had held quarterly meetings in 2020 (normally twice per year) to review expenditure and incomes, to monitor progress against budgets and to recommend budgets for ratification by the whole Council of Management of T.O.F.S. Thus the charity has had three revisions to its 2020 budget this year.

At the start of 2020, plans were in place to significantly increase expenditure, partly via raised expenditure on staff, in order to deliver improved near-term support and longer-term benefits to our members.

The initial budget for 2020 envisaged a very significant deficit for the year, using the charity's reserves to accommodate the planned spending increase. However, at the April FSC meeting, estimates of likely income for 2020 were greatly cut, as were expenditure plans.

To quite an extent, Covid restrictions made the latter inevitable: our planned conference could not be held; nor could smaller events for members; travel became most inadvisable / illegal; medical conferences (some of which we had expected to attend) were cancelled; and onerous new COVID-19 contract conditions with our printers encouraged us to abandon the printed versions of our second and third issues of our house magazine *Chew* in 2020.

Despite these restrictions we were able to continue with one particular project which incurred significant upfront costs. As noted elsewhere, a major achievement in 2020 was the creation of an appropriate recipe book, "The soft food recipe book". We estimate that T.O.F.S. has expended a total of £10,250 on this book, including the cost of an initial print run. The vast majority of this expense fell in 2020, and the largest element was staff time.

T.O.F.S.
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

Though T.O.F.S.' income fell substantially in the early stage of the Covid crisis, the charity found itself ineligible for most forms of Government support. Moreover, it was evident that the OATOF community needed the support of T.O.F.S. more than ever. Consequently, no use was made of the Government's furlough scheme: all staff have worked their normal hours through the crisis.

The developments of 2020 forced the charity to wholly adopt virtual meetings and remote working from home via Zoom and Teams. It is likely that we will continue to use these cost-effective options to a material extent even when Covid restrictions no longer apply.

Given the charity's good level of reserves, the Trustees chose to avoid panic income-generating measures. But despite an elevated level of straightforward donations to T.O.F.S., we observed the charity's income roughly halve in April and May. The Trustees decided upon considered action, setting up a Fundraising Working Group (FRWG) in June. This group has subsequently addressed many ideas for increasing the charity's income.

One very positive development early in the Covid-19 lockdown was that Britain as a whole took to virtual fundraising. There were some great examples of fundraising undertaken by individuals in their own gardens, and encouragement from the organisers of the London Marathon with their 2.6 Challenge was helpful in this respect.

During the summer and Autumn, we pro-actively encouraged members to fundraise for T.O.F.S. In October, we held a virtual Teddy Toddle which was a huge success with more than 40 families raising money for the charity, totalling more than £9,000. The finishers' medals which we sent out appear to have been much appreciated by all the children who took part.

More traditional fundraising activity, organised by members themselves, raised a large proportion of what T.O.F.S. received as Members' and Friends' fundraising. The Trustees are especially grateful to members who organise these events and raise so much for T.O.F.S.

We continue to offer them support with fundraising packs, items such as T.O.F.S. branded running vests and a fundraising guide with hints and tips.

The London Marathon is T.O.F.S.' highest-profile and largest fundraising activity, as we have purchased Charity "Golden Bond" runners' entries every year. Though it was delayed (and then cancelled so far as mass participation was concerned) several of "our" runners entered the alternative virtual London Marathon. Funds raised were about half of what T.O.F.S. would typically see from the London Marathon, a very positive achievement in the circumstances. Moreover the T.O.F.S. 2020 runners will get an entry in a future year, and so some further money will be raised for the charity.

A similar situation arose as regards the Great North Run, the world's largest half-marathon. We had obtained and allocated charity places for this, which was also cancelled, with many participants nonetheless doing a half-marathon virtually. This event did raise some money for TOFS, though materially less than in a normal year. The T.O.F.S. 2020 GNR runners will be offered a place to run (and raise money) in 2021 instead.

T.O.F.S. asks members to make a donation in respect of their membership, and many do so, especially upon joining. A significant number make regular monthly donations, and for this, we are very grateful. Membership donation income has increased slightly in 2020.

T.O.F.S. receives no public-sector support at all, and as noted above, was ineligible for any Covid relief. However, the number of donations from companies, clubs and societies such as Rotary clubs, sports clubs, Freemasons' lodges and local faith groups has continued to rise in 2020, albeit at a level dwarfed by our members' efforts. The Trustees regularly ask members to mention T.O.F.S. in the context of their employer's or club's charitable efforts, and we believe that this is effective.

As part of the work of the FRWG, the charity has applied for a carefully-selected handful of major grants in 2020. Though most grant-giving bodies are keenest to support "local" causes, and/or those helping an obviously disadvantaged group, some such bodies will help nationwide health-related causes. Unfortunately, our few major applications were unsuccessful, which was most galling in view of the amount of time they absorbed – tens of hours in each case.

T.O.F.S.
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

Some years ago, the Trustees decided to designate £20,000 in all to pay for sponsorship of relevant medical research and activities of similar long term "scientific" benefit to the OA/TOF community over several years. We have continued to use this money in 2020, mostly for the partial financial support for one PhD research project. In January 2021, in view of a significant number of anticipated research-related initiatives, and acknowledging the 2020 year-end financial position of the charity, the Trustees decided to transfer another £20,000 from general funds to this designated research fund.

In late 2019, the Trustees agreed to create another designated fund, called the "Projects and additional resources fund". The £62,000 involved is the same as the sum of the two substantial unanticipated and exceptional income items of recent times: the 2018 Pretious legacy of £22,000 and the £40,000 Forrester trust donation of 2019. As anticipated, the main use for this has been our now-increased staff resources, who joined T.O.F.S. on fixed-term contracts scheduled to end in 2021. However, we were not able to recruit staff in late 2019 to the extent planned, and one of our new staff experienced adverse personal circumstances and asked to resign and leave at short notice. Consequently, expenditure on staff was notably lower than we had wished and planned. Further recruitment is expected early in 2021.

As the year progressed, it became clear that the charity's income had not fallen as low as anticipated in our April review. Our expectations for 2020 income were raised back up in the July and especially October reviews. Much of the great success of fundraising came through in November 2020, so even the October income expectation was substantially bettered.

Thus TOFS ended 2020 recording income of £120,038. This must be judged as a huge success given that underlying income (excluding only the truly exceptional Pretious legacy and the Forrester Trust donation) has varied between £111,337 and £118,392 over the previous 3 years.

Overall expenditure in 2020 at £92,682 was unsurprisingly a little lower than the £97,239 of 2019, and the £101,017 spent in 2018, which has been the charity's highest-expenditure year to date.

The Trustees have been pleasantly surprised and gratified that T.O.F.S. has been able to record a material surplus in 2020 !

Public benefit

The Trustees have had due regard to the guidance published by the Charity Commission on public benefit when reviewing the charity's aims and objectives and in planning future activities.

Financial Review and Reserves policy

Like other charities, T.O.F.S. requires reserves in order to operate in the short term and to satisfy legal obligations in the event of the end of funding, a major reduction of funding or a delay in further funding becoming available. In the event of having to close the charity, the reserves would enable proper notice to be given to the beneficiaries and staff and for all legally due payments to be made to staff, volunteers and the organisations with which we do business. In view of the great uncertainties arising from the COVID-19 pandemic, the Trustees have raised the minimum level of reserves to an amount sufficient to cover all normal operating expenses for a full year. At the end of 2020, T.O.F.S. has significantly more in reserves than this policy demands, however some of the apparent excess has been set aside for special projects, as already mentioned.

Investment policy and objectives:

For the whole of 2020, T.O.F.S. has held current bank accounts with Lloyds Bank Ltd and CAF Bank Ltd (a part of the Charities Aid Foundation). For accepting payments and donations it also has accounts with PayPal, Amazon Smile, Facebook, Just Giving, Wonderful, Peoples' Fundraising and Virgin Money Giving. During the year, T.O.F.S. ceased to use the Wonderful fundraising website, as this closed down permanently, and started to use Peoples' Fundraising instead.

A new "investment" policy was adopted in February 2018. This enables (but does not commit) T.O.F.S. to invest up to approximately half of its apparently-excess reserves in risky assets – in pursuit of a meaningful return – via charity-specific diversified pooled investment funds with reputable financial institutions. However (in view of the uncertain/troubling investment horizon), the Trustees decided upon the recommendation of the FSC to continue to hold all reserves as cash in FSCS-protected savings accounts. The T.O.F.S. savings accounts are with Cambridge and Counties Bank, Mansfield Building Society, Hampshire Trust Bank, and Virgin Money.

T.O.F.S.
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by order of the Council on 20 March 2021 and signed on its behalf by:

D Jackson (Chair)

A handwritten signature in black ink, appearing to be 'D Jackson', written over a circular stamp or seal.

INDEPENDENT EXAMINER'S REPORT
TO THE TRUSTEES OF
T.O.F.S.

I report to the Charity Trustees on my examination of the accounts of the company, for the year ended 31 December 2020 set out on pages 14 to 23..

Responsibilities and basis of report

As the Charity Trustees of the company, (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your company's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. Accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. The accounts do not accord with those records; or
3. The accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
4. The accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)]

I have no concerns and have come across no other matters in connection with the examinations to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

K Mealand

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

21 April 2021

T.O.F.S.
STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2020

		Ended			Year	Year
		General	Designated	Restricted	Unrestricted funds	Unrestricted funds
	Notes	fund	funds	fund	31.12.20	31.12.19
		£	£	£	Total funds	Total funds
					£	£
INCOME AND ENDOWMENTS FROM:						
Donations and legacies	2	113,491	-	-	113,491	148,617
Other trading activities	3	2,739	-	-	2,739	5,559
Investments	4	3,808	-	-	3,808	2,775
Total income and endowments		120,038	-	-	120,038	156,951
EXPENDITURE ON:						
Raising funds	5	-	4,523	-	4,523	3,927
Charitable activities	6	64,274	21,479	-	85,753	90,922
Other	7	2,406	-	-	2,406	2,390
Total expenditure		66,680	26,002	-	92,682	97,239
NET INCOME/(EXPENDITURE)		53,358	(26,002)	-	27,356	59,712
Transfers between funds						
Net movement in funds		53,358	(26,002)	-	27,356	59,712
Reconciliation of funds						
TOTAL FUNDS BROUGHT FORWARD		182,275	72,414	-	254,689	194,977
TOTAL FUNDS CARRIED FORWARD		235,633	46,412	-	282,045	254,689

The notes form part of these financial statements

T.O.F.S. – COMPANY NUMBER 2202260
BALANCE SHEET
AT 31 DECEMBER 2020

	Notes	Unrestricted funds £	Restricted fund £	31.12.20 Total funds £	31.12.19 Total funds £
FIXED ASSETS					
Tangible assets	12	-	-	-	-
		-	-	-	-
CURRENT ASSETS					
Stock		7,482	-	7,482	1,381
Debtors: amounts falling due within one year	13	10,006	-	10,006	7,901
Investments	14	213,190	-	213,190	229,393
Cash at bank		53,893	-	53,893	22,598
		284,571	-	284,571	261,273
CREDITORS					
Amounts falling due within one year	15	2,526	-	2,526	6,584
NET CURRENT ASSETS		282,045	-	282,045	254,689
TOTAL ASSETS LESS CURRENT LIABILITIES		282,045	-	282,045	254,689
NET ASSETS		282,045	-	282,045	254,689
FUNDS					
	16				
General fund				235,633	182,275
Designated funds				46,412	72,414
Restricted fund					
TOTAL FUNDS				282,045	254,689

T.O.F.S. – COMPANY NUMBER 2202260
BALANCE SHEET - CONTINUED
AT 31 DECEMBER 2020

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2020.

The trustees have not required the charitable company to obtain an audit of its financial statements for the year ended 31 December 2020 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Section 386 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial period and of its surplus or deficit for each financial period in accordance with the requirements of Section 394 and Section 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies' regime.

The financial statements were approved by the Council of Management on 20 March 2021 and were signed on its behalf by:

D Jackson (Chair) – Trustee



J Pearce (Vice-Chair & Treasurer) – Trustee



G Slater (Secretary) - Trustee



The notes form part of these financial statements

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2020

1. ACCOUNTING POLICIES

Basis of preparing the financial statements and assessment of going concern

TOFS is a private charitable company limited by guarantee incorporated in England within the UK. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 1 of these financial statements. The nature of the charity's operations and principal activities are stated on page 3 of these financial statements.

The charity constitutes a public benefit entity as defined by FRS102. The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS102), the Charities Act 2011, the Companies Act 2006 and UK Generally Accepted Practice.

The financial statements are prepared on a going concern basis under the historical cost convention. The financial statements are presented in sterling which is the functional currency of the charity and rounded to the nearest £. The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

Income

Voluntary income is received by way of donation and gifts and is included in full in the Statement of Financial Activities when received. The value of services provided by volunteers has not been included.

Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with the use of resources.

Tangible Fixed Assets

Depreciation is provided at the following annual rate to write off each asset over its estimated useful life:

Office equipment	33% on cost
------------------	-------------

From January 2012, the Trustees decided to write off the cost of office equipment in full in the year of purchase

Stocks

Stock is valued at the lower of cost and estimated selling price.

Current asset investments

The charity holds cash on deposit for investment purposes, in order to obtain a better rate of return, thereby increasing their income enabling them to meet their objects.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Debtors and Creditors

Debtors and Creditors receivable and payable within one year are recorded at transaction price.

Cash at Bank

The charity holds sufficient funds in order to meet its short-term cash commitments as they fall due.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees. Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes. Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

2. DONATIONS AND LEGACIES

	2020	2019
Donations:		
Charitable Trusts, Clubs and Corporations	16,075	49,853
Individuals	7,921	2,675
In Memoria	4,406	6,451
Members and Friends	41,520	41,650
London Marathon/Great North Run/Teddy Toddle	21,206	24,682
Other	22,363	23,306
	113,491	148,617

- Other donations and gifts include donations made by members in respect of their membership.
- Members and Friends donations are made as a result of events run by them to raise funds for TOFS.
- London Marathon, Great North Run and Teddy Toddle are special cases of fundraising by members for TOFS.

3. INCOME FROM OTHER TRADING ACTIVITIES

	2020	2019
Sale of TOFS goods	2,659	2,816
Conference income	-	2,343
TOFS fundraisers and raffles	80	400
	2,739	5,559

4. INVESTMENT INCOME

Interest receivable	3,808	2,775
	3,808	2,775

5. COSTS OF RAISING FUNDS

Opening stock	1,381	2,555
Purchases	10,248	-
Closing stock	(7,482)	(1,381)
	4,147	1,174
Just giving subscription	216	446
London Marathon / Great North Run	160	2,307
	4,523	3,927

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

6. CHARITABLE ACTIVITIES

	2020	2019
Pastoral support and information exchange:		
Leaflets and newsletters	6,905	9,208
Conference expense	1,310	9,701
Gifts and entertaining children	782	431
Telephone	791	799
Printing, postage, stationery, fundraising costs and publicity	2,674	5,187
Support costs (note 8)	55,235	45,229
	67,697	70,555
Liaison with the medical profession:		
Projects - Medics to INOEA / Medical and Hospital Liaison	627	2,254
Research costs	3,499	3,565
Awareness week and other	1,495	-
TOFS presence at INoEA Rome	-	1,578
Support costs	10,298	10,438
	15,919	17,835
Co-operation with other organisations:		
Travel	-	-
Projects European Collaboration / EAT	230	213
Support costs	1,907	2,319
	2,137	2,532
	85,753	90,922

7. OTHER COSTS

	2020	2019
Accountancy and professional fees	2,406	2,390

8. SUPPORT COSTS

	Pastoral support & information exchange	Liaison with the medical profession	Co-operation with other organisations	2020 TOTAL	2019 TOTAL
Wages	47,866	8,775	1,595	58,236	47,167
Finance	186	43	10	239	106
Information Technology	2,749	504	92	3,345	2,360
Office accommodation	3,451	796	177	4,424	4,695
Travel and Sundry	983	180	33	1,196	3,658
	55,235	10,298	1,907	67,440	57,986

Support costs have been allocated to the activities based on time spent.

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

9. NET INCOMING RESOURCES

2020 **2019**

Net resources are stated after charging:

Depreciation – owned assets

Independent examiner's fees

-	-
1,588	1,542
<u> </u>	<u> </u>

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2020 nor for the year ended 31 December 2019.

Trustees' Expenses

Two of the trustees received reimbursed expenses in the period of £1,268 (2019 - £3,935).
None (2019 - Some) of their travel expenses were donated back to TOFS by the Trustees.

11. STAFF COSTS

The average number of full time equivalent employees during the period was 3 (2019 – 2)

No employee received total employee benefits of more than £60,000.

The total staff costs and employee benefits were as follows:

Wages and Salaries -	£56,894 (2019 - £46,305)
Social Security costs -	£nil (2019 - £nil)
Pension costs -	£1,342 (2019 - £862)

12. TANGIBLE FIXED ASSETS

	<u>Office Equipment</u> £
COST	
At 1 January 2020	3,944
Additions/(Disposals)	-
	<u> </u>
At 31 December 2020	3,944
	<u> </u>
DEPRECIATION	
At 1 January 2020	3,944
Charge for the year	-
	<u> </u>
At 31 December 2020	3,944
	<u> </u>
NET BOOK VALUE	
At 31 December 2020	-
	<u> </u>
At 31 December 2019	-
	<u> </u>

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>31.12.20</u>	<u>31.12.19</u>
	£	£
Accounts receivable	847	447
Prepayments and other debtors	4,535	3,511
Gift Aid	4,624	3,943
	10,006	7,901

14. CURRENT ASSET INVESTMENTS

Cash held for investments	213,190	229,393

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

Accountancy	1,590	1,542
Chew design, print and postage costs	-	2,191
Social Security & other taxes	698	733
Accruals	238	1,413
Deferred Income – VLM	-	705
	2,526	6,584

16. MOVEMENT IN FUNDS

	<u>At 1.1.20</u>	<u>Net Movement</u>	<u>Transfers</u>	<u>At 31.12.20</u>
	£	<u>in funds</u>	<u>between funds</u>	£
		£	£	
Unrestricted funds				
General Fund	182,275	53,358	-	235,633
Designated Fund - Medical research	10,414	(3,499)	-	6,915
Projects & resources	62,000	(22,503)	-	39,497
	254,689	27,356	-	282,045
Restricted fund	-	-	-	-
TOTAL FUNDS	254,689	27,356	-	282,045

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Gains and losses	Movement in funds
Unrestricted funds				
General Fund	120,038	66,680	-	53,358
Designated Funds	-	26,002	-	(26,002)
	120,038	92,682	-	27,356
Restricted fund	-	-	-	-
TOTAL FUNDS	120,038	92,682	-	27,356

16. MOVEMENT IN FUNDS

	<u>At 1.1.19</u>	<u>Net Movement in funds</u>	<u>Transfers between funds</u>	<u>At 31.12.19</u>
	£	£	£	£
Unrestricted funds				
General Fund	179,579	64,696	(62,000)	182,275
Designated Fund – Medical research	15,398	(4,984)	-	10,414
Projects & resources	-	-	62,000	62,000
	194,977	59,712	-	254,689
Restricted fund	-	-	-	-
TOTAL FUNDS	194,977	59,712	-	254,689

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

16. MOVEMENT IN FUNDS

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Gains and losses	Movement in funds
Unrestricted funds				
General Fund	156,951	92,255	-	64,696
Designated Funds	-	4,984	-	(4,984)
	156,951	97,239	-	59,712
Restricted fund	-	-	-	-
TOTAL FUNDS	156,951	97,239	-	59,712

The research designated fund was created in 2013. The Trustees added to this in 2014. A total of £20,000 of reserves is designated to support relevant medical research work, over several years. In 2019 the Trustees created an additional designated fund for "Projects and Additional Resources" – to cover principally staff costs over the next couple of years, but also other special project costs.

17. RELATED PARTY TRANSACTIONS.

During the year, TOFS has bought IT services amounting to £1,416 (2019 - £1,677) from Altido (formerly CRM Labs). The managing director of this firm is the son-in-law of Dennis Harvey, one of the Trustees.

During this year, none (2019 – some) of the expenses reimbursed to Trustees were donated back to the Charity, which totalled £nil (2019 - £571).