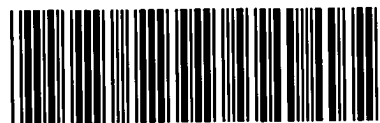


REGISTERED COMPANY NUMBER: 2202260 (England and Wales)  
REGISTERED CHARITY NUMBER: 327735

**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

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**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 20<sup>th</sup>, 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 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 2022**

#### **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.

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

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*

K Mealand FCCA  
Lemans  
29 Arboretum Street  
Nottingham  
NG1 4JA

*3 July 2023*

**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				
<b>INCOME AND ENDOWMENTS FROM:</b>					
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
<b>Total income and endowments</b>		<b>151,779</b>	<b>-</b>	<b>151,779</b>	<b>189,481</b>
<b>EXPENDITURE ON:</b>					
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
<b>Total expenditure</b>		<b>171,660</b>	<b>12,188</b>	<b>183,848</b>	<b>131,983</b>
<b>NET (EXPENDITURE)/INCOME</b>		<b>(19,881)</b>	<b>(12,188)</b>	<b>(32,069)</b>	<b>57,498</b>
<b>Transfers between funds</b>					
		-	-	-	-
<b>Net movement in funds</b>		<b>(19,881)</b>	<b>(12,188)</b>	<b>(32,069)</b>	<b>57,498</b>
<b>Reconciliation of funds</b>					
<b>TOTAL FUNDS BROUGHT FORWARD</b>		<b>312,629</b>	<b>26,914</b>	<b>339,543</b>	<b>282,045</b>
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b>292,748</b>	<b>14,726</b>	<b>307,474</b>	<b>339,543</b>

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 £
<b>FIXED ASSETS</b>					
Tangible assets	12	-	-	-	-
Investments	14	50,000	-	50,000	-
		<hr/>	<hr/>	<hr/>	<hr/>
		50,000	-	50,000	-
		<hr/>	<hr/>	<hr/>	<hr/>
<b>CURRENT ASSETS</b>					
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
		<hr/>	<hr/>	<hr/>	<hr/>
		247,244	14,726	261,970	343,486
<b>CREDITORS</b>					
Amounts falling due within one year	15	4,496	-	4,496	3,943
		<hr/>	<hr/>	<hr/>	<hr/>
<b>NET CURRENT ASSETS</b>		242,748	14,726	257,474	339,543
		<hr/>	<hr/>	<hr/>	<hr/>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		292,748	14,726	307,474	339,543
		<hr/>	<hr/>	<hr/>	<hr/>
<b>NET ASSETS</b>		292,748	14,726	307,474	339,543
		<hr/>	<hr/>	<hr/>	<hr/>
<b>FUNDS</b>	16				
General fund				292,748	312,629
Designated funds				14,726	26,914
				<hr/>	<hr/>
<b>TOTAL FUNDS</b>				<b>307,474</b>	<b>339,543</b>
				<hr/>	<hr/>

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

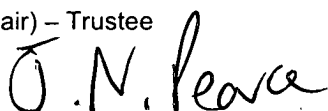
- (a) ensuring that the charitable company keeps accounting records that comply with Section 386 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial period and of its surplus 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**

	<b>2022</b>	<b>2021</b>
Donations:		
Charitable Trusts, Clubs and Corporations	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/Ride London 100	45,850	33,649
Other	25,310	26,526
	<hr/>	<hr/>
	135,789	178,035
	<hr/>	<hr/>

- 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**

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

**4. INVESTMENT INCOME**

Interest receivable	2,815	2,492
	<hr/>	<hr/>
	2,815	2,492
	<hr/>	<hr/>

**5. COSTS OF RAISING FUNDS**

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

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

**6. CHARITABLE ACTIVITIES**

	<b>2022</b>	<b>2021</b>
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
	<hr/>	<hr/>
	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	-
	<hr/>	<hr/>
	42,079	19,607
	<hr/>	<hr/>
	175,938	122,244
	<hr/>	<hr/>

**7. OTHER COSTS**

	<b>2022</b>	<b>2021</b>
Accountancy and professional fees	2,776	2,600
	<hr/>	<hr/>

**8. SUPPORT COSTS**

	<b>Pastoral support &amp; information exchange</b>	<b>Medical liaison research and co-operation</b>	<b>2022 TOTAL</b>	<b>2021 TOTAL</b>
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
	<hr/>	<hr/>	<hr/>	<hr/>
	111,686	24,518	136,204	101,065
	<hr/>	<hr/>	<hr/>	<hr/>

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

**9. NET INCOMING RESOURCES**

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

**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:

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

**12. TANGIBLE FIXED ASSETS**

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

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

**13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

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

	<b>2022</b>	<b>2021</b>
Current asset investments	197,051	251,182
Fixed asset investments	50,000	-
	<hr/>	<hr/>
	247,051	251,182
	<hr/>	<hr/>

**15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

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

**16. MOVEMENT IN FUNDS**

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

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

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

**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>	£
<b>Unrestricted funds</b>				
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
	<hr/>	<hr/>	<hr/>	<hr/>
<b>TOTAL FUNDS</b>	282,045	57,498	-	339,543
	<hr/>	<hr/>	<hr/>	<hr/>

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

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

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).