

National Tremor Foundation Charitable Trust

**Report & Financial Statements
for the year ended 31 December 2018**

Charity number: 1042013

National Tremor Foundation Charitable Trust

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Trustees' Annual Report for the Year Ended 31 December 2018

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.

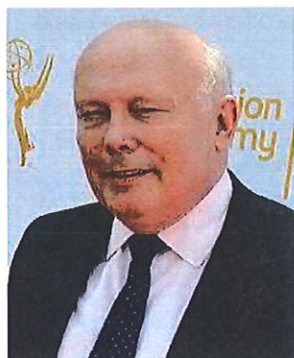
The Trust is currently able to resource these charitable activities:

- **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 2018 Lord Fellowes visited St Mary's hospital in Paddington to see for himself the work carried out by Imperial Health in researching the use of MR Guided Focussed ultrasound for essential tremor.

BOARD ACTIVITY

The trustees met in June 2018 & November 2018 to discuss in detail its future strategy, placing particular emphasis on its website development & support group growth. Jackie Farrell continued in her role as support group co-ordinator after a very successful year in recruiting further support group leaders throughout the UK.

INFORMATION

The website is the NTF's public face and is the main means for it to communicate with our audiences, driving in 383,376 users a year. It provides a range of information on tremors (from diagnosis and clinical characteristics to research topics and help for carers) and attracts a large number of people from around the globe.

The number of website users in the last 2-years has doubled, and this trend continues seeing a 22% increase in the 3rd year. With over 80% of website traffic coming from Google organic/paid search; 15% directly searching for NTF website addresses; and 5% from social media.

This is 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.

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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.

Constant management of the NTF's online advertising has meant that on average an extra 1535 people are visiting the website a month. Despite online advertising being an important part of the website's success, in 2018 Google changed its policies on Google Grants accounts requiring further optimisation in 2018.

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

In 2017 the newsletter was reintroduced, which is forwarded to everyone on the NTF database. The newsletter was a popular feature with members some years ago, but the costs of producing, printing and posting became too prohibitive. However, our increased web and IT capacity has allowed us to revive the newsletter when content is available.

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 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).

Online audiences

The website and social media attract different audiences. Most website users are aged between 24 to 35 (23%) and least number of users being 18 to 24 years of age (12%). 62% of website users are female and 38% male. 40% are from the UK; 35% are from USA.

Interestingly Facebook has also proven to be an important communications channel with the middle-aged audience and older (18% 45–54, 20% 55–64, 20% 56+ years of age) generally preferring to engage with the NTF using social media. The least represented group is 18–24 who account for 1% of the audience. Almost 77% of those that engage on Facebook with the NTF are female and are most likely to be from the UK or the USA.

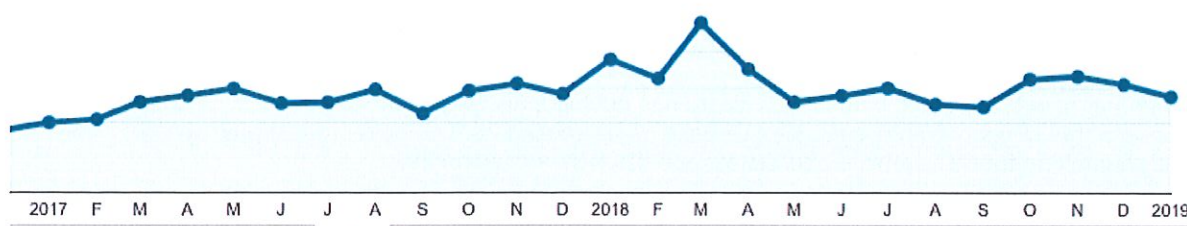
Website users last 3-years

Below shows how the number of website users has increased over the last 3-years. In the last year we have seen an increase of 22%.

Year	Total users	Percentage increase
2018	383,376	22%
2017	315,043	74%
2016	181,469	

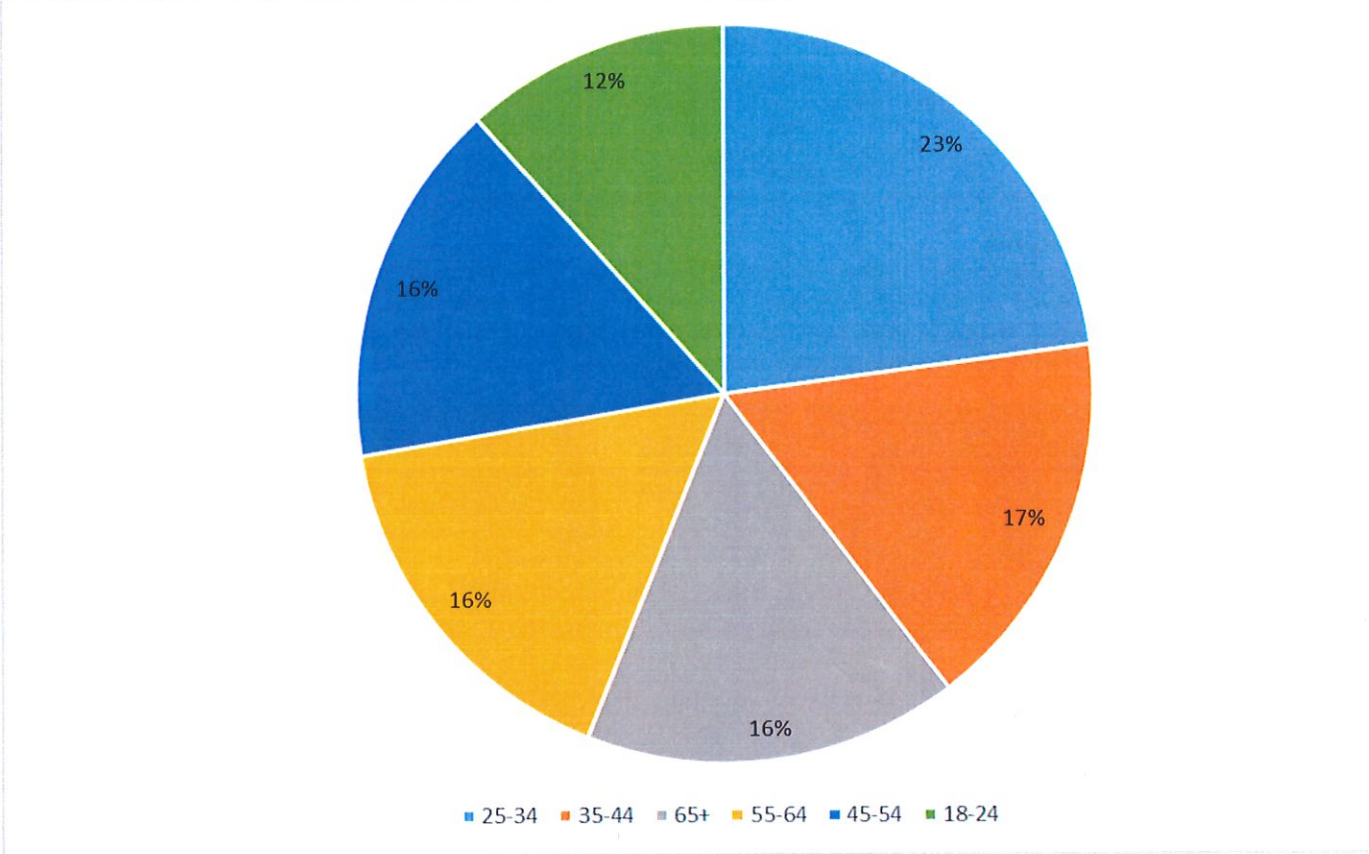
Website users 2018

Below should website user behaviour in 2018. The number of users increased dramatically in March with actor, Rob Mallard talking about tremor and the NTF on TV. The graph shows that the site generally sees a decrease in users during the summer months, but this picks up again autumn.

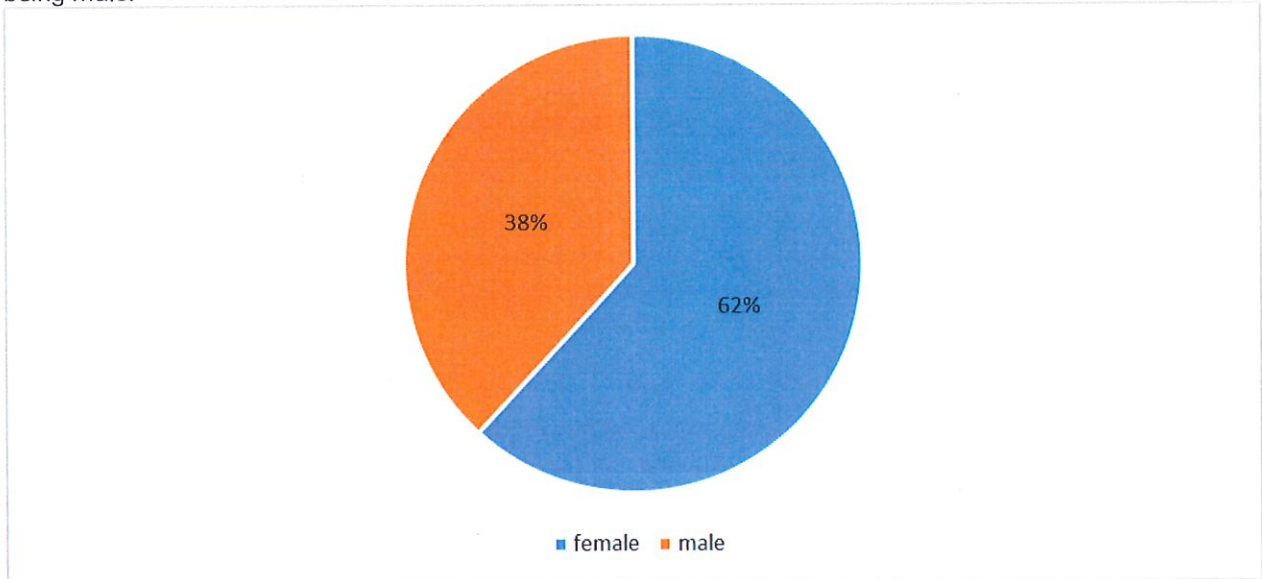


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Website user age Below shows the breakdown of website users by age. With the greatest number of users being 25 to 34 and least number of users being 18 to 24 years of age.



Website user gender Below shows the breakdown of users by gender with 62% being female and 38% being male.



Online advertising 2018. Below shows the average monthly performance of the NTFs online Google Grants account. The site receives on average 1,535 more people a month from the adverts and 21147 people see the NTF adverts online.

Average adverts click to website a month	Average number of adverts a month
1,535	21,147

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Social media. The NTF's social media networks continue to grow and be a major source of engagement. In 2018 Facebook grew by 23% on top of 2017.

Year	Likes	Percentage increase
01/01/2018	1478	23%
01/01/2017	1199	36%
01/01/2016	881	

MARATHON RUNS

Further to gaining an entry into the 2018 London Marathon, the National Tremor Foundation was delighted that its successful entrant Alan Corrigan complete the course successfully and in doing so raised £1,682 for the charity. Further runs to raise awareness of tremor & the National Tremor Foundation were completed in Liverpool, Chesterfield, Yorkshire & the Great North run.



Above: Alan Corrigan at the London Marathon.

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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 Mary's Hospital in Paddington (as shown below) is the only one in the UK. Dundee University is campaigning to get a similar machine installed at their hospital in Scotland & we were delighted to gain a £40K grant towards this campaign in July 2018. 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.

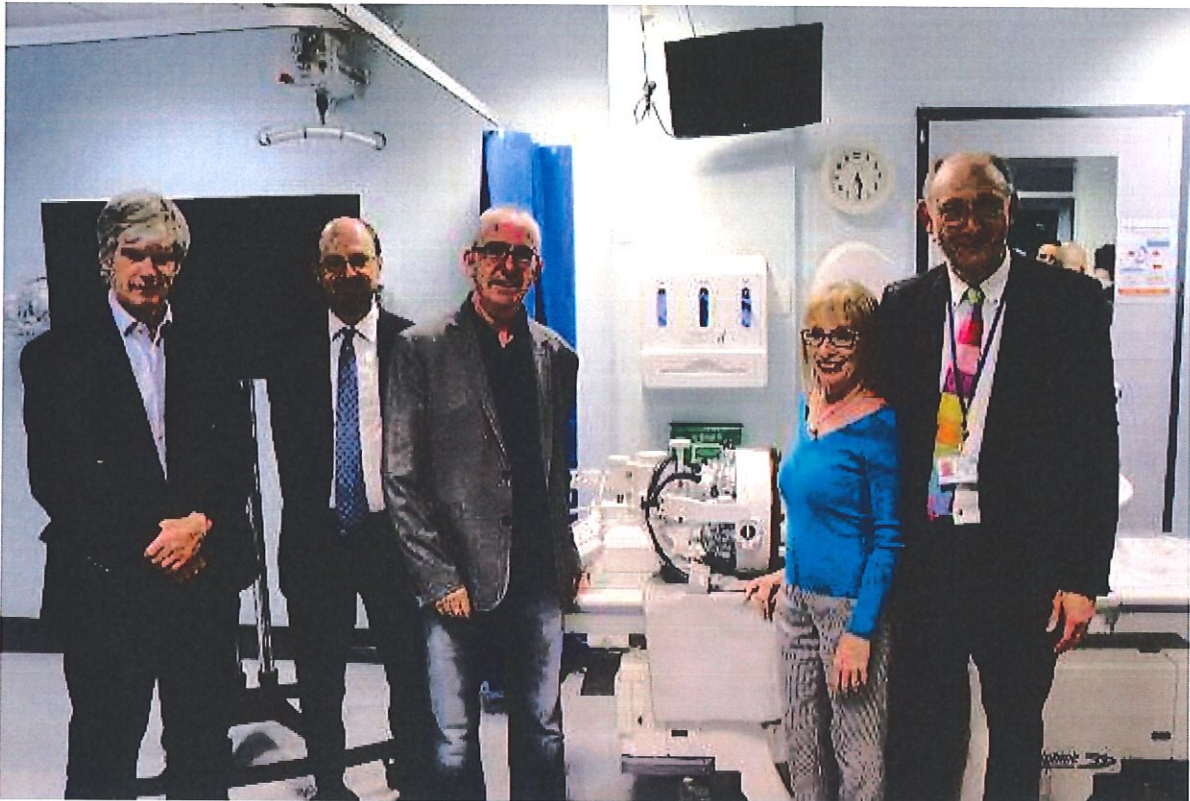
Magnetic resonance-guided focused ultrasound (MRgFUS) technology uses MRI imaging to guide high powered, focused ultrasound to a very small point.



At St Mary's Hospital in Paddington, The Tremor lifeline appeal was launched on Thursday June 21st and was attended by various members of the medical & charitable sectors including Parkinsons UK, EPDA & Insightec. The NTF were represented by chairman Kevin Harfoot, support group co-ordinator Jackie Farrell & Dr Peter Bain, consultant neurologist & founder trustee of the NTF. Dr Bain played a pivotal role in carrying out the trials and the National Tremor Foundation made a small grant available to help pay the costs of one of the researchers.

The Tremor Lifeline Appeal aims to enhance the Acute Imaging Centre at St Mary's hospital, enabling world-leading neurologists to offer the treatment to many more patients.

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(L-R) Dr Peter Bain neurologist & Trustee NTF, Ian Lush Chief Executive Imperial Health Charity, Kevin Harfoot NTF Chairman, Jackie Farrell NTF support group coordinator and Professor Gedroyc Consultant Radiologist.

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.

The treatment has now been recommended by NICE – the National Institute for Health and Care Excellence – meaning the team at St Mary's can continue their essential work.

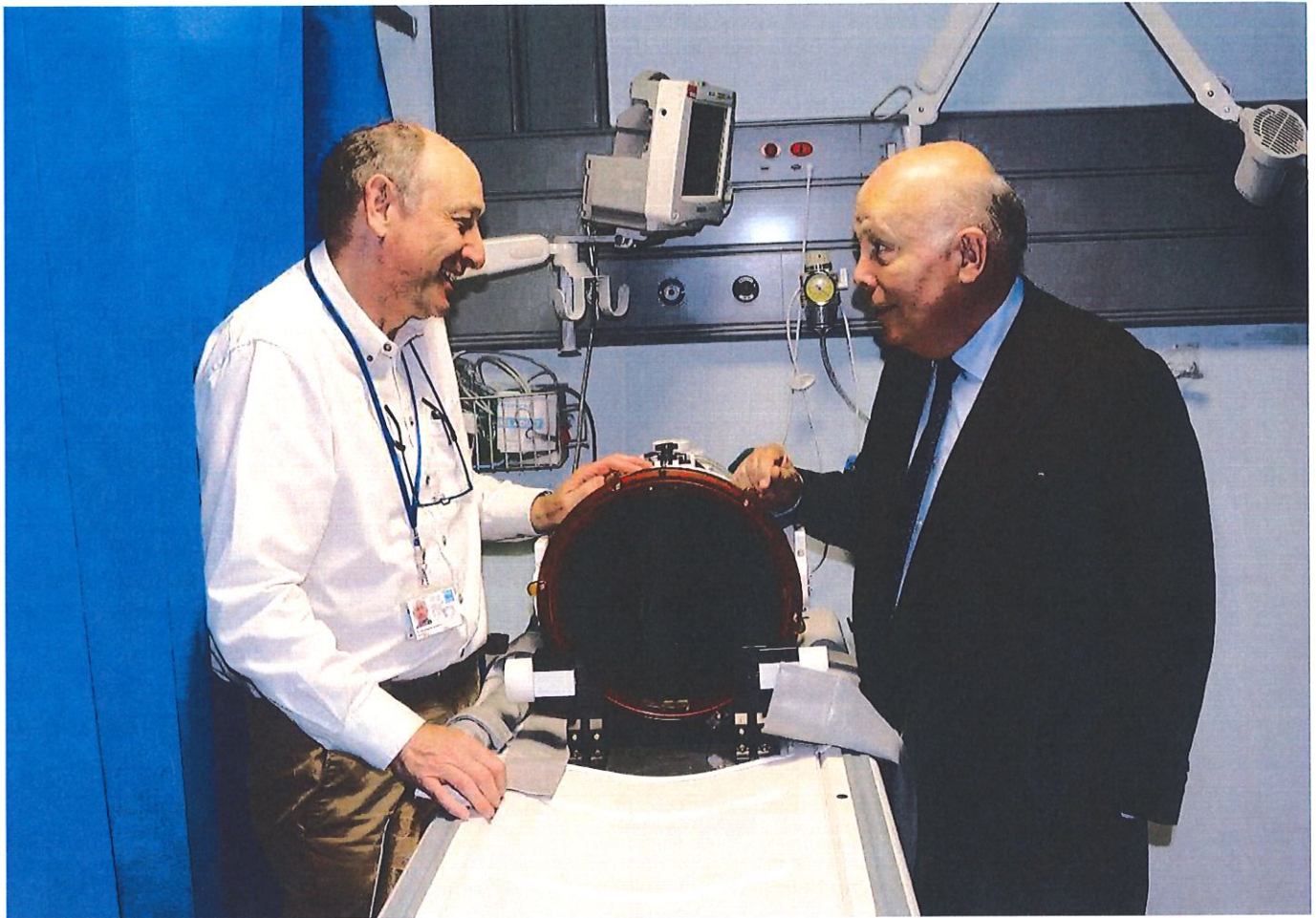
NTF Honorary president, Lord Julian Fellowes visited St Mary's Hospital in Paddington on Thursday 5th July to see for himself the work done to date in the treatment for essential tremor and to learn more about the Tremor Lifeline Appeal. Lord Fellowes was met by Professor Wladyslaw Geidroyc, consultant radiologist at St Mary's who explained the new procedure involving MRI guided focused ultrasound.

After his visit, Lord Fellowes said : "Essential Tremor is a serious disability that has been largely ignored for too long. It may, from the outside, seem trivial or even comic that a person cannot hold a cup or a glass or pour from a jug or write a postcard or tie their shoe laces or drink soup without the risk of leaving half of it down their front. But it is far from comic for the sufferer. It is distressing and degrading, a condition that makes hermits of its victims, that destroys skills and ruins social lives, and frequently results in chronic depression. The idea that there is now a real and effective treatment that works - as opposed to pills that often don't - is immensely heartening. Once this is available to the general public, it will release many, many men and women from a humiliating prison where they have been held for far too long. I speak with knowledge, for I am a sufferer. "

Having now been approved by NICE (The National Institute for Health & Care excellence), the next step is to sell it 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 as 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

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NTF were invited by NHS England onto a policy working group for Focussed Ultrasound treatment of essential tremor



Prof Gedroyc of St Marys Hospital, Paddington & NTF Honorary president Lord Julian Fellowes.

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 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.

On March 10th 2019, the National Tremor Foundation held its first ever children's support day in Sheffield, which proved a great success & was well received by those who attended.

SAFEGUARDING

As a charity we take our safeguarding responsibilities seriously. We will take all measures necessary to ensure we keep all of those associated with the NTF free from abuse and neglect. In doing so the NTF's Trustee and Children's Liaison Officer Kitty Reilly has taken on the role as the safeguarding lead person for

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the charity. Kitty brings with her a wealth of safeguarding knowledge including a MSC in Advanced Safeguarding Practice.

The NTF are aware of their ongoing responsibilities in relation to safeguarding children and adults at risk, and have an action plan in place to ensure that; there are policies and procedures in place in relation to safeguarding roles, responsibilities and how to raise a concern, all trustees to undertake safeguarding training particular to this role, safe recruitment processes are followed and that disclosure and barring (DBS) checks are undertaken where relevant etc.

Regular updates around the progress of the NTFs safeguarding action plan will be published on the website, discussed at Annual General Meetings, and has become a standing item at Trustee Meetings.

BENEFICIARY SUPPORT GROUPS

The number of support groups continued to grow and as a result 2018 saw an increase in events & exhibition stands in the UK

Support Group Co-Ordinator

Jackie Farrell had a remarkable first year as support group coordinator. As well as the long standing groups in Liverpool and Romford, six new groups have successfully started up (Cambridge, Leeds, Nuneaton, Oxford, Salisbury and Sutton). Having essential tremor herself in hands, head & legs, Jackie knows how valuable support groups are. Just being able to share experiences with others can be so beneficial. 2018 was an exceptional year for awareness days, with Jackie being invited to take part in many local community events. The NTF table attracts much interest and is great way to spread the word of essential tremor and orthostatic tremor.

The main Essential Tremor Awareness month event 2018 took place at Holiday Inn, Oxford on March 17th. Despite heavy snow which unfortunately stopped a few people from travelling, especially long distances, we still had a good turnout of 50+. BBC Radio Oxford agreed for Jackie to give an interview which they arranged to take place at BBC Wogan House in London and link up with Radio Oxford. This created much interest and resulted in listeners attending the event. Among the speakers on the day were representatives from Insightec & GyroGear.

In 2019 Jackie has been fortunate to secure a Neighbourhood Community Grant from Sutton council to arrange a local Tremor Open day. This has been booked Saturday 9th March 2019 at Holiday Inn, Sutton, Surrey. Speakers will include representatives from NTF, GyroGear & Insightec the makers of the focused ultrasound machine used for essential tremor.



Support group co-ordinator, Jackie Farrell, at one of the many events & exhibitions she attended in 2018.

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Location : Salisbury. Salisbury Shakers celebrated a successful first year in 2018. The first meeting was held in Salisbury last October, where they met for coffee and lunch. This first meeting was intended to decide where future meetings would take place and what activities members would like. Although there was a visit to Salisbury Christmas Market and a trip to the theatre, most people prefer an informal meeting where they can have some discussion and lunch together. During the year they were lucky enough to have a visit from Stuart Clarke from GyroGear who came all the way from Cambridge to one of their meetings to tell them about the development of the GyroGlove designed to minimise shaking. Four members of our group have now been to Islington to take part in the trials. Salisbury Shakers meet in St Thomas's Church in Salisbury where they kindly let them use a small room for their meeting. Usually, some relaxation and visualisation exercises are undertaken by the group, which is led by one of their members. Members come from a wide area, including Wimborne, Westbury, Warminster and Southampton, with the longest journey undertaken from Cornwall.

Location : Oxford. The major activities in Oxford in 2018 were the NTF Open Day which was held at the Holiday Inn on 17th March and a stall at the Botley Food Fayre on 15th September. The Open Day provided a great opportunity to meet people from other parts of the country and hear how other people cope and what their priorities are. The Oxford Group had a stall at the Botley Food Fayre which is held in St Peter and St Paul Church in Botley, in West Oxford which is about a mile and a half from the centre. It was a great opportunity to give away publicity and chat to people in such relaxed surroundings in order to raise awareness of the condition. The Oxford Group has met twice for brunch and to get to know each other, once in the centre of Oxford and once in the nearby town of Witney. They hope to meet up regularly in the coming year and also plan to re-visit the once a month open-air stall on the Cornmarket.

Location : Leeds. The Leeds NTF Group is growing from strength to strength, with new people frequently getting in contact via the group email. NTF Group posters are now up in Leeds NHS Trust Neurology clinics and wards & Community Centres. The group information folders have been well received and electronic links to information are available for anyone on request.



The Leeds group at their meet up in November 2018.

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Location : Cambridge. The Cambridge support Group held its first meeting on Saturday 3 November and was a great success. The support group organiser, Jamie Goodland, welcomed nine attendees from as far afield as Hertfordshire and Northamptonshire – as well as plenty of locals from the Cambridge area. They really enjoyed getting to know each other and several commented on how liberating it was to just be themselves without having to explain their tremor or worrying about how they may look with a shaking coffee cup. Stuart from GyroGear also joined the group to share the brilliant work the company has been doing in developing a gyroscopic device to make it easier for those of them with tremors to carry out everyday activities. They hadn't been expecting a physics lesson, but Stuart treated them to a fascinating explanation of the science behind the device and how the gyroscope works to stabilise certain kinds of arm tremors. Attendees also had the chance to sign up to GyroGear's trials to help get the device into action as soon as possible. This being their first meeting, they met in a coffee shop in Cambridge as they weren't sure how many people would be attending. Given how many people came, they will be booking a dedicated venue next time so that they can enjoy each other's company in a quieter, less hectic environment. Following this success of the meeting they all agreed they wanted to meet up again and planned to arrange to meet up on early 2019.



The Gyroglove is designed to increase hand stability. Mechanical gyroscopes within the glove are used to resist hand movements to allow for normal day-to-day activities.

Location : North West. The North West Tremor support group have had very well attended meetings in 2018, with an average of twelve people for each session. They have also had other people visit once or twice for advice and to meet others who suffer with tremor. In June the group had a day out and enjoyed afternoon tea together. In November they had a visit from Stuart from GyroGear to tell them about gyro glove, with several members of the group signing up for an assessment. In December the group rounded off the year with a Christmas meal at the Liner Hotel in Liverpool.

Primary Orthostatic group (POT). The Primary Orthostatic group held meetings in 2018 with the latest meeting being attended by 34 members, some of whom had travelled a long way to attend the meeting. 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 National Tremor Foundation had generously funded two 6ft promotional banners which are available to be displayed at future events. A new member to the group, Paul Elliott, is a Tai Chi and Reiki instructor and he very kindly agreed to give us a demonstration of this art, which he had adapted to enable those with orthostatic tremor to participate. Members all enjoyed discussing living with tremor whilst tasting a delicious afternoon tea of sandwiches, cakes and scones with fresh cream and jam.

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Location : Scotland. It has been a busy year for the Scottish support group. The group organised a Loch Ness cruise in May and group leader Mary Ramsey has been vocal in helping Ninewells hospital in Dundee to try get a focussed ultrasound scanner. This involved working with MSP Rhoda Grant, Matthew Walker of Insighte and Jean Freeman the Scottish Health Minister. The group leader was involved at a cross party debate in the Scottish parliament, has been a representative at an appeals tribunal; and been involved with Disabled People's Organisation (DPO) inclusion Scotland on a few different levels. In 2019 the group are arranging another Loch Ness cruise, planned for 11th May.

ANNUAL MEETING

On 16th June 2018, the National Tremor Foundation held its annual meeting at the Holiday Inn hotel in Brentwood, Essex. The event attracted speakers from Gyrogear, Insightec and a talk by Professor Chris Hawkes on a study he is carrying out on familial essential tremor & longevity of life .



Members at the annual meeting enjoying one of the various talks held during the day.

COMMUNICATIONS & 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 National Lottery Fund made a donation of £4,000 to develop more support groups around the UK, and Sutton Council made an award for an Awareness Day in Sutton. A grant of £40,000 was given to assist the purchase of a new ultrasound machine at Dundee University Hospital.

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. 2019 will present another challenge ,but every effort will be made to continue with fund raising.

PLANS FOR FUTURE PERIODS

The Trust's main priority in 2019 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.

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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 gallery of events & meetings already held. It is our hope that the E:Newsletter re-introduced in December 2017 will continue to be produced at regular quarterly intervals.

In 2019 the National Tremor Foundation will be getting involved in a policy working group with NHS England with the aim of getting focussed ultrasound recognised as a treatment for unilateral essential tremor. We will also assist Gyrogear in a partnership that will apply for grant funding for Gyrogear's latest project that will aim to see the Gyroglove assist people with essential tremor perform daily routine tasks.

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 2018 reached £104,031 (an increase on the prior year total of £44,167) thanks primarily to donations from various trusts. Of this total, £56,249 was restricted funding with £40,000 designated to help fund a MRI guided scanner for focussed ultrasound at Dundee's Ninewells hospital. With membership free, we encouraged members to voluntarily donate. Fundraising pages established on Virginmoneygiving raised £2,936 in 2018 thanks to efforts in the London Marathon, Great North Run, & Liverpool Rock & Roll run. The Foundation also received a £4,000 grant from the National Lottery for the purpose of developing its support group network.

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 spend of £101,984 (an increase on the prior year spend of £59,403) but included a £40,000 payment from a restricted fund to Ninewells hospital in Dundee. This resulted in a small surplus for the Foundation of £2,358 (prior year: deficit of £15,235).

The Imperial College research grant constitutes a designated fund of £11,108 with £6,930 still available to the College.

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 £64,091 (previous year £66,275); this level of holding gives a sound base for considering increased research activity.

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REFERENCE AND ADMINISTRATIVE DETAILS

Trustees

- at date of report's approval:

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	Solicitor/Legal Advisor

Registered Office

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

Bankers

National Westminster Bank

Independent Examiner

Frank Learner
Greengage Associates
8 Ffordd Cwm Cidi, Barry
Vale of Glamorgan CF62 6LH

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.

National Tremor Foundation Charitable Trust
Trustees' Annual Report for the Year Ended 31 December 2018

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 6 July 2019 and signed on their behalf by:

A handwritten signature in black ink, appearing to read 'K Harfoot', written in a cursive style.

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 2018, which are set out on pages 16 - 20.

Responsibilities and basis of report

As the trustees 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.



Frank Learner DChA
Fellow, Association of Charity Independent Examiners

Greengage Associates
8 Ffordd Cwm Cidi
Barry, Vale of Glamorgan CF62 6LH

6 July 2019

National Tremor Foundation Charitable Trust

Statement of Financial Activities for the Year Ended 31 December 2018

	Notes	Unrestricted funds £	Restricted funds £	Total for year	
				2018 £	2017 £
Income from:					
Donations and legacies					
Donations		10,422	249	10,671	12,674
Grants		37,670	56,000	93,670	31,494
Total Income		<u>48,092</u>	<u>56,249</u>	<u>104,341</u>	<u>44,168</u>
Expenditure on:					
Raising funds	2	20,393	179	20,572	21,478
Charitable Activities					
Information		19,776	10,730	30,506	30,657
Research		1,888	40,009	41,897	666
Beneficiary Support		8,219	790	9,009	6,602
Total Resources Expended		<u>50,276</u>	<u>51,708</u>	<u>101,984</u>	<u>59,403</u>
Net movement in funds		(2,184)	4,541	2,357	(15,235)
Reconciliation of funds					
Total funds brought forward		<u>73,205</u>	<u>5,592</u>	<u>78,797</u>	<u>94,032</u>
Total funds carried forward		<u>71,021</u>	<u>10,133</u>	<u>81,154</u>	<u>78,797</u>

National Tremor Foundation Charitable Trust

Balance Sheet as at 31 December 2018

	Notes	31 December 2018		31 December 2017	
		£	£	£	£
Current assets					
Debtors	5	-		1,035	
Cash at bank		<u>92,345</u>		<u>88,762</u>	
		92,345		89,797	
Creditors: Amounts falling due within one year	6	<u>(11,191)</u>		<u>(11,000)</u>	
Net current assets/(liabilities)			81,154		78,797
Net Assets			<u>81,154</u>		<u>78,797</u>
Funds					
Unrestricted income funds	7		71,021		73,205
Restricted income funds	8		<u>10,133</u>		<u>5,592</u>
			<u>81,154</u>		<u>78,797</u>

Approved by the trustees on 6 July 2019 and signed on their behalf by:



Kevin Harfoot
Chairman

The notes on pages 18 to 20 form part of these financial statements.

National Tremor Foundation Charitable Trust
Notes to the Financial Statements for the Year ended 31 December 2018

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 2018

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	2018	2017
	£	£	£	£	£
Cost of Generating Funds	751	12,265	7,557	20,573	21,478
Charitable Activities					
Information	8,435	18,785	3,286	30,506	30,657
Research	41,376	-	520	41,896	666
Beneficiary Support	5,359	1,939	1,711	9,009	6,602
Total Resources Expended	55,921	32,989	13,074	101,984	59,403

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

3 SUPPORT COSTS	Raising Funds	Info	Research	Beneficiary Support	2018	2017
	£	£	£	£	£	£
Governance	3,686	1,175	168	1,007	6,036	7,216
Communications	1,780	971	162	324	3,237	3,551
Office	2,090	1,141	190	380	3,801	3,472
Total Support	7,556	3,287	520	1,711	13,074	14,239

Costs are apportioned by the estimated percentage of time spent on each activity. Governance costs comprise: contractor £2,672 (prev yr £2,969), independent examination £ 645 (py £645), other services from independent examiner £690 (prev yr £690) and trustee-related expenses £2,028 (py £2,912).

4 OTHER TRANSACTION INFORMATION

2017 income was £44,168; the only restricted element was £2,794 for grants; 2017 expenditure was £59,403 - the only restricted elements were £415 for information and £442 for beneficiary support.

The charity does not employ any staff and relies on 2 contractors for office and website duties.

Four trustees were directly re-imbursed for travel expenses totalling £853 (previous year: 4 trustees £448). Expenditure attributable collectively to services for trustees (room-hire etc) was £1,175 (prev year £2,464).

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	2018	2017
	£	£
Prepayment	-	1,035
Total debtors	-	1,035

National Tremor Foundation Charitable Trust

Notes to the Financial Statements for the Year ended 31 December 2018

6 CREDITORS	2018	2017
	£	£
Trade creditors	2,995	2,804
Accruals	1,335	1,335
Other creditors	6,861	6,861
Total creditors	<u>11,191</u>	<u>11,000</u>

7 UNRESTRICTED FUNDS	1 Jan 2018	Income	Spend	31 Dec 2018
	£	£	£	£
General	66,275	48,092	50,276	64,091
Designated: Imperial College Grant	6,930	-	-	6,930
	<u>73,205</u>	<u>48,092</u>	<u>50,276</u>	<u>71,021</u>

8 RESTRICTED FUNDS	1 Jan 2018	Income	Spend	31 Dec 2018
	£	£	£	£
Orthostatic Tremor Group	-	249	249	-
Video Production	1,000	-	-	1,000
Yorkshire	660	-	127	533
Support Group/Helpline	2,766	-	-	2,766
Youngsters	1,166	-	-	1,166
Ultrasound Research	-	1,000	-	1,000
Constance Travis Trust	-	50,000	50,000	-
National Lottery	-	4,000	332	3,668
Rainford	-	1,000	1,000	-
	<u>5,592</u>	<u>56,249</u>	<u>51,708</u>	<u>10,133</u>

The Orthostatic Tremor funding is for the group's running costs. The video production funding is for an advice video on undergoing tremor-related surgery. The Yorkshire funding 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 from the George A Moore Foundation. The Constance Travis funding is £40,000 for a scanner for Dundee Hospital and £10,000 for website maintenance. The Lottery funding is for UK Support Group development. The Rainford funding is for the helpline service.

9 FUND/ASSET ANALYSIS	Unrestricted funds		Restricted funds	2018 total funds	2017 total funds
	General	Designated	funds	total funds	total funds
	£	£	£	£	£
Net current assets	64,091	6,930	10,133	81,154	78,797
	<u>64,091</u>	<u>6,930</u>	<u>10,133</u>	<u>81,154</u>	<u>78,797</u>