

NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

England & Wales · Charity number 1042013

Details

Status Registered

Legal form Trust

Registered 1994-11-09

Register [View on the Charity Commission register](#)

Contact

Address Harold Wood Polyclinic
Copse Avenue
Harold Wood
Romford
RM3 0FE

Phone 03333355196

Email Enquiries@Tremor.org.uk

Website www.tremor.org.uk

Activities

Objects: (1) TO PROMOTE, CENTRALISE AND CO-ORDINATE FOR THE BENEFIT OF THE PUBLIC ANY FORM OF RESEARCH INTO IDIOPATHIC AND HEREDITARY TREMOR (2) TO RELIEVE THE NEED OF SUFFERERS FROM ESSENTIAL IDIOPATHIC AND HEREDITARY TREMOR (3) TO ADVANCE THE EDUCATION OF THE PUBLIC IN THE SUBJECT OF ESSENTIAL, IDIOPATHIC AND HEREDITARY TREMOR

Activities: To Provide support for people with tremors, by means of raising monies through subscriptions & donations which go towards manning an office & helpline, maintaining a website, research & aid to individual support groups throughout England & Wales

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, The General Public/mankind

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£49,246	£76,814	-	-
2023-12-31	£49,174	£79,217	-	-
2022-12-31	£125,048	£70,177	-	-
2021-12-31	£35,452	£53,733	-	-
2020-12-31	£109,628	£61,150	-	-

Trustees

Name	Role	Appointed
Catherine Anne Reilly	Chair	2017-04-06
Dr Matteo Ciocca MD,PhD		2025-07-30
Jibril Osman Farah MD,FRCS		2025-07-30
KEITH FLAXMAN FCCA,CPFA		2017-11-26
Kevin Harfoot		2007-04-06
Prof PETER BAIN MBBSMAFRCP		

NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

England & Wales - Charity number 1042013

Accounts



National Tremor Foundation Charitable Trust

**Report & Financial Statements
for the year ended 31 December 2024**

Charity number: 1042013

National Tremor Foundation Charitable Trust

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National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2024

Objectives and Activities

The Trust's legal purpose (objects) is:

- To promote, centralise and co-ordinate for the benefit of the public any form of research into essential, idiopathic and hereditary tremor and to disseminate and publish the useful results of such research.
- To relieve the need of sufferers from essential, idiopathic and hereditary tremor.
- To advance the education of the public in the subject of essential, idiopathic and hereditary tremor.

The Trust is currently able to resource these charitable activities:

- **Information.** Provision of knowledge to people affected by tremor or movement disorders of various parts of the body in order to help them and their families/carers manage the condition. The initial source for the Trust's beneficiaries is the website which the Trust believes is the leading source of information for a number of tremors affecting people in the UK. Further sources are a newsletter (available in hard and soft copy), a general telephone enquiry service and access to an advisory panel.
- **Research.** Research opportunities are regularly reviewed but are dependent on the build-up of reserves available. Research is important because it progresses the understanding of tremors by investigating causes and potential treatments.
- **Beneficiary support.** This activity covers the annual conference, active support and the encouragement/subsidy of regional support groups where there are known clusters of interested beneficiaries.

Achievements and Performance

This section explains the activities for the reporting period; NTF generated a respectable amount of income for 2024, which was almost identical to 2023. Expenditure has unfortunately continued to exceed income for the second consecutive year. The additional expenditure which has increased by over 10% has mainly been due to additional staff costs, especially the appointment of a new General Manager, on a freelance basis, towards the third quarter of 2024. The appointment of a General Manager is a considerable investment by the NTF as part of our strategic approach towards growth over the coming years. The role's objectives will be operational in providing governance support for the Trustees, as well as helping to raise awareness of the tremors impacting people, and to increase the level of fundraising activities and identifying new fundraising streams.

There has also been continuous improvements and developments to our website, which is an important source of information and engagement for the public, and most importantly people living with neurological tremors.

The Charity is always conscious about keeping costs to a minimum while maintaining the central office support facility.

Honorary President Lord Julian Fellowes



We are delighted and honoured to continue to have Lord Julian Fellowes as Honorary President of the NTF. Lord Fellowes is world renowned for creating the hugely successful and critically acclaimed TV period drama

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Downton Abbey. In a recent newspaper interview, he revealed that he lives with Essential Tremor. In the last ever episode of Downton Abbey, it was revealed that a much-loved existing character was suffering with Essential Tremor which raised a great amount of awareness for this little-known condition.

Lord Fellowes was born in Cairo, Egypt, educated in Britain before moving to Los Angeles in 1981 and returned to the UK in 1991. He is well known as an actor, novelist, screenwriter and film director and his career spans over 40 years. Lord Fellowes has been a member of the House of Lords since January 2011. He is also chairman and patron of several UK charities.

Rob Mallard, Patron for Young People



In 2023 Coronation Street Actor Rob Mallard was appointed Patron for Young People. This appointment has been a step forward in raising awareness of the challenges facing young people with neurological tremors. He has spoken openly on television, radio, and at public events, sharing his personal journey and experiences with essential tremor. His involvement has also been notable during National Essential Tremor Awareness Month, where he actively promotes understanding of the condition in collaboration with the NTF.

Board Activity

The NTF continues to raise funds to support people with all forms of neurological tremors. The 2024 income was similar to 2023, however the expenditure continues to increase. The majority of charities continue to struggle to generate increased funds during the current economic climate, with expenditure also increasing due to inflation and the cost of living.

The board activity over the year has been positive, especially from a governance perspective, by meeting regularly, holding themselves accountable to the constitution and strategy plan, as well as reviewing the finances to ensure legal compliance. This approach has left the charity in a strong position at the end of the year.

The board have also made sure that our support groups have continued to meet regularly in-person during 2024, also having the option of attending one of the 13 online events throughout the year, co-hosted by Jackie Farrell and Duncan Crossland. The online events have been a huge success having an overall turnout of 425 people for the year. The success of these events is evidently down to the time and commitment put in by both Jackie and Duncan.

Three major events were organised by, or in collaboration with, the NTF during this year. These were the NTF Annual Conference in April, the 'Back the 1 in 6' awareness campaign during the summer and exhibiting at the Royal College of General Practitioners Conference 2024 in October. Further details about these events can be found below.

- **NTF Annual Conference, Sheffield, 20th April 2024**

The NTF Annual Conference in Sheffield was a success, bringing together people from all areas of the neurological tremor community and commemorating the NTF's 30-year anniversary.

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Rob Mallard, known as Daniel Osborne from the soap opera Coronation Street and NTF Patron for Young People, shared his personal journey with Essential Tremor during a thought-provoking Q&A session.

The overall day included a number of discussions as well as insightful talks on the advancements in cutting edge laser procedures for tremors, in particular offering a debate on the advantages and limitations of alternative surgical approaches.

- **Back the 1 in 6'**

The campaign raised awareness that one in six people in the UK live with one or more neurological conditions, including neurological tremors. However, there simply aren't enough workforce or services to provide the support they need. The campaign asked our supporters to encourage their MP to #BackThe1in6 and become a #NeuroChampion in Parliament by highlighting that neurological conditions are the leading cause of disability worldwide and affect, on average, 17,000 people in each UK Parliamentary constituency.

- **Exhibit at the Royal College of General Practitioners Conference 2024**

In October 2024, the National Tremor Foundation (NTF) attended the Royal College of General Practitioners (RCGP) Conference. At this prestigious event the NTF provided attendees with an opportunity to learn more about the charity and neurological tremors including Essential Tremor, a little known but common disorder which affects approximately 1 million people in the UK alone.

The Board of Trustees met in April at the Annual Conference and in October and December during 2024, these meetings supported the general business, and the Trustees began a review of its management arrangements and policies. In-person safeguarding training was also provided for Trustees during the morning of the Annual Conference in April.

The board was saddened by the news that Geoff Salmon had decided to retire after over two decades of dedicated service as Fundraising Manager. Geoff's tireless efforts have played a crucial role in raising awareness and funds to support those living with neurological tremors, and his departure marks the end of an era for the organisation.

Phoebe Dann left the NTF after nine months as the freelance administrator. The board was extremely grateful for all her efforts, especially with the organisation of the Annual Conference in Sheffield.

In September, the NTF advertised for the new position of General Manager, to support the board members and Jasbir Singh was appointed to start in October 2024. The board also recognised fundraising as a key area of development for the charity, especially with Geoff Salmon's departure, and engaged with a fundraising consultancy to assist with training and fundraising expertise.

The continuity and stability with Duncan Crossland, Digital Marketing Advisor, and Jackie Farrell, Support Group Co-ordinator is especially important during this period of change. They are dedicated and committed individuals that have ensued the success of the NTF over many years.

A programme of meetings was arranged for the latter quarter of 2024 to review the charity's strategic plan for the next three years, especially with the number of changes that have taken place within the NTF and to factor the difficult economic climate currently within the charity sector.

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Communication and Digital Report

Digital performance and analysis

The NTF's website remains the charity's main channel for communicating with the public. In 2024, it attracted **96,478 users** from around the world, helping to raise awareness and provide vital information about tremor.

The website offers a wide range of resources, including information on diagnosis, clinical characteristics, research topics, and support for carers, as well as details of support group events and the latest news.

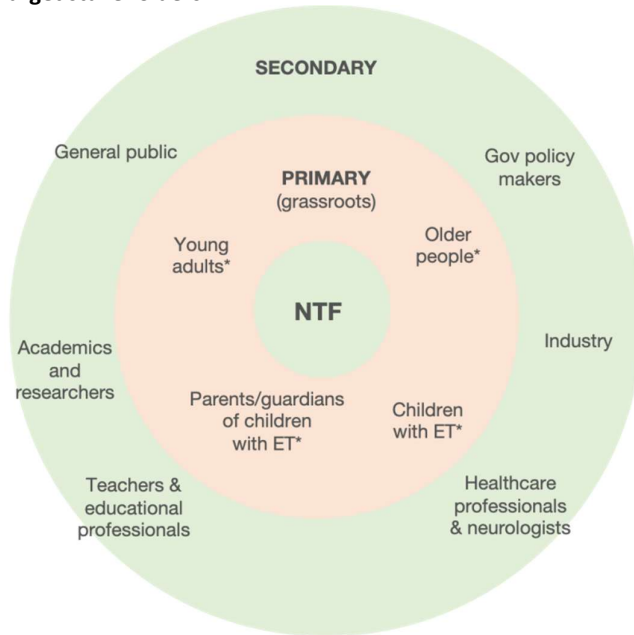
Note: In 2023, Google Analytics 4 was introduced, changing the metrics used to measure website traffic.

The following SWOT analysis identifies the charity's main strengths and weaknesses, as well as opportunities for development and areas of potential risk.

Strengths (internal) 1. Improved online donations process 2. Improved signing up for events and support events 3. Strong digital support network of potential volunteers 4. Surveys are helping us make better informed decisions. 5. Only charity representing ET which is driving traffic to the website.	Opportunities (external) 1. Demand for people to get involved in the NTF as volunteers. 2. Text message (SMS) marketing. 3. Need for more newsletters. 4. More non-clinical research on website. 5. More device research on website. 6. Opportunities for clinical trials on website. 7. Men with ET campaign. 8. More personal stories and coping tips.
Weaknesses (internal) 1. Still operating reactively not proactively due to limited capacity. 2. Audience data is limited and need to understand our audiences to conduct marketing more effectively. 3. Need additional support for Support Groups 4. Lack of awareness in schools and health care settings 5. Need to develop audience loyalty and advocacy. 6. Need for formal representation in Scotland. 7. Data needs segmenting. 8. Need for expert panel to deliver content. 9. Need for brand guidelines. 10. Need for brand guidelines for support groups. 11. Need to focus on push marketing i.e. paid advertising 12. Need more video content.	Threats (external) 1. Economic issues affecting online donations 2. Growth in dependence on charities for digital support due to NHS being overburdened 3. Increase in competition for digital engagement from other charities. 4. Increasing demand for a Scottish representation. 5. Demand for representation for ET only.

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Target stakeholders



*We also need to take into consideration the families of people with tremor.

Website audiences

- The majority of our audience has essential tremor.
- They are most likely to be female.
- Aged over 25 but marginally more likely to be aged 45-54.
- A significant number live in London.
- They prefer to access the website via mobile phone.
- Online behaviour: interested in food, entertainment and celebrities.

Paid advertising

In 2024, a total of 8,885 users were acquired through paid advertising campaigns. These were delivered across both social media platforms and Google Ads via the Google Ad Grants programme. Paid activity played an important role in increasing awareness of essential tremor, driving traffic to key pages, and encouraging donations and event participation.

Social media

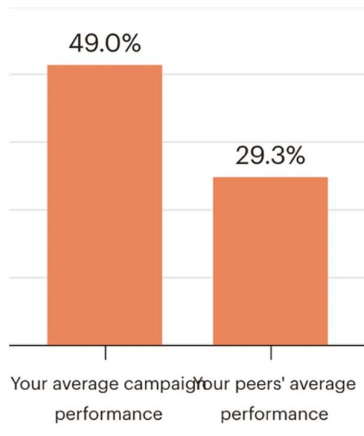
The NTF's social media presence continued to grow throughout 2024. Our established Facebook channel remains the most popular platform for engaging with the community, sharing updates, and promoting events. Meanwhile, Twitter (X) has seen increased interaction and follower growth, helping to reach new audiences and encourage wider conversation around essential tremor. The charity's consistent online presence has helped strengthen its visibility and connection with both supporters and professionals.

Newsletter

The NTF's monthly e-newsletter continues to be a valuable communication tool. Distributed to over 4,500 subscribers each month, it provides updates on research, events, fundraising activities, and support opportunities. With an average open rate of 49%, the newsletter performs well above the sector average, reflecting strong engagement and interest among readers.

Below is a bar chart showing newsletter performance.

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Marketing campaigns and fundraising highlights

In 2024, we ran a number of successful marketing campaigns to raise awareness and encourage donations.

March marked National Essential Tremor Awareness Month, during which we invited members of the public to display posters in community spaces such as GP surgeries. A total of 30 people took part, helping to make it one of our most successful awareness efforts to date.

Our 30 Days of June Challenge was another highlight. Twenty-eight dedicated participants took part in a range of exciting activities, from walking and cycling to an adventurous fossil hunt, helping to raise both awareness and funds in support of our cause.

Finally, our Christmas campaign brought the year to a strong close. We launched a festive activity calendar designed to keep people active over the holiday season, along with a series of seasonal e-cards that were warmly received by supporters.

Online donations

In 2024 online donations saw a slight dip in the light of economic uncertainty.

2024	£3153
2023	£3491
2022	£2740
2021	£5073

Research

The NTF is aware of research activities taking place and helps to promote and engage with request for involvement when required

Imperial College NHS Trust in London and the Walton Centre in Liverpool continue to treat patients with MRgFUS, although the number of treatments they are able to deliver is limited and they are currently the only NHS funded centres in England. That inevitably means that waiting lists will grow. However, it is important that Imperial College continue to treat those patients with severe or problematic Essential Tremor.

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Trustees' Annual Report for the Year Ended 31 December 2024

Essential Tremor in Children and Young People

The NTF continue to have a Children's Liaison Officer, the Chair of the Board of Trustees Kitty Reilly. Kitty sees her main role as a supportive one in the first instance, followed by raising awareness through our website for children with ET as well as relevant social media campaigns.

Coronation Street actor Rob Mallard, our Patron for Young People, was diagnosed with Essential Tremor in his teenage years and is a great advocate for the NTF in raising awareness of the condition.

Annual Meeting

The annual meeting was a great success as part of the Annual Conference in Sheffield.

Fundraising Review

The Foundation continued to receive support from many Charitable Trusts throughout the year. Postal applications and personal visits enabled funding to be obtained at low costs. Applications were generally for basic core costs.

The continuing low investment interest rates obtained by trust funds has again reduced the amount of money for distribution to beneficiaries and The Foundation greatly appreciates the support from all Charitable Trusts. During a difficult period, the Foundation did manage to raise £49.2k.

The appointment of the Fundraising Consultancy will help the NTF to develop a fundraising strategy as well as focusing our limited resources on areas which will generate the most funds.

Plans for 2025

1. To review the NTF 3-year strategy and ensure the focus is on our activity around raising awareness, fundraising and increasing our volunteer capacity.
2. To increase the number of support groups enabling more people with neurological tremor to have access to one.
3. Register the charity with the Office of the Scottish Charity Regulator and have a presence in Scotland.
4. To continue to expand and update the website to allow greater accessibility and quality of content.
5. Continuously strengthen the governance of the NTF and continue the review of policies

Public Benefit Statement

The Trustees confirm that they have complied with the duty in the Charities Act 2011 to have due regard to the Charity Commission's general guidance on public benefit. As stated elsewhere in this report, the Trust's charitable activity work is clear evidence of both the identifiable benefit provided and the relation of this benefit to the charity's aims. Continuing website feedback shows that the Trust is regularly reaching people affected by tremors - both in UK and overseas, with a continued large increase in visitors to the website in recent years.

Financial Review

Our income received for 2024 reached £49.2k, most charities have been struggling to raise funds due to the post covid and general economic situation. There was a total of £88.9k in the bank at year end, which still gives us a real basis to look to future developments. The NTF is not a membership organisation, so we encourage our supporters to voluntarily donate.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2024

Reserves Policy

The Trustees would ideally like to establish a level of reserves that would meet 12 months of basic operational costs should there be a gap in funding. At the year end the bank balance would keep NTF operational for over 12 months, assuming there were no further donations, and the Trustees have recognised the need for a substantial increase in income in order to create a 12 month reserve and to cover all ongoing operational and research costs.

Reference and Administration details

Trustees at date of report's approval 31st October 2024;

Chair of Board of Trustees

Kitty Reilly MSc, BSc

Trustees

Professor Leslie J Findley TD, M D, FRCP

Kevin Harfoot

Keith Flaxman FCCA, CPFA (Treasurer)

Dr Peter Bain MBBS MA MD FRCP (Consultant Neurologist)

Registered Office:

Harold Wood Polyclinic
Copse Avenue
Romford
RM3 0FE
Bankers

National Westminster Bank

Independent Examiner
Adrian Nunn FCCA

Charity Registration Details

Name: National Tremor Foundation Charitable Trust

No: 1042013

Structure, Governance & Management

Governing Document

The Trust is governed by a Declaration of Trust dated 19 October 1994 and was registered as a charity on 9 November 1994.

Recruitment and Appointment of Trustees

New trustees are recruited for the special contribution they can make to the Trust and are appointed by resolution of the Trustees.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2024

Statement of Trustees Responsibilities

Charity law requires the Trustees to prepare a trustees' annual report and financial statements for each financial year which show a true and fair view of the state of affairs of the Trust and its financial activities for that period. In preparing those financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles in the applicable Charities SORP.
- Make judgements and estimates that are reasonable and prudent.
- State whether applicable accounting standards and statements of recommended practice have been followed, subject to any departures disclosed and explained in the financial statements.
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Trust will continue in operational existence.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports)

Regulations and the provisions of the constitution. They are also responsible for the maintenance and integrity of the Trust, safeguarding the assets of the Trust and for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The financial statements have been prepared in accordance with the accounting policies set out in notes to the accounts and comply with the charity's governing document, the Charities Act 2011 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 (FRS 102) published on 16 July 2014.

Statement as to disclosure to the independent examiner

In so far as the Trustees are aware at the time of approving the trustees' annual report:

There is no relevant information needed by the independent examiner in connection with preparing his report, of which the independent examiner is unaware.

The Trustees, having made enquiries of fellow trustees and the independent examiner that they ought to have individually taken, have each taken all steps that they are obliged to take as a trustee in order to make themselves aware of any relevant information for the independent examination and to establish that the independent examiner is aware of that information.

Approved by the Trustees on 31st Oct 2024 and signed on their behalf by:

A handwritten signature in black ink, appearing to read 'Kitty Reilly', is written over a light grey rectangular background.

Chair

Kitty Reilly (MSc, BSc)

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

I report on the accounts of the National Tremor Foundation Charitable Trust for the year ended 31 December 2024, which are set out on pages 10-14

Responsibilities and basis of report

As the trustee of the charity, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

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

Accounting records were kept in respect of the Trust as required by Section 130 of the Act.

The accounts accord with those records.

The accounts comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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



Adrian Nunn
FCCA
Flat 9 Millenium Court
4, College Road
Liverpool
L23 0YE

National Tremor Foundation Charitable Trust
Statement of Financial Activities for the Year Ended 31st December 2024

	Note	Unrestricted Funds £	Restricted Funds £	Total for Year 2024 £	2023 £
Income	1				
Donations		49,246	0	49,246	49,174
Grants				0	0
		<u>49,246</u>	<u>0</u>	<u>49,246</u>	<u>49,174</u>
Expenditure	2				
Fund Raising		16,926		16,926	15,826
Reversal of Provision not required	3	-6,861		-6,861	
Charitable Activities					
Information		43,596		43,596	48,445
Research			0	0	0
Beneficiary Support	4	21,484	1,669	23,153	14,946
		<u>75,145</u>	<u>1,669</u>	<u>76,814</u>	<u>79,217</u>
Net Movement in Funds		<u>-25,899</u>	<u>-1,669</u>	<u>-27,567</u>	<u>-30,043</u>
Reconciliation of Funds		<u>90,133</u>	<u>-1,669</u>	<u>88,464</u>	<u>116,031</u>

Balance Sheet as at 31st December 2024

		31st December 2023 £	31st December 2024 £
Current Assets			
Debtors	5	0	0
Cash at Bank		123,192	88,964
Creditors:Falling due within one year	6	<u>-7,161</u>	<u>-500</u>
Net Current Assets		116,031	88,464
Net Assets		<u>116,031</u>	<u>88,464</u>
Funds			
Unrestricted Funds	7	100,550	74,652
Restricted Funds	8	15,481	13,812
		<u>116,031</u>	<u>88,464</u>

National Tremor Foundation Charitable Trust
Notes to the Financial Statements for the Year ended 31 December 2024

1. ACCOUNTING POLICIES

Basis of preparation. The accounts (financial statements) have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts. The financial statements have also been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 (and as updated by Update Bulletin 1 issued on 2 Feb 16) and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

The accounts (financial statements) have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The National Tremor Foundation (the charity) meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Preparation of the accounts on a going concern basis. The trustees consider that charity can continue as a going concern for at least the next 12 months.

1 Income. Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Interest receivable. Interest on any funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

Fund accounting. Unrestricted funds are available to spend on activities that further any of the purposes of charity. Restricted funds are donations which the donor, or charity when making an appeal, has specified are to be solely used for particular areas of the charity's work.

2 Expenditure and irrecoverable VAT. Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is classified under the following activity headings:

- Costs of raising funds cover all expenditure incurred by the charity to raise funds for its charitable purposes - including the costs of all fundraising activities, events and non-charitable trading activities, plus the associated support costs.
- Expenditure on charitable activities includes the costs of information provision and beneficiary support undertaken to further the purposes of the charity and their associated support costs.
- Other expenditure represents those items not falling into any other heading.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

3 Provision. A provision had been made some years ago against the likelihood of the Charity having a Corporation Tax liability, this is no longer the case and therefore the provision has been removed.

4 Allocation of support costs. Support costs are those functions, such as office overheads and governance, that assist the work of the charity but are not a direct cost of reported activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities. The bases on which support costs have been allocated are set out in note 3.

Tangible fixed assets. Individual fixed assets costing £1,000 or more are capitalised at cost and are depreciated over an estimated useful economic life of 4 years on a straight line basis. The charity has no such eligible assets.

Stock. Stock is included at the lower of cost or net realisable value. The charity has no material stock holdings.

Financial instruments. The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

5 Debtors Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Cash at bank and in hand. Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

6 Creditors and provisions. Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

2 EXPENDITURE	Direct	Contractor	Support	2024	2023
	£	£	£	£	£
Cost of Generating Funds	4,072	11,467	1,388	16,926	15,826
Charitable Activities					
Information	6,452	36,358	786	43,596	48,445
Research	0	0	0	0	0
Beneficiary Support	3,070	11,342	8,740	23,153	14,946
Total Resources Expended	13,595	59,167	10,913	83,675	79,217

Costs have been attributed on a basis consistent with the use of resources. Where costs cannot be allocated, they are proportioned by the estimated percentage of time spent on each activity.

3 SUPPORT COSTS	Raising Funds	Info	Research	Beneficiary Support	2024	2023
	£	£	£	£	£	£
Governance	250	282	0	438	970	987
Communications	652	303	0	8,236	9,191	914
Office	485	201	0	66	752	1,049
Total Support	1,387	786	0	8,740	10,913	2,950

4 OTHER TRANSACTION INFORMATION

The charity does not employ any staff directly but relies on two contractors for fundraising, and web site activities. A new contractor has recently been appointed to support administration

No Trustee received remuneration or other benefits in connection with Trustee duties or other services

There were no related party transactions in this reporting period that require disclosure

5 DEBTORS

	2024	2023
	£	£
Prepayments	0	0
	<u>0</u>	<u>0</u>

6 CREDITORS

	2024	2023
	£	£
Trade Creditors	0	6,861
Accruals	500	300
Other Creditors		
	<u>500</u>	<u>7,161</u>

7 UNRESTRICTED FUNDS

	2024	2023
	£	£
General	74,652	100,800
	<u>74,652</u>	<u>100,800</u>

8 RESTRICTED FUNDS

	2024	2023
	£	£
Orthostatic Tremor Group	679	2,348
Video Production	1,000	1,000
Yorkshire	533	533
Support Group/Helpline	3,060	3,060
Youngsters	1,166	1,166
Ultrasound Research	1,500	1,500
National Lottery	3,668	3,668
POT Group	500	500
Meeting Sponsorship	1,000	1,000
Leeds Group	456	456
Sutton and Worthing Shakers	250	250
	<u>13,812</u>	<u>15,481</u>

The Orthostatic Tremor funding is for the group's running costs. The video production is for a video on undergoing tremor related surgery. The Yorkshire funding is for has a geographic restriction. The support group/helpline funding is for the expansion of these services. The Youngsters funding is for educating & assisting young people with essential tremor. The ultrasound research funding is specifically related to that area of research. The Lottery funding is for UK support group development. The Leeds group fund is geographically restricted.

NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

England & Wales - Charity number 1042013

Accounts



National Tremor Foundation Charitable Trust

**Report & Financial Statements
for the year ended 31 December 2023**

Charity number: 1042013

National Tremor Foundation Charitable Trust

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National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2023

Objectives and Activities

The Trust's legal purpose (objects) is:

- To promote, centralise and co-ordinate for the benefit of the public any form of research into essential, idiopathic and hereditary tremor and to disseminate and publish the useful results of such research.
- To relieve the need of sufferers from essential, idiopathic and hereditary tremor.
- To advance the education of the public in the subject of essential, idiopathic and hereditary tremor.

The Trust is currently able to resource these charitable activities:

- **Information.** Provision of knowledge to people affected by tremor or movement disorders of various parts of the body in order to help them and their families/carers manage the condition. The initial source for the Trust's beneficiaries is the website which the Trust believes is the leading source of information on this condition for over one million sufferers in the UK. Further sources are a newsletter (available in hard and soft copy), a general telephone enquiry service and access to an advisory panel.
- **Research.** Research progresses the understanding of tremors by investigating causes and potential treatments.
- **Beneficiary support.** This activity covers the annual conference, active support and the encouragement/subsidy of regional support groups where there are known clusters of interested beneficiaries.

Achievements and Performance

This section explains the activities for the reporting period; NTF generated a respectable amount of income for 2023, but substantially less than 2022. Expenditure also exceeded income, which is a rare occurrence, to make necessary improvements and developments to our website, which is an important source of information and engagement for the public, and most importantly people living with neurological tremors.

The Charity is always conscious about keeping costs to a minimum and maintain the central office support facility.

Honorary President Lord Julian Fellowes



We are delighted and honoured to continue to have Lord Julian Fellowes as Honorary President of the NTF. Lord Fellowes is world renowned for creating the hugely successful and critically acclaimed TV period drama Downton Abbey. In a recent newspaper interview, he revealed that he lives with Essential Tremor. In the last ever episode of Downton Abbey, Lord Fellowes wrote into the script a character who suffered with Essential Tremor and in doing so raised a great amount of awareness for this little-known condition.

Lord Fellowes was born in Cairo, Egypt, educated in Britain before moving to Los Angeles in 1981 and returned to the UK in 1991. He is well known as an actor, novelist, screenwriter and film director and his career spans over 40 years. Lord Fellowes has been a member of the House of Lords since January 2011. He is also chairman and patron of several UK charities.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2023

Board Activity

The NTF was able to raise significant funds and continue its work to support people with essential tremor. The 2023 income was considerably lower than 2022, however in 2022 the Charity benefited from a significant number of legacies by generous supporters.

Our support groups have continued to meet regularly in-person during 2023, also having the option of attending one of the 14 online events throughout the year, co-hosted by Jackie Farrell and Duncan Crossland. The online events have been a huge success having an overall turnout of 618 people for the year. The success of these events is evidently down to the time and commitment put in by both Jackie and Duncan.

Three major events were organised by, or in collaboration with, the NTF during this year. These were 'Support Yourself, Support Others' event in June, our political campaign to raise awareness with Members of Parliament in August and the Essential Tremor Awareness Day in October. Further details about these events can be found below.

- **Support Yourself, Support Others, Manchester, 16th June 2023**

"Support Yourself, Support Others" in Manchester, was well attended hosted by Jackie with guest speakers: Karen Hull, Neurological Physiotherapist; Gavin Thompson, Warrington Disability Partnership; and Anthony Murphy, Young Adult with ET.

- **Political campaign**

In August 2023, a campaign was launched to engage local Members of Parliament (MPs) and raise awareness about the need to improve access to MR-Guided Focused Ultrasound (MRgFUS) treatment centres. The NTF encouraged the neurological community to send letters to their local MPs as part of this effort.

- **Essential Tremor Awareness Day, London, 7th October 2023**

Essential Tremor Awareness Day, held at The Royal National Hotel in October 2023, aimed to raise awareness about Essential Tremor (ET) and its treatments, while also providing support to individuals affected by the condition. The event was co-hosted and supported by Insightec and attracted over 60 delegates from London and across the UK, including attendees from Cornwall and Yorkshire. The day featured expert speakers, interactive sessions, and a unique "Carousel of Chat" concept to facilitate discussions on living with ET.

The speakers at the Essential Tremor Awareness Day event were:

1. **James Blann (Insightec)** - He facilitated the event and opened the proceedings.
2. **Professor Ludvic Zrinzo (The National Hospital for Neurology and Neurosurgery)** - He provided an overview of Essential Tremor, discussed treatment options, and explained the science behind surgical approaches like deep brain stimulation and ablation.
3. **Karen Hull (Neuro-Physiotherapist from Bradford)** - She focused on the importance of balance in managing Essential Tremor and shared techniques to improve core stability.
4. **Jackie Farrell (National Tremor Foundation Support Group Coordinator)** - She gave a talk on the benefits of mindfulness and meditation for reducing tremor amplitude.
5. **Oscar Gomez-Reaney (Young Adult Living with Essential Tremor)** - He spoke about his personal experience with Essential Tremor as a young adult, highlighting that the condition affects people of all ages.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2023

The Board of Trustees met in January, April, July and October during 2023, these meetings supported the general business and the Trustees began a review of its management arrangements and policies. The board agreed to initially Amanda Fry from February 2023 and then Phoebe Dann from November 2023 to provide the Trustees with administrative support. Everyone at the NTF would like to thank them for their support and diligence during this time.

A programme of meetings were arranged for 2024 to review the strengths and weaknesses of the NTF and what we felt needed to be our priorities for the forthcoming two to three years.

Communication and Digital Report

Digital overview

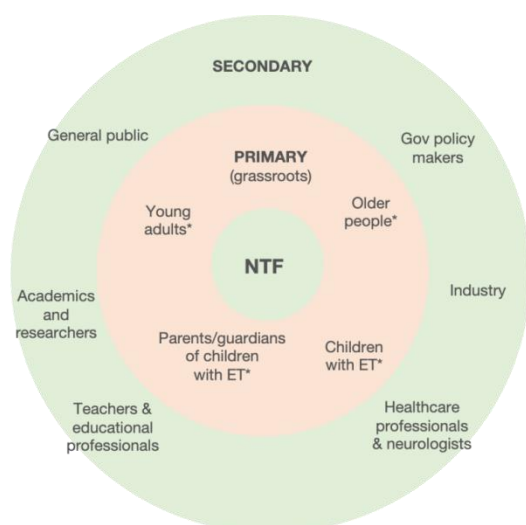
The NTF's website is the main means for the charity to communicate to the public. In 2023 it drove 250,775 users a year from across the globe. It provides a range of information on tremors (from diagnosis and clinical characteristics to research topics and help for carers), support group events and news.

Below is a SWOT analysis identifying areas for improvement, opportunity, and areas that could be at risk.

Strengths (internal) 1. Improved online donations process 2. Improved signing up for events and support events 3. Strong digital support network of potential volunteers 4. Surveys are helping us make better informed decisions. 5. Only charity representing ET which is driving traffic to the website.	Opportunities (external) 1. Demand for people to get involved in the NTF as volunteers. 2. Text message (SMS) marketing. 3. Need for more newsletters. 4. More non-clinical research on website. 5. More device research on website. 6. Opportunities for clinical trials on website. 7. Men with ET campaign. 8. More personal stories and coping tips.
Weaknesses (internal) 1. Still operating reactively not proactively due to limited capacity. 2. Audience data is limited and need to understand our audiences to conduct marketing more effectively. 3. Need additional support for Support Groups 4. Lack of awareness in schools and health care settings 5. Need to develop audience loyalty and advocacy. 6. Need for formal representation in Scotland. 7. Data needs segmenting. 8. Need for expert panel to deliver content. 9. Need for brand guidelines. 10. Need for brand guidelines for support groups. 11. Need to focus on push marketing i.e. paid advertising 12. Need more video content.	Threats (external) 1. Economic issues affecting online donations 2. Growth in dependence on charities for digital support due to NHS being overburdened 3. Increase in competition for digital engagement from other charities. 4. Increasing demand for a Scottish representation. 5. Demand for representation for ET only.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2023

Target stakeholders



*We also need to take into consideration the families of people with tremor.

Website

Below shows how the number of website users has increased.

Year	Value	Percentage Increase
2023	250,775	3%
2022	242,278	35%
2021	179,215	

Website audiences

- The majority of our audience has essential tremor.
- They are most likely to be female.
- Aged over 25 but marginally more likely to be aged 45-54.
- A significant number live in London.
- They prefer to access the website via mobile phone.
- Online behaviour: interested in food, entertainment and celebrities.

Google Advertising

The NTF receives a Google Grant to give the charity free but limited online advertising. Constant management of the NTF's online advertising has meant that on average an extra 1600 people are visiting the website a month.

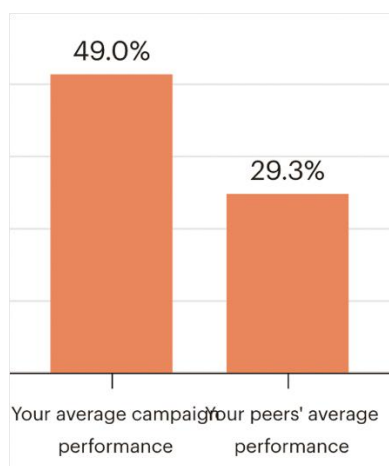
Furthermore, the NTFs Social media network has continued to grow with our established Facebook channel being popular and Twitter attracting increased interest.

Newsletter

In 2023 the e-newsletter is being distributed to over 3500 people a month with an average open rate of 49% which is higher than other charities.

Below is a bar chart showing newsletter performance.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2023



Online donations

In 2023 online donations have begun to increase despite economic uncertainty.

2023	£3491
2022	£2740
2021	£5073

Research

Research continues to be undertaken, although there were no calls on the Foundation's finances for a contribution.

Imperial College NHS Trust continues to treat sufferers with MRgFUS although the number of treatments they are able to deliver is limited and they are currently the only NHS funded centre in England. That inevitably means that waiting lists will grow.

Essential Tremor in Children and Young People

The NTF continue to have a Children's Liaison Officer, the Chair of the Board of Trustees Kitty Reilly. Kitty sees her main role as a supportive one in the first instance, followed by raising awareness through our website about children with ET and social media campaigns.

Coronation Street Actor Rob Mallard, NTF Patron for Young People

In October 2023 the NTF was delighted to announce the appointment of Rob Mallard, widely recognized for his role as Daniel Osborne on the popular television series *Coronation Street*, as a new patron focused on young people. This appointment marks a significant milestone in increasing awareness of the challenges faced by young individuals living with neurological tremors.

About Rob Mallard's Advocacy

Rob Mallard, in addition to his television work, has been a prominent advocate for those living with essential tremor (ET). He has spoken openly on television, radio, and at public events, sharing his personal journey and experiences with essential tremor. His involvement has also been notable during National Essential Tremor Awareness Month, where he actively promotes understanding of the condition in collaboration with the NTF.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2023

Statements from Rob Mallard and NTF Chair Kitty Reilly

Rob said: "I am thrilled to be joining the NTF. As someone who has been living with ET for most of my life, I am acutely aware of the importance of their work and I'm proud to join them in spreading awareness and understanding of this debilitating condition."

NTF Chair Kitty Reilly said: "The National Tremor Foundation are absolutely delighted to welcome Rob Mallard as a patron of the charity. With Rob's lived experience of essential tremor and TV popularity, this will certainly go a long way to raising awareness of people living with neurological tremors and the impact this has on their lives."



Looking Ahead

The NTF looks forward to continuing its partnership with Rob Mallard, aiming to raise awareness and promote better understanding of essential tremor and its effects on young people's lives. His advocacy and personal experience with ET will play a crucial role in advancing the foundation's mission and supporting those affected by this challenging condition.

Annual Meeting

The annual meeting was a great success.

Fundraising Review

The Foundation continued with support from many Charitable Trusts throughout the year. Postal applications and personal visits enabled funding to be obtained at low costs. Applications were generally for basic core costs.

The continuing low investment interest rates obtained by trust funds has again reduced the amount of money for distribution to beneficiaries and The Foundation greatly appreciates the support from all Charitable Trusts. During a difficult period, the Foundation did manage to raise £125,000 and spent over £70,000 maintaining its communication links and supporting sufferers.

Plans for 2024

1. To develop the NTF 3-year strategy and focus our activity around raising awareness, fundraising and increasing our volunteer capacity
2. To continue to expand and update the website to allow greater accessibility and quality of content.
3. Further strengthen the governance of the NTF and continue the review of policies

Public Benefit Statement

The Trustees confirm that they have complied with the duty in the Charities Act 2011 to have due regard to the Charity Commission's general guidance on public benefit. As stated elsewhere in this report, the Trust's charitable activity work is clear evidence of both the identifiable benefit provided and the relation of this benefit to the charity's aims. Continuing website feedback shows that the Trust is regularly reaching people affected by tremors - both in UK and overseas, with a continued large increase in visitors to the website in recent years.

Financial Review

Our income received for 2023 reached just over £49,000. There was a total of over £115,000 in the bank at year end, which still gives us a real basis to look to future developments. With membership free, we encouraged members to voluntarily donate.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2023

Our primary costs continue to be invested in fundraising and our website, with a dedicated IT consultant to continually monitor and upgrade the website. Increased activity, particularly website development and an effort to establish further support groups in the UK, resulted in further expenditure in this area.

Reserves Policy

The Trustees would ideally like to establish a level of reserves that would meet 12 months of basic operational costs (approximately £60k) should there be a gap in funding. At the year end the reserves held were £116,031 (previous year £146,114); this level of holding gives a sound base for considering increased research activity.

Reference and Administration details

Trustees at date of report's approval 30th October 2024;

Chair of Board of Trustees

Kitty Reilly MSc, BSc

Trustees

Professor Leslie J Findley TD, M D, FRCP

Kevin Harfoot

Keith Flaxman FCCA CPFA (Treasurer)

Dr Peter Bain MBBS MA MD FRCP (Consultant Neurologist)

Registered Office:

Harold Wood Polyclinic
Copse Avenue
Harold Wood
Romford RM3 0FE

Bankers

National Westminster Bank

Independent Examiner
Adrian Nunn FCCA

Charity Registration Details

Name: National Tremor Foundation Charitable Trust

No: 1042013

Structure, Governance & Management

Governing Document

The Trust is governed by a Declaration of Trust dated 19 October 1994 and was registered as a charity on 9 November 1994.

Recruitment and Appointment of Trustees

New trustees are recruited for the special contribution they can make to the Trust and are appointed by resolution of the Trustees.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2023

Statement of Trustees Responsibilities

Charity law requires the Trustees to prepare a trustees' annual report and financial statements for each financial year which show a true and fair view of the state of affairs of the Trust and its financial activities for that period. In preparing those financial statements, the Trustees are required to:

Select suitable accounting policies and then apply them consistently.

Observe the methods and principles in the applicable Charities SORP.

Make judgements and estimates that are reasonable and prudent.

State whether applicable accounting standards and statements of recommended practice have been followed, subject to any departures disclosed and explained in the financial statements.

Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Trust will continue in operational existence.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports)

Regulations and the provisions of the constitution. They are also responsible for the maintenance and integrity of the Trust, safeguarding the assets of the Trust and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The financial statements have been prepared in accordance with the accounting policies set out in notes to the accounts and comply with the charity's governing document, the Charities Act 2011 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 (FRS 102) published on 16 July 2014.

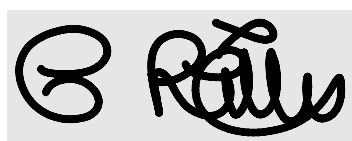
Statement as to disclosure to the independent examiner

In so far as the Trustees are aware at the time of approving the trustees' annual report:

There is no relevant information, being information needed by the independent examiner in connection with preparing his report, of which the independent examiner is unaware.

The Trustees, having made enquiries of fellow trustees and the independent examiner that they ought to have individually taken, have each taken all steps that they are obliged to take as a trustee in order to make themselves aware of any relevant information for the independent examination and to establish that the independent examiner is aware of that information.

Approved by the Trustees on 30st Oct 2024 and signed on their behalf by:

A handwritten signature in black ink, appearing to read 'Kitty Reilly', is shown within a light gray rectangular box.

Chair

Kitty Reilly (MSc, BSc)

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

I report on the accounts of the National Tremor Foundation Charitable Trust for the year ended 31 December 2023, which are set out on pages 10 - 13.

Responsibilities and basis of report

As the trustee of the charity, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

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

Accounting records were kept in respect of the Trust as required by section 130 of the Act.

The accounts accord with those records.

The accounts comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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



Adrian Nunn
FCCA
Flat 9 Millenium Court
4, College Road
Liverpool
L23 0YE

National Tremor Foundation Charitable Trust
Statement of Financial Activities for the Year Ended 31st December 2023

	Note	Unrestricted Funds £	Restricted Funds £	Total for Year 2023 £	2022 £
Income					
Donations		48,924	250	49,174	125,048
Grants				0	0
		<u>48,924</u>	<u>250</u>	<u>49,174</u>	<u>125,048</u>
Expenditure					
Fund Raising	2	15,826		15,826	22,442
Charitable Activities					
Information		48,445		48,445	36,917
Research			0	0	0
Beneficiary Support		14,814	132	14,946	10,818
		<u>79,085</u>	<u>132</u>	<u>79,217</u>	<u>70,177</u>
Net Movement in Funds		<u>-30,161</u>	<u>118</u>	<u>-30,043</u>	<u>54,781</u>
Reconciliation of Funds		<u>115,913</u>	<u>118</u>	<u>116,031</u>	<u>146,114</u>

Balance Sheet as at 31st December 2023

		31st December 2022 £	31st December 2023 £
Current Assets			
Debtors	5	0	0
Cash at Bank		153,235	123,192
Creditors: Falling due within one year	6	<u>-7,121</u>	<u>-7,161</u>
Net Current Assets		146,114	116,031
Net Assets		<u>146,114</u>	<u>116,031</u>
Funds			
Unrestricted Funds	7	130,883	100,550
Restricted Funds	8	15,231	15,481
		<u>146,114</u>	<u>116,031</u>

National Tremor Foundation Charitable Trust
Notes to the Financial Statements for the Year ended 31 December 2023

1. ACCOUNTING POLICIES

Basis of preparation. The accounts (financial statements) have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts. The financial statements have also been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 (and as updated by Update Bulletin 1 issued on 2 Feb 16) and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

The accounts (financial statements) have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The National Tremor Foundation (the charity) meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Preparation of the accounts on a going concern basis. The trustees consider that charity can continue as a going concern for at least the next 12 months.

Income. Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Interest receivable. Interest on any funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

Fund accounting. Unrestricted funds are available to spend on activities that further any of the purposes of charity. Restricted funds are donations which the donor, or charity when making an appeal, has specified are to be solely used for particular areas of the charity's work.

Expenditure and irrecoverable VAT. Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is classified under the following activity headings:

- Costs of raising funds cover all expenditure incurred by the charity to raise funds for its charitable purposes - including the costs of all fundraising activities, events and non-charitable trading activities, plus the associated support costs.
- Expenditure on charitable activities includes the costs of information provision and beneficiary support undertaken to further the purposes of the charity and their associated support costs.
- Other expenditure represents those items not falling into any other heading.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

Allocation of support costs. Support costs are those functions, such as office overheads and governance, that assist the work of the charity but are not a direct cost of reported activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities. The bases on which support costs have been allocated are set out in note 3.

Tangible fixed assets. Individual fixed assets costing £1,000 or more are capitalised at cost and are depreciated over an estimated useful economic life of 4 years on a straight line basis. The charity has no such eligible assets.

Stock. Stock is included at the lower of cost or net realisable value. The charity has no material stock holdings.

National Tremor Foundation Charitable Trust

Notes to the Financial Statements for the Year ended 31 December 2023

Financial instruments. The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

Debtors Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Cash at bank and in hand. Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

Creditors and provisions. Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

2 EXPENDITURE	Direct	Contractor	Support	2023	2022
	£	£	£	£	£
Cost of Generating Funds	1,190	13,418	1,218	15,826	29,744
Charitable Activities					
Information	2,349	44,694	1,402	48,445	29,188
Research	0	0	0	0	0
Beneficiary Support	9,328	5,288	330	14,946	11,245
Total Resources Expended	12,867	63,400	2,950	79,217	70,177

Costs have been attributed on a basis consistent with the use of resources. Where costs cannot be allocated, they are proportioned by the estimated percentage of time spent on each activity.

3 SUPPORT COSTS	Raising Funds	Info	Research	Beneficiary Support	2023	2022
	£	£	£	£	£	£
Governance	438	388	0	161	987	1,196
Communications	362	473	0	79	914	1,017
Office	418	541	0	90	1,049	1,170
Total Support	1,218	1,402	0	330	2,950	3,383

4 OTHER TRANSACTION INFORMATION

The charity does not employ any staff directly but relies on two contractors for fundraising, and web site activities. A new contractor has recently been appointed to support administration
No Trustee received remuneration or other benefits in connection with Trustee duties or other services
There were no related party transactions in this reporting period that require disclosure

5 DEBTORS	2023	2022
	£	£
Prepayments	0	0
	<u>0</u>	<u>0</u>

6 CREDITORS	2023	2022
	£	£
Trade Creditors	6,861	6,861
Accruals	300	260
Other Creditors		
	<u>7,161</u>	<u>7,121</u>

7 UNRESTRICTED FUNDS	2023	2022
	£	£
General	100,800	130,833
	<u>100,800</u>	<u>130,833</u>

8 RESTRICTED FUNDS	2023	2022
	£	£
Orthostatic Tremor Group	2,348	2,348
Video Production	1,000	1,000
Yorkshire	533	533
Support Group/Helpline	3,060	3,060
Youngsters	1,166	1,166
Ultrasound Research	1,500	1,500
National Lottery	3,668	3,668
POT Group	500	500
Meeting Sponsorship	1,000	1,000
Leeds Group	456	456
Sutton and Worthing Shakers	250	
	<u>15,481</u>	<u>15,231</u>

The Orthostatic Tremor funding is for the group's running costs. The video production is for a video on undergoing tremor related surgery. The Yorkshire funding is for has a geographic restriction. The support group/helpline funding is for the expansion of these services. The Youngsters funding is for educating & assisting young people with essential tremor. The ultrasound research funding is specifically related to that area of research. The Lottery funding is for UK support group development. The Leeds and Sutton and Worthing Shakers groups funds are geographically restricted.

NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

England & Wales - Charity number 1042013

Accounts



National Tremor Foundation Charitable Trust

**Report & Financial Statements
for the year ended 31 December 2022**

Charity number: 1042013

National Tremor Foundation Charitable Trust

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National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2022

Objectives and Activities

The Trust's legal purpose (objects) is:

- To promote, centralise and co-ordinate for the benefit of the public any form of research into essential, idiopathic and hereditary tremor and to disseminate and publish the useful results of such research.
- To relieve the need of sufferers from essential, idiopathic and hereditary tremor.
- To advance the education of the public in the subject of essential, idiopathic and hereditary tremor.

The Trust is currently able to resource these charitable activities:

- **Information.** Provision of knowledge to people affected by tremor or movement disorders of various parts of the body in order to help them and their families/carers manage the condition. The initial source for the Trust's beneficiaries is the website which the Trust believes is the leading source of information on this condition for over one million sufferers in the UK. Further sources are a newsletter (available in hard and soft copy), a general telephone enquiry service and access to an advisory panel.
- **Research.** This is a recently new activity enabled by the build-up of reserves over recent years. Research progresses the understanding of tremors by investigating causes and potential treatments.
- **Beneficiary support.** This activity covers the annual conference, active support and the encouragement/subsidy of regional support groups where there are known clusters of interested beneficiaries.

Achievements and Performance

This section explains the activities for the reporting period; in a difficult economic environment the charity has managed to keep costs to a minimum and maintain the central office support facility.

Honorary President Lord Julian Fellowes



We are delighted and honoured to continue to have Lord Julian Fellowes as Honorary President of the NTF. Lord Fellowes is world renowned for creating the hugely successful and critically acclaimed TV period drama Downton Abbey. In a recent newspaper interview, he revealed that he lives with Essential Tremor. In the last ever episode of Downton Abbey, Lord Fellowes wrote into the script a character who suffered with Essential Tremor and in doing so raised a great amount of awareness for this little-known condition.

Lord Fellowes was born in Cairo, Egypt, educated in Britain before moving to Los Angeles in 1981 and returned to the UK in 1991. He is well known as an actor, novelist, screenwriter and film director and his career spans over 40 years. Lord Fellowes has been a member of the House of Lords since January 2011. He is also chairman and patron of several UK charities.

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Board Activity

Despite the ongoing aftermath of Covid, the NTF was able to raise significant funds and continue its work to support people with essential tremor. Our support groups had continued to meet during 2022, albeit on a slightly reduced number of occasions due to the ongoing fears around Covid.

The Board of Trustees met in April, July, September and November during 2022, these meetings supported the general business and the Trustees began a review of its management arrangements and policies. In November 2022 the Board of Trustees unanimously agreed to appoint a new chair, one of our existing trustees Kitty Reilly to act in a permanent capacity and move the NTF forwards, as temporary arrangements had previously been in place due to the then Chair no longer being able to continue in the capacity appointed. A programme of meetings were arranged for 2023 to discuss the strengths and weaknesses of the NTF and what we felt needed to be our priorities for the forthcoming three to four years.

Despite the ongoing Covid issues, we decided to hold an annual open day in Liverpool in October 2022. We were delighted to be joined by leading experts from across the neurology. The ability to meet face-to-face - at the iconic Liver building in Liverpool – for the first time in over two years made the event all the more valuable.

Huge credit should be given to Support Groups Co-ordinator Jackie Farrell, who worked tirelessly with James Blann of Insightec, in the planning and preparation of this first in-person event post Covid. It was all the more frustrating therefore that Jackie was unable to attend herself, due to herself succumbing to Covid.

Our esteemed panel of speakers, including Professor Leslie Findley (retired Senior neurologist, Queen's Hospital, Essex, and Professor of Health Sciences, London University South Bank), Dr Jay Panicker (Clinical Director for Neurology, The Walton Centre, Liverpool) and Mr Jibril Farah (Consultant Neurosurgeon and clinical lead of the Functional and Stereotactic Neurosurgical Service, the Walton Centre, Liverpool) offered attendees some valuable insights in to the very latest developments in patient experience, treatment options and trends in the neurology space.

The NTF Open Day aimed to raise awareness of the organisation and essential tremor: 'The National Tremor Foundation, we urge you to advertise it, and talk about it and show your tremors to everyone, because unless we raise awareness we will be back in 1992 when this organisation was founded.' - Professor Leslie Findley

This year we were also delighted to be joined by Rob Mallard, a British actor best known for his role in iconic soap opera Coronation Street. Rob has been vocal about his experience with Essential Tremor on national TV such as The Morning Show and chatted openly about his experiences of living with the condition.

'More often than not, younger people who would just come up to me and put their hand in my face and go look at my hand shake – like a secret handshake, you knew we're in...it's weird to think I've had influence on peoples' lives but if it has a positive one I'm more than happy to keep talking about [essential tremor]' – Rob Mallard

In total we had 150 attendees, from patients to HCPs. All attendees had the opportunity to attend a networking session where they could speak directly with healthcare leaders, industry representatives and holistic care providers. This was in addition to a lively Q&A session with our panel of experts, where questions around essential tremor were answered and debated.

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Thank you to our exhibitors: Insightec, Boston Scientific, Warrington Disability Partnership, and neuro-physiotherapist Karen Hull.

Communication and Digital Report

Digital overview

The NTF's website is the main means for the charity to communicate to the public. In 2022 it drove 250,218 users a year from across the globe. It provides a range of information on tremors (from diagnosis and clinical characteristics to research topics and help for carers), support group events and news.

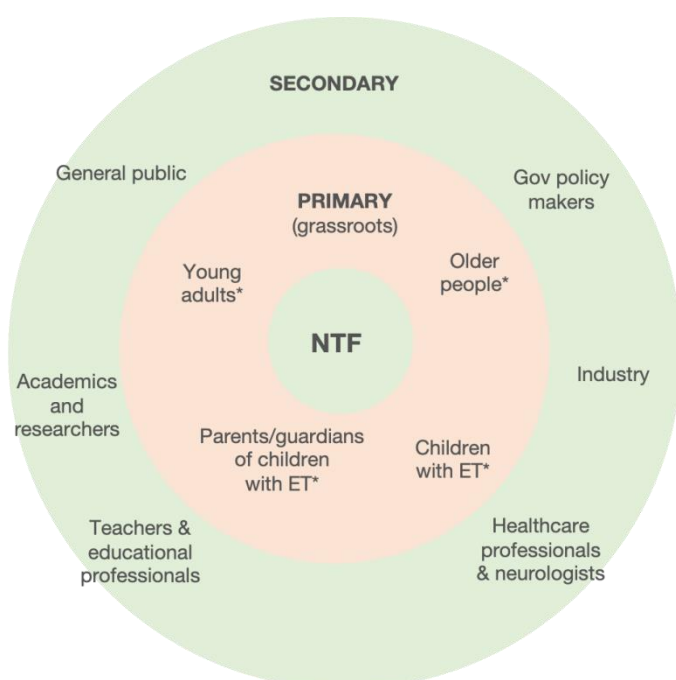
In 2022 the NTF changed their logo and this involved making major changes to the look of marketing promotion. The new logo represents concentric circles found in vibrations and represents a friendly yet professional organisation.

Below is a SWOT analysis highlighting the digital opportunities and threats.

Strengths (internal) 1.Improved donations process 2.Improved signing up for events and support events 3.Strong digital support network of potential volunteers 4.Increased internal communication and teamwork has contributed to success. 5.Surveys are helping us make better informed decisions.	Opportunities (external) 1.Market for people to use online meetups is growing and have been highly successful 2.Increased in people taking part in challenge events 3.Demand for online goods 4.Demand for people to get involved in the NTF as volunteers. 5.Increased demand for partnerships with industry
Weaknesses (internal) 1.NTF operating beyond capacity 2.Audience data is limited and we need to understand our audiences to conduct marketing more effectively. 3.Need to improve the internal communication system. 4.Need centralised filing system and contacts need to be shared. 5.Brand is not well known. 6.Need for formal representation in Scotland and Ireland. 7.Still operating reactively not proactively due to limited capacity.	Threats (external) 1.Rise in cost of living 2.Reduction in individual and fundraiser donations 3.Economic issues facing users such as unemployment affecting donations 4.Growth in dependence on charities for digital support due to NHS being overburdened 5.Increase in competition for digital engagement from other charities.

Target stakeholders

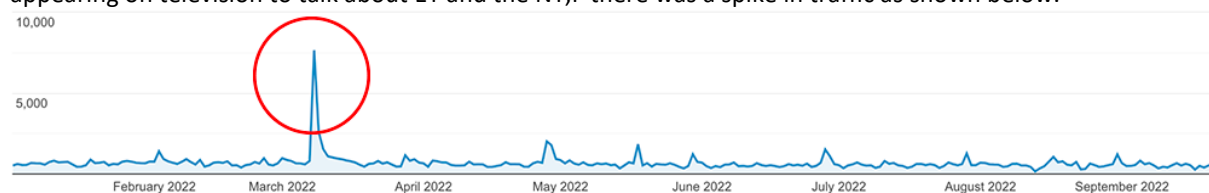
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*We also need to take into consideration the families of people with tremor.

Website

In 2022 growth continued at a steady rate of 3.4%. In March 2022 due to PR activity with Rob Mallard appearing on television to talk about ET and the NT,F there was a spike in traffic as shown below.



Below shows how the number of website users has increased.

Year	Total users	Percentage change
2022	250,218	3.4%
2021	241,755	30%
2020	178,733	

Website audiences

Most of our audience are female (57%) between the ages of 25-34 and 65+ (19% for both age groups) and are in the UK . The majority of our traffic comes from searching for pages/content (organic 58%); Direct links (23%); NHS website (5%) and 2% from Social Media.

Google Advertising

The NTF receives a Google Grant to give the charity free but limited online advertising. Constant management of the NTF's online advertising has meant that on average an extra 1600 people are visiting the website a month.

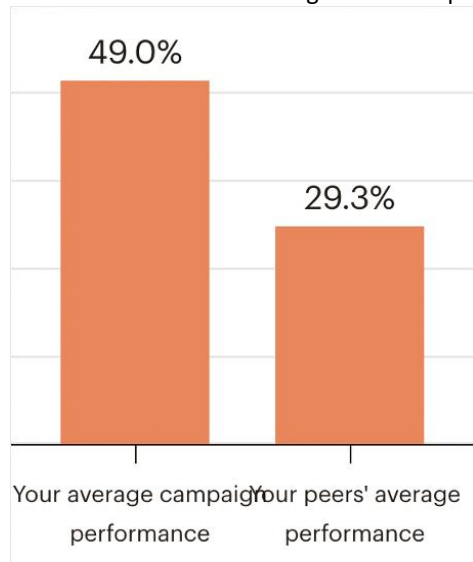
Furthermore, the NTFs Social media network has continued to grow with our established Facebook channel being popular and Twitter attracting increased interest.

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Newsletter

In 2022 the e-newsletter is being distributed to over 3000 people a month with an average open rate of 49% which is higher than other charities.

Below is a bar chart showing newsletter performance.



Campaigns in 2022

Below are the awareness and fundraising campaign cycles for 2022

Campaign	Period
NETA month	January – March
Fundraiser challenges	April – June
Summer Tea Party	July – August
OT month	August–September
Christmas	October – December

Online donations

In 2022 through the NTF website, the NTF were able to raise £2740 excluding Gift Aid. This is a decrease from 2021 during the COVID pandemic which saw £5073 people donate.

Online support group events

In 2022 the NTF held 22 online support group events which attracted 858 people.

Notes

1. The website has seen continued growth due to a major overhaul in 2016 and our Digital Consultant continuing to develop the website further, with regular updates and continual links to our social media channels, Facebook and Instagram, optimisation of keywords and online advertising to increase its ranking on Google. This growth has occurred with increased community activity such as support groups and events.
2. In 2018 the website home page was redesigned to reflect the current needs of the website. With over 50% of users accessing the website using mobile the new design is “mobile first”. The new homepage aims to promote Support Groups, events, photographs and fundraising. The website also has given

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Orthostatic Tremor a new separate section of its own. In addition, Twitter feed was added to the home page and a Donation button was added to the top of the website to increase funds raised.

3. 2018 saw the introduction of GDPR. GDPR is the law on data protection and privacy for all individuals. This has meant that major changes were made to how the NTF handles data. All people with data held by the NTF had to re-consent to the NTF using their data. A number of emails were sent out to all members asking them to re-subscribe to our database. In addition, changes were made to the website so that people had to consent to the use of their information when signing up to forms; additional security settings were added; and a secure domain certificate was added (https).

Research

Research continues to be undertaken, although there were no calls on the Foundation's finances for a contribution.

Imperial College NHS Trust continues to treat sufferers with MRgFUS although the number of treatments they are able to deliver is limited and they are currently the only NHS funded centre in England. That inevitably means that waiting lists will grow.

Essential Tremor in Children and Young People

The NTF continue to have a Children's Liaison Officer, the Chair of the Board of Trustees Kitty Reilly. Kitty sees her main role as a supportive one in the first instance, followed by raising awareness through our website about children with ET and social media campaigns.

Coronation Street actor Rob Mallard, who appeared at the Liverpool meeting mentioned above, was diagnosed with Essential Tremor in his teenage years and will hopefully be a great advocate for the NTF in raising awareness of the condition.

Annual Meeting

The annual in Liverpool was a great success, details are mentioned above.

Fundraising Review

The Foundation continued with support from many Charitable Trusts throughout the year. Postal applications and personal visits enabled funding to be obtained at low costs. Applications were generally for basic core costs.

The continuing low investment interest rates obtained by trust funds has again reduced the amount of money for distribution to beneficiaries and The Foundation greatly appreciates the support from all Charitable Trusts. During a difficult period, the Foundation did manage to raise £125,000 and spent over £70,000 maintaining its communication links and supporting sufferers.

Plans for 2023

1. To develop the NTF 3-year strategy and focus our activity around raising awareness, fundraising and increasing our volunteer capacity
2. To continue to expand and update the website to allow greater accessibility and quality of content.
3. Further strengthen the governance of the NTF and continue the review of policies

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Public Benefit Statement

The Trustees confirm that they have complied with the duty in the Charities Act 2011 to have due regard to the Charity Commission's general guidance on public benefit. As stated elsewhere in this report, the Trust's charitable activity work is clear evidence of both the identifiable benefit provided and the relation of this benefit to the charity's aims. Continuing website feedback shows that the Trust is regularly reaching people affected by tremors - both in UK and overseas, with a continued large increase in visitors to the website in recent years.

Financial Review

Our income received for 2022 reached over £125,000 during a difficult year. There was a total of over £150,000 in the bank at year end, giving us a real basis to look to future developments. With membership free, we encouraged members to voluntarily donate.

Our primary costs continue to be invested in fundraising and our website, with a dedicated IT consultant to continually monitor and upgrade the website. Increased activity, particularly website development and an effort to establish further support groups in the UK, resulted in further expenditure in this area.

Reserves Policy

The Trustees would ideally like to establish a level of reserves that would meet 12 months of basic operational costs (approximately £60k) should there be a gap in funding. At the year end the reserves held were £ £146,114 (previous year £91,242); this level of holding gives a sound base for considering increased research activity.

Reference and Administration details

Trustees at date of report's approval 31st October 2023;

Chair of Board of Trustees

Kitty Reilly MSc, BSc

Trustees

Professor Leslie J Findley TD, M D, FRCP

Kevin Harfoot

Keith Flaxman (Treasurer)

Dr Peter Bain MBBS MA MD FRCP (Consultant Neurologist)

Registered Office:

Harold Wood Polyclinic
St Clements Avenue
Harold Wood
Romford RM3 0FE

Bankers

National Westminster Bank

Independent Examiner

National Tremor Foundation Charitable Trust
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Adrian Nunn FCCA

Charity Registration Details

Name: National Tremor Foundation Charitable Trust

No: 1042013

Structure, Governance & Management

Governing Document

The Trust is governed by a Declaration of Trust dated 19 October 1994 and was registered as a charity on 9 November 1994.

Recruitment and Appointment of Trustees

New trustees are recruited for the special contribution they can make to the Trust and are appointed by resolution of the Trustees.

Statement of Trustees Responsibilities

Charity law requires the Trustees to prepare a trustees' annual report and financial statements for each financial year which show a true and fair view of the state of affairs of the Trust and its financial activities for that period. In preparing those financial statements, the Trustees are required to:

Select suitable accounting policies and then apply them consistently.

Observe the methods and principles in the applicable Charities SORP.

Make judgements and estimates that are reasonable and prudent.

State whether applicable accounting standards and statements of recommended practice have been followed, subject to any departures disclosed and explained in the financial statements.

Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Trust will continue in operational existence.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports)

Regulations and the provisions of the constitution. They are also responsible for the maintenance and integrity of the Trust, safeguarding the assets of the Trust and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The financial statements have been prepared in accordance with the accounting policies set out in notes to the accounts and comply with the charity's governing document, the Charities Act 2011 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 (FRS 102) published on 16 July 2014.

Statement as to disclosure to the independent examiner

In so far as the Trustees are aware at the time of approving the trustees' annual report:

There is no relevant information, being information needed by the independent examiner in connection with preparing his report, of which the independent examiner is unaware.

The Trustees, having made enquiries of fellow trustees and the independent examiner that they ought to have individually taken, have each taken all steps that they are obliged to take as a trustee in order to make themselves aware of any relevant information for the independent examination and to establish that the independent examiner is aware of that information.

Approved by the Trustees on 31st Oct 2023 and signed on their behalf by:

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2022

A handwritten signature in black ink on a light gray background. The signature appears to be 'Kitty Reilly' written in a cursive, flowing style.

Chair

Kitty Reilly (MSc, BSc)

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

I report on the accounts of the National Tremor Foundation Charitable Trust for the year ended 31 December 2022, which are set out on pages 11 - 15.

Responsibilities and basis of report

As the trustee of the charity, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

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

Accounting records were not kept in respect of the Trust as required by section 130 of the Act.

The accounts do not accord with those records.

The accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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



Adrian Nunn
FCCA
59 Gainsford Gardens
Clacton-On-Sea
Essex
CO15 5BJ

National Tremor Foundation Charitable Trust
Statement of Financial Activities for the Year Ended 31st December 2022

	Note	Unrestricted Funds £	Restricted Funds £	Total for Year	
				2022 £	2021 £
Income					
Donations		125,048	0	125,048	35,452
Grants				0	0
		<u>125,048</u>	<u>0</u>	<u>125,048</u>	<u>35,452</u>
Expenditure					
Fund Raising	2	22,442		22,442	15,003
Charitable Activities					
Information		36,917		36,917	32,026
Research			0	0	0
Beneficiary Support		10,818	0	10,818	6,704
		<u>70,177</u>	<u>0</u>	<u>70,177</u>	<u>53,733</u>
Net Movement in Funds		<u>54,871</u>	<u>0</u>	<u>54,871</u>	<u>-18,280</u>
Reconciliation of Funds		<u>146,114</u>	<u>0</u>	<u>146,114</u>	<u>91,242</u>

Balance Sheet as at 31st December 2022

		31st December 2021	31st December 2022
Current Assets			
Debtors	5	0	0
Cash at Bank		98,363	153,235
Creditors:Falling due within one year	6	<u>-7,121</u>	<u>-7,121</u>
Net Current Assets		91,242	146,114
Net Assets		<u>91,242</u>	<u>146,114</u>
Funds			
Unrestricted Funds	7	76,011	130,883
Restricted Funds	8	15,231	15,231
		<u>91,242</u>	<u>146,114</u>

National Tremor Foundation Charitable Trust

Notes to the Financial Statements for the Year ended 31 December 2022

1. ACCOUNTING POLICIES

Basis of preparation. The accounts (financial statements) have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts. The financial statements have also been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 (and as updated by Update Bulletin 1 issued on 2 Feb 16) and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

The accounts (financial statements) have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The National Tremor Foundation (the charity) meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Preparation of the accounts on a going concern basis. The trustees consider that charity can continue as a going concern for at least the next 12 months.

Income. Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Interest receivable. Interest on any funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

Fund accounting. Unrestricted funds are available to spend on activities that further any of the purposes of charity. Restricted funds are donations which the donor, or charity when making an appeal, has specified are to be solely used for particular areas of the charity's work.

Expenditure and irrecoverable VAT. Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is classified under the following activity headings:

- Costs of raising funds cover all expenditure incurred by the charity to raise funds for its charitable purposes - including the costs of all fundraising activities, events and non-charitable trading activities, plus the associated support costs.
- Expenditure on charitable activities includes the costs of information provision and beneficiary support undertaken to further the purposes of the charity and their associated support costs.
- Other expenditure represents those items not falling into any other heading.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

Allocation of support costs. Support costs are those functions, such as office overheads and governance, that assist the work of the charity but are not a direct cost of reported activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities. The bases on which support costs have been allocated are set out in note 3.

Tangible fixed assets. Individual fixed assets costing £1,000 or more are capitalised at cost and are depreciated over an estimated useful economic life of 4 years on a straight line basis. The charity has no such eligible assets.

Stock. Stock is included at the lower of cost or net realisable value. The charity has no material stock holdings.

National Tremor Foundation Charitable Trust

Notes to the Financial Statements for the Year ended 31 December 2022

Financial instruments. The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

Debtors Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Cash at bank and in hand. Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

Creditors and provisions. Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

2 EXPENDITURE	Direct	Contractor	Support	2022	2021
	£	£	£	£	£
Cost of Generating Funds	2,236	25,218	2,290	29,744	19,795
Charitable Activities					
Information	1,415	26,928	845	29,188	25,626
Research	0	0	0	0	0
Beneficiary Support	7,018	3,979	248	11,245	8,311
Total Resources Expended	<u>10,669</u>	<u>56,125</u>	<u>3,383</u>	<u>70,177</u>	<u>53,732</u>

Costs have been attributed on a basis consistent with the use of resources. Where costs cannot be allocated, they are proportioned by the estimated percentage of time spent on each activity.

3 SUPPORT COSTS	Raising Funds	Info	Research	Beneficiary Support	2022	2021
	£	£	£	£	£	£
Governance	704	268	0	224	1,196	1,373
Communications	581	327	0	109	1,017	1,187
Office	671	374	0	125	1,170	1,365
Total Support	<u>1,956</u>	<u>969</u>	<u>0</u>	<u>458</u>	<u>3,383</u>	<u>3,925</u>

4 OTHER TRANSACTION INFORMATION

The charity does not employ any staff directly but relies on two contractors for fundraising, administration and web site activities

No Trustee received remuneration or other benefits in connection with Trustee duties or other services

There were no related party transactions in this reporting period that require disclosure

5 DEBTORS	2022	2021
	£	£
Prepayments	0	0
	<u>0</u>	<u>0</u>
6 CREDITORS	2022	2021
	£	£
Trade Creditors	6,861	6,861
Accruals	260	260
Other Creditors		
	<u>7,121</u>	<u>7,121</u>
7 UNRESTRICTED FUNDS	2022	2021
	£	£
General	130,883	94,292
	<u>130,883</u>	<u>94,292</u>
8 RESTRICTED FUNDS	2022	2021
	£	£
Orthostatic Tremor Group	2,348	2,348
Video Production	1,000	1,000
Yorkshire	533	533
Support Group/Helpline	3,060	3,060
Youngsters	1,166	1,166
Ultrasound Research	1,500	1,500
National Lottery	3,668	3,668
POT Group	500	500
Meeting Sponsorship	1,000	1,000
Leeds Group	456	456
	<u>15,231</u>	<u>15,231</u>

The Orthostatic Tremor funding is for the group's running costs. The video production is for a video on undergoing tremor related surgery. The Yorkshire funding is for has a geographic restriction. The support group/helpline funding is for the expansion of these services. The Youngsters funding is for educating & assisting young people with essential tremor. The ultrasound research funding is specifically related to that area of research. The Lottery funding is for UK support group development. The Leeds group fund is geographically restricted.

NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

England & Wales - Charity number 1042013

Accounts



National Tremor Foundation Charitable Trust

**Report & Financial Statements
for the year ended 31 December 2021**

Charity number: 1042013

National Tremor Foundation Charitable Trust

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OBJECTIVES & ACTIVITIES

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- **Research.** This is a recently new activity enabled by the build-up of reserves over recent years. Research progresses the understanding of tremors by investigating causes and potential treatments.
- **Beneficiary support.** This activity covers the annual conference, active support and the encouragement/subsidy of regional support groups where there are known clusters of interested beneficiaries.

ACHIEVEMENTS & PERFORMANCE

This section explains the activities for the reporting period; in a difficult economic environment the Trust has managed to keep costs to a minimum and maintain the central office support facility.

HONORARY PRESIDENT – LORD JULIAN FELLOWES



We are delighted and honoured to continue to have Lord Julian Fellowes as Honorary President of the NTF. Lord Fellowes, is world renowned for creating the hugely successful and critically acclaimed TV period drama Downton Abbey. In a recent newspaper interview, he revealed that he lives with Essential Tremor. In the last ever episode of Downton Abbey, Lord Fellowes wrote into the script a character who suffered with Essential Tremor and in doing so raised a great amount of awareness for this little-known condition.

Lord Fellowes was born in Cairo, Egypt, educated in Britain before moving to Los Angeles in 1981 and returned to the UK in 1991. He is well known as an actor, novelist, screenwriter and film director and his career spans over 40 years. Lord Fellowes has been a member of the House of Lords since January 2011. He is also chairman and patron of several UK charities.

BOARD ACTIVITY

The trustees met online via Zoom in January, April, August, October and November 2021. The meetings dealt with general business and the review of our management policies.

COMMUNICATIONS AND DIGITAL REPORT 2021

Digital overview

The NTF's website is the main means for the charity to communicate to the public, driving in 241,755 users a year from across the globe. It provides a range of information on tremors (from diagnosis and clinical characteristics to research topics and help for carers), support group events and news.

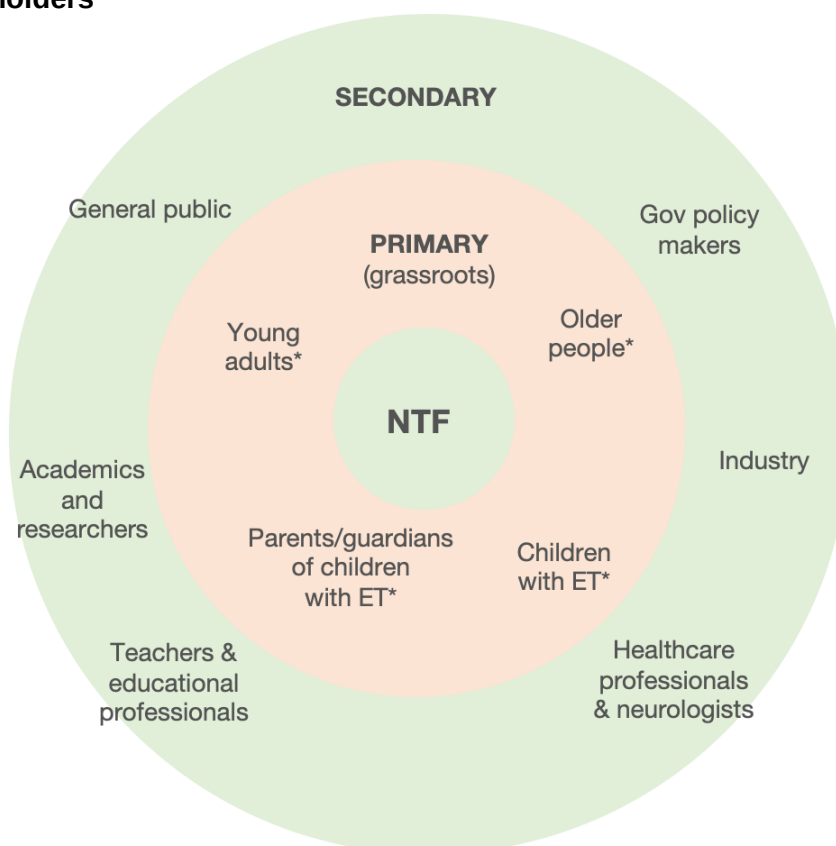
The corona virus outbreak which changed the way the NTF operated and saw the NTF become completely digital.

The new website allowed increased digital engagement during the lockdown and catered for the new virtual way of living. As we saw a shift in support groups from being face-to-face to online which have proved very popular. In addition users were able to donate more easily boosting individual fundraising.

Below is a SWOT analysis highlighting the digital opportunities and threats facing the NTF.

Strengths (internal) 1.Improved donations process 2.Improved signing up for events and support events 3.Strong digital support network of potential volunteers 4.Increased internal communication and teamwork has contributed to success. 5.Surveys are helping us make better informed decisions.	Opportunities (external) 1.Market for people to use online meetups is growing and have been highly successful 2.Increased in people taking part in challenge events 3.Demand for online goods 4.Demand for people to get involved in the NTF as volunteers. 5.Increased demand for partnerships with industry
Weaknesses (internal) 1.NTF operating beyond capacity 2.Audience data is limited and we need to understand our audiences to conduct marketing more effectively. 3.Need to improve the internal communication system. 4.Need centralised filing system and contacts need to be shared. 5.Brand is not well known. 6.Need for formal representation in Scotland and Ireland. 7.Still operating reactively not proactively due to limited capacity.	Threats (external) 1.Rise in cost of living 2.Reduction in individual and fundraiser donations 3.Economic issues facing users such as unemployment affecting donations 4.Growth in dependence on charities for digital support due to NHS being overburdened 5.Increase in competition for digital engagement from other charities.

Target stakeholders



*We also need to take into consideration the families of people with tremor.

Website

Between 2016–2019 the number of website users between 2016 and 2019 had doubled, but due to a change in the website design to comply with GDPR by Tribal Systems in December 2019 Google Analytics was only tracking 20% of traffic. This resulted in a major dip in recorded traffic of 58% in 2020.

However 2020 saw the launch of the new website and in the third quarter were able to recapture some of the data and work to optimise the new website.

During 2021 there were additional Google Algorithms introduced limiting traffic. Despite this in 2021 we successfully regained 30% of the traffic.

Below shows how the number of website users has increased over the last six years.

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Year	Total users	Percentage change
2021	241,755	30%
2020	178,733	-58%
2019	427,904	12%
2018	383,376	22%
2017	315,043	74%
2016	181,469	

Website audiences

Most of our audience are female (57%) between the ages of 25-34 and 65+ (19% for both age groups) and are in the UK

The majority of our traffic comes from searching for pages/content (organic 64%); Direct links (24%) and only 5% is from social media. **Google Advertising**

The NTF receives a Google Grant to give the charity free but limited online advertising. Constant management of the NTF's online advertising has meant that on average an extra 1600 people are visiting the website a month.

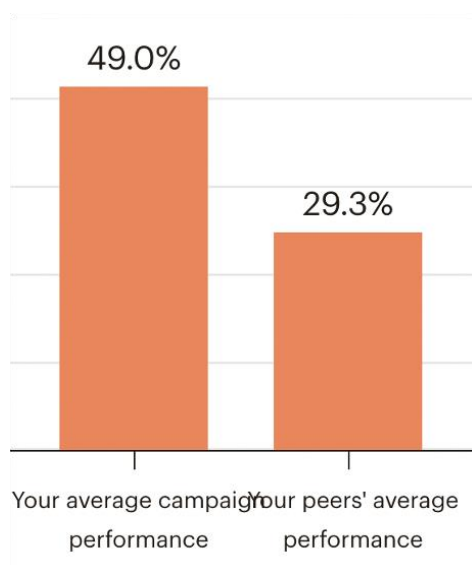
Furthermore, the NTF's Social media network has continued to grow with our established Facebook channel being popular and Twitter attracting increased interest.

Newsletter

In 2020 with the increase in digital engagement it was decided to move from producing a quarterly PDF newsletter to producing a monthly e-newsletter. By 2021 the e-newsletter is being distributed to 2200 people a month with an average open rate of 49% which is higher than other charities.

Below is a bar chart showing newsletter performance

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Campaigns in 2021

Below are the awareness and fundraising campaign cycles for 2021

Campaign	Period
NETA month	January – March
Fundraiser challenges	April – June
The Journey summer campaign	July – August
Schools campaigns	July–September
OT month	August–September
Christmas	October – December

Online donations

In 2021 through the NTF website the NTF were able to raise £5073 excluding Gift Aid. Making it the most successful year for online fundraising to date for the NTF.

Online support group events

In 2021 the NTF continued to support people with tremor post the Covid pandemic with regular online support group events. In 2021 NTF held 31 online support group events which attracted 1383 people.

Notes

1. The website has seen continued growth due to a major overhaul in 2016 and our Digital Content Consultant continuing to develop the website further, with regular updates and continual links to our social media channels, Facebook and Instagram, optimisation of keywords and online advertising to increase its ranking on Google. This growth has occurred with increased community activity such as support groups and events.

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2. In 2018 the website home page was redesigned to reflect the current needs of the website. With over 50% of users accessing the website using mobile the new design is "mobile first". The new homepage aims to promote Support Groups, events, photographs and fundraising. The website also has given Orthostatic Tremor a new separate section of its own. In addition, Twitter feed was added to the home page and a Donation button was added to the top of the website to increase funds raised.

2018 saw the introduction of GDPR. GDPR is the law on data protection and privacy for all individuals. This has meant that major changes were made to how the NTF handles data. All people with data held by the NTF had to re-consent to the NTF using their data. A number of emails were sent out to all members asking them to re-subscribe to our database. In addition, changes were made to the website so that people had to consent to the use of their information when signing up to forms; additional security settings were added; and a secure domain certificate

RESEARCH

A grant of £11,106 was made available to Imperial College for a research study in 2016. The study was in the evaluation of the effectiveness and safety of MRI-guided focused ultrasound thalamotomy treatment at Charing Cross hospital for people with medically refractory Essential Tremor syndrome.

Essential Tremor is a shake of a part of the body that cannot be controlled. There are many causes of severe tremor – it is a syndrome rather than a specific condition. There are over one million people with Essential Tremor in Britain and around 250,000 people with the syndrome are severely disabled by their tremor. Current treatments include drug therapies, surgery and deep brain stimulation. These treatments are of limited effectiveness or cannot be used in all sufferers; some have moderate risks and side effects.

However, clinical researchers have recently developed a technique that allows MRgFUS to be used in the brain to treat Essential Tremor. There is a growing body of clinical evidence from around the world that this procedure is safe and effective, and it has been shown recently to have very successful outcomes in the treatment of Essential Tremor, with many fewer risks than deep brain stimulation and at a substantially decreased cost per patient treated.

The MRI-guided focused ultrasound machinery at St Marys hospital in Paddington (as shown below) is the only one in the UK. Dundee University are campaigning to get a similar machine installed at Ninewells hospital in Scotland & we were delighted to gain a £40K grant towards this campaign in July 2018 followed by a further £15K grant in December 2019. Through the persistence of the NTF Scottish tremor support group, the matter of MR guided focussed ultrasound treatment of essential tremor was debated in the Scottish parliament and the subsequent campaign was launched.

...

Current treatments for essential tremor such as drug therapies, surgery and a technique known as deep brain stimulation are often ineffective, and some carry significant risks and side effects.

But the new procedure – MRI-guided focused ultrasound – can be carried out without the need for invasive surgery. It involves using a powerful MRI machine to focus ultrasound waves on a specific area of brain tissue. At that point, molecules are vibrated extremely quickly, which creates intense heat to destroy only the targeted tissue and break the abnormal electrical circuits causing the tremor.

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The first UK clinical trial of the treatment took place at St Mary's Hospital in 2016, using the £1.1 million MRI machine funded by Imperial Health Charity. During the trial, the procedure was used to treat 13 patients. All experienced significant improvements in the severity of their tremor.

Having now been approved by NICE (The National Institute for Health & Care excellence), a policy working group was set up to sell the procedure to NHS England as a treatment that is sufficiently needed in the community to be funded by the NHS. This step is something in which the NTF has already got involved with and have written to NHS England & met with MP's at the houses of parliament to put the case forward for this treatment. In March 2019, the NTF were invited by NHS England onto a policy working group for Focussed Ultrasound treatment of essential tremor. However, a final decision on the outcome of these discussions were delayed in 2020 due to the Covid-19 pandemic

The two year post MR-guided focused ultrasound for essential tremor results from Imperial College NHS Healthcare show that the treated arm essential tremor remains well suppressed, with no or minimal return of tremor and positive effects on the patients' quality of life. Furthermore, using a novel two lesion approach in which small burns are made into adjacent areas of the brain (the anterior part of the Ventralis Intermedius nucleus and the Zona incerta) the incidence of persistent sensory adverse effects, typically numbness in the fingers or lips, was reduced to zero. This area of functional surgery continues to advance with the first staged bilateral MRgFUS treatment showing excellent results that are stable at 12 months post MRgFUS.

A drop in event to arrange awareness of MRI guided focussed ultrasound was arranged in October 2019 at the houses of parliament and was attended by many MP's, Lord Julian Fellowes & representatives from the National Tremor Foundation.

Research Update 2021

Unfortunately, the covid pandemic has stopped any MR-guided focused ultrasound treatment of tremor for the first lockdown in March 2020

However, the very positive news that NHS England would fund MRgFUS treatment of essential tremor with effect from April 2021 was received, so that we should be able to start treating patients at Imperial College NHS Trust once the pandemic restrictions are lifted and routine treatments can restart. During the 'delay in initiating treatment resulting from NHS England's protracted process and the pandemic a waiting list of over 150 patients with essential tremor has developed. Even so hopefully treatment for these patients with MRgFUS will begin in the later part of 2021.

We treated our first patient with essential tremor using staged bilateral MRgFUS in January 2020, successfully in the context of a clinical trial. the patient had one arm treated and then the other about a year later. We hope to be able to resume this trial soon and then be able to report on the safety of doing staged bilateral MRgFUS in 2022.

ESSENTIAL TREMOR IN CHILDREN

As Children's Liaison Officer, Kitty Reilly has had many email contacts from parent and carers across the country who also have children having tests for or being diagnosed with ET, who need some support and advice. Given ET is the most common neurological disorder in children, our work in the NTF needs to reflect this.

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Kitty sees her main role as a supportive one in the first instance, followed by raising awareness through our website about children with ET and social media campaigns.

Through Kitty's work she has noticed one of the primary difficulties for children with ET is school. Raising awareness in school is key. Whilst treatment for ET is limited we need to be able to support children through school by providing the schools with knowledge and recommendations for equipment to ensure children are not penalised in their education simply because they are not able to write at an accepted standard. As well as educating teachers on the other difficulties associated with ET in children (i.e. fatigue, dressing and undressing for PE, eating, drinking etc), Kitty has started this campaign in her son's school. She would like to see this being escalated to the Department of Education to ensure children with ET, whose writing ability is compromised etc, are not held back from achieving.

BENEFICIARY SUPPORT GROUPS

Clearly as a result of lock down, groups struggled to meet although a number managed through Zoom meetings.

Annual Meeting

Due to Covid restrictions, the National Tremor Foundation was unable to hold its very popular annual meeting in 2021. As soon as it is safe to do so we look forward to seeing our friends & supporters at the next meeting.

FUNDRAISING REVIEW

The Foundation continued with support from many Charitable Trusts throughout the year. Postal applications and personal visits enabled funding to be obtained at low costs. Applications were generally for basic core costs.

The continuing low investment interest rates obtained by trust funds has again reduced the amount of money for distribution to beneficiaries and The Foundation greatly appreciates the support from all Charitable Trusts. During a difficult period, the Foundation managed to raise in excess of £35,000 and spent over £50,000 maintaining its communication links and supporting sufferers.

PLANS FOR FUTURE PERIOD

1. To encourage the activity and development of local support groups, using a zoom format where appropriate.
2. To appoint a local Support Group Co-ordinator with responsibilities for support group activities and development.
3. To arrange national 'Tremor Open Day' in the form of a face-to-face meeting with zoom facilities for those who cannot attend in person. The plan is for this to occur in Autumn 2022.
4. To increase membership of the Board of Trustees by at least two.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2021

5. To redesign and update all NTF logos and printed documents. External advice to be sought and Trustees to be offered choices.
6. To continue to expand and update the website to allow greater accessibility and quality of content.
7. To promote children's services – Kitty Reilly to take lead in her role as Children's Officer.
8. To elect new chairperson for the Board of Trustees.

PUBLIC BENEFIT STATEMENT

The Trustees confirm that they have complied with the duty in the Charities Act 2011 to have due regard to the Charity Commission's general guidance on public benefit. As stated elsewhere in this report, the Trust's charitable activity work is clear evidence of both the identifiable benefit provided and the relation of this benefit to the charity's aims. Continuing website feedback shows that the Trust is regularly reaching people affected by tremors - both in UK and overseas, with a continued large increase in visitors to the website in recent years.

FINANCIAL REVIEW

Our income received for 2021 reached over £35,000 during a difficult year. There was a total of over £98,000 in the bank at year end. With membership free, we encouraged members to voluntarily donate.

Our primary costs continue to be invested in fundraising and our website, with a dedicated IT consultant to continually monitor and upgrade the website. Increased activity, particularly website development and an effort to establish further support groups in the UK, resulted in further expenditure in this area.

RESERVES POLICY

The Trustees would ideally like to establish a level of reserves that would meet 12 months of operational costs (approximately £50k) should there be a gap in funding. At the year end the reserves held were £ £98,364 (previous year £116,664); this level of holding gives a sound base for considering increased research activity.

REFERENCE AND ADMINISTRATIVE DETAILS

Trustees

- at date of report's approval: 21th October 2022

Professor Leslie J Findley TD, M D, FRCP

Chairman

Kevin Harfoot

Keith Flaxman

Treasurer

Dr Peter Bain MBBS MA MD FRCP (Consultant Neurologist)

Kitty Reilly

Registered Office Harold Wood Polyclinic
St Clements Avenue
Harold Wood
Romford RM3 0FE

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2021

Bankers National Westminster Bank

Independent Examiner Adrian Nunn FCCA

Charity Registration Details Name: National Tremor Foundation Charitable Trust
No: 1042013

STRUCTURE, GOVERNANCE & MANAGEMENT

Governing Document

The Trust is governed by a Declaration of Trust dated 19 October 1994 and was registered as a charity on 9 November 1994.

Recruitment and Appointment of Trustees

New trustees are recruited for the special contribution they can make to the Trust and are appointed by resolution of the Trustees.

STATEMENT OF TRUSTEES' RESPONSIBILITIES

Charity law requires the Trustees to prepare a trustees' annual report and financial statements for each financial year which show a true and fair view of the state of affairs of the Trust and its financial activities for that period. In preparing those financial statements, the Trustees are required to:

Select suitable accounting policies and then apply them consistently.

Observe the methods and principles in the applicable Charities SORP.

Make judgements and estimates that are reasonable and prudent.

State whether applicable accounting standards and statements of recommended practice have been followed, subject to any departures disclosed and explained in the financial statements.

Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Trust will continue in operational existence.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports)

Regulations and the provisions of the constitution. They are also responsible for the maintenance and integrity of the Trust, safeguarding the assets of the Trust and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The financial statements have been prepared in accordance with the accounting policies set out in notes to the accounts and comply with the charity's governing document, the Charities Act 2011 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 (FRS 102) published on 16 July 2014. Statement as to disclosure to the independent examiner

In so far as the Trustees are aware at the time of approving the trustees' annual report: There is no relevant information, being information needed by the independent examiner in connection with preparing his report, of which the independent examiner is unaware.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2021

The Trustees, having made enquiries of fellow trustees and the independent examiner that they ought to have individually taken, have each taken all steps that they are obliged to take as a trustee in order to make themselves aware of any relevant information for the independent examination and to establish that the independent examiner is aware of that information.

Approved by the Trustees on 21st Oct 2022 and signed on their behalf by:

LJFindley

Professor Leslie Findley
Chairman

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

I report on the accounts of the National Tremor Foundation Charitable Trust for the year ended 31 December 2021, which are set out on pages 13 - 16.

Responsibilities and basis of report

As the trustee of the charity, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect: Accounting records were not kept in respect of the Trust as required by section 130 of the Act. The accounts do not accord with those records. The accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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



Adrian Nunn
FCCA
59 Gainsford Gardens
Clacton-On-Sea
Essex
CO15 5BJ

National Tremor Foundation Charitable Trust
Statement of Financial Activities for the Year Ended 31st December 2021

	Note	Unrestricted Funds £	Restricted Funds £	Total for Year	
				2021 £	2020 £
Income					
Donations		35,452	0	35,452	109,628
Grants				0	0
		<u>35,452</u>	<u>0</u>	<u>35,452</u>	<u>109,628</u>
Expenditure					
Fund Raising	2	15,003		15,003	24,204
Charitable Activities					
Information		32,026		32,026	27,789
Research			0	0	0
Beneficiary Support		6,704	0	6,704	9,157
		<u>53,733</u>	<u>0</u>	<u>53,733</u>	<u>61,150</u>
Net Movement in Funds		<u>-18,280</u>	<u>0</u>	<u>-18,280</u>	<u>48,478</u>
Reconciliation of Funds		<u>76011</u>	<u>15231</u>	<u>91,242</u>	<u>109523</u>

Balance Sheet as at 31st December 2021

		31st December 2021	31st December 2020
Current Assets			
Debtors	5	0	0
Cash at Bank		98363	116644
Creditors: Amounts Falling due within one year	6	<u>-7121</u>	<u>-7121</u>
Net Current Assets		91242	109523
Net Assets		<u>91242</u>	<u>109523</u>
Funds			
Unrestricted Funds	7	76,011	94292
Restricted Funds	8	15,231	15231
		<u>91,242</u>	<u>109523</u>

National Tremor Foundation Charitable Trust

Notes to the Financial Statements for the Year ended 31 December 2021

1. ACCOUNTING POLICIES

Basis of preparation. The accounts (financial statements) have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts. The financial statements have also been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 (and as updated by Update Bulletin 1 issued on 2 Feb 16) and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

The accounts (financial statements) have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The National Tremor Foundation (the charity) meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Preparation of the accounts on a going concern basis. The trustees consider that charity can continue as a going concern for at least the next 12 months.

Income. Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Interest receivable. Interest on any funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

Fund accounting. Unrestricted funds are available to spend on activities that further any of the purposes of charity. Restricted funds are donations which the donor, or charity when making an appeal, has specified are to be solely used for particular areas of the charity's work.

Expenditure and irrecoverable VAT. Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is classified under the following activity headings:

- Costs of raising funds cover all expenditure incurred by the charity to raise funds for its charitable purposes - including the costs of all fundraising activities, events and non-charitable trading activities, plus the associated support costs.
- Expenditure on charitable activities includes the costs of information provision and beneficiary support undertaken to further the purposes of the charity and their associated support costs.
- Other expenditure represents those items not falling into any other heading.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

Allocation of support costs. Support costs are those functions, such as office overheads and governance, that assist the work of the charity but are not a direct cost of reported activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities. The bases on which support costs have been allocated are set out in note 3.

Tangible fixed assets. Individual fixed assets costing £1,000 or more are capitalised at cost and are depreciated over an estimated useful economic life of 4 years on a straight line basis. The charity has no such eligible assets.

Stock. Stock is included at the lower of cost or net realisable value. The charity has no material stock holdings.

National Tremor Foundation Charitable Trust

Notes to the Financial Statements for the Year ended 31 December 2020

Financial instruments. The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

Debtors Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Cash at bank and in hand. Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

Creditors and provisions. Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

2 EXPENDITURE	Direct	Contractor	Support	2021	2020
	£	£	£	£	£
Cost of Generating Funds	2,158	14,980	2,657	19,795	24,204
Charitable Activities					
Information	1,366	23,280	980	25,626	27,789
Research	0	0	0	0	0
Beneficiary Support	6,775	1,248	288	8,311	9,157
Total Resources Expended	10,299	39,508	3,925	53,732	61,150

Costs have been attributed on a basis consistent with the use of resources. Where costs cannot be allocated, they are proportioned by the estimated percentage of time spent on each activity.

3 SUPPORT COSTS	Raising Funds	Info	Research	Beneficiary Support	2021	2020
	£	£	£	£	£	£
Governance	780	297	48	248	1,373	2,906
Communications	644	362	60	121	1,187	2,497
Office	743	415	69	138	1,365	2,865
Total Support	2,167	1,074	177	507	3,925	8,268

4 OTHER TRANSACTION INFORMATION

The charity does not employ any staff directly but relies on two contractors for fundraising, administration and web site activities

No Trustee received remuneration or other benefits in connection with Trustee duties or other services

There were no related party transactions in this reporting period that require disclosure

5 DEBTORS	2021	2020
	£	£
Prepayments	0	0
	<u>0</u>	<u>0</u>
6 CREDITORS	2021	2020
	£	£
Trade Creditors	6,861	6,861
Accruals	260	260
Other Creditors		
	<u>7,121</u>	<u>7,121</u>
7 UNRESTRICTED FUNDS	2021	2020
	£	£
General	76,011	109,523
	<u>76,011</u>	<u>109,523</u>
8 RESTRICTED FUNDS	2021	2020
	£	£
Orthostatic Tremor Group	2,348	2,348
Video Production	1,000	1,000
Yorkshire	533	533
Support Group/Helpline	3,060	3,060
Youngsters	1,166	1,166
Ultrasound Research	1,500	1,000
National Lottery	3,668	3,668
POT Group	500	500
Meeting Sponsorship	1,000	1,000
Leeds Group	456	456
	<u>15,231</u>	<u>15,231</u>

The Orthostatic Tremor funding is for the group's running costs. The video production is for a video on undergoing tremor related surgery. The Yorkshire funding is for has a geographic restriction. The support group/helpline funding is for the expansion of these services. The Youngsters funding is for educating & assisting young people with essential tremor. The ultrasound research funding is specifically related to that area of research. The Lottery funding is for UK support group development. The Leeds group fund is geographically restricted.

NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

England & Wales - Charity number 1042013

Accounts

National Tremor Foundation Charitable Trust

**Report & Financial Statements
for the year ended 31 December 2020**

Charity number: 1042013

National Tremor Foundation Charitable Trust

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National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2020

OBJECTIVES & ACTIVITIES

The Trust's legal purpose (objects) are:

- To promote, centralise and co-ordinate for the benefit of the public any form of research into essential, idiopathic and hereditary tremor and to disseminate and publish the useful results of such research.
- To relieve the need of sufferers from essential, idiopathic and hereditary tremor.
- To advance the education of the public in the subject of essential, idiopathic and hereditary tremor.

The Trust is currently able to resource these charitable activities:

- **Information.** Provision of knowledge to people affected by tremor or movement disorders of various parts of the body in order to help them and their families/carers manage the condition. The initial source for the Trust's beneficiaries is the website which the Trust believes is the leading source of information on this condition for over one million sufferers in the UK. Further sources are a newsletter (available in hard and soft copy), a general telephone enquiry service and access to an advisory panel.
- **Research.** This is a recently new activity enabled by the build-up of reserves over recent years. Research progresses the understanding of tremors by investigating causes and potential treatments.
- **Beneficiary support.** This activity covers the annual conference, active support and the encouragement/subsidy of regional support groups where there are known clusters of interested beneficiaries.

ACHIEVEMENTS & PERFORMANCE

This section explains the activities for the reporting period; in a difficult economic environment the Trust has managed to keep costs to a minimum and maintain the central office support facility.

HONORARY PRESIDENT – LORD JULIAN FELLOWES



We are delighted and honoured to continue to have Lord Julian Fellowes as Honorary President of the NTF. Lord Fellowes, is world renowned for creating the hugely successful and critically acclaimed TV period drama Downton Abbey. In a recent newspaper interview, he revealed that he lives with Essential Tremor. In the last ever episode of Downton Abbey, Lord Fellowes wrote into the script a character who suffered with Essential Tremor and in doing so raised a great amount of awareness for this little-known condition.

Lord Fellowes was born in Cairo, Egypt, educated in Britain before moving to Los Angeles in 1981 and returned to the UK in 1991. He is well known as an actor, novelist, screenwriter and film director and his career spans over 40 years. Lord Fellowes has been a member of the House of Lords since January 2011. He is also chairman and patron of several UK charities.

During 2020 Lord Fellowes joined an online Zoom meeting and took part in a Q&A session hosted by NTF support group co-ordinator Jackie Farrell .

BOARD ACTIVITY

The trustees met online via Zoom in October 2020 and again in November 2020. The meetings generated an action plan which included updating our safeguarding policy, DBS Checks for all NTF personnel including support group leaders.

MARATHON RUNS

As a result of the cancellation of the 2020 London Marathon, the National Tremor Foundation were delighted to have 2 runners in the 2020 London Marathon virtual event in October. Despite the short notice the 2 runners raised over £2000.

Digital report 2020

Digital overview

The NTF's website is the main means for the charity to communicate to the public, driving in 178,733 users a year from across the globe. It provides a range of information on tremors (from diagnosis and clinical characteristics to research topics and help for carers), support group events and news.

2020 was a challenging year with the corona virus outbreak which changed the way the NTF operated and saw the NTF become completely digital. The UK was in lockdown by March 2020 and the NTF launched its new website in June, which has improved features and is far more usable for users.

The new website allowed increased digital engagement during the lockdown and catered for the new virtual way of living. As we saw a shift in support groups from being face-to-face to online which have proved very popular. In addition users were able to donate more easily boosting individual fundraising.

Below is a SWOT analysis highlighting the digital opportunities and threats facing the NTF.

Strengths • Improved donations process • Improved signing up for events and support events • Improved Friends of signing up process • Strong digital support network of potential volunteers • Out performing given our size • Increased internal communication and teamwork has contributed in success.	Opportunities • Market for people to use online meetups is growing and have been highly successful • Increase in people using virtual challenge events (i.e. London Marathon and The Journey) which opens opportunities to access new audiences • Businesses interested in events fundraising • Demand for online goods such as NTF T-Shirts • Demand for people to get involved in the NTF as volunteers or friends
Weaknesses • NTF operating beyond capacity • GDPR consent to website traffic (cookie consent) reduced recorded traffic • Need for more photography to show types of tremor. • Need to drive to research content to website • No advertising budget.	Threats • Changes in work patterns such as furlough and lockdown affecting events • Economic issues facing users such as unemployment affecting donations • Growth in dependence on charities for digital support due to NHS being overburdened. • Potential for market saturation in digital services with an increase in competition for digital engagement from other/bigger charities.

Website

The number of website users between 2016 and 2019 had doubled, but due to a change in the website design to comply with GDPR by Tribal Systems in December 2019 Google Analytics was only tracking 20% of traffic. This resulted in a major dip in recorded traffic of 58% in 2020.

However with the launch of the new website we have been able to recapture some of the data and working to optimise the new website. We are currently on track to regaining the traffic lost.

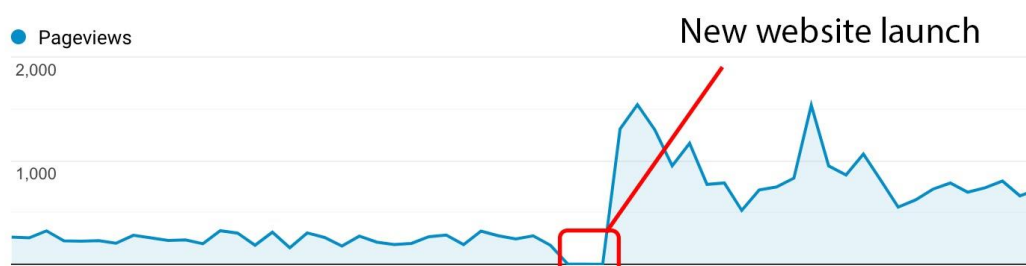
Below shows how the number of website users has increased over the last five years.

Year	Total users	Percentage change
2020	178,733	-58%
2019	427,904	12%
2018	383,376	22%
2017	315,043	74%
2016	181,469	

Below is a graph showing the exact time in 2019 the GDPR change was implemented and how it dramatically reduced website traffic.



Below is a graph showing when the new website was launched in 2020 and how traffic was recaptured.



Website audiences

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From Google Analytics most users are aged 65+ (21%); most are female (57%); most live in the UK (74%); over half live in London (53%) and over half use the website using mobile (53%).

Age

65+	21%
25-34	19%
55-64	18%
45-54	16%
35-44	15%
18-24	10%

Gender

Female	57%
Male	43%

Device

mobile	53%
desktop	37%
tablet	10%

Country

United Kingdom	74%
United States	24%
Australia	3%

City

London	53%
Birmingham	7%
Leeds	6%
Glasgow	6%
Bristol	5%
Liverpool	5%
Manchester	5%
Dublin	5%
Sheffield	4%
	4%
Newcastle upon Tyne	

Google Advertising

The NTF receives a Google Grant to give the charity free but limited online advertising. Constant management of the NTF's online advertising has meant that on average an extra 1600 people are visiting the website a month.

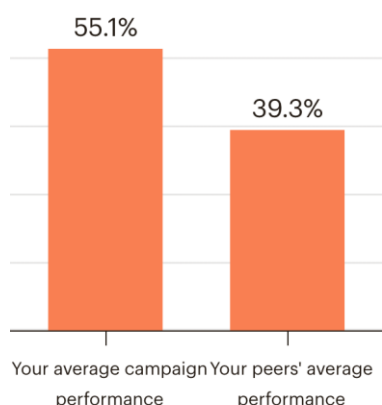
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Furthermore, the NTF's Social media network has continued to grow with our established Facebook channel being popular and Twitter attracting increased interest.

Newsletter

In 2020 with the increase in digital engagement it was decided to move from producing a quarterly PDF newsletter to producing a monthly e-newsletter. By 2020 the newsletter was being distributed to 1,844 people and with an open rate of 55.1% they are out performing other charities.

Below is a bar chart showing newsletter performance.



Online Support Groups

2020 saw support groups go online using Zoom. During 2020 we ran over 40 digital events with a total number of over 700 people registering (100 different people; with 35 people signing up to an event on average).

Online donations

With the introduction of the new website 2020 has seen a significant increase in the number of donations. In 2020 the new website drove in an additional £2045 in donations compared to £1015 in 2019.

Month	Amount
June	£187
July	£338
August	£386
September	£251
October	£193
November	£378

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December	£312
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Campaigns for 2021

Below are the awareness and fundraising campaign cycles planned for 2021.

Campaign	Period
NETA month	January – March
Fundraiser challenges	April – June
The Journey summer campaign	July – August
Schools campaigns	July–September
OT month	August–September
Christmas	October – December

Notes

1. The website has seen continued growth due to a major overhaul in 2016 and our Digital Content Consultant continuing to develop the website further, with regular updates and continual links to our social media channels, Facebook and Instagram, optimisation of keywords and online advertising to increase its ranking on Google. This growth has occurred with increased community activity such as support groups and events.
2. In 2018 the website home page was redesigned to reflect the current needs of the website. With over 50% of users accessing the website using mobile the new design is “mobile first”. The new homepage aims to promote Support Groups, events, photographs and fundraising. The website also has given Orthostatic Tremor a new separate section of its own. In addition, Twitter feed was added to the home page and a Donation button was added to the top of the website to increase funds raised.
3. 2018 saw the introduction of GDPR. GDPR is the law on data protection and privacy for all individuals. This has meant that major changes were made to how the NTF handles data. All people with data held by the NTF had to re-consent to the NTF using their data. A number of emails were sent out to all members asking them to re-subscribe to our database. In addition, changes were made to the website so that people had to consent to the use of their information when signing up to forms; additional security settings were added; and a secure domain certificate was added (https).

RESEARCH

A grant of £11,106 was made available to Imperial College for a research study in 2016. The study was in the evaluation of the effectiveness and safety of MRI-guided focused ultrasound thalamotomy treatment at Charing Cross hospital for people with medically refractory Essential Tremor syndrome.

Essential Tremor is a shake of a part of the body that cannot be controlled. There are many causes of severe tremor – it is a syndrome rather than a specific condition. There are over one million people with Essential Tremor in Britain and around 250,000 people with the syndrome are severely disabled by their tremor. Current treatments include drug therapies, surgery and deep brain stimulation. These treatments are of limited effectiveness or cannot be used in all sufferers; some have moderate risks and side effects.

However, clinical researchers have recently developed a technique that allows MRgFUS to be used in the brain to treat Essential Tremor. There is a growing body of clinical evidence from around the world that this procedure is safe and effective, and it has been shown recently to have very successful outcomes in the treatment of Essential Tremor, with many fewer risks than deep brain stimulation and at a substantially decreased cost per patient treated.

The MRI-guided focused ultrasound machinery at St Marys hospital in Paddington (as shown below) is the only one in the UK. Dundee University are campaigning to get a similar machine installed at Ninewells hospital in Scotland & we were delighted to gain a £40K grant towards this campaign in July 2018 followed by a further £15K grant in December 2019. Through the persistence of the NTF Scottish tremor support group, the matter of MR guided focussed ultrasound treatment of essential tremor was debated in the Scottish parliament and the subsequent campaign was launched.

...

Current treatments for essential tremor such as drug therapies, surgery and a technique known as deep brain stimulation are often ineffective, and some carry significant risks and side effects.

But the new procedure – MRI-guided focused ultrasound – can be carried out without the need for invasive surgery. It involves using a powerful MRI machine to focus ultrasound waves on a specific area of brain tissue. At that point, molecules are vibrated extremely quickly, which creates intense heat to destroy only the targeted tissue and break the abnormal electrical circuits causing the tremor.

The first UK clinical trial of the treatment took place at St Mary's Hospital in 2016, using the £1.1 million MRI machine funded by Imperial Health Charity. During the trial, the procedure was used to treat 13 patients. All experienced significant improvements in the severity of their tremor.

Having now been approved by NICE (The National Institute for Health & Care excellence), a policy working group was set up to sell the procedure to NHS England as a treatment that is sufficiently needed in the community to be funded by the NHS. This step is something in which the NTF has already got involved with and have written to NHS England & met with MP's at the houses of parliament to put the case forward for this treatment. In March 2019, the NTF were invited by NHS England onto a policy working group for Focussed Ultrasound treatment of essential tremor. However, a final decision on the outcome of these discussions were delayed in 2020 due to the Covid-19 pandemic

The two year post MR-guided focused ultrasound for essential tremor results from Imperial College NHS Healthcare show that the treated arm essential tremor remains well

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suppressed, with no or minimal return of tremor and positive effects on the patients' quality of life. Furthermore, using a novel two lesion approach in which small burns are made into adjacent areas of the brain (the anterior part of the Ventralis Intermedius nucleus and the Zona incerta) the incidence of persistent sensory adverse effects, typically numbness in the fingers or lips, was reduced to zero. This area of functional surgery continues to advance with the first staged bilateral MRgFUS treatment showing excellent results that are stable at 12 months post MRgFUS.

A drop in event to arrange awareness of MRI guided focussed ultrasound was arranged in October 2019 at the houses of parliament and was attended by many MP's, Lord Julian Fellowes & representatives from the National Tremor Foundation.

Research Update 2021

Unfortunately, the covid pandemic has stopped any MR-guided focused ultrasound treatment of tremor for the first lockdown in March 2020

However, the very positive news that NHS England would fund MRgFUS treatment of essential tremor with effect from April 2021 was received, so that we should be able to start treating patients at Imperial College NHS Trust once the pandemic restrictions are lifted and routine treatments can restart. During the 'delay in initiating treatment resulting from NHS England's protracted process and the pandemic a waiting list of over 150 patients with essential tremor has developed. Even so hopefully treatment for these patients with MRgFUS will begin in the later part of 2021.

We treated our first patient with essential tremor using staged bilateral MRgFUS in January 2020, successfully in the context of a clinical trial. the patient had one arm treated and then the other about a year later. We hope to be able to resume this trial soon and then be able to report on the safety of doing staged bilateral MRgFUS in 2022.

ESSENTIAL TREMOR IN CHILDREN

As Children's Liaison Officer, Kitty Reilly has had many email contacts from parent and carers across the country who also have children having tests for or being diagnosed with ET, who need some support and advice. Given ET is the most common neurological disorder in children, our work in the NTF needs to reflect this.

Kitty sees her main role as a supportive one in the first instance, followed by raising awareness through our website about children with ET and social media campaigns.

Through Kitty's work she has noticed one of the primary difficulties for children with ET is school. Raising awareness in school is key. Whilst treatment for ET is limited we need to be able to support children through school by providing the schools with knowledge and recommendations for equipment to ensure children are not penalised in their education simply because they are not able to write at an accepted standard. As well as educating teachers on the other difficulties associated with ET in children (i.e. fatigue, dressing and undressing for PE, eating, drinking etc), Kitty has started this campaign in her son's school. She would like to see this being escalated to the Department of Education to ensure children with ET, whose writing ability is compromised etc, are not held back from achieving.

BENEFICIARY SUPPORT GROUPS

The number of support groups remained constant in 2020 as a result of the Covid-19 pandemic. In the absence of support group meetings held locally, the NTF hosted weekly online meetings via Zoom, which allowed people to chat & interact in a friendly, informal environment.

Support Group Co-Ordinator

The start of 2020 looked set to be a promising year for new groups.

January 18th – Two new groups were launched

Worthing Shakers – led by Jackie Farrell - Launched by Mayor of Worthing, Cllr Hazel Thorpe. BBC South News attended and made a short documentary which went out the following day on 6pm and 10pm news across the South.

Central Scotland led by Scott Pender

Preparations were also in place to launch two more new groups in Canterbury & Chelmsford in April 2020. Sadly due to Covid restrictions these did not materialise, but we are hopeful of future activity in these areas.

Existing groups in Leeds, Sheffield, Salisbury, North West and Sutton groups continued to be active up until March.

March is National Essential Tremor Awareness Month (NETA)
2020 was set to be the biggest year yet with three ET Awareness Days planned.

Two local ET awareness days took place (prior to lockdown).

March 7th - Worthing – attended by Worthing Mayor Cllr Hazel Thorpe and Worthing Town Crier Cllr Bob Smytherman

March 14th - Sutton, Greater London

The main NTF Awareness Day 2020 was planned to take place in Leeds, 28th March. Dr Sarah Jarvis was to be facilitator and actor Rob Mallard was due to attend. But by 26th March complete lockdown came into force and no meetups were permitted, which meant the event had to be postponed.

The Journey of a thousand miles

At the time, lockdown restrictions made it look unlikely face to face groups would take place for a few months, so NTF looked at alternative ways to support the tremor community. One way was to use Zoom for a weekly online group which launched March 28th. We are pleased to say, it proved popular and the "Journey of a Thousand Miles" virtual awareness campaign was launched online July 4th by NTF Honorary President Lord Julian Fellows.

The Journey was based on the Lao Tzu quote "A journey of thousand miles begins with a single step". The aim was to use "The Journey" as a vehicle to give people the confidence to talk about their tremor disorder. Also to raise awareness of essential tremor and orthostatic tremor in a collective way. One of the highlights of The Journey was when Corrie actor Rob Mallard joined us online and "The Journey" completed September 2nd.

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By September, Covid restrictions still meant no face to face groups and not looking likely to happen well into 2021. At this point we looked into supporting tremor folk online up to Christmas with a new format. There would now be a monthly Saturday group with additional weekly Wednesday lunchtime popin sessions. Saturday's topics would vary with, social events, quizzes, speakers or just general chat.

An added bonus was a monthly activity challenge #ntfchallenges.

How are NTF challenges different to other NTF events?

These are not online Zoom events but instead a way to encourage people to get active, especially over the winter months whilst having fun.

2020 culminated with a Christmas Party 23rd December and fun and games were had by all.

Primary Orthostatic group (POT)

The Primary Orthostatic group continues to grow its membership and held online meetings in 2020, due to the Covid pandemic.

Many were happy to meet with friends, those who were there for first time received a warm welcome and realised they were not alone in coping with this rare debilitating condition. All members felt it was important to raise the awareness of this rare condition, which is still unknown to many.

The closed facebook page provides a great medium for social interaction and discussion. Membership to the page continues to grow.

Annual Meeting

Due to Covid restrictions, the National Tremor Foundation was unable to hold its very popular annual meeting in 2020. As soon as it is safe to do so we look forward to seeing our friends & supporters at the next meeting.

FUNDRAISING REVIEW

The Foundation continued with support from many Charitable Trusts throughout the year. Postal applications and personal visits enabled funding to be obtained at low costs. Applications were generally for basic core costs.

The continuing low investment interest rates obtained by trust funds has again reduced the amount of money for distribution to beneficiaries and The Foundation greatly appreciates the support from all Charitable Trusts. Several branches of Rotary and Probus Clubs have added to income as well as direct donations from the public via the website. A number of donations were received from funeral directors where relatives of deceased ET patients requested donations in lieu of flowers. General fundraising produced approximately £93,000 , and a legacy of £24,900 was also received.

PLANS FOR FUTURE PERIOD

The Trust's main priority in 2020 is to further encourage & develop its support group network in the UK.

With new rules & guidelines in place and the willingness of younger people to run a support group, we hope to attract funding allowing us to gain increased coverage of support groups throughout the UK.

We will continue to develop the website further with the aid of our dedicated IT specialist, with particular emphasis given to the support group pages, their forthcoming events & a

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gallery of events & meetings already held. The E:Newsletter re-introduced in December 2017 which was initially produced at regular quarterly intervals, were beginning to be produced at regular monthly intervals from May 2020.

In 2020 the National Tremor Foundation continued to be involved in a policy working group with NHS England with the aim of getting focussed ultrasound recognised as a treatment for unilateral essential tremor. In 2020 it was agreed by NHS England that this treatment would be available on the NHS in England from April 2021

It is our aim to strengthen links with Insightec to raise awareness of essential tremor and getting focussed ultrasound recognised as a treatment for essential tremor. An awareness day was arranged in Leeds in March 2020 to show how this partnership has been used to good effect. However, the Covid-19 pandemic meant that this event and many more that were scheduled had to be postponed until further notice. The pandemic resulted in the NTF looking at other methods of supporting people and online meetings via Zoom became increasingly popular in 2020, with weekly meetings arranged and well attended.

Internationally, we hope to strengthen our ties & interaction with the IETF (International Essential Tremor Foundation) in the USA along with making increased contact with our European counterparts and their organisations to form a stronger partnership allowing us to raise awareness further as a bigger community.

Our ultimate objective is to provide some funding for research into basic mechanisms and therapies for tremors of all types, particularly those in the Essential Tremor groups, including primary orthostatic tremor which is generally poorly supported from other funding bodies. Such activities are dependent on continued funding availability, which is secondarily dependent on the economic climate.

Access to our all parts of our website, the information within it & our helpline will continue to be free to every individual – the National Tremor Foundation wants everyone to be able to view & access all the comprehensive medical information held on its website & be able to contact our office for expert & professional advice.

PUBLIC BENEFIT STATEMENT

The Trustees confirm that they have complied with the duty in the Charities Act 2011 to have due regard to the Charity Commission's general guidance on public benefit. As stated elsewhere in this report, the Trust's charitable activity work is clear evidence of both the identifiable benefit provided and the relation of this benefit to the charity's aims. Continuing website feedback shows that the Trust is regularly reaching people affected by tremors - both in UK and overseas, with a continued large increase in visitors to the website in recent years. In early 2019 the emphasis to expand its support group network continued with lottery grant funding driving the initiative further.

FINANCIAL REVIEW

Our income received for 2020 reached £109,628 (a significant increase over 2019) . There was a total of £116,644 in the bank at year end. With membership free, we encouraged members to voluntarily donate.

Our primary costs continue to be invested in fundraising and our website, with a dedicated IT consultant to continually monitor and upgrade the website. Increased activity, particularly website development and an effort to establish further support groups in the UK, resulted in further expenditure in this area.

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It is anticipated that the continued increase in the number of support groups in 2019 will result in increased expenditure in this area. It is hoped The National Lottery grant received for support groups will allow the growth in this area with the NTF also assisting financially.

RESERVES POLICY

The Trustees would ideally like to establish a level of reserves that would meet 12 months of operational costs (approximately £50k) should there be a gap in funding. At the year end the reserves held were £ 69,304 (previous year £92,345); this level of holding gives a sound base for considering increased research activity.

REFERENCE AND ADMINISTRATIVE DETAILS

Trustees

- at date of report's approval: 20th October 2021

Kevin Harfoot

Chairman

Professor Leslie J Findley TD,MD, FRCP (Consultant Neurologist)

Keith Flaxman

Treasurer

Dr Peter Bain MBBS MA MD FRCP (Consultant Neurologist)

Kitty Reilly

John Kidney resigned as a trustee on 19 November 2019

Registered Office Harold Wood Polyclinic
St Clements Avenue
Harold Wood
Romford RM3 0FE

Bankers National Westminster Bank

Independent Examiner Adrian Nunn FCCA

Charity Registration Details Name: National Tremor Foundation Charitable Trust
No: 1042013

STRUCTURE, GOVERNANCE & MANAGEMENT

Governing Document

The Trust is governed by a Declaration of Trust dated 19 October 1994 and was registered as a charity on 9 November 1994.

Recruitment and Appointment of Trustees

New trustees are recruited for the special contribution they can make to the Trust and are appointed by resolution of the Trustees.

STATEMENT OF TRUSTEES' RESPONSIBILITIES

Charity law requires the Trustees to prepare a trustees' annual report and financial statements for each financial year which show a true and fair view of the state of affairs of the Trust and its financial activities for that period. In preparing those financial statements, the Trustees are required to:

National Tremor Foundation Charitable Trust
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Select suitable accounting policies and then apply them consistently.
Observe the methods and principles in the applicable Charities SORP.
Make judgements and estimates that are reasonable and prudent.
State whether applicable accounting standards and statements of recommended practice have been followed, subject to any departures disclosed and explained in the financial statements.
Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Trust will continue in operational existence.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports)

Regulations and the provisions of the constitution. They are also responsible for the maintenance and integrity of the Trust, safeguarding the assets of the Trust and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The financial statements have been prepared in accordance with the accounting policies set out in notes to the accounts and comply with the charity's governing document, the Charities Act 2011 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 (FRS 102) published on 16 July 2014. Statement as to disclosure to the independent examiner

In so far as the Trustees are aware at the time of approving the trustees' annual report: There is no relevant information, being information needed by the independent examiner in connection with preparing his report, of which the independent examiner is unaware. The Trustees, having made enquiries of fellow trustees and the independent examiner that they ought to have individually taken, have each taken all steps that they are obliged to take as a trustee in order to make themselves aware of any relevant information for the independent examination and to establish that the independent examiner is aware of that information.

Approved by the trustees on 20th Oct 2020 and signed on their behalf by:

Kevin Harfoot
Chairman

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE NATIONAL TREMOR FOUNDATION CHARITABLE TRUST

I report on the accounts of the National Tremor Foundation Charitable Trust for the year ended 31 December 2020, which are set out on pages 15 - 18.

Responsibilities and basis of report

As the trustee of the charity, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect: Accounting records were not kept in respect of the Trust as required by section 130 of the Act. The accounts do not accord with those records. The accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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



Adrian Nunn
FCCA
59 Gainsford Gardens
Clacton-On-Sea
Essex
CO15 5BJ

National Tremor Foundation Charitable Trust
Statement of Financial Activities for the Year Ended 31st December 2020

	Note	Unrestricted Funds £	Restricted Funds £	Total for Year	
				2020 £	2019 £
Income					
Donations		108,715	913	109,628	19,226
Grants				0	42,500
		<u>108,715</u>	<u>913</u>	<u>109,628</u>	<u>61,726</u>
Expenditure					
Fund Raising	2	24,204		24,204	22,692
Charitable Activities					
Information		27,789		27,789	32,165
Research			0	0	15,000
Beneficiary Support		9,157	0	9,157	11,994
		<u>61,150</u>	<u>0</u>	<u>61,150</u>	<u>81,851</u>
Net Movement in Funds		<u>47,565</u>	<u>913</u>	<u>48,478</u>	<u>-20,126</u>
Reconciliation of Funds		<u>94292</u>	<u>15231</u>	<u>109,523</u>	<u>61033</u>

Balance Sheet as at 31st December 2020

		31st December 2020	31st December 2019
Current Assets			
Debtors	5	0	0
Cash at Bank		116644	69301
Creditors: Amounts Falling due within one year	6	<u>-7121</u>	<u>-8271</u>
Net Current Assets		109523	61030
Net Assets		<u>109523</u>	<u>61030</u>
Funds			
Unrestricted Funds	7	94292	46712
Restricted Funds	8	15231	14318
		<u>109523</u>	<u>61030</u>

National Tremor Foundation Charitable Trust

Notes to the Financial Statements for the Year ended 31 December 2020

1. ACCOUNTING POLICIES

Basis of preparation. The accounts (financial statements) have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts. The financial statements have also been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 (and as updated by Update Bulletin 1 issued on 2 Feb 16) and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

The accounts (financial statements) have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The National Tremor Foundation (the charity) meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Preparation of the accounts on a going concern basis. The trustees consider that charity can continue as a going concern for at least the next 12 months.

Income. Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Interest receivable. Interest on any funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

Fund accounting. Unrestricted funds are available to spend on activities that further any of the purposes of charity. Restricted funds are donations which the donor, or charity when making an appeal, has specified are to be solely used for particular areas of the charity's work.

Expenditure and irrecoverable VAT. Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is classified under the following activity headings:

- Costs of raising funds cover all expenditure incurred by the charity to raise funds for its charitable purposes - including the costs of all fundraising activities, events and non-charitable trading activities, plus the associated support costs.

- Expenditure on charitable activities includes the costs of information provision and beneficiary support undertaken to further the purposes of the charity and their associated support costs.
- Other expenditure represents those items not falling into any other heading.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

Allocation of support costs. Support costs are those functions, such as office overheads and governance, that assist the work of the charity but are not a direct cost of reported activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities. The bases on which support costs have been allocated are set out in note 3.

Tangible fixed assets. Individual fixed assets costing £1,000 or more are capitalised at cost and are depreciated over an estimated useful economic life of 4 years on a straight line basis. The charity has no such eligible assets.

Stock. Stock is included at the lower of cost or net realisable value. The charity has no material stock holdings.

National Tremor Foundation Charitable Trust

Notes to the Financial Statements for the Year ended 31 December 2020

Financial instruments. The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

Debtors Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Cash at bank and in hand. Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

Creditors and provisions. Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

2 EXPENDITURE	Direct	Contractor	Support	2020	2019
	£	£	£	£	£
Cost of Generating Funds	2,283	15,406	6,515	24,204	23,014
Charitable Activities					
Information	1,445	23,942	2,402	27,789	34,398
Research	0	0	0	0	15,600
Beneficiary Support	7,168	1,283	706	9,157	8,839
Total Resources Expended	10,896	40,631	9,623	61,150	81,851

Costs have been attributed on a basis consistent with the use of resources. Where costs cannot be allocated, they are proportioned by the estimated percentage of time spent on each activity.

3 SUPPORT COSTS	Raising Funds	Info	Research	Beneficiary Support	2020	2019
	£	£	£	£	£	£
Governance	1,677	615	100	514	2,906	3,890
Communications	1,373	749	125	250	2,497	3,342
Office	1,576	860	143	286	2,865	3,836
Total Support	4,626	2,224	368	1,050	8,268	11,068

4 OTHER TRANSACTION INFORMATION

The charity does not employ any staff directly but relies on two contractors for fundraising, administration and web site activities

No Trustee received remuneration or other benefits in connection with Trustee duties or other services

There were no related party transactions in this reporting period that require disclosure

5 DEBTORS	2020	2019
	£	£
Prepayments	0	0
	<u>0</u>	<u>0</u>
6 CREDITORS	2020	2019
	£	£
Trade Creditors	6,861	8,141
Accruals	260	130
Other Creditors		
	<u>7,121</u>	<u>8,271</u>
7 UNRESTRICTED FUNDS	2020	2019
	£	£
General	94,292	65,649
	<u>94,292</u>	<u>65,649</u>
8 RESTRICTED FUNDS	2020	2019
	£	£
Orthostatic Tremor		
Group	2,348	2,227
Video Production	1,000	1,000
Yorkshire	533	533
Support Group/Helpline	3,060	2,766
Youngsters	1,166	1,166
Ultrasound Research	1,500	1,000
National Lottery	3,668	3,668
POT Group	500	500
Meeting Sponsorship	1,000	1,000
Leeds Group	456	456
	<u>15,231</u>	<u>14,318</u>

The Orthostatic Tremor funding is for the group's running costs. The video production is for a video on undergoing tremor related surgery. The Yorkshire funding is for has a geographic restriction. The support group/helpline funding is for the expansion of these services. The Youngsters funding is for educating & assisting young people with essential tremor. The ultrasound research funding is specifically related to that area of research. The Lottery funding is for UK support group development. The Leeds group fund is geographically restricted.

