

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

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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

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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.

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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

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- 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 (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 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.

T.O.F.S
REPORT OF THE TRUSTEES
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

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

4 May 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	Year Ended
		General fund	Designated funds	31.12.21	31.12.20
		£	£	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	-	-	-	-
		<hr/>	<hr/>	<hr/>	<hr/>
		-	-	-	-
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
		<hr/>	<hr/>	<hr/>	<hr/>
		316,572	26,914	343,486	284,571
CREDITORS					
Amounts falling due within one year	15	3,943	-	3,943	2,526
		<hr/>	<hr/>	<hr/>	<hr/>
NET CURRENT ASSETS		312,629	26,914	339,543	282,045
		<hr/>	<hr/>	<hr/>	<hr/>
TOTAL ASSETS LESS CURRENT LIABILITIES		312,629	26,914	339,543	282,045
		<hr/>	<hr/>	<hr/>	<hr/>
NET ASSETS		312,629	26,914	339,543	282,045
		<hr/>	<hr/>	<hr/>	<hr/>
FUNDS	16				
General fund				312,629	235,633
Designated funds				26,914	46,412
				<hr/>	<hr/>
TOTAL FUNDS				339,543	282,045
				<hr/>	<hr/>

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



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
	<hr/>	<hr/>
	178,035	113,491
	<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

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

4. INVESTMENT INCOME

Interest receivable	2,492	3,808
	<hr/>	<hr/>
	2,492	3,808
	<hr/>	<hr/>

5. COSTS OF RAISING FUNDS

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

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
	<hr/>	<hr/>
	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
	<hr/>	<hr/>
	19,607	18,056
	<hr/>	<hr/>
	122,244	85,753
	<hr/>	<hr/>

7. OTHER COSTS

	2021	2020
Accountancy and professional fees	2,600	2,406
	<hr/>	<hr/>

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
	<hr/>	<hr/>	<hr/>	<hr/>
	83,885	17,180	101,065	67,440
	<hr/>	<hr/>	<hr/>	<hr/>

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
	<hr/>	<hr/>

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
	<hr/>	<hr/>
	90,396	58,236
	<hr/>	<hr/>

12. TANGIBLE FIXED ASSETS

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

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
	<hr/>	<hr/>
	11,564	10,006
	<hr/>	<hr/>

2021

2020

14. CURRENT ASSET INVESTMENTS

Cash held for investments	251,182	213,190
	<hr/>	<hr/>

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

16. MOVEMENT IN FUNDS

	<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
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	282,045	57,498	-	339,543
	<hr/>	<hr/>	<hr/>	<hr/>

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)
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	189,481	131,983	-	57,498
	<hr/>	<hr/>	<hr/>	<hr/>

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>£</u>	<u>in funds</u>	<u>between funds</u>	<u>£</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
	<u> </u>	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	254,689	27,356	-	282,045
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

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)
	<u> </u>	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	120,038	92,682	-	27,356
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

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).