

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

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

Lemans
29 Arboretum Street
Nottingham
NG1 4JA

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

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

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number
2202260 (England and Wales)

Registered Charity number
327735

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

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

Chief Executive Officer
Diane Stephens

Independent Examiner
K Mealand FCCA
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29 Arboretum Street
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Bankers
Caf Bank
25 Kings Hill Avenue
Kings Hill
West Malling
Kent
ME19 4JQ

SPECIAL NOTE CONCERNING THE COVID-19 PANDEMIC

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

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

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

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

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

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

STRUCTURE, GOVERNANCE AND MANAGEMENT

Objectives and aims

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

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

Constitution

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

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

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

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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 (finance; pastoral support; medical liaison & research; staffing & recruitment; strategy & projects); which are chaired by either a Trustee or the CEO and which, where appropriate, are attended not only by one or more other trustees but also by persons from across the wider T.O.F.S. membership.

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

Policies and Documentation

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

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

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

Risk Management

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

Risks are reviewed and mitigated by:

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

Recruitment and Appointment of Trustees

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

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

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

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

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

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

Staff Recruitment

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

Strategic Direction

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

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

Activities and Achievements in 2020

Pastoral support and information exchange

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

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2020 Awareness week

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

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

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

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

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

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

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

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

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

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

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

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

Liaison with the medical profession

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

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

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

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

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

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

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

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

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

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

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

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

Use of Information Technology (IT)

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

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

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Co-operation with other organisations

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

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

EAT's key successes during 2020 were:

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

Funding, Financial Management and Governance

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Overall expenditure in 2020 at £92,682 was unsurprisingly a little lower than the £97,239 of 2019, and the £101,017 spent in 2018, which has been the charity's highest-expenditure year to date.

The Trustees have been pleasantly surprised and gratified that T.O.F.S. has been able to record a material surplus in 2020 !

Public benefit

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

Financial Review and Reserves policy

Like other charities, T.O.F.S. requires reserves in order to operate in the short term and to satisfy legal obligations in the event of the end of funding, a major reduction of funding or a delay in further funding becoming available. In the event of having to close the charity, the reserves would enable proper notice to be given to the beneficiaries and staff and for all legally due payments to be made to staff, volunteers and the organisations with which we do business. In view of the great uncertainties arising from the COVID-19 pandemic, the Trustees have raised the minimum level of reserves to an amount sufficient to cover all normal operating expenses for a full year. At the end of 2020, T.O.F.S. has significantly more in reserves than this policy demands, however some of the apparent excess has been set aside for special projects, as already mentioned.

Investment policy and objectives:

For the whole of 2020, T.O.F.S. has held current bank accounts with Lloyds Bank Ltd and CAF Bank Ltd (a part of the Charities Aid Foundation). For accepting payments and donations it also has accounts with PayPal, Amazon Smile, Facebook, Just Giving, Wonderful, Peoples' Fundraising and Virgin Money Giving. During the year, T.O.F.S. ceased to use the Wonderful fundraising website, as this closed down permanently, and started to use Peoples' Fundraising instead.

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

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

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

Approved by order of the Council on 20 March 2021 and signed on its behalf by:

D Jackson (Chair)

A handwritten signature in black ink, appearing to be 'D Jackson', written over a circular stamp or seal.

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

I report to the Charity Trustees on my examination of the accounts of the company, for the year ended 31 December 2020 set out on pages 14 to 23..

Responsibilities and basis of report

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

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

Independent examiner's statement

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

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

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

K Mealand

K Mealand FCCA
Lemans
29 Arboretum Street
Nottingham
NG1 4JA

21 April 2021

T.O.F.S.
STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2020

		Ended			Year	Year
		General	Designated	Restricted	Unrestricted funds	Unrestricted funds
	Notes	fund	funds	fund	31.12.20	31.12.19
		£	£	£	Total funds	Total funds
					£	£
INCOME AND ENDOWMENTS FROM:						
Donations and legacies	2	113,491	-	-	113,491	148,617
Other trading activities	3	2,739	-	-	2,739	5,559
Investments	4	3,808	-	-	3,808	2,775
Total income and endowments		120,038	-	-	120,038	156,951
EXPENDITURE ON:						
Raising funds	5	-	4,523	-	4,523	3,927
Charitable activities	6	64,274	21,479	-	85,753	90,922
Other	7	2,406	-	-	2,406	2,390
Total expenditure		66,680	26,002	-	92,682	97,239
NET INCOME/(EXPENDITURE)		53,358	(26,002)	-	27,356	59,712
Transfers between funds						
Net movement in funds		53,358	(26,002)	-	27,356	59,712
Reconciliation of funds						
TOTAL FUNDS BROUGHT FORWARD		182,275	72,414	-	254,689	194,977
TOTAL FUNDS CARRIED FORWARD		235,633	46,412	-	282,045	254,689

The notes form part of these financial statements

T.O.F.S. – COMPANY NUMBER 2202260
BALANCE SHEET
AT 31 DECEMBER 2020

	Notes	Unrestricted funds £	Restricted fund £	31.12.20 Total funds £	31.12.19 Total funds £
FIXED ASSETS					
Tangible assets	12	-	-	-	-
		<hr/>	<hr/>	<hr/>	<hr/>
		-	-	-	-
CURRENT ASSETS					
Stock		7,482	-	7,482	1,381
Debtors: amounts falling due within one year	13	10,006	-	10,006	7,901
Investments	14	213,190	-	213,190	229,393
Cash at bank		53,893	-	53,893	22,598
		<hr/>	<hr/>	<hr/>	<hr/>
		284,571	-	284,571	261,273
CREDITORS					
Amounts falling due within one year	15	2,526	-	2,526	6,584
		<hr/>	<hr/>	<hr/>	<hr/>
NET CURRENT ASSETS		282,045	-	282,045	254,689
		<hr/>	<hr/>	<hr/>	<hr/>
TOTAL ASSETS LESS CURRENT LIABILITIES		282,045	-	282,045	254,689
		<hr/>	<hr/>	<hr/>	<hr/>
NET ASSETS		282,045	-	282,045	254,689
		<hr/>	<hr/>	<hr/>	<hr/>
FUNDS					
	16				
General fund				235,633	182,275
Designated funds				46,412	72,414
Restricted fund				<hr/>	<hr/>
TOTAL FUNDS				282,045	254,689
				<hr/>	<hr/>

T.O.F.S. – COMPANY NUMBER 2202260
BALANCE SHEET - CONTINUED
AT 31 DECEMBER 2020

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2020.

The trustees have not required the charitable company to obtain an audit of its financial statements for the year ended 31 December 2020 in accordance with Section 476 of the Companies Act 2006.

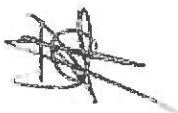
The trustees acknowledge their responsibilities for

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

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

The financial statements were approved by the Council of Management on 20 March 2021 and were signed on its behalf by:

D Jackson (Chair) – Trustee



J Pearce (Vice-Chair & Treasurer) – Trustee



G Slater (Secretary) - Trustee



The notes form part of these financial statements

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2020

1. ACCOUNTING POLICIES

Basis of preparing the financial statements and assessment of going concern

TOFS is a private charitable company limited by guarantee incorporated in England within the UK. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 1 of these financial statements. The nature of the charity's operations and principal activities are stated on page 3 of these financial statements.

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

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

Income

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

Expenditure

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

Tangible Fixed Assets

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

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

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

Stocks

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

Current asset investments

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

Taxation

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

Debtors and Creditors

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

Cash at Bank

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

Fund accounting

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

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

2. DONATIONS AND LEGACIES

	2020	2019
Donations:		
Charitable Trusts, Clubs and Corporations	16,075	49,853
Individuals	7,921	2,675
In Memoria	4,406	6,451
Members and Friends	41,520	41,650
London Marathon/Great North Run/Teddy Toddle	21,206	24,682
Other	22,363	23,306
	<hr/>	<hr/>
	113,491	148,617
	<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

	2020	2019
Sale of TOFS goods	2,659	2,816
Conference income	-	2,343
TOFS fundraisers and raffles	80	400
	<hr/>	<hr/>
	2,739	5,559
	<hr/>	<hr/>

4. INVESTMENT INCOME

Interest receivable	3,808	2,775
	<hr/>	<hr/>
	3,808	2,775
	<hr/>	<hr/>

5. COSTS OF RAISING FUNDS

Opening stock	1,381	2,555
Purchases	10,248	-
Closing stock	(7,482)	(1,381)
	<hr/>	<hr/>
	4,147	1,174
Just giving subscription	216	446
London Marathon / Great North Run	160	2,307
	<hr/>	<hr/>
	4,523	3,927
	<hr/>	<hr/>

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

6. CHARITABLE ACTIVITIES

	2020	2019
Pastoral support and information exchange:		
Leaflets and newsletters	6,905	9,208
Conference expense	1,310	9,701
Gifts and entertaining children	782	431
Telephone	791	799
Printing, postage, stationery, fundraising costs and publicity	2,674	5,187
Support costs (note 8)	55,235	45,229
	<hr/> 67,697	<hr/> 70,555
Liaison with the medical profession:		
Projects - Medics to INOEA / Medical and Hospital Liaison	627	2,254
Research costs	3,499	3,565
Awareness week and other	1,495	-
TOFS presence at INoEA Rome	-	1,578
Support costs	10,298	10,438
	<hr/> 15,919	<hr/> 17,835
Co-operation with other organisations:		
Travel	-	-
Projects European Collaboration / EAT	230	213
Support costs	1,907	2,319
	<hr/> 2,137	<hr/> 2,532
	<hr/> 85,753	<hr/> 90,922

7. OTHER COSTS

	2020	2019
Accountancy and professional fees	2,406	2,390

8. SUPPORT COSTS

	Pastoral support & information exchange	Liaison with the medical profession	Co-operation with other organisations	2020 TOTAL	2019 TOTAL
Wages	47,866	8,775	1,595	58,236	47,167
Finance	186	43	10	239	106
Information Technology	2,749	504	92	3,345	2,360
Office accommodation	3,451	796	177	4,424	4,695
Travel and Sundry	983	180	33	1,196	3,658
	<hr/> 55,235	<hr/> 10,298	<hr/> 1,907	<hr/> 67,440	<hr/> 57,986

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

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

9. NET INCOMING RESOURCES

2020 **2019**

Net resources are stated after charging:

Depreciation – owned assets

Independent examiner's fees

-	-
1,588	1,542
<u> </u>	<u> </u>

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2020 nor for the year ended 31 December 2019.

Trustees' Expenses

Two of the trustees received reimbursed expenses in the period of £1,268 (2019 - £3,935).
None (2019 - Some) of their travel expenses were donated back to TOFS by the Trustees.

11. STAFF COSTS

The average number of full time equivalent employees during the period was 3 (2019 – 2)

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

The total staff costs and employee benefits were as follows:

Wages and Salaries -	£56,894 (2019 - £46,305)
Social Security costs -	£nil (2019 - £nil)
Pension costs -	£1,342 (2019 - £862)

12. TANGIBLE FIXED ASSETS

	<u>Office Equipment</u> £
COST	
At 1 January 2020	3,944
Additions/(Disposals)	-
	<u> </u>
At 31 December 2020	3,944
	<u> </u>
DEPRECIATION	
At 1 January 2020	3,944
Charge for the year	-
	<u> </u>
At 31 December 2020	3,944
	<u> </u>
NET BOOK VALUE	
At 31 December 2020	-
	<u> </u>
At 31 December 2019	-
	<u> </u>

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>31.12.20</u>	<u>31.12.19</u>
	£	£
Accounts receivable	847	447
Prepayments and other debtors	4,535	3,511
Gift Aid	4,624	3,943
	<hr/>	<hr/>
	10,006	7,901
	<hr/>	<hr/>

14. CURRENT ASSET INVESTMENTS

Cash held for investments	213,190	229,393
	<hr/>	<hr/>

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

Accountancy	1,590	1,542
Chew design, print and postage costs	-	2,191
Social Security & other taxes	698	733
Accruals	238	1,413
Deferred Income – VLM	-	705
	<hr/>	<hr/>
	2,526	6,584
	<hr/>	<hr/>

16. MOVEMENT IN FUNDS

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

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

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

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

16. MOVEMENT IN FUNDS

	<u>At 1.1.19</u>	<u>Net Movement in funds</u>	<u>Transfers between funds</u>	<u>At 31.12.19</u>
	£	£	£	£
Unrestricted funds				
General Fund	179,579	64,696	(62,000)	182,275
Designated Fund – Medical research	15,398	(4,984)	-	10,414
Projects & resources	-	-	62,000	62,000
	<hr/>	<hr/>	<hr/>	<hr/>
	194,977	59,712	-	254,689
Restricted fund	-	-	-	-
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<hr/> 194,977 <hr/>	<hr/> 59,712 <hr/>	<hr/> - <hr/>	<hr/> 254,689 <hr/>

T.O.F.S.
NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2020

16. MOVEMENT IN FUNDS

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

	Incoming resources	Resources expended	Gains and losses	Movement in funds
Unrestricted funds				
General Fund	156,951	92,255	-	64,696
Designated Funds	-	4,984	-	(4,984)
	<hr/>	<hr/>	<hr/>	<hr/>
	156,951	97,239	-	59,712
Restricted fund	-	-	-	-
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	156,951	97,239	-	59,712
	<hr/>	<hr/>	<hr/>	<hr/>

The research designated fund was created in 2013. The Trustees added to this in 2014. A total of £20,000 of reserves is designated to support relevant medical research work, over several years. In 2019 the Trustees created an additional designated fund for "Projects and Additional Resources" – to cover principally staff costs over the next couple of years, but also other special project costs.

17. RELATED PARTY TRANSACTIONS.

During the year, TOFS has bought IT services amounting to £1,416 (2019 - £1,677) from Altido (formerly CRM Labs). The managing director of this firm is the son-in-law of Dennis Harvey, one of the Trustees.

During this year, none (2019 – some) of the expenses reimbursed to Trustees were donated back to the Charity, which totalled £nil (2019 - £571).