THE NEUROFIBROMATOSIS ASSOCIATION

England & Wales · Charity number 1078790

Details

Other names	NFA, THE NEURO FOUNDATION, Nerve Tumours UK
Status	Registered
Legal form	Charitable company
Company number	03798407
Registered	2000-01-05
Register	View on the Charity Commission register

Contact

Address	First Floor 44 Coombe Lane London SW20 0LA
Phone	02084391234
Email	info@nervetumours.org.uk
Website	www.nervetumours.org.uk

Activities

Objects: TO RELIEVE PERSONS SUFFERING FROM NEUROFIBROMATOSIS.

Activities: The charity's mission is to enable people concerned about neurofibromatosis to find solutions appropriate for them.

Classification

- **How:** Provides Human Resources, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Charities Or Voluntary Bodies, The General Public/mankind

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Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-10-31	£555,411	£548,010	£656,018	6
2024-10-31	£487,431	£485,887	-	-
2023-10-31	£456,409	£424,665	-	-
2022-10-31	£512,516	£448,334	£615,329	5
2021-10-31	£397,174	£390,589	-	-
2020-10-31	£325,236	£330,724	-	-

Trustees

Name	Role	Appointed
Richard Eric Greenway Goode	Chair	2015-11-28
Alexis Rohan Chanmugam		2020-06-08
Dr Sheelagh Harwell		2026-06-01
Jeremy Howard Bogush		2026-06-01
Jonathan Peter Bruce		2020-06-08
Matthew William Buchan Jones		2021-06-14
Professor Meena Upadhyaya		2021-06-14
Professor Rosalie Elaine Ferner		2017-06-17

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THE NEUROFIBROMATOSIS ASSOCIATION

England & Wales - Charity number 1078790

Accounts

The Neurofibromatosis Association

Report of the Board of Trustees

Year ended 31 October 2025

Charity Registration Number 1078790
Scottish Charity Registration Number SC045051
Company Registration Number 03798407

The Neurofibromatosis Association
Report and Financial Statements
Year Ended 31 October 2025

Reference and administrative information

Charity Name:	The Neurofibromatosis Association
Charity Registration Number:	1078790
Scottish Charity Registration Number:	SC045051
Company Registration Number:	3798407
Charity Working Name:	Nerve Tumours UK
Registered office and operational address:	44 Coombe Lane West Wimbledon London SW20 0LA
Telephone:	020 8439 1234
E-mail address:	info@nervetumours.org.uk
Website address:	www.nervetumours.org.uk

Nerve Tumours UK

Nerve Tumours UK is the working name of the charity, which retains its legal name "The Neurofibromatosis Association".

Board of Trustees
The current Board of Trustees is:

Richard Goode (Chair)
Michael Fry
Professor Rosalie Ferner
Jonathan Bruce (Vice Chair)
Rohan Chanmugam
Professor Meena Upadhyaya
Matthew Jones

Senior Management Personnel
The Trustees delegate day-to-day management of the charity to:
Karen Cockburn, Charity Director

Patrons
Gillian Anderson
Simon Callow
Thomas Young
Prof. D.Gareth Evans

Ambassadors
Emily Owen
Georgia Baum
Amit Ghose

Independent Auditors
David Howard Chartered Accountants
1 Park Road
Hampton Wick
Kingston - upon - Thames
Surrey
KT1 4AS

Bankers
National Westminster Bank Plc
5 Market Place
Kingston - upon - Thames
Surrey
KT1 1VX

The Neurofibromatosis Association
Report and Financial Statements
Year Ended 31 October 2025

Board of Trustees Report for the Year Ended 31 October 2025

The Trustees of The Neurofibromatosis Association, trading as Nerve Tumours UK (NTUK), are pleased to present their annual report and financial statements for the year ended 31 October 2025.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, Trustee Investment (Scotland) Act 2005, the charities Accounts (Scotland) Regulations 2006 (as amended), the Memorandum and Articles of Association, and the Charities Statement of Recommended Practice ("Charities SORP") (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland; FRS 102) effective from 1 January 2019.

Objectives and Activities

Nerve Tumours UK's vision sees a future in which the needs of everyone with NF are met, and the charity is central to making that happen.

To allow the charity to deliver this vision of helping to improve the lives of those affected by NF, the group medical name for Neurofibromatosis Type 1 (NF1), NF2-related-Schwannomatosis (NF2) and Schwannomatosis (SWN), and in being central to making this happen, we work in collaboration with the Highly Specialised Commissioning Services, formerly the National Commissioning Group (NCG) funded service, other associated medical professional and educational establishments around the UK, and also in collaboration with wider international partners.

Nerve Tumours UK's mission is to improve the lives of everyone affected by NF through support services, advocacy and promoting understanding and knowledge of the condition.

Central to our mission, is our ambition to be the UK's authoritative voice on NF and our determination to serve, support and celebrate the lives of people impacted by the condition, and their wider support network.

The charity continues to deliver its mission through five key services to members, supporters, and beneficiaries. It endeavours to:

- **Inform** — We provide accurate, relevant, and up to date information that explains the conditions of NF1, NF2 and SWN, the implications, challenges and opportunities, in language understood by all.
- **Advise** — We provide practical and emotional advice to help people find the best services and support available. We enable people to make choices about how they approach and live with NF.
- **Advocate** — We aim to increase knowledge, awareness and understanding of NF, and will campaign for change in areas we believe will improve the lives of those affected by NF.
- **Connect** — We take a pivotal role in bringing together groups of people interested in NF to maximise the support and information available to them.
- **Fund** — We make funds available for small projects to bodies and patient groups where we believe it will make a difference in terms of awareness, understanding & quality of life.

The charity works with the following groups to achieve its mission:

- Patients and carers
- Families with NF
- The medical community
- The NF Specialist Network of Nurses and Advisors
- The research community (particularly The Nerve Tumours UK Medical Advisory Board)
- Leading UK Universities

- NTUK Sponsored PHD researchers
- Supporters
- Volunteers
- Other charities and umbrella organisations

Overview: Achievements and Performance

Service

We fund a unique and vital service, which is not provided by any other organisation. Our services are particularly important for people diagnosed with NF, their families and carers. Many people with NF are vulnerable and often isolated.

A lasting legacy of the Covid pandemic is the NF community's ongoing fear of attending hospital appointments and large scale events, as people are more susceptible to the virus due to the associated complications of NF. This impacts on both the care that they receive, and the charity's community fundraising capabilities.

There is still a significant backlog of appointments for genetics and neurology clinics. This was initially caused by reduced NHS staffing in 2020 and subsequent years, as many had been redeployed to critical and Covid services, but was made far worse by the continuing NHS strikes over the last couple of years, and the length of time it currently takes to fill NHS vacancies. The charity is extremely concerned about the ongoing potential impact on mental health both for our beneficiaries and our staff, due to workload as our services continue to face increased demand.

This increased demand is due to both the economic climate and the resulting absence or difficulty in obtaining primary and secondary care services. Some services are still provided virtually or by telephone consultation which cause immense problems for people with NF, who either do not have the facilities to join virtual appointments, or due to cognitive issues will lack the capacity to organise and engage.

In response, the charity has continued to provide and grow services to ensure that we can reach and support our beneficiaries, in any way possible. Due to this ongoing situation in the wider care sector, the charity took the decision to expand the National NF Helpline service from two to three days per week from the end of 2022, and now also operates a triage booking system on the intervening days. We will continue to monitor demand to ensure the service meets the needs of the community, and adapt as funds permit.

The charity continues to concentrate on its central five services. We have also continued working to strengthen and develop our core support structures to ensure that we maintain the best possible support and advise services for anyone affected by NF. We are constantly in negotiations with NHS trusts around the UK, discussing how we can roll out our support services in the most economic and efficient manner possible.

Funding

As the charity does not receive statutory or local authority funding, the bulk of the charity's income comes from charitable giving and monies raised from events. Fortunately most major events, except for RideLondon, have returned to the calendar, however the community's ongoing fear of mixing, means that community small scale fundraising has all but disappeared. This has had a significant adverse effect on income streams.

As we fund a network of Specialist NF Nurses and Advisors (Specialist Advisors), our policy requires us to maintain a minimum of 12 months of reserves. The charity continues to react quickly to the constraints placed on it by the current economic climate, and by the latest large public sector pay awards, and the increase in National Insurance Contributions. This has minimised the impact on the level of reserves held over the last few financial years, and at this time, we are confident that we are able to continue to maintain our reserves policy.

Plans for Future Sustainability

Post pandemic, the charity was forced to reconsider our strategic plan, and the Board implemented a strategy group, which continues to look at how the charity can provide and expand its services, in this very testing economic climate, when demand for our services have increased dramatically, alongside the huge hike in delivering our services.

Key Strategic Aims

The charity's key strategic aims continue to be:

- Increase awareness and understanding of NF, particularly amongst medical professionals.
- Provide timely and meaningful support and guidance to those living with NF and their wider support network.
- Promote and support research into NF.

Our focus continues to be on how we can streamline, yet expand, our services; co-ordinate our work with all partners including research bodies; and improve the education of the medical profession.

In a survey during the reporting period:

93% of respondents wanted us to continue to raise awareness of NF conditions with the medical profession.

Our aim is to ensure that people are able to access accurate and timely advice and support as effectively and efficiently as possible, whether or not that is from the charity. The charity's staff and medical network continue to promote the new medical hub on our website, which gives easy access to lectures, guidelines and other relevant tools to educate wider allied healthcare professionals.

The charity also strives to find new ways of working, including virtual clinics, appointments and meetings. Although online services are not practical for all (for example, patients with cognitive impairment and learning issues), we can see that improved online connectivity and familiarity leads to reduced delivery costs and greater efficiency. In the future our intention is that a balance of online and in person delivery will allow the charity to provide services to more people.

Specialist Support Network

The charity will continue to maintain its Specialist Support Network of Nurses & Advisors (Specialist Advisors) and continue to seek to identify areas of the country where we can engage and work with the NHS to make joint appointments.

The charity currently funds a network of ten Specialist Advisors across the UK, supporting posts in Newcastle, Birmingham (2), Plymouth (2), Liverpool, Southampton, Sheffield, Leeds, and Wales, and has an association with Northern Ireland. Unfortunately, the post in Scotland is still vacant, as despite our best efforts to engage with the clinical community, there appears to be a blanket ban on recruitment in the region and as an interim, we are continuing to work closely with the Scottish Office for Rare Diseases, and the National Helpline works closely with Clinical Genetics at the Queen Elizabeth University Hospital based in Glasgow. We envisage that the Bristol post, after several years in the planning, will be up and running in 2026.

Two Specialist NF Nurses operate the Nerve Tumours UK National Helpline on a part time basis, which provides advice and connects people affected by NF with relevant practical help, either in their community, or in clinic, across three days of the working week. On interim days, the head office staff operate a triage helpline, booking in appointments or referring to regional Specialist NF Nurses.

We aim to introduce five new posts during the next financial year in parts of the UK, where there has never been any regional support. However, this timescale totally depends on the effectiveness of the internal mechanisms of the individual NHS trusts, which can become long and wieldy processes. Each of our current posts supports

between 180 – 3,420 patients per year working via clinics, home visits, school meetings, workplace meetings, advisory services, and telephone consultations.

The role of Specialist Nurses/Advisors is very diverse. We have had excellent feedback from the families supported by our team and it is plain to see that for those families, the support they receive from the Specialist Support Network is pivotal in helping them to cope with NF.

In a recent survey complied during the reporting period:

70% of the NF community wanted the charity to increase the availability of support by having more Specialist Nurses and Advisors.

Funding, and expanding, the Specialist Support Network will continue to be the key role for Nerve Tumours UK.

Over 60% of patients with NF1 have learning difficulties, and approximately 30% are registered as disabled, as are 75% of those patients diagnosed with NF2. However, awareness of NF across all professions including the medical profession, is low. Our experience is that this can lead to some children with NF struggling at school, with inappropriate, or non-existent support.

Nerve Tumours UK offers a schools' advisory service, iNForm, operated by our Specialist Support Network. Where engaged, the team works closely with teachers, SENCO's, allied healthcare professionals, and parents, supporting tailored learning plans, and suggesting mechanisms for enhancing the child's experience at school. As a result of the pandemic, we have found that we can still operate iNForm effectively, albeit virtually, and in the years since we have found that more allied healthcare professionals are willing and able to join the iNForm meetings if they are held virtually.

Nerve Tumours UK continues to offer an extensive range of literature and information, for lay people, which is also widely used by allied healthcare professionals across the UK, and further afield. Our leaflets and pamphlets are subject to constant review and update.

We continue to expand our iNForm programme, helping those diagnosed with NF to reach their goals, with a successful and well received launch of the "iNForm Your University" project.

We continue to raise awareness amongst the wider medical professionals community, at every opportunity, be it our Specialist Advisors giving talks to local groups or members of the Head Office Senior Management Team attending national conferences. Medics are invited to use the Nerve Tumours UK National Helpline as required and to subscribe to the on-line Medical Hub.

Charity Reach

The Nerve Tumours UK Head Office team continue to work exceptionally hard, going above and beyond in response to the fallout from the last few years, and the Board are again very grateful for their efforts. Key workstreams include the constant development of our website, in particular the medical section, the research hub, and the collaborative useful organisations section. We received extremely positive feedback on, and after, the launch of the medical section, and have seen how this improves and widens our engagement with medical professionals, particularly GP's.

Social media remains an important and growing aspect of the charity's communications and marketing strategy, and we continue to see healthy website traffic, despite an increasingly challenging digital landscape. Dedicating ongoing time and resource to these areas ensures that we meet our communications goals of serving the community, supporting the community and raising awareness of and within the community.

Facebook remains our biggest social media channel with strong engagement. Throughout the financial year, our updates received just under 4 million views, while we also saw more interaction and engagement from our followers with a 60% increase on the previous year. Our total following grew by 4.5% and now sits just short of 8, 500. Our other primary social media channel is Instagram, where visual storytelling takes a greater role, giving us the opportunity to share and showcase the real-life stories of our beneficiaries. Our following there exceeded 2,400 and throughout the year we reached just under 138,000 people.

We also host a private NF Community Group on Facebook, of circa 1,600 members, where patients or their carers can talk, ask questions and share experiences in a safe space.

Through the year, our website received over 181,500 views from almost 52,500 users, while the number of subscribers to the monthly Nerve Tumours UK e-newsletters grew to circa 3,475.

During World NF Awareness Week in May 2025, we saw major high points in our yearly engagement totals: through the respective NF1 and NF2 days; the annual Shine A Light campaign, which saw 176 strategic building and landmarks light up in blue in support; and our annual digital media campaign. This year's campaign grabbed public attention with a cheeky and thought-provoking question, "Do Charity Ads Get On Your Nerves?", raising awareness of NF in multiple strategic locations by running across 25 major rail hubs, and reaching a footfall of some 2.3 million people. A campaign running in parallel on FaceBook and YouTube reached over 970,000 users with 1,150,000 plus impressions, and resulted in 531 link clicks on the campaign. The adverts have also seen 49,000 plus, post engagements.

We also continue to seek to develop and strengthen our institutional partnerships with organisations including The Centre for Appearance Research, The Genetic Alliance, and The Neurological Alliance. We have another medical information day planned for 2026, which will be both in-person and live-streamed, to reach as many of the community as possible.

The continued rollout of core services throughout the period is an excellent reflection of the combined efforts and dedication of the Specialist Network of Nurses/Advisors, our members, supporters, head office staff and the Medical Advisory Board, and the Trustees are very grateful for the exceptionally hard work, which has been put into the charity.

There are no immediate financial concerns for the charity, although the current economic climate and upheaval remains of concern. The trustees maintain that Nerve Tumours UK is still currently on track to meet its long-term strategic and financial targets.

Structure, Governance and Management

Nerve Tumours UK is a Charitable Company, limited by guarantee, incorporated on 30 June 1999, and registered as a charity on 5th January 2000 (previously 284653 registered 1982) with a membership base. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required by the adopted Constitution to contribute an amount not exceeding £1.

The directors of the company are also charity trustees for the purposes of charity law, and under the company's Articles are known as members of the Board of Trustees. The Board of Trustees meets at least four times a year and is responsible for the strategic direction and policy of the charity and appointing auditors to ensure financial compliance. Medical input is given via our Medical Advisory Board, a representative of which sits on the Board of Trustees. Trustees are selected for their knowledge of NF and the various professions, that optimize the knowledge and ability of the Board.

A sub group of the Board of Trustees, the Financial Advisory Group, and including the Charity Director, has been established to consider and monitor the financial and investment activities of the charity.

Medical Background

The charity's membership is mostly drawn from families affected by NF. NF1 affects 1 in every 2,500 people worldwide, which means that there are more than 25,000 in the UK; NF2 is much rarer, with 1 in 35,000 affected worldwide, with 1,000 in the UK, and there are approximately 500 people diagnosed with SWN.

An affected person of either sex has a 1 in 2 (50:50) chance of passing the altered (abnormal) gene on to their children. However, everyone has a risk of having an affected child because 50% of all those affected by NF are the first person in their family to be so affected.

NF1 is a hugely variable condition, which has the potential to develop a large number of complications. Some people with NF1 only having skin involvement, but potential complications include: specific learning difficulties and behavioural problems - which affects about 60% of all people with NF1; high blood pressure (hypertension); curvature of the spine (scoliosis); malformation of the long bones (below the knee and below the elbow) (pseudarthrosis); large benign skin tumours (plexiform neurofibromas); tumours on the nerves of sight (optic glioma); internal, spinal and brain tumours – which are usually benign however 10-15% of people will develop a malignant tumour related to their NF1. The most significant issue for people with NF1 is that the occurrence of these complications cannot be predicted even within families. Many people with NF1 also have low self-esteem and this can cause problems forming friendships, which leads to isolation.

NF2 consistently causes more problems than NF1, and it has an increased risk of developing brain tumours. Although these tumours are benign, the position in which they grow can cause major problems. The most common site is on the hearing and balance nerves causing problems with deafness and coordination. The sense of isolation from deafness onset in adulthood can be immense. People with NF2 may also develop spinal cord tumours, with their own significant complications.

NF is an unpredictable and variable genetic condition that can affect all people regardless of gender, race or age. During their lifetime, patients may see a wide range of health and social care professionals, both in community and hospital settings. The Specialist Advisors act as a point of reference for families helping them navigate through routine planned events and at times of crisis. Essentially, their role is to help people to learn to live with their diagnosis of NF and to equip them with the knowledge of when, where, and how to seek help, if necessary.

As a multi-system condition, NF has an impact on many areas of people's lives, not just health. The Specialist Advisors take a lead role in liaison and advocacy with health, education, and social services to support the quality and continuity of care for families affected by NF. They seek to develop a service that is professional, timely and responsive to need. Their setting may be clinical, visiting families at home or telephone contact. The quality of the relationships they establish is critical to their effectiveness and may continue over many years.

Financial Review

Income Generating Activities

Our head office team continue to develop innovative virtual fundraising ideas and source new income streams at every opportunity. During the period the charity had income resources of £555,411 and a total expenditure of £548,010, resulting in net resources of £7,401.

This has resulted in total funds of £656,018 being carried forward. Of this figure £28,681 is restricted to projects as specified by the terms and conditions of certain donations.

Investment Policy

The charity's funds have been invested in a mixture of one year fixed income bonds and short-term deposits this financial year. The Financial Advisory & Investment Group, established in late 2022, reporting to the Board of Trustees, continue to review this position and further investment opportunities, to ensure all income potential is maximised, with minimum risk.

We give careful consideration as to how we can make our reserves generate an income for the charity and have considered a number of options and informal advice. At present, given the current rate of return, the costs involved in investing, and the inherent risk, we have continued to elect to hold the reserves in a mixture of short and medium term deposits with a number of banks. However, we continue to monitor all other options available.

Reserves Policy and Going Concern

Reserves are needed to bridge the gap between the spending and receiving of income and to cover unplanned emergency expenditure. The Trustees consider a minimum of £500,000 is the ideal level of reserves and being sufficient unrestricted reserves to fund the Specialist Support Network for a minimum of twelve months due to the

number of multi-year contractual commitments; and the charity's administrative and operating costs for at least six months.

The Trustees consider that adequate resources continue to be available to fund the activities of the charity for the foreseeable future. The Trustees are of the view that the charity is a going concern.

Key Expenditure Areas

The key areas of expenditure continue to be the operational costs of the Specialist Support Network of Nurses & Advisors. Each year, we aim to raise sufficient funds to maintain the twelve months' reserves. If the charity provides further funding for the Specialist Network, this expenditure, and the required level of reserves, is likely to increase.

Public Benefit

All our charitable activities focus on improving the lives of those affected by NF and are undertaken to further our charitable purposes for public benefit. The Trustees have regard to the Charity Commission's guidance on the need for charities to deliver a public benefit and have complied with the duty in section 17(2) of the Charities Act 2011.

Recruitment, Appointment & Induction of Board of Trustees

Under the requirements of the Memorandum and Articles of Association, the one-third longest standing members of the Board of Trustees shall retire or put themselves forward for re-election at the next Annual General Meeting. The maximum time a trustee can remain in post is ten years, although that time may be extended for a short period by the Board on an exceptional basis.

The Board of Trustees seeks to recruit a diverse mix of business, medical and patient expertise, although preferred, there is no requirement for a Board member to have any direct or indirect experience of NF. All Trustees, upon election, meet with the Chair to discuss and agree specific requirements of the role.

Statement of Trustees responsibilities

The Trustees, who are also the directors of the Neurofibromatosis Association for the purpose of company law, are responsible for preparing the Trustees Report and the financial statements in accordance with FRS102 and the charity SORP (FRS 102). The Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity at the end of the financial year and of its surplus or deficit for that period. In doing so, the Trustees are responsible for:

- selecting suitable accounting policies and then apply them consistently;
- observing the methods and principles in the Charities SORP;
- making judgements and estimates that are reasonable and prudent;
- preparing the financial statements on the going concern basis unless it is not appropriate to assume that the company will continue on that basis; and
- the maintenance and integrity of the corporate and financial information included on the charity's website.

The Board of Trustees is responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time that the financial statements comply with the Companies Act 2006. The Board of Trustees is also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Members of the Board of Trustees

Members of the Board of Trustees, who are directors for the purpose of company law, and Trustees for the purpose of charity law, who served during the year and up to the date of this report, are set out on page 1.

Auditors

David Howard was appointed as auditor under section 145 of the Charities Act 2011 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

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

- there is no relevant information, being information needed by the auditor in connection with preparing their report, of which the auditor is unaware; and
- the Trustees, having made enquiries of fellow Trustees and the charity's auditors that they ought to have individually taken, have each taken all steps that he/she is obliged to take as a Trustee in order to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

Small company provisions

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

Approved by the Board of Trustees on 10 February 2026, and signed on its behalf by:



Richard Goode
Chair of the Board of Trustees
& Company Secretary



Jonathan Bruce
Vice Chair

Independent Auditors' Report to the Trustees of The Neurofibromatosis Association (Nerve Tumours UK)

We have audited the financial statements of The Neurofibromatosis Association for the year ended 31st October 2025, set out over pages 14 to 25 in this report, which comprise the statement of financial activities, the balance sheet and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019) – (Charities SORP (FRS 102).

Opinion on the financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31st October 2025, and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least 12 months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other Information

The other information comprises the information included in the annual report, including the Trustees' report, other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' Annual Report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report.

We have nothing to report in respect of the following matters where the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- adequate and proper accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us;
- the financial statements are not in agreement with the accounting records and returns;
- certain disclosures of Trustees' remuneration specified by law are not made, or
- we have not received all the information and explanations we require for our audit.
- the Trustees were not entitled to prepare the financial statements and the Trustees' report in accordance with the small companies' regime.

Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities statement set out on page 2 to 9, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the company or to cease operations, or have no realistic alternative but to do so.

Auditors' responsibilities for the audit of the financial statements

We have been appointed as auditor under section 145 of the Charities Act 2011 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The

extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Our approach to identifying and assessing the risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, was as follows:

- the engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities and skills to identify or recognise non-compliance with applicable laws and regulations;
- we identified the laws and regulations applicable to the company through discussions with Trustees and other management, and from our commercial knowledge and experience of the charity sector;
- we focused on specific laws and regulations which we considered may have a direct material effect on the financial statements or the operations of the company, including such as the Charities Act 2011, taxation legislation, data protection, anti-bribery, and health and safety legislation;
- we assessed the extent of compliance with the laws and regulations identified above through making enquiries of management and inspecting legal correspondence; and
- identified laws and regulations were communicated within the audit team regularly and the team remained alert to instances of non-compliance throughout the audit.

We assessed the susceptibility of the company's financial statements to material misstatement, including obtaining an understanding of how fraud might occur, by:

- making enquiries of management as to where they considered there was susceptibility to fraud, their knowledge of actual, suspected and alleged fraud;
- considering the internal controls in place to mitigate risks of fraud and non-compliance with laws and regulations; and
- To address the risk of fraud through management bias and override of controls, we:
- performed analytical procedures to identify any unusual or unexpected relationships;
- tested journal entries to identify unusual transactions;
- assessed whether judgements and assumptions made in determining the accounting estimates set out in Note 16 were indicative of potential bias; and
- investigated the rationale behind significant or unusual transactions

In response to the risk of irregularities and non-compliance with laws and regulations, we designed procedures which included, but were not limited to:

- agreeing financial statement disclosures to underlying supporting documentation;
- reading the minutes of meetings of those charged with governance;
- enquiring of Trustees as to actual and potential litigation and claims;
- reviewing correspondence with relevant regulators

There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the directors and other management and the inspection of regulatory and legal correspondence, if any. Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities]. This description forms part of our auditor's report.

Other matters which we are required to address

In the previous accounting period, the trustees of the charity took advantage of audit exemption under Section 477 of the Companies Act 2006. Therefore, the prior period financial statements were not subject to audit.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of part 16 of the Companies Act 2006, and to the charitable company's Trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members and Trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone

other than the charitable company and, the charitable company's members as a body and the charitable company's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Binod Dongol FCCA (Senior Statutory Auditor)
For and on behalf of David Howard, Statutory Auditor

1 Park Road
Hampton Wick
Kingston Upon Thames
Surrey
KT1 4AS

Date: 23 February 2026

Statement of Financial Activities (including Income & Expenditure Accounts) for the Year ended 31 October 2025

	Notes	Unrestricted funds 2025	Restricted funds 2025	Total funds 2025	Total funds 2024 Unaudited
		£	£	£	£
Incoming Resources from Generated Funds					
Donations & Legacies	2	354,303	118,353	472,656	402,954
Income from Charitable Activities	2	52,123	1,730	53,853	71,163
Investment Income	2	28,902		28,902	13,314
Incoming Resources from Charitable Activities		**435,329**	**120,083**	**555,411**	**487,431**
Other Incoming Resources		-	-	-	-
Total Income		**435,329**	**120,083**	**555,411**	**487,431**
Expenditure	4				
Cost of raising funds		133,788	-	133,788	114,890
Expenditure on charitable activities		300,695	113,526	414,221	370,998
Total Resources Expended		**434,483**	**113,526**	**548,010**	**485,887**
Net Income (Expenditure)		**846**	**6,556**	**7,401**	**1,544**
Reconciliation of funds					
Total funds brought forward		626,491	22,126	648,618	647,073
Net movement in funds for the year		846	6,556	7,401	1,544
Total funds carried forward		**627,337**	**28,681**	**656,018**	**648,617**

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing operations.

Balance sheet as at 31 October 2025

		2025	2024 Unaudited
		£	£
Tangible fixed assets	10	1,320	2,284
Current assets			
Debtors	11	14,162	14,352
Cash at bank and in hand		754,090	720,194
		768,252	734,547
Creditors : amounts falling due within one year	12	113,554	88,214
Net current assets		**654,698**	**646,333**
Net assets		**656,018**	**648,617**
Analysis of net assets between funds			
Unrestricted funds	13	627,337	626,491
Restricted funds	13	*28,681*	22,126
Total funds		**656,018**	**648,617**

The trustees acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of accounts.

The financial statements are prepared in accordance with the special provisions of the Companies Act 2006 and section 138 of the Charities Act 2011. These accounts are prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) – (Charities SORP (FRS 102)).

The notes at pages 17 - 25 form part of these accounts.

Approved by the Board of Trustees on 10 February 2026, and signed on its behalf by:

Richard Goode
Chair of The Board of Trustees
& Company Secretary

Jonathan Bruce
Vice Chair

Company Registration No. 03798407
Charity Registration No. 1078790
Scottish Charity Register No. SC045051

Statement of Cashflows for the year ended 31 October 2025

	2025		2024 Unaudited	
	£	£	£	£
Cash flows from operating activities				
Cash absorbed by operations	7,634		(76,478)	
Net cash outflow from operating activities		7,634		(76,478)
Investing activities				
Purchase of tangible fixed assets	(2,641)		(4,569)	
Interest received	28,902		13,314	
Net inflow		26,261		8,745
Net (decrease)/increase in cash & cash equivalents		33,895		(67,734)
Cash & cash equivalents at beginning of Period		720194		787,928
Cash & cash equivalents at end of Period		754,090		720,194

Notes to the Financial Statements

1. Accounting policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the year and the preceding year.

a) Basis of accounting

The financial statements comply with the Charities Act 2011, the Companies Act 2006, Trustee Investment (Scotland) Act 2005, the charities Accounts (Scotland) Regulations 2006 (as amended), the Memorandum and Articles of Association, and the Charities Statement of Recommended Practice ("Charities SORP") (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland; FRS 102) effective from 1 January 2019.

The Neurofibromatosis Association meets the definition of a public benefit entity under FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the Charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

b) Fund accounting

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the Charity, and
- Restricted funds are subjected to restrictions on their expenditure imposed by the donor.

c) Income

All incoming resources are included in the statement of financial activities when the charity is entitled to the income, and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

- Income from donations and legacies is received by way of grants, donations, fundraising and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant,
- The value of services provided by volunteers has not been included in these accounts,
- Income from charitable activities are accounted for when earned, and
- Income resources from grants, where related to performance and specific deliverables, are accounted for as the charity earns the right to consideration by its performance.

d) Expenditure

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

- Costs of raising funds comprise the costs associated with attracting voluntary income. These include those costs associated with meeting the constitutional and statutory requirements of the charity and the strategic management of the charity. Governance costs comprise the costs associated with the governance of the charity, including audit fees, and are shown separately within the Statement of Financial Activities
- Expenditure on charitable activities comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- All costs are allocated between expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resource.
- Depreciation: Assets are written off over two years on the straight line basis of depreciation.

e) Fixed Assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Individual fixed assets costing £250 or more are capitalised at cost.
Depreciation: the value of each asset is written off over two years, on a straight-line basis.

f) Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

g) Debtors
Trade and other debtors are recognised at the settlement amount due.

h) 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.

i) Information and legal status of the charity
Nerve Tumours UK is a Charitable Company, limited by guarantee, incorporated on 30 June 1999, and registered as a charity on 5th January 2000 (previously 284653 registered 1982) with a membership base. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required by the adopted Constitution to contribute an amount not exceeding £1.

j) Pensions
The pension costs charged in the financial statements represent the contribution payable by the charity during the year. Contributions are made to defined contribution schemes in the UK.

2. Income

	Unrestricted funds 2025	Restricted funds 2025	Total funds 2025	Total funds 2024 Unaudited
	£	£	£	£
a) Donations & Legacies				
Donations and gifts	62,918	-	62,918	54,653
Events	119,445	-	119,445	127,552
Gift Aid	31,796	-	31,796	33,140
Grants	12,850	118,353	131,203	131,350
Legacies	121,391	-	121,391	50,231
Subscriptions	5,904	-	5,904	6,028
	354,303	118,353	472,656	402,954
b) Income from Charitable Activities				
Fundraising	52,123	1,730	53,853	71,163
	52,123	1,730	53,853	71,163
c)Investment Income				
Interest	28,902	-	28,902	13,314

3. Grants

	Unrestricted funds 2025	Restricted funds 2025	Total funds 2025	Total funds 2024 Unaudited
	£	£	£	£
The Grace Trust			-	1,500
The Peacock Trust		8,000	8,000	6,000
The Garfield Weston Foundation		20,000	20,000	-
The Three Oaks Trust		10,000	10,000	10,000
The Norman Family Charitable Trust			-	1,000
The Baron Davenport Charity		2,000	2,000	2,000
The Schon Charitable Trust			-	500
The Sir James Rolls Charitable Trust	1,500		1,500	1,500
The Ardwick Trust	200		200	-
The Limbrick Hall Foundation	150		150	-
The James Tudor Foundation			-	8,000
The February Foundation		5,000	5,000	-
Alexion Pharmaceuticals UK		15,000	15,000	40,000
St Jude's Trust			-	1,000
The Sir John & Lady Amory Charitable Trust			-	300
The Claire Milne Trust		5,000	5,000	-
The Roger & Jean Jefcoate Trust			-	10,000
Community Lottery Fund		18,853	18,853	-
The Cuthbert Horn Trust	7,000		7,000	7,000
The Joseph Hopkins Charitable Foundation		700	700	1,200
The Hadrian Trust		500	500	500
The PF Edwards Charitable Trust	4,000		4,000	4,000
The John Avins Trust			-	1,000
The Roger & Douglas Turner Trust		5,000	5,000	5,000
The Thomas J Horne Memorial Trust		6,000	6,000	-
The Grantham Yorke Trust		2,300	2,300	-
The Sheffield Town Trust			-	2,000
The Woodhall Charitable Trust			-	100
The D'Oyly Carte Charitable Trust			-	5,000
Jeans 4 Genes			-	750
The Bunzl Family Charitable Trust		20,000	20,000	20,000
The BCH 1971 Charitable Trust			-	1,000
The ISED Foundation			-	1,000
The Stockwell Cliffe Trust			-	1,000
	12,850	**118,353**	**131,203**	**131,350**

4. Expenditure

£	Cost of raising funds				Charitable activities			
	Events	Voluntary income	Trusts	Governance	Information and meetings	Helpline & Clinical Support	Specialist NF Nurses	Total
Costs directly allocated to activities								
Independent Auditors Fee	-	-	-	6,600	-		-	6,600
Independent Auditors Fee for other works	-	-	-	945	-		-	945
Events	36,156	-	-	-	-		-	36,156
Fundraising	-	35,133	40,952	-	-		-	76,085
Newsletters and information	-	-	-	-	198,758		-	198,758
Helpline & Clinical Support						34,804		34,804
NSA's	-	-	-	-	-		108,953	108,953
	36,156	35,133	40,952	7,545	198,758	34,804	108,953	462,301
Support costs allocated to activities **								
Staff costs	2,031	4,343	6,204	1,001	30,106	-	6,349	50,035
Consultancy/Professional Fees	-	-	-	-	-	-	-	-
Depreciation	146	313	447	72	2,169	-	457	3,605
Premises	1,056	2,258	3,225	520	15,651	-	3,301	26,011
Printing, postage and stationery	47	100	143	23	693	-	146	1,152
IT, telephone and fax	199	426	608	98	2,951	-	622	4,905
Other	-	-	-	-	-	-	-	-
	3,480	7,439	10,628	1,714	51,570	-	10,876	85,708
Total	39,636	42,572	51,579	9,259	250,329	34,804	119,829	548,010

** allocated on % staff costs

Staff Cost	Allocation based on time spent on activities
Premises Costs	Allocation based on staff costs
Depreciation	Allocation based on premises costs
It, etc	Allocation based on staff costs

5. Net Incoming Resources for the Year

This is stated after charges:	2025	2024 Unaudited
	£	£
Depreciation	3605	3042
Independent Audit Fee	6600	2904
	10,205	**5,946**

6. Staff costs and numbers

	2025	2024 Unaudited
	£	£
Salaries and wages	253,722	219,175
Social security costs	17,549	14,051
Pension costs	5,759	4,270
	277,030	**237,497**

No employees received emoluments of more than £60,000. The charity operates a pension scheme for its employees, as currently required.

The average number of employees during year, calculated on the basis of full-time equivalents, was as follows:

	2025	2024 Unaudited
CEO		
Membership Secretary		
IT/Information	2.2	1.5
Fundraising	2.3	2.3
Specialist Support	0.6	0.6
Change manager		
Development managers	0.6	0.6
	5.7	**5.0**

7. Trustee remuneration

No members of the Board of Trustees received any remuneration, or expenses, during the year, as with the previous financial year.

8. Related party transactions

There were no Related Party Transactions during the year. No Trustee, or other person related to the charity, had any personal interest in any transaction.

9. Taxation

As a charity, The Neurofibromatosis Association is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or s256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the Association.

10. Tangible fixed assets

	2025	2024 Unaudited
	£	£
Cost		
As at 1 November	16,205	11,636
Additions	2,641	4,569
Removal of fully depreciated assets		
As at 31 October	18,846	16,205
Accumulated depreciation		
As at 1 November	13,921	10,879
Charge for the year	3,605	3,042
Removal of fully depreciated assets		
As at 31 October	17,526	13,921
Net book value		
As at 1 November	2,284	757
As at 31 October	**1,320**	**2,284**

11. Debtors

	2025	2024 Unaudited
	£	£
Debtor Control Account	2,642	72
Rent Deposit	-	-
Other debtors	-	-
Prepayments	11,520	14,280
	14,162	**14,352**

12. Creditors: amounts falling due within one year

	2025	2024 Unaudited
	£	£
Trade Creditors	18,811	15,427
Taxation	8,669	4,791
Lottery Grant	-	-
Other Creditors	14,324	20,587
Accruals and deferred income	71,751	47,410
	113,554	**88,214**

13. Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds
	£	£	£
Tangible fixed assets	1,320	-	1,320
Current assets	739,571	28,681	768,252
Current liabilities	113,554	-	113,554
	627,337	**28,681**	**656,018**

Unrestricted reserves totalling £627,337 have been carried forward, but 80.4% of this figure, £503,870 is already designated expenditure, due to the number of multi year contracts with NHS Trusts for the Specialist NF Nurse posts, the head office rental contract and other specific projects.

This leaves a figure for free reserves of £123,466, for expenditure in the next financial year.

14. Movement in funds

	At 1 November 2024	Incoming Resources	Outgoing Resources	At 31 October 2025
	Unaudited			
Restricted Funds				
Support Groups/Medical Info Days	5,000	-	2,120	2,880
Research/Specialist Support Network	1,057	86,230	86,230	1,057
Awareness Campaigns	-	33,853	24,426	9,427
NF2 Activities	16,068	-	750	15,318
	22,126	120,083	113,526	28,681
Unrestricted Funds	626,491	435,329	434,483	627,337
Total Funds	**648,617**	**555,411**	**548,010**	**656,018**

Purposes of Restricted Funds:

Support Groups/Medical Info Days:	funding restricted for expenditure on Medical Information Days
Research/SSN:	funding restricted for expenditure on Research
NF2 activities:	funding restricted for expenditure on NF2 activities
Awareness Campaigns/Mtgs:	funding restricted for expenditure on information/meetings

15. Financial commitments

At 31 October 2025, the charity had annual commitments under non-cancellable operating leases, following rent renegotiations, as follows:

	2025
	£
Expiry date:	
Not later than one year	12,000
Later than one year and not later than five years	7,000
	19,000

16. Reconciliation of profit to net cash (outflow)/inflow from operating activities

	2025	2024 Unaudited
	£	£
Surplus/(Deficit) for the year	7,401	1,544
Adjustments to reconcile profit for the year to net		
Cashflow from operating activities:		
Depreciation	3,605	3,042
Finance Income	(28,902)	(13,314)
Working Capital Movements		
(Increase)/decrease in debtors	190	(870)
Increase/(decrease) in creditors	25,340	(66,880)
Cash absorbed by Operations	7,634	(76,478)

17. Critical accounting estimates and judgements

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for revenues and expenses during the year. However, the nature of estimation means that actual outcomes could differ from those estimates.

There were no key judgements. The main accounting estimates are depreciation and accruals.

THE NEUROFIBROMATOSIS ASSOCIATION

England & Wales - Charity number 1078790

Accounts

The Neurofibromatosis Association

Report of the Board of Trustees

Year ended 31 October 2024

Charity Registration Number 1078790
Scottish Charity Registration Number SC045051
Company Registration Number 03798407

Reference and administrative information

Charity Name:	The Neurofibromatosis Association
Charity Registration Number:	1078790
Scottish Charity Registration Number:	SC045051
Company Registration Number:	3798407
Charity Working Name:	Nerve Tumours UK
Registered office and operational address:	44 Coombe Lane West Wimbledon London SW20 0LA
Telephone:	020 8439 1234
E-mail address:	info@nervetumours.org.uk
Website address:	www.nervetumours.org.uk

Nerve Tumours UK

Nerve Tumours UK is the working name of the charity, which retains its legal name "The Neurofibromatosis Association".

Board of Trustees

The current Board of Trustees is:

Richard Goode (Chair – appointed 03 June 2024)
Michael Fry (Chair – retired 03 June 2024)
Professor Rosalie Ferner
Jonathan Bruce (Vice Chair - appointed 03 June 2024)
Rohan Chanmugam
Professor Meena Upadhyaya
Matthew Jones

Senior Management Personnel

The Trustees delegate day-to-day management of the charity to:
Karen Cockburn, Charity Director

Patrons

Gillian Anderson
Simon Callow
Thomas Young
Prof. D.Gareth Evans

Independent Examiners

David Howard Chartered Accountants
1 Park Road
Hampton Wick
Kingston - upon - Thames
Surrey
KT1 4AS

Bankers

National Westminster Bank Plc
5 Market Place
Kingston - upon - Thames
Surrey
KT1 1VX

Board of Trustees Report for the Year Ended 31 October 2024

The Trustees of The Neurofibromatosis Association, trading as Nerve Tumours UK (NTUK), are pleased to present their annual report and financial statements for the year ended 31 October 2024.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, Trustee Investment (Scotland) Act 2005, the charities Accounts (Scotland) Regulations 2006 (as amended), the Memorandum and Articles of Association, and the Charities Statement of Recommended Practice ("Charities SORP") (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland; FRS 102) effective from 1 January 2019.

Objectives and Activities

Nerve Tumours UK's vision sees a future in which the needs of everyone with NF are met, and the charity is central to making that happen.

To allow the charity to deliver this vision of helping to improve the lives of those affected by NF, the new medical name for Neurofibromatosis Type 1 (NF1), NF2-related-Schwannomatosis (NF2) and Schwannomatosis (SWN), and in being central to making this happen, we work in collaboration with the Highly Specialised Commissioning Services, formerly the National Commissioning Group (NCG) funded service, other associated medical professional and educational establishments around the UK, and also in collaboration with wider international partners.

Nerve Tumours UK's mission is to improve the lives of everyone affected by NF through support services, advocacy and promoting understanding and knowledge of the condition. Central to our mission is our ambition to be the UK's authoritative voice on NF and our determination to serve, support and celebrate the lives of people impacted by the condition, and their wider support network.

The charity continues to deliver its mission through five key services to members, supporters, and beneficiaries. It endeavours to:

- **Inform** — We provide accurate, relevant, and up to date information that explains the conditions of NF1, NF2 and SWN, the implications, challenges and opportunities, in language understood by all.
- **Advise** — We provide practical and emotional advice to help people find the best services and support available. We enable people to make choices about how they approach and live with NF.
- **Advocate** — We aim to increase knowledge, awareness and understanding of NF, and will campaign for change in areas we believe will improve the lives of those affected by NF.
- **Connect** — We take a pivotal role in bringing together groups of people interested in NF to maximise the support and information available to them.
- **Fund** — We make funds available for small projects to bodies and patient groups where we believe it will make a difference.

The charity works with the following groups to achieve its mission:

- Patients and carers
- Families with NF
- The medical community
- NF Specialist Network of Nurses and Advisors
- The research community (particularly The Nerve Tumours UK Medical Advisory Board)

- Leading UK Universities
- NTUK Sponsored PHD researchers
- Supporters
- Volunteers
- Other charities and umbrella organisations

Achievements and Performance

We continue to be hindered by the ongoing repercussions of the Covid-19 pandemic, as people with NF are more susceptible to the virus due to the associated complications of NF. However, the charity continues to concentrate on its central five services. We have also continued working to strengthen and develop our core support structures to ensure that we maintain the best possible support and advise services for anyone affected by NF.

However, our services continue to face increased demand. This is due to the uncertain economic climate and the resulting absence or difficulty in obtaining primary and secondary care services. Some services are still provided virtually or by telephone consultation which cause immense problems for people with NF, who either do not have the facilities to join virtual appointments, or lack the capacity to organise and engage. However this is the world we must now adapt to.

As a result of this ongoing situation in the wider care sector, the charity took the decision to expand the National NF Helpline service from two to three days per week from the end of 2022, and will continue to monitor demand to ensure the service meets the needs of the community.

Continuing Impact of Covid on Charity Services & Finances

We fund a unique and vital service, which is not provided by any other organisations. Our services are particularly important for people diagnosed with NF and their carers. Many people with NF are vulnerable and often isolated. Our experience is that many are still distressed by the ongoing health crisis, as some of their complications may make them more susceptible to Covid. The effect on the broader group of people with NF continues, as there continues to be a significant backlog of appointments for genetics and neurology clinics. This was initially caused by reduced NHS staffing in 2020 and subsequent years, as many had been redeployed to critical and Covid services, but was made far worse by the NHS strikes over the last couple of years. In response, the charity has continued to provide and grow services to ensure that we can reach and support our beneficiaries, in any way necessary. The charity is still extremely concerned about the ongoing potential impact on mental health both for our beneficiaries and our staff, due to workload.

As the charity does not receive statutory or local funding, the bulk of the charity's income comes from charitable giving and monies raised from events. Fortunately most major events have returned to the calendar, however the community's ongoing fear of mixing with Covid still prevalent, means that all community small scale fundraising has all but disappeared for now. This has had a significant adverse effect on income streams. However, the head office team continue to fundraise as much as possible with new, innovative, and virtual initiatives.

As we fund a network of Specialist NF Nurses and Advisors (Specialist Advisors), our policy requires us to maintain a minimum of 12 months of reserves. The charity continues to react quickly to the constraints placed on it by the current economic climate. This has minimised the impact on the level of reserves over the last few financial years, and at this time, we are confident that we are able to continue to maintain our reserves policy.

Plans for Future Sustainability

The pandemic and current economic climate forced us to reconsider our strategic plan. The Board implemented a strategy group, which continues to look at how the charity can provide and expand its services, in this post-Covid and recessionary economic environment.

Key Strategic Aims

The charity's key strategic aims are to:

- Increase awareness and understanding of NF.
- Provide timely and meaningful support and guidance to those living with NF and their wider support network.
- Promote and support research into NF.

Our focus continues to be on how we can streamline, yet expand, our services; co-ordinate our work with all partners including research bodies; and improve the education of the medical profession. Our aim is to ensure that people are able to access accurate and timely advice and support as effectively and efficiently as possible, whether or not that is from the charity. The charity's staff and medical network continue to promote the new medical hub on our website, which gives easy access to lectures, guidelines and other relevant tools to educate wider allied healthcare professionals.

The charity also strives to find new ways of working, including virtual clinics, appointments and meetings. Although online services are not practical for all (for example, patients with cognitive impairment and learning issues), we can see that improved online connectivity and familiarity leads to reduced delivery costs and greater efficiency. In the future our intention is that a balance of online and in person delivery will allow the charity to provide services to more people.

Specialist Support Network

The charity will continue to maintain its Specialist Support Network of Nurses & Advisors and will seek to identify areas of the country where we can work with the NHS to make joint appointments.

The charity currently funds a network of eleven Specialist Advisors across the UK, supporting posts in Newcastle (1), Birmingham (2), Plymouth (2), Liverpool, Southampton, Sheffield, Leeds, London, Wales, and has an association with Northern Ireland. Unfortunately, the post in Scotland is still vacant, and as an interim, we are working closely with the Scottish Office for Rare Diseases, and the National Helpline works closely with Clinical Genetics at the Queen Elizabeth University Hospital based in Glasgow

Two Specialist NF Nurses operate the Nerve Tumours UK National Helpline on a part time basis, which provides advice and connects people affected by NF with relevant practical help, either in their community, or in clinic, across three days of the working week. On interim days, the head office staff operate a triage helpline, booking in appointments or referring to regional Specialist NF Nurses.

We aim to introduce two new posts during the next financial year in parts of the UK, where there has never been any regional support. Each of our current posts supports between 180 – 3,320 patients per year working via clinics, home visits, schools, advisory services, and telephone consultation.

The role of Specialist Nurses/Advisors is very diverse. We have had excellent feedback from the families supported by our team and it is plain to see that for those families, the support they receive from the Specialist Support Network is pivotal in helping them to cope with NF. Funding and expanding the Specialist Support Network will continue to be the key role for Nerve Tumours UK.

Over 60% of patients with NF1 have learning difficulties, and approximately 30% are registered as disabled, as are 75% of those patients with NF2. However, awareness of NF across all professions including the medical profession, is low. Our experience is that this can lead to some children with NF struggling at school, with inappropriate, or non-existent support. Nerve Tumours UK offers a schools' advisory service, iNForm, operated by our Specialist Support Network. Where engaged, the team works closely with teachers, SENCO's, allied healthcare professionals, and parents, supporting tailored learning plans, and suggesting mechanisms for enhancing the child's experience at school. As a result of the pandemic, we have found that we can still operate iNForm effectively, albeit virtually, and

in the years since we have found that more allied healthcare professionals are willing and able to join the iNForm meetings if they are held virtually.

Nerve Tumours UK continues to offer an extensive range of literature and information, for lay people and is also widely used by allied healthcare professionals across the UK, and further afield. Our leaflets and pamphlets are subject to constant review and update. Medical professionals are also invited to use the Nerve Tumours UK National Helpline and on-line Medical Hub.

Charity Reach

The Nerve Tumours UK Head Office team continue to work exceptionally hard. They continue to go above and beyond in response to the continuing fallout of the last few years, and the Board are again very grateful for their efforts. Key workstreams continue to be the ever further development of our website, in particular the medical section, the constantly updated research hub, and the collaborative useful organisations section. We continue to receive extremely positive feedback since the launch of the medical section in 2023, and have seen how this improves and widens our engagement with medical professionals, particularly GP's.

Social media remains an important and ever growing aspect of the charity's engagement strategy, and we continue to see an increased number of visits to our website, which has greatly increased our interaction and the ongoing support we can provide for the community. Facebook coverage and engagement has continued to grow and at the end of the year, a figure of 96,967 people were reached organically each month, and our page views are up by 9.3% this year. Our website achieved an average of 79,303 users per month. Nerve Tumours UK's Facebook reach also continues to grow steadily with 8,009 followers and a monthly reach of 1.1million. Instagram, with the implementation of stories and marketing content adjustments, now stands at 2,224 followers and a reach of 256,000 by the end of the year. The number of subscribers to the monthly Nerve Tumours UK newsletter stands at 3,412.

Direct messaging and communication via social media, within the community, centres around the close community group, which has 1412 members. During World NF Awareness Week in May 2024 total social media posts on the respective NF1 and NF2 Days, coinciding with our billboard campaign "Everybody is born a Champion" featuring our new patron, Para GB Sprinter, Thomas Young, led to the highest peak of activity across social media, and the resultant highest web traffic, of the year.

We also continue to seek to develop and strengthen our institutional partnerships with organisations including The Centre for Appearance Research, The Genetic Alliance, The Neurological Alliance, Genetic Disorders UK and Embracing Complexity. We also have three medical information days planned, which will be both in-person and livestreamed, to reach as many of the community as possible.

The continued rollout of core services throughout the period is an excellent reflection of the combined efforts and dedication of the Specialist Network of Nurses/Advisors, our members, supporters, head office staff and the Medical Advisory Board, and the Trustees are very grateful for the exceptionally hard work, which has been put into the charity.

There are no immediate financial concerns for the charity, although the current economic climate and upheaval remains of concern. The trustees maintain that Nerve Tumours UK is still currently on track to meet its long-term strategic and financial targets.

Structure, Governance and Management

Nerve Tumours UK is a Charitable Company, limited by guarantee, incorporated on 30 June 1999, and registered as a charity on 5th January 2000 (previously 284653 registered 1982) with a membership base. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required by the adopted Constitution to contribute an amount not exceeding £1.

The directors of the company are also charity trustees for the purposes of charity law, and under the company's Articles are known as members of the Board of Trustees. The Board of Trustees meets at least four times a year and is responsible for the strategic direction and policy of the charity and appointing auditors to ensure financial

compliance. Medical input is given via our Medical Advisory Board, a representative of which sits on the Board of Trustees. Trustees are selected for their knowledge of NF and the various professions, that optimize the knowledge and ability of the Board.

A sub group of the Board of Trustees, the Financial Advisory Group, and including the Charity Director, has been established to consider and monitor the financial and investment activities of the charity.

Medical Background

The charity's membership is mostly drawn from families affected by NF. NF1 affects 1 in every 2,500 people worldwide, which means that there are more than 25,000 in the UK; NF2 is much rarer, with 1 in 35,000 affected worldwide, with 1,000 in the UK, and there are approximately 500 people diagnosed with SWN.

An affected person of either sex has a 1 in 2 (50:50) chance of passing the altered (abnormal) gene on to their children. However, everyone has a risk of having an affected child because 50% of all those affected by NF are the first person in their family to be so affected.

NF1 is a hugely variable condition, which has the potential to develop a large number of complications. Some people with NF1 only having skin involvement, but potential complications include: specific learning difficulties and behavioural problems - which affects about 60% of all people with NF1; high blood pressure (hypertension); curvature of the spine (scoliosis); malformation of the long bones (below the knee and below the elbow) (pseudarthrosis); large benign skin tumours (plexiform neurofibromas); tumours on the nerves of sight (optic glioma); internal, spinal and brain tumours – which are usually benign however 10-15% of people will develop a malignant tumour related to their NF1. The most significant issue for people with NF1 is that the occurrence of these complications cannot be predicted even within families. Many people with NF1 also have low self-esteem and this can cause problems forming friendships, which leads to isolation.

NF2 consistently causes more problems than NF1, and it has an increased risk of developing brain tumours. Although these tumours are benign, the position in which they grow can cause major problems. The most common site is on the hearing and balance nerves causing problems with deafness and coordination. The sense of isolation from deafness onset in adulthood can be immense. People with NF2 may also develop spinal cord tumours, with their own significant complications.

NF is an unpredictable and variable genetic condition that can affect all people regardless of gender, race or age. During their lifetime, patients may see a wide range of health and social care professionals, both in community and hospital settings. The Specialist Advisors act as a point of reference for families helping them navigate through routine planned events and at times of crisis. Essentially, their role is to help people to learn to live with their diagnosis of NF and to equip them with the knowledge of when, where, and how to seek help, if necessary.

As a multi-system condition, NF has an impact on many areas of people's lives, not just health. The Specialist Advisors take a lead role in liaison and advocacy with health, education, and social services to support the quality and continuity of care for families affected by NF. They seek to develop a service that is professional, timely and responsive to need. Their setting may be clinical, visiting families at home or telephone contact. The quality of the relationships they establish is critical to their effectiveness and may continue over many years.

Financial Review

Income Generating Activities

Our head office team continue to develop innovative virtual fundraising ideas and source new income streams at every opportunity. During the period the charity had income resources of £487,431 and a total expenditure of £485,887, resulting in net resources of £1,544.

This has resulted in total funds of £648,617 being carried forward. Of this figure £22,126 is restricted to projects as specified by the terms and conditions of certain donations. Of the balance, circa 80%, although unrestricted, is

already designated expenditure, due to the number of multi-year Specialist Nurse contractual commitments, employee and head office contracts.

Investment Policy

The charity's funds have been invested in a mixture of one year fixed income bonds and short-term deposits this financial year. The Financial Advisory & Investment Group, established in late 2022, reporting to the Board of Trustees, continue to review this position and further investment opportunities, to ensure all income potential is maximised, with minimum risk.

We give careful consideration as to how we can make our reserves generate an income for the charity and have considered a number of options and informal advice. At present, given the current rate of return, the costs involved in investing, and the inherent risk, we have continued to elect to hold the reserves in a mixture of short and medium term deposits with a number of banks. However, we continue to monitor all other options available.

Reserves Policy and Going Concern

Reserves are needed to bridge the gap between the spending and receiving of income and to cover unplanned emergency expenditure. The Trustees consider a minimum of £500,000 is the ideal level of reserves and being sufficient unrestricted reserves to fund the Specialist Support Network for a minimum of twelve months due to the number of multi-year contractual commitments; and the charity's administrative and operating costs for at least six months.

The Trustees consider that adequate resources continue to be available to fund the activities of the charity for the foreseeable future. The Trustees are of the view that the charity is a going concern.

Key Expenditure Areas

The key areas of expenditure continue to be the operational costs of the Specialist Support Network of Nurses/Advisors. Each year, we aim to raise sufficient funds to maintain the twelve months' reserves. If the charity provides further funding for the Specialist Network, this expenditure, and the required level of reserves, is likely to increase.

Public Benefit

All our charitable activities focus on improving the lives of those affected by NF and are undertaken to further our charitable purposes for public benefit. The Trustees have regard to the Charity Commission's guidance on the need for charities to deliver a public benefit and have complied with the duty in section 17(2) of the Charities Act 2011.

Recruitment, Appointment & Induction of Board of Trustees

Under the requirements of the Memorandum and Articles of Association, the one-third longest standing members of the Board of Trustees shall retire or put themselves forward for re-election at the next Annual General Meeting. The maximum time a trustee can remain in post is ten years, although that time may be extended for a short period by the Board on an exceptional basis.

The Board of Trustees seeks to recruit a diverse mix of business, medical and patient expertise, although preferred, there is no requirement for a Board member to have any direct or indirect experience of NF. All Trustees, upon election, meet with the Chair to discuss and agree specific requirements of the role.

Statement of Trustees responsibilities

The Trustees, who are also the directors of the Neurofibromatosis Association for the purpose of company law, are responsible for preparing the Trustees Report and the financial statements in accordance with FRS102 and the charity SORP (FRS 102). The Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity at the end of the financial year and of its surplus or deficit for that period. In doing so, the Trustees are responsible for:

- selecting suitable accounting policies and then apply them consistently;
- observing the methods and principles in the Charities SORP;
- making judgements and estimates that are reasonable and prudent;
- preparing the financial statements on the going concern basis unless it is not appropriate to assume that the company will continue on that basis; and
- the maintenance and integrity of the corporate and financial information included on the charity's website.

The Board of Trustees is responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time that the financial statements comply with the Companies Act 2006. The Board of Trustees is also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Members of the Board of Trustees

Members of the Board of Trustees, who are directors for the purpose of company law, and Trustees for the purpose of charity law, who served during the year and up to the date of this report, are set out on page 1.

Small company provisions

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

Approved by the Board of Trustees on 03 March 2025, and signed on its behalf by:

Richard Goode
Chair of the Board of Trustees
& Company Secretary

Jonathan Bruce
Vice Chair

Independent Examiners' Report to the Trustees of The Neurofibromatosis Association (Nerve Tumours UK)

I report on the accounts of the company for the year ended 31st October 2024, which are set out on pages 10 to 19.

Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under Part 16 of The Companies Act 2006, section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10(1)(a) to (c) of the Charities Accounts (Scotland) Regulations 2006 ("The 2006 Regulations") and that an independent examination is needed. The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Association on Chartered Certified Accountants and it is my responsibility to:

- examine the accounts under section 145 of the Charities Act 2011 and under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

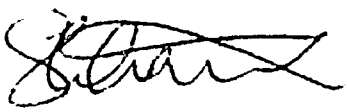
My examination was carried out in accordance with the general Directions given by the Charity Commission and is in accordance with Regulations 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:
(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 386 of the Companies Act 2006 and section 44(1)(a) of the 2005 Act and regulation 4 of the 2006 Accounts Regulations; and
- to prepare accounts which accord with the accounting records, comply with the accounting requirements under Section 396 of the Companies Act 2006, section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations
- which are consistent with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities (SORP FRS102)

have not been met; or
(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Siobhan Glenister, ACA
For and on behalf of David Howard Chartered Accountants
1 Park Road
Hampton Wick
Kingston Upon Thames
Surrey
KT1 4AS
Date: 3rd March 2025

Statement of Financial Activities (including Income & Expenditure Accounts) for the Year ended 31 October 2024

	Notes	Unrestricted funds 2024 £	Restricted funds 2024 £	Total funds 2024 £	Total funds 2023 £
Incoming Resources from Generated Funds					
Donations & Legacies	2	300,204	102,750	402,954	368,155
Income from Charitable Activities	2	66,983	4,180	71,163	80,162
Investment Income	2	13,314		13,314	8,091
Incoming Resources from Charitable Activities		**380,501**	**106,930**	**487,431**	**456,409**
Other Incoming Resources		-	-	-	-
Total Income		**380,501**	**106,930**	**487,431**	**456,409**
Expenditure	4				
Cost of raising funds		114,890	-	114,890	102,689
Expenditure on charitable activities		262,221	108,776	370,998	321,975
Total Resources Expended		**377,111**	**108,776**	**485,887**	**424,665**
Net Income (Expenditure)		**3,390**	**(1,846)**	**1,544**	**31,744**
Reconciliation of funds					
Total funds brought forward		623,101	23,972	647,073	615,329
Net movement in funds for the year		3,390	(1,846)	1,544	31,744
Total funds carried forward		**626,491**	**22,126**	**648,617**	**647,073**

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing operations.

Balance sheet as at 31 October 2024

		2024	2023
		£	£
Tangible fixed assets	10	2,284	757
Current assets			
Debtors	11	14,352	13,482
Cash at bank and in hand		720,194	787,928
		734,547	801,410
Creditors : amounts falling due within one year	12	88,214	155,094
Net current assets		**646,333**	**646,316**
Net assets		**648,617**	**647,073**
Analysis of net assets between funds			
Unrestricted funds	13	626,491	623,101
Restricted funds	13	*22,126*	23,972
Total funds		**648,617**	**647,073**

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 October 2024 relating to small companies.

The trustees have not required the charitable company to obtain an audit of its financial statements for the year ended 31 October 2024 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of accounts.

The financial statements are prepared in accordance with the special provisions of the Companies Act 2006 and section 138 of the Charities Act 2011. These accounts are prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) – (Charities SORP (FRS 102)).

The notes at pages 12-19 form part of these accounts.

Approved by the Board of Trustees on 03 March 2025, and signed on its behalf by:

Richard Goode
Chair of The Board of Trustees
& Company Secretary

Jonathan Bruce
Vice Chair

Company Registration No. 03798407
Charity Registration No. 1078790
Scottish Charity Register No. SC045051

1. Accounting policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the year and the preceding year.

a) Basis of accounting

The financial statements comply with the Charities Act 2011, the Companies Act 2006, Trustee Investment (Scotland) Act 2005, the charities Accounts (Scotland) Regulations 2006 (as amended), the Memorandum and Articles of Association, and the Charities Statement of Recommended Practice ("Charities SORP") (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland; FRS 102) effective from 1 January 2019.

The Neurofibromatosis Association meets the definition of a public benefit entity under FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the Charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

b) Fund accounting

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the Charity, and
- Restricted funds are subjected to restrictions on their expenditure imposed by the donor.

c) Income

All incoming resources are included in the statement of financial activities when the charity is entitled to the income, and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

- Income from donations and legacies is received by way of grants, donations, fundraising and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant,
- The value of services provided by volunteers has not been included in these accounts,
- Income from charitable activities are accounted for when earned, and
- Income resources from grants, where related to performance and specific deliverables, are accounted for as the charity earns the right to consideration by its performance.
- There has been a change in the accounting policy for Lifetime Subscriptions from 2010/11. Henceforth income resources from lifetime subscriptions will be fully accounted for in the year in which the subscription is registered.

d) Expenditure

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

- Costs of raising funds comprise the costs associated with attracting voluntary income, and also include governance costs. These include those costs associated with meeting the constitutional and statutory requirements of the charity and include the independent examination fees and costs linked to the strategic management of the charity.
- Expenditure on charitable activities comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be

allocated directly to such activities and those costs of an indirect nature necessary to support them.

- All costs are allocated between expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resource.
- Depreciation: Assets are written off over two years on the straight line basis of depreciation.

e) Fixed Assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Individual fixed assets costing £250 or more are capitalised at cost.
Depreciation: the value of each asset is written off over two years, on a straight-line basis.

f) Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

g) Debtors
Trade and other debtors are recognised at the settlement amount due.

h) 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.

i) Information and legal status of the charity
Nerve Tumours UK is a Charitable Company, limited by guarantee, incorporated on 30 June 1999, and registered as a charity on 5th January 2000 (previously 284653 registered 1982) with a membership base. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required by the adopted Constitution to contribute an amount not exceeding £1.

j) Pensions
The pension costs charged in the financial statements represent the contribution payable by the charity during the year. Contributions are made to defined contribution schemes in the UK.

2. Income

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total funds 2024 £	Total funds 2023 £
a) Donations & Legacies				
Donations and gifts	54,653	-	54,653	36,089
Events	127,552	-	127,552	120,189
Gift Aid	33,140	-	33,140	24,164
Grants	28,600	102,750	131,350	104,300
Legacies	50,231	-	50,231	77,452
Subscriptions	6,028	-	6,028	5,962
	300,204	102,750	402,954	368,156
b) Income from Charitable Activities				
Fundraising	66,983	4,180	71,163	80,162
Goods for Sale	-		-	-
	66,983	4,180	71,163	80,162
c)Investment Income				
Interest	13,314	-	13,314	8,091

3. Grants

	Unrestricted funds	Restricted funds	Total funds	Total funds
	2024	2024	2024	2023
	£	£	£	£
The Grace Trust		1,500	1,500	750
The Peacock Trust	6,000		6,000	5,000
The Childwick Charitable Trust			-	10,000
The Three Oaks Trust		10,000	10,000	10,000
The Norman Family Charitable Trust		1,000	1,000	-
The Baron Davenport Charity		2,000	2,000	1,200
The Schon Charitable Trust	500		500	550
The Sir James Rolls Charitable Trust		1,500	1,500	1,250
The Eveson Charitable Trust			-	10,000
The Hilary Awdry Charitable Trust			-	500
The James Tudor Foundation		8,000	8,000	5,000
Anonymous			-	10,000
Alexion Pharmaceuticals UK		40,000	40,000	-
St Jude's Trust		1,000	1,000	15,000
The Sir John & Lady Amory Charitable Trust		300	300	-
The Claire Milne Trust			-	5,000
The Roger & Jean Jefcoate Trust	10,000		10,000	-
The Dixie Rose Findlay Charitable Trust			-	-
The Cuthbert Horn Trust	7,000		7,000	7,000
The Pears Foundation			-	8,500
The Joseph Hopkins Charitable Foundation		1,200	1,200	700
The Hadrian Trust		500	500	1,000
The PF Edwards Charitable Trust	4,000		4,000	4,000
The John Avins Trust		1,000	1,000	2,000
The Roger & Douglas Turner Trust		5,000	5,000	-
The Thomas J Horne Memorial Trust			-	6,000
LSEG			-	850
The Sheffield Town Trust		2,000	2,000	-
The Woodhall Chaitable Trust	100		100	-
The D'Oyly Carte Charitable Trust		5,000	5,000	-
The CGD Society		750	750	-
The Bunzl Family Charitable Trust		20,000	20,000	-
The BCH 1971 Charitable Trust		1,000	1,000	-
The ISED Foundation	1,000		1,000	-
The Stockwell Cliffe Trust		1,000	1,000	-
	28,600	**102,750**	**131,350**	**104,300**

4. Expenditure

£	Cost of raising funds				Charitable activities			
	Events	Voluntary income	Trusts	Governance	Information and meetings	Helpline & Clinical Support	Specialist NF Nurses	Total
Costs directly allocated to activities								
Independent Examiner Fee	-	-	-	2,904	-		-	2,904
Independent Examiner Fee for other works	-	-	-	1,550	-		-	1,550
Events	33,659	-	-	-	-		-	33,659
Fundraising	-	23,627	38,160	-	-		-	61,787
Newsletters and information	-	-	-	-	145,456		-	145,456
Helpline & Clinical Support						34,111		34,111
NSA's	-	-	-	-	-		117,685	117,685
Research	-	-	-	-	5,000		-	5,000
Trustee and committee meetings	-	-	-	-	-		-	-
	33,659	23,627	38,160	4,454	150,456	34,111	117,685	402,153
Support costs allocated to activities								
Staff costs	2,130	3,154	6,605	1,229	31,247	-	6,835	51,199
Consultancy/Professional Fees	150	222	464	86	2,197	-	481	3,600
Depreciation	127	187	392	73	1,857	-	406	3,042
Premises	834	1,235	2,585	481	12,232	-	2,676	20,042
Printing, postage and stationery	40	60	125	23	591	-	129	968
IT, telephone and fax	203	301	630	117	2,980	-	652	4,883
Other	-	-	-	-	-	-	-	-
	3,483	5,158	10,802	2,010	51,103	-	11,178	83,734
Total	37,143	28,785	48,962	6,464	201,559	34,111	128,863	485,887

Staff Cost	Allocation based on time spent on activities
Premises Costs	Allocation based on staff costs
Depreciation	Allocation based on premises costs
It, etc	Allocation based on staff costs

5. Net Incoming Resources for the Year

This is stated after charges:	2024 £	2023 £
Depreciation	3042	1511
Independent Examination/ Audit Fee	2904	2400
	5946	3911

6. Staff costs and numbers

	2024 £	2023 £
Salaries and wages	219,175	199,310
Social security costs	14,051	11,739
Pension costs	4,270	4,261
	237,497	**215,310**

No employees received emoluments of more than £60,000. The charity operates a pension scheme for its employees, as currently required.

The average number of employees during year, calculated on the basis of full-time equivalents, was as follows:

	2024	2023
CEO		
Membership Secretary		
IT/Information	1.5	1.5
Fundraising	2.3	2.3
Specialist Support	0.6	0.6
Change manager		
Development managers	0.6	0.6
	5.0	**5.0**

7. Trustee remuneration

No members of the Board of Trustees received any remuneration, or expenses, during the year (last year, £146.14 was reimbursed to one member of the Board of Trustees).

8. Related party transactions

There were no Related Party Transactions during the year. No Trustee, or other person related to the charity, had any personal interest in any transaction.

9. Taxation

As a charity, The Neurofibromatosis Association is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or s256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the Association.

10. Tangible fixed assets

	2024 £	2023 £
Cost		
As at 1 November	11,636	10,121
Additions	4,569	1,515
Removal of fully depreciated assets		
As at 31 October	16,205	11,636
Accumulated depreciation		
As at 1 November	10,879	9,368
Charge for the year	3,042	1,511
Removal of fully depreciated assets		
As at 31 October	13,921	10,879
Net book value		
As at 1 November	757	754
As at 31 October	**2,284**	**757**

11. Debtors

	2024 £	2023 £
Debtor Control Account	72	162
Rent Deposit	-	-
Other debtors	-	-
Prepayments	14,280	13,320
	14,352	**13,482**

12. Creditors: amounts falling due within one year

	2024 £	2023 £
Trade Creditors	15,427	62,133
Taxation	4,791	4,661
Lottery Grant	-	-
Other Creditors	20,587	20,836
Accruals and deferred income	47,410	67,465
	88,214	**155,094**

13. Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds
	£	£	£
Tangible fixed assets	2,284	-	2,284
Current assets	712,421	22,126	734,547
Current liabilities	88,214	-	88,214
	626,491	**22,126**	**648,617**

14. Movement in funds

	At 1 November 2023	Incoming Resources	Outgoing Resources	At 31 October 2024
Restricted Funds				
Support Groups/Medical Info Days	3,744	15,000	13,744	5,000
Research/Specialist Support Network	3,377	76,930	79,250	1,057
Awareness Campaigns	-	15,000	15,000	-
NF2 Activities	16,851	-	782	16,068
	23,972	106,930	108,776	22,125
Unrestricted Funds	623,101	380,501	377,111	626,491
Total Funds	**647,073**	**487,431**	**485,887**	**648,617**

Purposes of Restricted Funds

Support Groups/Medical Info Days:	funding restricted for expenditure on Medical Information Days
Research/NSA's:	funding restricted for expenditure on Research
NF2 activities:	funding restricted for expenditure on NF2 activities
Awareness Campaigns:	funding restricted for expenditure on information campaigns

15. Financial commitments

At 31 October 2024, the charity had annual commitments under non-cancellable operating leases, following rent renegotiations, as follows:

	2024
	£
Expiry date:	
Not later than one year	12,000
Later than one year and not later than five years	19,000
	31,000

THE NEUROFIBROMATOSIS ASSOCIATION

England & Wales - Charity number 1078790

Accounts

The Neurofibromatosis Association

Report of the Board of Trustees

Year ended 31 October 2023

Charity Registration Number 1078790
Scottish Charity Registration Number SC045051
Company Registration Number 03798407

The Neurofibromatosis Association
Report and financial statements
Year ended 31 October 2023

Reference and administrative information

Charity Name:	The Neurofibromatosis Association
Charity Registration Number:	1078790
Scottish Charity Registration Number:	SC045051
Company Registration Number:	3798407
Charity Working Name:	Nerve Tumours UK
Registered office and operational address:	44 Coombe Lane West Wimbledon London SW20 0LA
Telephone:	020 8439 1234
E-mail address:	info@nervetumours.org.uk
Website address:	www.nervetumours.org.uk

Nerve Tumours UK

Nerve Tumours UK is the working name of the charity, which retains its legal name "The Neurofibromatosis Association".

Board of Trustees
The current Board of Trustees is:

Michael Fry (Chair)
Stewart Lee
Richard Goode (Vice Chair)
Professor Rosalie Ferner
Jonathan Bruce
Rohan Chanmugam
Professor Meena Upadhyaya
Matthew Jones

Senior Management Personnel
The Trustees delegate day-to-day management of the charity to:
Karen Cockburn, Charity Director

Patrons
Gillian Anderson
Simon Callow
Thomas Young

Independent Examiners
David Howard Chartered Accountants
1 Park Road
Hampton Wick
Kingston - upon - Thames
Surrey
KT1 4AS

Bankers
National Westminster Bank Plc
5 Market Place
Kingston - upon - Thames
Surrey
KT1 1VX

Board of Trustees Report for the Year Ended 31 October 2023

The Trustees are pleased to present their annual report and financial statements for the year ended 31 October 2023.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, Trustee Investment (Scotland) Act 2005, the charities Accounts (Scotland) Regulations 2006 (as amended), the Memorandum and Articles of Association, and the Charities Statement of Recommended Practice ("Charities SORP") (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland; FRS 102) effective from 1 January 2019.

Objectives and Activities

Nerve Tumours UK's vision sees a future in which the needs of everyone with NF are met, and the charity is central to making that happen.

To allow the charity to deliver this vision of helping to improve the lives of those affected by NF, (the new medical name for Neurofibromatosis Type 1 (NF1), NF2-related-Schwannomatosis (NF2) and Schwannomatosis (SWN)), and in being central to making this happen, we work in collaboration with the Highly Specialised Commissioning Services, formerly the National Commissioning Group (NCG) funded service, and other associated medical professional units around the UK.

Nerve Tumours UK's mission is to improve the lives of everyone affected by Neurofibromatosis through support services, advocacy and promoting understanding and knowledge of the condition. Central to our mission is our ambition to be the UK's authoritative voice on Neurofibromatosis and our determination to serve, support and celebrate the lives of people impacted by the condition, and their wider support network.

The charity continues to deliver its mission through five key services to members, supporters, and beneficiaries. It endeavours to:

- **Inform** — We provide accurate, relevant, and up to date information that explains the conditions of NF1, NF2 and SWN, the implications, challenges and opportunities, in language understood by all.
- **Advise** — We provide practical and emotional advice to help people find the best services and support available. We enable people to make choices about how they approach and live with NF.
- **Advocate** — We aim to increase knowledge, awareness and understanding of NF, and will campaign for change in areas we believe will improve the lives of those affected by NF.
- **Connect** — We take a pivotal role in bringing together groups of people interested in NF to maximise the support and information available to them.
- **Fund** — We make funds available for small projects to bodies and patient groups where we believe it will make a difference.

The charity works with the following groups to achieve its mission:

- Patients and carers
- Families with NF
- The medical community
- NF Specialist Network of Nurses and Advisors
- The research community (particularly The Nerve Tumours UK Medical Advisory Board)
- Supporters
- Volunteers

- Other charities and umbrella organisations

Achievements and Performance

We continue to be hindered by the ongoing repercussions of the Covid-19 pandemic, as people with NF are more susceptible to the virus due to the associated complications of NF, however, the charity has continued to concentrate on its central five services again this year. We have continued working to strengthen and develop our core support structures to ensure that we could continue to provide the best possible support and information to anyone affected by NF. However, our services continue to face increased demand. This is due to the uncertain economic climate and the resulting absence or difficulty in obtaining primary and secondary care services. Most face-to-face consultations have now returned, but some services are still provided virtually or by telephone consultation.

As a result of this ongoing situation in the wider care sector, the charity took the decision to expand the National NF Helpline service from two to three days per week from the beginning of this reporting year and will continue to monitor demand to ensure the service meets the needs of the community.

Continuing Impact of Covid-19 on Charity Services & Finances

We fund a unique and vital service, which is not provided by other organisations. Our services are particularly important for people diagnosed with NF and their carers. Many people with NF are vulnerable and often isolated. Our experience is that many are still distressed by the ongoing health crisis, as some of their complications may make them more susceptible to Covid-19. The effect on the broader group of people with NF continues, as there is continues to be a significant backlog of appointments for genetics and neurology clinics. This was initially caused by reduced NHS staffing, many of whom had been redeployed to critical and Covid-19 services and made worse by the NHS strikes over the last year. In response, the charity continued to provide and grow services to ensure that we could continue to reach and support our beneficiaries. In particular, the charity is concerned about the ongoing potential impact on mental health both for our beneficiaries and our staff.

As the charity does not receive statutory or local funding, the bulk of the charity's income comes from charitable giving and monies raised from events. Many events were again either postponed or cancelled, which has again had a significant adverse effect on income streams. However, we continue to fundraise as much as possible with new, innovative, and virtual initiatives.

As we fund a network of Specialist NF Nurses and Advisors (Specialist Advisors), our policy requires us to maintain a minimum of 12 months of reserves. The charity continues to react quickly to the constraints of the pandemic and the resultant economic climate. This has minimised the impact on the level of reserves over the last few financial years. At this time, we are confident that we are able to continue to maintain our reserves policy.

Plans for Future Sustainability

The pandemic and current economic climate forced us to reconsider our strategic plan. The Board implemented a strategy group to look at how we can continue to provide our services, in a post-Covid world and recessionary economic environment.

Key Strategic Aims:

- To increase awareness and understanding of NF.
- To provide timely and meaningful support and guidance to those living with NF and their wider support network.
- To promote and support research into NF.

Our focus continues to be on how we can streamline our services, co-ordinate our work with partners and improve the education of the medical profession. Our aim is to ensure that people are able to access advice and support as effectively and efficiently as possible, whether or not that is from the charity. This year, we have launched a new medical hub on our website, with easy access to lectures, guidelines and other relevant tools to educate wider allied healthcare professionals.

The charity continues to look at new ways of working, including virtual clinics, appointments and meetings. Although online services are not practical for all (for example, patients with cognitive impairment and learning issues), we can see that improved online connectivity and familiarity leads to reduced delivery costs and greater efficiency. In the future our intention is that a balance of online and in person delivery will allow the charity to provide services to more people.

Specialist Advisors

The charity will continue to maintain its Specialist Advisors and will seek to identify areas of the country where we can work with the NHS to make joint appointments.

The charity currently funds a network of ten Specialist Advisors across the UK, supporting posts in Newcastle (1), Birmingham (2), Plymouth, Liverpool, Southampton, Sheffield, Leeds, London, Wales, and Northern Ireland. Unfortunately, two posts became vacant during the year. For Scotland, as an interim, we are working closely with the Scottish Office for Rare Diseases. Two Specialist Advisors operate the Nerve Tumours UK national helpline on a part time basis, which provides advice and connects people affected by NF with relevant practical help, either in their community, or in clinic. We aim to introduce two new posts during the next financial year in parts of the UK, where there has never been any regional support. Each post supports between 150 – 3,320 patients per year working via clinics, home visits, schools, advisory services, and telephone consultation.

The role of Specialist Advisors is very diverse. We have had excellent feedback from the families supported by our Specialist Advisors. It is plain to see that for those families, the support they receive from the charity and our Specialist Advisors is pivotal in helping them to cope with NF. Supporting the Specialist Advisors network will continue to be a key role for Nerve Tumours UK.

Over 60% of patients with NF1 have learning difficulties, and approximately 30% are registered as disabled, as are 75% of those patients with NF2. However, public awareness of NF is low. Our experience is that this can lead to some children with NF struggling at school, with inappropriate, or non-existent support. Nerve Tumours UK offers a schools' advisory service, iNForm, staffed by our Specialist Advisors. Where engaged, the team works closely with teachers, supporting tailored learning plans, and suggesting mechanisms for enhancing the child's experience at school. Even during the pandemic, we have found that we can still operate iNForm effectively, albeit virtually, and in the last year, plus, we have found that more allied healthcare professionals are willing and able to join the iNForm meetings if held virtually.

Nerve Tumours UK continues to offer an extensive range of literature and information, for lay people and professionals. Our literature is widely used by medical teams across the country. Our leaflets and pamphlets are subject to constant review and update. Medical professionals are also invited to use the Nerve Tumours UK national helpline.

Charity Reach

The Nerve Tumours UK Head Office team continue to work exceptionally hard. They continue to go above and beyond in response to the continuing fallout from the pandemic, and the Board are once again very grateful for their efforts. Key workstreams have included the further development of our website, in particular the new medical section, and the constantly updated research hub. We have had extremely positive feedback since its launch in 2023, and trust this improves and widens our engagement with medical professionals, particularly GP's.

Social media remains an important and growing aspect of the charity's engagement strategy. We continue to see increasing visits to our website. This has greatly increased our interactions and the support we can provide to the community. Facebook coverage and engagement has continued to grow. Over 76,700 people are reached organically each month, and our page views are up by 7.2% this year. Our website achieves an average of 68,000 users per month. Nerve Tumours UK's Twitter reach continues to grow steadily with 1,712 followers. Our tweets

make an average of 345,000 impressions per month. Our Instagram reach is also increasing, and we now have 2087 followers.

The number of subscribers to the Nerve Tumours UK newsletter has increased to 4,585 this year. We continue our membership of a number of other social and marketing branches such as MeetUp groups, which directly target our challenge events outside the community. At 194 members, we are reaching a wider audience than before. On World NF Awareness Day in May 2023 total social media posts on the respective NF1 and NF2 Days led to the highest peak of activities across social media and the web that year.

We also continue to seek to develop and strengthen our institutional partnerships with organisations including The Centre for Appearance Research, The Genetic Alliance, The Neurological Alliance, Genetic Disorders UK and Embracing Complexity. We also intend to launch three medical information days in the forthcoming year.

The continued rollout of core services throughout the period is an excellent reflection of the combined efforts and dedication of the Specialist Advisors, our members, supporters, head office staff and Medical Advisory Board and the Trustees are very grateful for the exceptionally hard work, which has been put into the charity.

There are no immediate financial concerns for the charity, although the economic climate remains of concern, and Nerve Tumours UK is still currently on track to meet its long-term financial targets.

Structure, Governance and Management

Nerve Tumours UK is a Charitable Company, limited by guarantee, incorporated on 30 June 1999, and registered as a charity on 5th January 2000 (previously 284653 registered 1982) with a membership base. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required by the adopted Constitution to contribute an amount not exceeding £1.

The directors of the company are also charity Trustees for the purposes of charity law, and under the company's Articles are known as members of the Board of Trustees. The Board of Trustees meets at least four times a year and is responsible for the strategic direction and policy of the charity and appointing auditors to ensure financial compliance. Medical input is given via our Medical Advisory Board, a representative of which sits on the Board of Trustees.

Medical Background

The charity's membership is mostly drawn from families affected by NF. NF1 affects 1 in every 2,500 people worldwide, which means that there are more than 25,000 in the UK; NF2 is much rarer, with 1 in 35,000 affected worldwide (1,000 in the UK).

An affected person of either sex has a 1 in 2 (50:50) chance of passing the altered (abnormal) gene on to their children. However, everyone has a risk of having an affected child because 50% of all those affected by NF are the first person in their family to be so affected.

NF1 is a hugely variable condition, which has the potential to develop a large number of complications. Some people with NF1 only having skin involvement, but potential complications include: specific learning difficulties and behavioural problems - which affects about 60% of all people with NF1; high blood pressure (hypertension); curvature of the spine (scoliosis); malformation of the long bones (below the knee and below the elbow) (pseudarthrosis); large benign skin tumours (plexiform neurofibromas); tumours on the nerves of sight (optic glioma); internal, spinal and brain tumours – which are usually benign however 10-15% of people will develop a malignant tumour related to their NF1. The most significant issue for people with NF1 is that the occurrence of these complications cannot be predicted even within families. Many people with NF1 also have low self-esteem and this can cause problems forming friendships, which leads to isolation.

NF2 consistently causes more problems than NF1, and it has an increased risk of developing brain tumours. Although these tumours are benign, the position in which they grow can cause major problems. The most common site is on the hearing and balance nerves causing problems with deafness and coordination. The sense of isolation from deafness onset in adulthood can be immense. People with NF2 may also develop spinal cord tumours, with

their own significant complications.

NF is an unpredictable and variable genetic condition that can affect all people regardless of gender, race or age. During their lifetime, patients may see a wide range of health and social care professionals, both in community and hospital settings. The Specialist Advisors act as a point of reference for families helping them navigate through routine planned events and at times of crisis. Essentially, their role is to help people to learn to live with their diagnosis of NF and to equip them with the knowledge of when, where, and how to seek help, if necessary.

As a multi-system condition, NF has an impact on many areas of people's lives, not just health. The Specialist Advisors take a lead role in liaison and advocacy with health, education, and social services to support the quality and continuity of care for families affected by NF. They seek to develop a service that is professional, timely and responsive to need. Their setting may be clinical, visiting families at home or telephone contact. The quality of the relationships they establish is critical to their effectiveness and may continue over many years.

Financial Review

Income Generating Activities

Our head office team continue to develop innovative virtual fundraising ideas and source new income streams.

During the period the charity had income resources of £456,409 and a total expenditure of £424,665 resulting in net resources of £31,744.

Investment Policy

The charity's funds have been invested in a mixture of one year fixed income bonds and short-term deposits this financial year. A Financial Advisory & Investment Group, established in late 2022, reporting to the Board of Trustees, continue to review this position and further investment opportunities, to ensure all income potential is maximised, with minimum risk.

We give careful consideration as to how we can make our reserves generate an income for the charity and have considered a number of options and informal advice. At present, given the current rate of return, the costs involved in investing, and the inherent risk, we have continued to elect to hold the reserves in a mixture of short and medium term deposits with a number of banks. However, we will continue to monitor all other options available.

Reserves Policy and Going Concern

Reserves are needed to bridge the gap between the spending and receiving of income and to cover unplanned emergency expenditure. The Trustees consider a minimum of £500,000 is the ideal level of reserves and being sufficient unrestricted reserves to fund the Specialist Advisor network for a minimum of twelve months due to the number of multi-year contractual commitments, and the charity's administrative and operating costs for at least six months.

The Trustees consider that adequate resources continue to be available to fund the activities of the charity for the foreseeable future. The Trustees are of the view that the charity is a going concern.

Key Expenditure Areas

The key areas of expenditure continue to be the operational costs of the Specialist Advisor network. Each year, we aim to raise sufficient funds to maintain the twelve months' reserves. If the charity provides further funding for the Specialist Advisor network, this expenditure, and the required reserves, is likely to increase.

Public Benefit

All our charitable activities focus on improving the lives of those affected by NF and are undertaken to further our charitable purposes for public benefit. The Trustees have regard to the Charity Commission's guidance on the need for charities to deliver a public benefit and have complied with the duty in section 17(2) of the Charities Act 2011.

Recruitment, Appointment & Induction of Board of Trustees

Under the requirements of the Memorandum and Articles of Association, the one-third longest standing members of the Board of Trustees shall retire or put themselves forward for re-election at the next Annual General Meeting. The maximum time a trustee can remain in post is ten years, although that time may be extended for a short period by the Board on an exceptional basis.

The Board of Trustees seeks to recruit a diverse mix of business, medical and patient expertise, there is no requirement for a Board member to have any direct or indirect experience of NF. All Trustees, upon election, meet with the Chair to discuss and agree specific requirements of the role.

Statement of Trustees responsibilities

The Trustees, who are also the directors of the Neurofibromatosis Association for the purpose of company law, are responsible for preparing the Trustees Report and the financial statements in accordance with FRS102 and the charity SORP (FRS 102). The Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity at the end of the financial year and of its surplus or deficit for that period. In doing so, the Trustees are responsible for:

- selecting suitable accounting policies and then apply them consistently;
- observing the methods and principles in the Charities SORP;
- making judgements and estimates that are reasonable and prudent;
- preparing the financial statements on the going concern basis unless it is not appropriate to assume that the company will continue on that basis; and
- the maintenance and integrity of the corporate and financial information included on the charity's website.

The Board of Trustees is responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time that the financial statements comply with the Companies Act 2006. The Board of Trustees is also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Members of the Board of Trustees

Members of the Board of Trustees, who are directors for the purpose of company law, and Trustees for the purpose of charity law, who served during the year and up to the date of this report, are set out on page 1.

Small company provisions

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

Approved by the Board of Trustees on 04 March 2024, and signed on its behalf by:

Michael Fry
Chair of the Board of Trustees

Richard Goode
Vice Chair & Company Secretary

Independent Examiners' Report to the Trustees of The Neurofibromatosis Association (Nerve Tumours UK)

I report on the accounts of the company for the year ended 31st October 2023, which are set out on pages 8 to 18.

Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under Part 16 of The Companies Act 2006, section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10(1)(a) to (c) of the Charities Accounts (Scotland) Regulations 2006 ("The 2006 Regulations") and that an independent examination is needed. The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Association on Chartered Certified Accountants and it is my responsibility to:

- examine the accounts under section 145 of the Charities Act 2011 and under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

Basis of Independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission and is in accordance with Regulations 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below

Independent examiner's statement

In connection with my examination, no matter has come to my attention:
(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 386 of the Companies Act 2006 and section 44(1)(a) of the 2005 Act and regulation 4 of the 2006 Accounts Regulations; and
- to prepare accounts which accord with the accounting records, comply with the accounting requirements under Section 396 of the Companies Act 2006, section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations
- which are consistent with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities (SORP FRS102)

have not been met; or
(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Siobhan Glenister, ACA
For and on behalf of David Howard Chartered Accountants
1 Park Road
Hampton Wick
Kingston Upon Thames
Surrey
KT1 4AS
Date: 14th **March 2024**

Statement of Financial Activities (including Income & Expenditure Accounts) for the Year ended 31 October 2023

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total funds 2023 £	Total funds 2022 £
Income:					
Donations & Legacies	2	277,705	90,450	368,155	424,495
Income from Charitable Activities	2	71,377	8,786	80,162	87,353
Investment Income	2	8,091		8,091	668
Incoming Resources from Charitable Activities		**357,173**	**99,236**	**456,409**	**512,516**
Other Incoming Resources		-	-	-	-
Total Income		**357,173**	**99,236**	**456,409**	**512,516**
Expenditure:	4				
Cost of raising funds		102,689	-	102,689	106,132
Expenditure on charitable activities		198,847	123,128	321,975	342,202
Total Resources Expended		**301,536**	**123,128**	**424,665**	**448,334**
Net Income (Expenditure)		**55,637**	**(23,892)**	**31,744**	**64,183**
Reconciliation of funds					
Total funds brought forward		567,465	47,864	615,329	551,146
Net movement in funds for the year		55,637	(23,892)	31,744	64,183
Total funds carried forward		**623,101**	**23,972**	**647,073**	**615,329**

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing operations.

Balance sheet as at 31 October 2023

		2023	2022
		£	£
Tangible fixed assets	10	757	754
Current assets			
Debtors	11	13,482	302
Cash at bank and in hand		787,928	733,613
		801,410	733,915
Creditors : amounts falling due within one year	12	155,094	119,341
Net current assets		**646,316**	**614,575**
Net assets		**647,073**	**615,329**
Analysis of net assets between funds			
Unrestricted funds	13	623,101	567,465
Restricted funds	13	23,972	47,864
Total funds		**647,073**	**615,329**

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 October 2023 relating to small companies.

The trustees have not required the charitable company to obtain an audit of its financial statements for the year ended 31 October 2023 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of accounts.

The financial statements are prepared in accordance with the special provisions of the Companies Act 2006 and section 138 of the Charities Act 2011. These accounts are prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) – (Charities SORP (FRS 102)).

The notes at pages 11-18 form part of these accounts.

Approved by the Board of Trustees on 04 March 2024, and signed on its behalf by:

Michael Fry
Chair of The Board of Trustees

Richard Goode
Vice Chair & Company Secretary

Company Registration No. 03798407
Charity Registration No. 1078790
Scottish Charity Register No. SC045051

1. Accounting policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the year and the preceding year.

a) Basis of accounting

The financial statements comply with the Charities Act 2011, the Companies Act 2006, Trustee Investment (Scotland) Act 2005, the charities Accounts (Scotland) Regulations 2006 (as amended), the Memorandum and Articles of Association, and the Charities Statement of Recommended Practice ("Charities SORP") (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland; FRS 102) effective from 1 January 2019.

The Neurofibromatosis Association meets the definition of a public benefit entity under FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the Charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

b) Fund accounting

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the Charity, and
- Restricted funds are subjected to restrictions on their expenditure imposed by the donor.

c) Income

All incoming resources are included in the statement of financial activities when the charity is entitled to the income, and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

- Income from donations and legacies is received by way of grants, donations, fundraising and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant,
- The value of services provided by volunteers has not been included in these accounts,
- Income from charitable activities are accounted for when earned, and
- Income resources from grants, where related to performance and specific deliverables, are accounted for as the charity earns the right to consideration by its performance.
- There has been a change in the accounting policy for Lifetime Subscriptions from 2010/11. Henceforth income resources from lifetime subscriptions will be fully accounted for in the year in which the subscription is registered.

d) Expenditure

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

- Costs of raising funds comprise the costs associated with attracting voluntary income, and also include governance costs. These include those costs associated with meeting the constitutional and statutory requirements of the charity and include the independent examination fees and costs linked to the strategic management of the charity.
- Expenditure on charitable activities comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- All costs are allocated between expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resource.
- Depreciation: Assets are written off over two years on the straight line basis of depreciation.

e) Fixed Assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Individual fixed assets costing £250 or more are capitalised at cost.
Depreciation: the value of each asset is written off over two years, on a straight-line basis.

f) Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

g) Debtors

Trade and other debtors are recognised at the settlement amount due.

h) 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.

i) Information and legal status of the charity

Nerve Tumours UK is a Charitable Company, limited by guarantee, incorporated on 30 June 1999, and registered as a charity on 5th January 2000 (previously 284653 registered 1982) with a membership base. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required by the adopted Constitution to contribute an amount not exceeding £1.

j) Pensions

The pension costs charged in the financial statements represent the contribution payable by the charity during the year. Contributions are made to defined contribution schemes in the UK.

2. Income

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total funds 2023 £	Total funds 2022 £
a) Donations & Legacies				
Donations and gifts	36,089	-	36,089	34,357
Events	120,189	-	120,189	79,046
Gift Aid	24,164	-	24,164	27,940
Grants	13,850	90,450	104,300	131,250
Legacies	77,452	-	77,452	144,996
Subscriptions	5,962	-	5,962	6,906
	277,705	**90,450**	**368,155**	**424,495**
b) Income from Charitable Activities				
Fundraising	71,377	8,786	80,162	81,056
Goods for Sale	-		-	6,297
	71,377	**8,786**	**80,162**	**87,353**
c)Investment Income				
Interest	**8,091**	-	**8,091**	**668**

3. Grants

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total funds 2023 £	Total funds 2022 £
The Grace Trust		750	750	-
The Peacock Trust		5,000	5,000	10,000
The Childwick Charitable Trust		10,000	10,000	-
The Three Oaks Trust		10,000	10,000	10,000
The Norman Family Charitable Trust			-	1,000
The Baron Davenport Charity		1,200	1,200	1,000
The Schon Charitable Trust		550	550	400
The Sir James Rolls Charitable Trust		1,250	1,250	-
The Eveson Charitable Trust		10,000	10,000	10,000
The Hilary Awdry Charitable Trust		500	500	1,000
The James Tudor Foundation		5,000	5,000	7,500
Anonymous		10,000	10,000	10,000
AstraZeneca PLC			-	30,000
Alexion Pharmaceuticals UK		15,000	15,000	-
The Hospital Saturday Fund		-	-	2,000
The Claire Milne Trust		5,000	5,000	-
The Roger & Jean Jefcoate Trust			-	5,000
The Dixie Rose Findlay Charitable Trust			-	3,000
The Cuthbert Horn Trust	7,000		7,000	-
The Pears Foundation		8,500	8,500	8,500
The Joseph Hopkins Charitable Foundation		700	700	750
The Gaia Foundation			-	3,000
The Hadrian Trust		1,000	1,000	1,000
The PF Edwards Charitable Trust		4,000	4,000	3,000
The Orr Mack Foundation			-	5,000
The John Avins Trust		2,000	2,000	1,000
The Roger & Douglas Turner Trust			-	5,000
The Thomas J Horne Memorial Trust	6,000		6,000	11,000
LSEG	850		850	-
The Sheffield Town Trust			-	2,000
The Woodhall Chaitable Trust			-	100
	13,850	**90,450**	**104,300**	**131,250**

4. Expenditure

£	Cost of raising funds				Charitable activities		
	Events	Voluntary income	Trusts	Governance	Information and meetings	Specialist NF Nurses	Total
Costs directly allocated to activities							
Independent Examiner Fee	-	-	-	2,400	-	-	2,400
Independent Examiner Fee for other works	-	-	-	2,339	-	-	2,339
Events	37,977	-	-	-	-	-	37,977
Fundraising	-	22,674	22,577	-	-	-	45,251
Newsletters and information	-	-	-	-	110,047	-	110,047
Helpline & Clinical Support							-
NSA's	-	-	-	-	-	152,847	152,847
Research	-	-	-	-	-	-	-
Trustee and committee meetings	-	-	-	198	-	-	198
	37,977	22,674	22,577	4,937	110,047	152,847	351,059
Support costs allocated to activities **							
Staff costs	3,107	2,936	5,863	2,125	25,446	5,552	45,029
Consultancy/Professional Fees	-	-	-	-	-	-	-
Depreciation	104	99	197	71	854	186	1,511
Premises	1,441	1,362	2,719	986	11,803	2,575	20,886
Printing, postage and stationery	84	80	159	58	692	151	1,224
IT, telephone and fax	342	323	645	234	2,800	611	4,955
Other	-	-	-	-	-	-	-
	5,079	4,799	9,583	3,474	41,595	9,076	73,606
Total	43,056	27,473	32,160	8,411	151,641	161,923	424,665

Staff Cost	Allocation based on time spent on activities
Premises Costs	Allocation based on staff costs
Depreciation	Allocation based on premises costs
It, etc	Allocation based on staff costs

5. Net Incoming Resources for the Year

This is stated after charges:	2023 £	2022 £
Depreciation	1511	2037
Independent Examination Fee	2400	4680
	3911	6717

6. Staff costs and numbers

	2023 £	2022 £
Salaries and wages	199,310	180,658
Social security costs	11,739	10,450
Pension costs	4,261	3,708
	215,310	**194,816**

No employees received emoluments of more than £60,000. The charity operates a pension scheme for its employees as currently required.

The average number of employees during year, calculated on the basis of full-time equivalents, was as follows:

	2023	2022
CEO		
Membership Secretary		
IT/Information	1.5	1.5
Fundraising	2.3	2.3
Specialist Support	0.6	0.4
Change manager		
Development managers	0.6	0.6
	5.0	**4.8**

7. Trustee remuneration

No members of the Board of Trustees received any remuneration during the year; travel costs totaling £146.14 were reimbursed during the year to one member of the Board of Trustees (last year, £64.70 was reimbursed to one member of the Board of Trustees).

8. Related party transactions

There were no Related Party Transactions during the year. No Trustee, or other person related to the charity, had any personal interest in any transaction.

9. Taxation

As a charity, The Neurofibromatosis Association is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or s256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the Association.

10. Tangible fixed assets

	2023 £	2022 £
Cost		
As at 1 November	10,121	8,613
Additions	1,515	1,508
Removal of fully depreciated assets		
As at 31 October	11,636	10,121
Accumulated depreciation		
As at 1 November	9,368	7,331
Charge for the year	1,511	2,037
Removal of fully depreciated assets		
As at 31 October	10,879	9,368
Net book value		
As at 1 November	754	1,283
As at 31 October	**757**	**754**

11. Debtors

	2023 £	2022 £
Debtor Control Account	162	302
Rent Deposit	-	-
Other debtors	-	-
Prepayments	13,320	-
	13,482	**302**

12. Creditors: amounts falling due within one year

	2023 £	2022 £
Trade Creditors	62,133	44,585
Taxation	4,661	5,621
Lottery Grant	-	-
Other Creditors	20,836	-
Accruals and deferred income	67,465	69,135
	155,094	**119,341**

13. Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds
	£	£	£
Tangible fixed assets	757	-	757
Current assets	777,438	23,972	801,410
Current liabilities	155,094	-	155,094
	623,101	**23,972**	**647,073**

14. Movement in funds

	At 1 November 2022	Incoming Resources	Outgoing Resources	At 31 October 2023
Restricted Funds				
Support Groups	3,744	-	-	3,744
Research/Specialist Support Network	27,269	75,736	99,628	3,377
Awareness Campaigns	-	15,000	15,000	-
NF2 Activities	16,851	-	-	16,851
Support Costs	-	8,500	8,500	-
	47,864	99,236	123,128	23,972
Unrestricted Funds	567,465	357,173	301,536	623,101
Total Funds	**615,329**	**456,409**	**424,665**	**647,073**

Purposes of Restricted Funds

Support Groups:	This grant is for the funding of support groups in various parts of the country
Research/NSA's:	Donations made to be spent on Research/ Specialist Support Network.
Awareness Campaigns:	Donations restricted to spend on information campaigns
NF2 activities:	Donations made specifically for the running of the NF2 activities each year
Support Costs:	Donations made for spend on head office staff to support the NSA operations

15. Financial commitments

At 31 October 2023, the charity had annual commitments under non-cancellable operating leases, following rent renegotiations, as follows:

	2023
	£
Expiry date:	
Not later than one year	12,000
Later than one year and not later than five years	31,000
	43,000

THE NEUROFIBROMATOSIS ASSOCIATION

England & Wales - Charity number 1078790

Accounts

The Neurofibromatosis Association

Report of the Board of Trustees

Year ended 31 October 2022

Charity Registration Number 1078790
Scottish Charity Registration Number SC045051
Company Registration Number 03798407

The Neurofibromatosis Association
Report and financial statements
Year ended 31 October 2022

Reference and administrative information

Charity Name:	The Neurofibromatosis Association
Charity Registration Number:	1078790
Scottish Charity Registration Number:	SC045051
Company Registration Number:	3798407
Charity Working Name:	Nerve Tumours UK
Registered office and operational address:	44 Coombe Lane West Wimbledon London SW20 0LA
Telephone:	020 8439 1234
Fax:	020 8439 1200
E-mail address:	info@nervetumours.org.uk
Website address:	www.nervetumours.org.uk

Nerve Tumours UK

Nerve Tumours UK is the working name of the charity, which retains its legal name "The Neurofibromatosis Association".

Board of Trustees
The current Board of Trustees is:

Michael Fry (Chair)
Dr. Timothy Corn
Emily Owen
Stewart Lee
Richard Goode (Vice Chair)
Professor Rosalie Ferner
Jonathan Bruce
Rohan Chanmugam
Professor Meena Upadhyaya
Matthew Jones

Senior Management Personnel
The Trustees delegate day-to-day management of the charity to:
Karen Cockburn, Charity Director

Patrons
Gillian Anderson
Simon Callow

Auditors
David Howard Chartered Accountants
1 Park Road
Hampton Wick
Kingston - upon - Thames
Surrey
KT1 4AS

Bankers
National Westminster Bank Plc
5 Market Place
Kingston - upon - Thames
Surrey
KT1 1VX

Board of Trustees Report for the Year Ended 31 October 2022

The Trustees are pleased to present their annual report and financial statements for the year ended 31 October 2022.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, Trustee Investment (Scotland) Act 2005, the charities Accounts (Scotland) Regulations 2006 (as amended), the Memorandum and Articles of Association, and the Charities Statement of Recommended Practice ("Charities SORP") (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland; FRS 102) effective from 1 January 2019.

Objectives and Activities

The charity's vision is "To improve the lives of those affected by Neurofibromatosis".

To allow the charity to deliver this vision of helping to improve the lives of those affected by Neurofibromatosis (NF), and in being central to making this happen, we work in collaboration with the Highly Specialised Commissioning Services, formerly the National Commissioning Group (NCG) funded service, and other associated medical professional units around the UK.

The mission for the charity is to "Enable people concerned about Neurofibromatosis to find solutions appropriate to them by increasing awareness, and by providing support and information on Neurofibromatosis".

Central to this mission, is our ambition to be the UK's authoritative voice on Neurofibromatosis and our determination to serve, support and celebrate the lives of people impacted by the condition, and their wider support network.

The charity continues to deliver its mission through five key services to members, supporters and beneficiaries. It endeavours to:

- **Inform** — We provide accurate, relevant, and up to date information that explains the conditions of NF1 and NF2, the implications, challenges and opportunities, in language understood by all.
- **Advise** — We provide practical and emotional advice to help people find the best services and support available. We enable people to make choices about how they approach and live with Neurofibromatosis.
- **Advocate** — We aim to increase knowledge, awareness and understanding of Neurofibromatosis, and will campaign for change in areas we believe will improve the lives of those affected by Neurofibromatosis.
- **Connect** — We take a pivotal role in bringing together groups of people interested in Neurofibromatosis to maximise the support and information available to them.
- **Fund** — We make funds available for small projects to bodies and patient groups where we believe it will make a difference.

The charity works with the following groups to achieve its mission:

- Patients and carers
- Families with neurofibromatosis
- The medical community
- NF Specialist Network of Nurses and Advisors
- The research community (particularly The Nerve Tumours UK Medical Advisory Board)
- Supporters

- Volunteers
- Other charities and umbrella organisations

Achievements and Performance

Although hindered by the ongoing repercussions of the Covid-19 pandemic over the last few years, the charity has continued to concentrate on its central five services again this year. The pandemic did not detract from working to strengthen and develop our core support structures to ensure that we could continue to provide the best possible support and information to anyone affected by NF. However, our services continue to face increased demand. This is due to the uncertain economic climate and the resulting absence or difficulty in obtaining primary and secondary care services. Most face-to-face consultations have now returned, but some services are still provided virtually or by telephone consultation.

As a result of this ongoing situation in the wider care sector, the charity took the decision to expand the National Neurofibromatosis Helpline service from two to three days per week.

Impact of Covid-19 on Charity Services & Finances

We fund a unique and vital service, which is not provided by other organisations. Our services are particularly important for people diagnosed with NF and their carers. Many people with NF are vulnerable and often isolated. Our experience is that many are distressed by the ongoing health crisis, as some of their complications may make them more susceptible to Covid-19. Many still have to shield. The effect on the broader group of people with NF continues, as there is a significant backlog of appointments for genetics and neurology clinics. This was caused by reduced NHS staffing, many of whom had been redeployed to critical and Covid-19 services. In response, the charity continued to provide and grow services to ensure that we could continue to reach and support our beneficiaries. In particular, the charity is concerned about the ongoing potential impact on mental health both for our beneficiaries and our staff.

As the charity does not receive statutory or local funding, the bulk of the charity's income has been from charitable giving and monies raised from events. For a third year, many events were either postponed or cancelled, which has again had a significant adverse effect on those income streams. However, we continue to fundraise as much as possible with new, innovative, and virtual initiatives.

As we fund a network of Specialist NF Nurses and Advisors (Specialist Advisors), our policy requires us to maintain a minimum of 12 months of reserves. The charity continues to react quickly to the constraints of the pandemic and the resultant economic climate. This has minimised the impact on the level of reserves over the last few financial years. At this time, we are confident that we are able to continue to maintain our reserves policy.

Plans for Future Sustainability

The pandemic and current economic climate forced us to reconsider our strategic plan. The Board implemented a strategy group to look at how we can continue to provide our services, in a post-Covid world and recessionary economic environment.

Key Strategic Aims:

To increase awareness and understanding of Neurofibromatosis.

To provide timely and meaningful support and guidance to those living with Neurofibromatosis and their wider support network.

To promote and support research into Neurofibromatosis.

Our focus continues to be on how we can streamline our services, co-ordinate our work with partners and improve the education of the medical profession. Our aim is to ensure that people are able to access advice and support as effectively and efficiently as possible, whether or not that is from the charity.

The charity continues to look at new ways of working, including virtual clinics, appointments and meetings. Although online services are not practical for all (for example, patients with cognitive impairment and learning issues), we can see that improved online connectivity and familiarity leads to reduced delivery costs and greater efficiency. In the future our intention is that a balance of online and in person delivery will allow the charity to provide services to more people.

Specialist Advisors

The charity will continue to maintain its Specialist Advisors and will seek to identify areas of the country where we can work with the NHS to make joint appointments.

The charity currently funds a network of twelve Specialist Advisors across the UK, supporting posts in Newcastle (2), Birmingham (2), Plymouth, Liverpool, Southampton, Sheffield, Leeds, Wales, Scotland and Northern Ireland. Two Specialist Advisors provide the Nerve Tumours UK national helpline on a part time basis, which provides advice and connects people affected by NF with relevant practical help, either in their community, or in clinic. We aim to introduce two new posts during the next financial year in parts of the UK, where there has never been any regional support. Each post supports between 150 – 3,300 patients per year working via clinics, home visits, schools, advisory services, and telephone consultation.

The role of Specialist Advisors is very diverse. We have had excellent feedback from the families supported by our Specialist Advisors. It is plain to see that for those families, the support they receive from the charity and our Specialist Advisors is pivotal in helping them to cope with NF. Supporting the Specialist Advisors network will continue to be a key role for Nerve Tumours UK.

Over 60% of patients with NF1 have learning difficulties, and approximately 30% are registered as disabled, as are 75% of those patients with NF2. However, public awareness of NF is low. Our experience is that this can lead to some people with NF struggling at school, with inappropriate, or non-existent support. Nerve Tumours UK offers a schools' advisory service, iNForm, staffed by our Specialist Advisors. Where engaged, the team works closely with teachers, supporting tailored learning plans, and suggesting mechanisms for enhancing the child's experience at school. Even during the pandemic, we have found that we can still operate iNForm effectively, albeit virtually.

Nerve Tumours UK continues to offer an extensive range of literature and information, for lay people and professionals. Our literature is widely used by medical teams across the country. Our leaflets and pamphlets are subject to constant review and update. Medical professionals are also invited to use the Nerve Tumours UK national helpline.

The Nerve Tumours UK Head Office team continue to work exceptionally hard. They continue to go above and beyond in response to the continuing fallout from the pandemic, and the Board are once again very grateful for their efforts. Key workstreams have included the further development of our website, in particular the sections on partner charities, mental health, the cost-of-living crisis and research. A new "medics only" section of the website is due to be launched in Spring 2023. We hope that this improves and widens our engagement with medical professionals, particularly GP's.

Social media remains an important and growing aspect of the charity's engagement strategy. We continue to see increasing visits to our website. This has greatly increased our interactions and the support we can provide to the community. Facebook coverage and engagement has continued to grow. Over 73,800 people are reached organically each month and our page views are up by 3.2% year on year. Our website achieves an average of 53,000 users per month, with 58,328 in December 2022 alone. Nerve Tumours UK's Twitter reach continues to grow steadily with 1,594 followers. Our tweets make an average of 319,000 impressions per month. Our Instagram reach is also increasing, and we now have 1,912 followers.

The number of subscribers to the Nerve Tumours UK newsletter has increased to 4,148, an increase of 36% this year. We continue our membership of a number of other social and marketing branches such as MeetUp groups, which directly target our challenge events outside the community. At 189 members, we are reaching a wider audience than before. On World NF Awareness Day in May 2022 total social media posts on the respective NF1 and NF2 Days led to the highest peak of activities across social media and the web that year.

We also continue to seek to develop and strengthen our institutional partnerships with organisations including The Centre for Appearance Research, The Genetic Alliance, The Neurological Alliance, Genetic Disorders UK and Embracing Complexity. We have started planning for conferences, events and outreach in 2023.

There are no immediate financial concerns, although the economic climate is of concern, Nerve Tumours UK is still currently on track to meet its long-term financial targets.

The continued rollout of core services throughout the period is an excellent reflection of the combined efforts and dedication of the Specialist Advisors, our members, supporters, head office staff and Medical Advisory Board during this continued unprecedented period. The Trustees are very grateful for the exceptionally hard work which has been put into the charity.

Structure, Governance and Management

Nerve Tumours UK is a Charitable Company, limited by guarantee, incorporated on 30 June 1999, and registered as a charity on 5th January 2000 (previously 284653 registered 1982) with a membership base. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required by the adopted Constitution to contribute an amount not exceeding £1.

The directors of the company are also charity Trustees for the purposes of charity law, and under the company's Articles are known as members of the Board of Trustees. The Board of Trustees meets at least four times a year and is responsible for the strategic direction and policy of the charity and appointing auditors to ensure financial compliance. Medical input is given via our Medical Advisory Board, a representative of which sits on the Board of Trustees.

Medical Background

The charity's membership is mostly drawn from families affected by NF. There are two types of NF. NF1 affects 1 in every 2,500 people worldwide, which means that there are more than 25,000 in the UK; NF2 is much rarer, with 1 in 35,000 affected worldwide (1,000 in the UK). An affected person of either sex has a 1 in 2 (50:50) chance of passing the altered (abnormal) gene on to their children. However, everyone has a risk of having an affected child because 50% of all those affected by NF are the first person in their family to be so affected.

NF1 is a hugely variable condition, which has the potential to develop a large number of complications. Some people with NF1 only having skin involvement, but potential complications include: specific learning difficulties and behavioural problems - which affects about 60% of all people with NF1; high blood pressure (hypertension); curvature of the spine (scoliosis); malformation of the long bones (below the knee and below the elbow) (pseudarthrosis); large benign skin tumours (plexiform neurofibromas); tumours on the nerves of sight (optic glioma); internal, spinal and brain tumours – which are usually benign however 10-15% of people will develop a malignant tumour related to their NF1. The most significant issue for people with NF1 is that the occurrence of these complications cannot be predicted even within families. Many people with NF1 also have low self-esteem and this can cause problems forming friendships, which leads to isolation.

NF2 consistently causes more problems than NF1, and it has an increased risk of developing brain tumours. Although these tumours are benign, the position in which they grow can cause major problems. The most common site is on the hearing and balance nerves causing problems with deafness and coordination. The sense of isolation from deafness onset in adulthood can be immense. People with NF2 may also develop spinal cord tumours, with

their own significant complications.

Neurofibromatosis Type 2 is a misnomer as people affected do not have neurofibromas, therefore there is to be a name change to NF2-Schwannomatosis for this condition, which will mean a significant workload and cost for the charity as the website and literature will require modifications.

Neurofibromatosis is an unpredictable and variable genetic condition that can affect all people regardless of gender, race or age. During their lifetime, patients may see a wide range of health and social care professionals, both in community and hospital settings. The Specialist Advisors act as a point of reference for families helping them navigate through routine planned events and at times of crisis. Essentially, their role is to help people to learn to live with their diagnosis of Neurofibromatosis and to equip them with the knowledge of when, where, and how to seek help, if necessary.

As a multi-system condition, NF has an impact on many areas of people's lives, not just health. The Specialist Advisors take a lead role in liaison and advocacy with health, education, and social services to support the quality and continuity of care for families affected by NF. They seek to develop a service that is professional, timely and responsive to need. Their setting may be clinical, visiting families at home or telephone contact. The quality of the relationships they establish is critical to their effectiveness and may continue over many years.

Financial Review

Income Generating Activities

Our head office team continue to develop innovative virtual fundraising ideas and source new income streams. Our membership and supporters have once again worked hard this year generating new and fantastic fundraising events, and we are extremely grateful for all their continued support. This has provided the charity with new and diverse funding streams that can hopefully be harnessed for years to come.

During the period the charity had income resources of £512,516 and a total expenditure of £448,333 resulting in net resources of £64,183.

Investment Policy

The charity's funds have been invested in short-term deposits this financial year. A Financial Advisory & Investment Group, reporting to the Board of Trustees, has been established to continue to review this position and further investment opportunities, to ensure all income potential is maximised with minimum risk.

We give careful consideration as to how we can make our reserves generate an income for the charity and have considered a number of options and informal advice. At present, given the current rate of return, the costs involved in investing, and the inherent risk, we have continued to elect to hold the reserves in a mixture of short and medium term deposits with our bankers. However, we will continue to monitor all other options available.

Reserves Policy and Going Concern

Reserves are needed to bridge the gap between the spending and receiving of income and to cover unplanned emergency expenditure. The Trustees consider £500,000 is the ideal level of reserves and being sufficient unrestricted reserves to fund the Specialist Advisor network for a minimum of twelve months due to the number of multi-year contractual commitments, and the charity's administrative and operating costs for at least six months.

The Trustees consider that adequate resources continue to be available to fund the activities of the charity for the foreseeable future. The Trustees are of the view that the charity is a going concern.

Key Expenditure Areas

The key areas of expenditure continue to be the operational costs of the Specialist Advisor network. Each year, we aim to raise sufficient funds to maintain the twelve months' reserves. If the charity provides further funding for the

Specialist Advisor network, this expenditure, and the required reserves, is likely to increase.

Public Benefit

All our charitable activities focus on improving the lives of those affected by Neurofibromatosis and are undertaken to further our charitable purposes for public benefit. The Trustees have regard to the Charity Commission's guidance on the need for charities to deliver a public benefit and have complied with the duty in section 17(2) of the Charities Act 2011.

Recruitment, Appointment & Induction of Board of Trustees

Under the requirements of the Memorandum and Articles of Association, the one-third longest standing members of the Board of Trustees shall retire or put themselves forward for re-election at the next Annual General Meeting. The maximum time a trustee can remain in post is nine years, although that time may be extended for a short period by the Board on an exceptional basis.

The Board of Trustees seeks to recruit a diverse mix of business, medical and patient expertise, there is no requirement for a Board member to have any direct or indirect experience of NF. Our new Trustees are also required to undergo DBS checks. All Trustees, upon election, meet with the Chair to discuss and agree specific requirements of the role.

Statement of Trustees responsibilities

The Trustees, who are also the directors of the Neurofibromatosis Association for the purpose of company law, are responsible for preparing the Trustees Report and the financial statements in accordance with FRS102 and the charity SORP (FRS 102). The Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity at the end of the financial year and of its surplus or deficit for that period. In doing so, the Trustees are responsible for:

- selecting suitable accounting policies and then apply them consistently;
- observing the methods and principles in the Charities SORP;
- making judgements and estimates that are reasonable and prudent;
- preparing the financial statements on the going concern basis unless it is not appropriate to assume that the company will continue on that basis; and
- the maintenance and integrity of the corporate and financial information included on the charity's website.

The Board of Trustees is responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time that the financial statements comply with the Companies Act 2006. The Board of Trustees is also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Members of the Board of Trustees

Members of the Board of Trustees, who are directors for the purpose of company law, and Trustees for the purpose of charity law, who served during the year and up to the date of this report, are set out on page 1.

Auditors

David Howard was appointed as auditor under section 145 of the Charities Act 2011 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

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

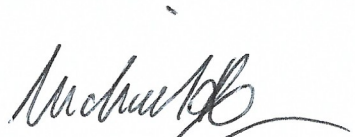
- there is no relevant information, being information needed by the auditor in connection with preparing their report, of which the auditor is unaware; and

- the Trustees, having made enquiries of fellow Trustees and the charity's auditors that they ought to have individually taken, have each taken all steps that he/she is obliged to take as a Trustee in order to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

Small company provisions

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

Approved by the Board of Trustees on 06 March 2023 and signed on its behalf by:



Michael Fry
Chair of the Board of Trustees



Richard Goode
Vice Chair & Company Secretary

Independent Auditors' Report to the Trustees of The Neurofibromatosis Association (Nerve Tumours UK)

We have audited the financial statements of The Neurofibromatosis Association for the year ended 31st October 2022, set out over pages 11 to 23 in this report, which comprise the statement of financial activities, the balance sheet and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019) – (Charities SORP (FRS 102).

Opinion on the financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31st October 2022, and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.
Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least 12 months from when the financial statements are authorised for issue.
Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other Information

The other information comprises the information included in the annual report, including the Trustees' report, other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' Annual Report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report.

We have nothing to report in respect of the following matters where the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- adequate and proper accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us;
- the financial statements are not in agreement with the accounting records and returns;
- certain disclosures of Trustees' remuneration specified by law are not made, or
- we have not received all the information and explanations we require for our audit.
- the Trustees were not entitled to prepare the financial statements and the Trustees' report in accordance with the small companies' regime.

Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities statement set out on page 2 to 9, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the company or to cease operations, or have no realistic alternative but to do so.

Auditors' responsibilities for the audit of the financial statements

We have been appointed as auditor under section 145 of the Charities Act 2011 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Our approach to identifying and assessing the risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, was as follows:

- the engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities and skills to identify or recognise non-compliance with applicable laws and regulations;
- we identified the laws and regulations applicable to the company through discussions with Trustees and other management, and from our commercial knowledge and experience of the charity sector;
- we focused on specific laws and regulations which we considered may have a direct material effect on the financial statements or the operations of the company, including such as the Charites Act 2011, taxation legislation, data protection, anti-bribery, and health and safety legislation;
- we assessed the extent of compliance with the laws and regulations identified above through making enquiries of management and inspecting legal correspondence; and
- identified laws and regulations were communicated within the audit team regularly and the team remained alert to instances of non-compliance throughout the audit.

We assessed the susceptibility of the company's financial statements to material misstatement, including obtaining an understanding of how fraud might occur, by:

- making enquiries of management as to where they considered there was susceptibility to fraud, their knowledge of actual, suspected and alleged fraud;
- considering the internal controls in place to mitigate risks of fraud and non-compliance with laws and regulations; and
- To address the risk of fraud through management bias and override of controls, we:
- performed analytical procedures to identify any unusual or unexpected relationships;
- tested journal entries to identify unusual transactions;
- assessed whether judgements and assumptions made in determining the accounting estimates set out in Note 16 were indicative of potential bias; and
- investigated the rationale behind significant or unusual transactions

In response to the risk of irregularities and non-compliance with laws and regulations, we designed procedures which included, but were not limited to:

- agreeing financial statement disclosures to underlying supporting documentation;
- reading the minutes of meetings of those charged with governance;
- enquiring of Trustees as to actual and potential litigation and claims;
- reviewing correspondence with relevant regulators

There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the directors and other management and the inspection of regulatory and legal correspondence, if any. Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities]. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of part 16 of the Companies Act 2006, and to the charitable company's Trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members and Trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and, the charitable company's members as a body and the charitable company's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Philip Lane FCCA (Senior Statutory Auditor)
For and on behalf of David Howard, Statutory Auditor

1 Park Road
Hampton Wick
Kingston Upon Thames
Surrey
KT1 4AS

Date: 6 March 2023

Statement of Financial Activities (including Income & Expenditure Accounts) for the Year ended 31 October 2022

	Notes	Unrestricted funds 2022 £	Restricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Income:					
Donations & Legacies	2	317,345	107,150	424,495	308,059
Income from Charitable Activities	2	85,521	1,832	87,353	89,059
Investment Income	2	668		668	56
Incoming Resources from Charitable Activities		**403,534**	**108,982**	**512,516**	**397,174**
Other Incoming Resources		-	-	-	-
Total Income		**403,534**	**108,982**	**512,516**	**397,174**
Expenditure	4				
Cost of raising funds		106,132	-	106,132	94,940
Expenditure on charitable activities		201,135	141,067	342,202	295,649
Total Expenditure		**307,266**	**141,067**	**448,334**	**390,589**
Net Income (Expenditure)		**96,267**	**(32,085)**	**64,183**	**6,584**
Reconciliation of funds					
Total funds brought forward		471,197	79,949	551,146	544,562
Net movement in funds for the year		96,267	(32,085)	64,183	6,584
Total funds carried forward		**567,465**	**47,864**	**615,329**	**551,146**

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing operations.

Balance sheet as at 31 October 2022

		2022	2021
		£	£
Tangible fixed assets	10	754	1,283
Current assets			
Debtors	11	302	1,769
Cash at bank and in hand		733,614	685,944
		733,916	687,713
Creditors : amounts falling due within one year	12	119,341	137,850
Net current assets		**614,575**	**549,863**
Net assets		**615,329**	**551,146**
Analysis of net assets between funds			
Unrestricted funds	13	567,465	471,197
Restricted funds	13	47,864	79,949
Total funds		**615,329**	**551,146**

The financial statements are prepared in accordance with the special provisions of the Companies Act 2006 and section 138 of the Charities Act 2011. These accounts are prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) – (Charities SORP (FRS 102)).

The notes at pages 16-23 form part of these accounts.

Approved by the Board of Trustees on 06 March 2023 and signed on its behalf by:

Michael Fry
Chair of The Board of Trustees

Richard Goode
Vice Chair & Company Secretary

Company Registration No. 03798407
Charity Registration No. 1078790
Scottish Charity Register No. SC045051

Statement of Cashflows as at 31 October 2022

	Notes	2022 £	2022 £	2021 £	2021 £
Cash flows from operating activities					
Cash absorbed by operations	15	48,510		83,973	
Net cash outflow from operating activities			48,510		83,973
Investing activities					
Purchase of tangible fixed assets		1,508		-3,115	
Interest received		668		56	
Net cash used in investing activities			-840		3,059
Net (decrease)/increase in cash and cash equivalents			47,670		80,914
Cash and cash equivalents at beginning of Period			685,944		605,030
Cash and cash equivalents at end of Period			733,614		685,944

The financial statements are prepared in accordance with the special provisions of the Companies Act 2006 and section 138 of the Charities Act 2011. These accounts are prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) – (Charities SORP (FRS 102)).

1. Accounting policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the year and the preceding year.

a) Basis of accounting

The financial statements comply with the Charities Act 2011, the Companies Act 2006, Trustee Investment (Scotland) Act 2005, the charities Accounts (Scotland) Regulations 2006 (as amended), the Memorandum and Articles of Association, and the Charities Statement of Recommended Practice ("Charities SORP") (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland; FRS 102) effective from 1 January 2019.

The Neurofibromatosis Association meets the definition of a public benefit entity under FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the Charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

b) Fund accounting

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the Charity, and
- Restricted funds are subjected to restrictions on their expenditure imposed by the donor.

c) Income

All incoming resources are included in the statement of financial activities when the charity is entitled to the income, and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

- Income from donations and legacies is received by way of grants, donations, fundraising and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant,
- The value of services provided by volunteers has not been included in these accounts,
- Income from charitable activities are accounted for when earned, and
- Income resources from grants, where related to performance and specific deliverables, are accounted for as the charity earns the right to consideration by its performance.
- There has been a change in the accounting policy for Lifetime Subscriptions from 2010/11. Henceforth income resources from lifetime subscriptions will be fully accounted for in the year in which the subscription is registered.

d) Expenditure

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

- Costs of raising funds comprise the costs associated with attracting voluntary income, and also include governance costs. These include those costs associated with meeting the constitutional and statutory requirements of the charity and include the independent audit fees and costs linked to the strategic management of the charity.
- Expenditure on charitable activities comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be

allocated directly to such activities and those costs of an indirect nature necessary to support them.

- All costs are allocated between expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resource.
- Depreciation: Assets are written off over two years on the straight line basis of depreciation.

e) Fixed Assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Individual fixed assets costing £250 or more are capitalised at cost.
Depreciation: the value of each asset is written off over two years, on a straight-line basis.

f) Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

g) Debtors

Trade and other debtors are recognised at the settlement amount due.

h) 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.

i) Information and legal status of the charity

Nerve Tumours UK is a Charitable Company, limited by guarantee, incorporated on 30 June 1999, and registered as a charity on 5th January 2000 (previously 284653 registered 1982) with a membership base. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required by the adopted Constitution to contribute an amount not exceeding £1.

j) Pensions

The pension costs charged in the financial statements represent the contribution payable by the charity during the year. Contributions are made to defined contribution schemes in the UK.

2. Income

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
a) Donations & Legacies				
Donations and gifts	34,357	-	34,357	32,937
Events	79,046	-	79,046	57,982
Gift Aid	27,940	-	27,940	10,849
Grants	24,100	107,150	131,250	140,767
Legacies	144,996	-	144,996	59,727
Subscriptions	6,906	-	6,906	5,797
	317,345	107,150	424,495	308,059
b) Income from Charitable Activities				
Fundraising	79,224	1,832	81,056	84,314
Goods for Sale	6,297		6,297	4,745
	85,521	1,832	87,353	89,059
c)Investment Income				
Interest	668	-	668	56

3. Grants

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
The Peter Sowerby Foundation			-	15,000
The Peacock Trust		10,000	10,000	5,000
The Childwick Charitable Trust			-	15,000
The Three Oaks Trust		10,000	10,000	10,000
The Norman Family Charitable Trust		1,000	1,000	500
The Baron Davenport Charity		1,000	1,000	1,000
The Schon Charitable Trust		400	400	1,650
The Sir James Rolls Charitable Trust			-	1,000
The Eveson Charitable Trust		10,000	10,000	4,000
The Hilary Awdry Charitable Trust		1,000	1,000	1,000
The James Tudor Foundation		7,500	7,500	-
The Sobell Foundation		10,000	10,000	10,000
The AstraZeneca PLC		30,000	30,000	30,000
The Hospital Saturday Fund		2,000	2,000	2,000
The Alan Boswell Group Charitable Trust			-	10,000
The Roger & Jean Jefcoate Trust	5,000		5,000	-
The Dixie Rose Findlay Charitable Trust		3,000	3,000	2,000
The Ardwick Charitable Trust			-	200
The Pears Foundation		8,500	8,500	10,000
The Joseph Hopkins Charitable Foundation		750	750	1,000
The Gaia Foundation	3,000		3,000	-
The Hadrian Trust		1,000	1,000	1,000
The PF Edwards Charitable Trust		3,000	3,000	2,000
The Coral Samuel Charitable Trust			-	3,000
The Orr Mack Foundation	5,000		5,000	-
The February Foundation			-	3,000
The John Avins Trust		1,000	1,000	-
The Sir Jules Thorn Charitable Trust			-	1,000
The Roger & Douglas Turner Trust		5,000	5,000	2,000
The Thomas J Horne Memorial Trust	11,000		11,000	5,000
The BCH 1971 Charitable Trust			-	1,000
Genetic Disorders UK			-	3,417
The Sheffield Town Trust		2,000	2,000	-
The Woodhall Chaitable Trust	100		100	-
	24,100	**107,150**	**131,250**	**140,767**

4. Expenditure

	Cost of raising funds				Charitable activities			
	Events	Voluntary income	Trusts	Governance	Research, Campaigns & Education	Specialist Support Network	2022	2021
Costs directly allocated to activities								
Independent Auditors Fee	-	-	-	4,680	-	-	4,680	1,620
Independent Auditors Fee for other works	-	-	-	1,095	-	-	1,095	808
Events	37,756	-	-	-	-	-	37,756	28,638
Fundraising	-	25,699	23,205	-	-	-	48,904	46,719
Medical & Beneficiary Awareness Campaigns & Education	-	-	-	-	137,039	-	137,039	112,006
Specialist Neurofibromatosis Advisors & National Helpline	-	-	-	-	-	149,225	149,225	132,128
Research	-	-	-	-	1,000	-	1,000	-
Trustee and committee meetings	-	-	-	1,242	-	-	1,242	907
	37,756	25,699	23,205	7,018	138,039	149,225	380,941	322,826
Support costs allocated to activities								
Staff costs	3,564	3,184	5,870	2,000	23,750	5,307	43,675	41,380
Consultancy/Professional Fees	-	-	-	-	-	-	-	-
Depreciation	166	149	274	93	1,108	248	2,037	2,312
Premises	1,412	1,260	2,322	790	9,396	2,099	17,279	17,650
Printing, postage and stationery	67	60	110	37	444	99	817	2,136
IT, telephone and fax	293	261	482	164	1,949	435	3,584	4,285
Other	-	-	-	-	-	-	-	-
	5,502	4,913	9,057	3,086	36,647	8,188	67,392	67,763
	43,258	30,612	32,262	10,103	174,686	157,413	448,333	390,589

Staff Cost	Allocation based on time spent on activities
Premises Costs	Allocation based on staff costs
Depreciation	Allocation based on premises costs
It, etc	Allocation based on staff costs

5. Net Incoming Resources for the Year

This is stated after charges:	2022 £	2021 £
Depreciation	2037	2312
Independent Audit Fee	4680	1620
	6717	3932

6. Staff costs and numbers

	2022 £	2021 £
Salaries and wages	180,658	184,914
Social security costs	10,450	11,117
Pension costs	3,708	3,691
	194,816	**199,723**

No employees received emoluments of more than £60,000. The charity operates a pension scheme for its employees as currently required.

The average number of employees during year, calculated on the basis of full-time equivalents, was as follows:

	2022	2021
CEO		
Membership Secretary		
IT/Information	1.5	1.5
Fundraising	2.3	2.3
Administration and support	0.4	0.4
Change manager		
Development managers	0.6	0.8
	4.8	**5.0**

7. Trustee remuneration

No members of the Board of Trustees received any remuneration during the year; travel costs totaling £64.70 were reimbursed during the year to one member of the Board of Trustees (last year, no costs were reimbursed to any member of the Board of Trustees).

8. Related party transactions

There were no Related Party Transactions during the year. No Trustee, or other person related to the charity, had any personal interest in any transaction.

9. Taxation

As a charity, The Neurofibromatosis Association is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or s256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the Association.

10. Tangible fixed assets

	2022 £	2021 £
Cost		
As at 1 November	8,613	5,498
Additions	1,508	3,115
Removal of fully depreciated assets		
As at 31 October	10,121	8,613
Accumulated depreciation		
As at 1 November	7,331	5,019
Charge for the year	2,037	2,312
Removal of fully depreciated assets		
As at 31 October	9,368	7,331
Net book value		
As at 1 November	1,283	479
As at 31 October	**754**	**1,283**

11. Debtors

	2022 £	2021 £
Debtor Control Account	302	(89)
Rent Deposit	-	
Other debtors	-	
Prepayments	-	1,858
	302	**1,769**

12. Creditors: amounts falling due within one year

	2022 £	2021 £
Trade Creditors	44,585	42,946
Taxation	5,621	-
Lottery Grant	-	10,000
Other Creditors	-	-
Accruals and deferred income	69,135	84,905
	119,341	**137,850**

13. Analysis of net assets between funds

	Unrestricted funds £	Restricted funds £	Total funds £
Tangible fixed assets	754	-	754
Current assets	686,051	47,864	733,915
Current liabilities	119,341	-	119,341
	567,465	**47,864**	**615,329**

14. Movement in funds

	At 1 November 2021	Incoming Resources	Outgoing Resources	At 31 October 2022
Restricted Funds				
Support Groups	3,744	-	-	3,744
Research/NSA's	59,349	108,982	141,062	27,269
CWT Camps	5	-	5	-
NF2 Activities	16,851	-	-	16,851
	79,949	108,982	141,067	47,864
Unrestricted Funds	471,197	403,534	307,266	567,465
Total Funds	**551,146**	**512,516**	**448,333**	**615,329**

Purposes of Restricted Funds

Support Groups:	This grant is for the funding of support groups in various parts of the country
Research/NSA's:	Donations made to be spent on Research/ Specialist Support Network.
CWT Camps:	Donations restricted to spend on camps for children
NF2 activities:	Donations made specifically for the running of the NF2 activities each year

15. Reconciliation of profit to net cash (outflow)/inflow from operating activities

	2022 £	2021 £
Surplus/(Deficit) for the year	64,183	6,584
Adjustments to reconcile profit for the year to net		
Cashflow from operating activities:		
Depreciation	2,037	2,312
Finance income	- 668	- 56
Working capital movements		
(Increase)/Decrease in debtors	1,467	13,260
Increase/(Decrease) in creditors	- 18,509	61,873
Cash Absorbed by Operations	**48,510**	**83,973**

16. Critical accounting estimates and judgements

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for revenues and expenses during the year. However, the nature of estimation means that actual outcomes could differ from those estimates.

There were no key judgements. The main accounting estimates are depreciation and accruals.

THE NEUROFIBROMATOSIS ASSOCIATION

England & Wales - Charity number 1078790

Accounts

The Neurofibromatosis Association

Report of the Board of Trustees

Year ended 31 October 2021

Charity Registration Number 1078790
Scottish Charity Registration Number SC045051
Company Registration Number 3798407

The Neurofibromatosis Association
Report and financial statements
Year ended 31 October 2021

Reference and administrative information

Charity Name:	The Neurofibromatosis Association
Charity Registration Number:	1078790
Scottish Charity Registration Number:	SC045051
Company Registration Number:	3798407
Charity Working Name:	Nerve Tumours UK
Registered office and operational address:	44 Coombe Lane West Wimbledon London SW20 0LA
Telephone:	020 8439 1234
Fax:	020 8439 1200
E-mail address:	info@nervetumours.org.uk
Website address:	www.nervetumours.org.uk

Nerve Tumours UK

Nerve Tumours UK is the working name of the charity, which retains its legal name "The Neurofibromatosis Association".
(Prior to 01 November 2018, the working name was The Neuro Foundation.)

Board of Trustees
The current Board of Trustees is:

Michael Fry (Chair)
Dr. Timothy Corn
Emily Owen
Stewart Lee
Richard Goode (Vice Chair)
Professor Rosalie Ferner
Jonathan Bruce
Rohan Chanmugam
Professor Meena Upadhyaya
Matthew Jones

Senior Management Personnel
The trustees delegate day-to-day management of the charity to:
Karen Cockburn, Charity Director

Patrons
Gillian Anderson
Simon Callow

Independent Examiners
David Howard Chartered Accountants
1 Park Road
Hampton Wick
Kingston - upon - Thames
Surrey
KT1 4AS

Bankers
National Westminster Bank Plc
5 Market Place
Kingston - upon - Thames
Surrey
KT1 1VX

Board of Trustees Report for the Year Ended 31 October 2021

The Trustees are pleased to present their annual report and financial statements for the year ended 31 October 2021.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, Trustee Investment (Scotland) Act 2005, the charities Accounts (Scotland) Regulations 2006 (as amended), the Memorandum and Articles of Association, and the Charities Statement of Recommended Practice ("Charities SORP") (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland; FRS 102) effective from 1 January 2019.

Objectives and Activities

The charity's vision is "To improve the lives of those affected by Neurofibromatosis".

To allow the charity to deliver this vision of helping to improve the lives of those affected by Neurofibromatosis (NF), and in being central to making this happen, we work in collaboration with the Highly Specialised Commissioning Services, formerly the National Commissioning Group (NCG) funded service, and other associated medical professional units around the UK.

The mission for the charity is to "Enable people concerned about Neurofibromatosis to find solutions appropriate to them by increasing awareness, and by providing support and information on Neurofibromatosis".

Central to this mission, is our ambition to be the UK's authoritative voice on Neurofibromatosis and our determination to serve, support and celebrate the lives of people impacted by the condition, and their wider support network.

The charity continues to deliver its mission through five key services to members, supporters and beneficiaries. It endeavours to:

- **Inform** — We provide accurate, relevant, and up to date information that explains the conditions of NF1 and NF2, the implications, challenges and opportunities, in language understood by all.
- **Advise** — We provide practical and emotional advice to help people find the best services and support available. We enable people to make choices about how they approach and live with neurofibromatosis.
- **Advocate** — We aim to increase knowledge, awareness and understanding of NF, and will campaign for change in areas we believe will improve the lives of those affected by neurofibromatosis.
- **Connect** — We take a pivotal role in bringing together groups of people interested in neurofibromatosis to maximise the support and information available to them.
- **Fund** — We make funds available for small projects to bodies and patient groups where we believe it will make a difference.

The charity works with the following groups to achieve its mission:

- Patients and carers
- Families with neurofibromatosis
- The medical community
- NF Specialist Network of Nurses and Advisors
- The research community (particularly The Nerve Tumours UK Medical Advisory Board)
- Supporters
- Volunteers

- Other charities and umbrella organisations

Achievements and Performance

Although hindered by the Covid-19 pandemic for the latter 19 months, encompassing the whole of the last financial year, the charity has continued to concentrate on its central five services again this year. The pandemic does not detract from working to strengthen and develop our core support structures to ensure that we can continue to provide the best possible support and information to anyone affected by NF. However, our services continue to be subject to increased demand, due to the uncertain climate and the absence or difficulty in obtaining primary care services. Although face to face consultations have gradually returned, many of our services were provided virtually or by telephone consultation.

Impact of Covid-19 on Charity Services & Finances

We fund a unique and vital service, which is not provided by other organisations. Our services are particularly important for people diagnosed with NF and their carers. Many people with NF are vulnerable and often isolated. They continue to be immensely distressed by the current situation, as some of their complications may make them more susceptible to catching Covid-19. Many have had to shield. The effect on the broader group of people with NF continues, as there is a huge backlog of appointments as many genetics and neurology clinics had been significantly reduced as staff have been redeployed to critical and Covid-19 services. We have therefore continued to roll out virtual services to ensure that we can continue to reach and support our beneficiaries. We are acutely aware of the ongoing potential impact on mental health both for our beneficiaries and our staff.

We do not receive statutory or local funding, and the bulk of the charity's income has been from charitable giving and monies raised from events. For a second year, nearly all events were either postponed or cancelled, which has had a significant adverse effect on our income streams, and we were not able to access any emergency funding this year.

However, we continue to fundraise as much as possible with new, innovative, and virtual initiatives. We maintained our decision not to furlough our staff as we considered that all staff members were needed in order to resource and maintain services, and to continue fundraising initiatives remotely. Our continued assessment is that our strategy has been appropriate and, as such, has allowed us to make a small surplus in the current financial year.

As we fund a network of Specialist NF Nurses and Advisors (Specialist Advisors), our policy requires us to maintain a minimum of 12 months of reserves. The charity reacted quickly to the constraints of the pandemic and the resultant economic climate. This has minimised the impact on the level of reserves over the last two financial years. At this time, we are confident that we are able to continue to maintain our reserves policy.

Plans for Future Sustainability

The pandemic forced us to reconsider our strategic plan. The Board implemented a strategy group to look at how we can continue to provide our services, in a post Covid world. Our focus is on how we can streamline our services, co-ordinate our work with partners and improve the education of the medical profession. Our aim is to ensure that people are able to access advice and support as effectively and efficiently as possible, whether or not that is from the charity.

The charity has also adopted new ways of working, including virtual clinics. Although online services are not practical for all (for example, patients with cognitive impairment and learning issues), we anticipate that improved online connectivity and familiarity may lead to reduced delivery costs and greater efficiency. Post pandemic, we anticipate that a balance of online and in person delivery will allow the charity to provide services to more people.

Specialist Advisors

The charity will continue to maintain its Specialist Advisors and will seek to identify areas of the country where we can work with the NHS to make joint appointments.

The charity currently funds a network of twelve Specialist Advisors across the UK, supporting posts in Newcastle (2), Birmingham (2), Plymouth, Liverpool, Southampton, Sheffield, Leeds, Wales and Northern Ireland. Two Specialist Advisors provide the Nerve Tumours UK national helpline on a part time basis, which provides advice and connects people affected by NF with relevant practical help, either in their community, or in clinic. We aim to introduce two new posts during the next financial year in parts of the UK, where there has never been any regional support. Each post supports between 200 – 3,750 patients per year working via clinics, home visits, schools, advisory services, and telephone consultation.

The role of Specialist Advisors is very diverse. We have had excellent feedback from the families supported by our Specialist Advisors. It is plain to see that for those families, the support they receive from the charity and our Specialist Advisors is pivotal in helping them to cope with NF. Supporting the Specialist Advisors network will continue to be a key role for Nerve Tumours UK.

Over 60% of patients with NF1 will have learning difficulties, and approximately 30% are registered as disabled, as are 75% of those patients with NF2. However, public awareness of NF is low. Our experience is that this can lead to some people with NF struggling at school, with inappropriate, or non-existent support. Nerve Tumours UK offers a schools' advisory service, iNForm, staffed by our Specialist Advisors. Where engaged, the team works closely with teachers, supporting tailored learning plans, and suggesting mechanisms for enhancing the child's experience at school. Even during the pandemic, we have found that we can still operate iNForm effectively, albeit virtually.

Nerve Tumours UK continues to offer an extensive range of literature and information, for lay people and professionals. Our literature is widely used by medical teams across the country. Our leaflets and pamphlets are subject to constant review and update. Medical professionals are also invited to use the Nerve Tumours UK national helpline.

The Nerve Tumours UK Head Office team continue to work exceptionally hard. They continue to go above and beyond in response to the continuing fallout from the pandemic, and the Board are once again very grateful for their efforts. Key workstreams have included the further development of our website, in particular the sections on partner charities, government Covid-19 advice, mental health, and research.

We continue to see a surge in activity on our website, and this has greatly increased our interactions and the support available to the community. Facebook coverage and engagement has continued to grow. Over 71,500 people are reached organically each month and our page views are up by 145%. Our website achieves an average of 45,000 users per month, with 61,262 in December 2021 alone. Nerve Tumours UK's Twitter reach continues to grow steadily with 1,497 followers. Our tweets make an average of 248,000 impressions per month. Our Instagram reach is also increasing, and we now have 1,800 followers.

The number of subscribers to the Nerve Tumours UK newsletter has increased to 3,042, an increase of 17% on last year's count. We continue our membership of a number of other social and marketing branches such as MeetUp groups, which directly target our challenge events outside the community, and at 173 members, we are reaching a wider audience than before. On World NF Awareness Day in May 2021, despite lockdown, total social media posts on the respective NF1 and NF2 Days led to the highest peak of activities across social media and the web during the year.

We also continue to seek to develop and strengthen our institutional partnerships with organisations including The Small Charities Coalition, Embracing Complexity, Genetic Alliance, and Genetic Disorders UK. We have started planning for conferences, events and outreach in 2022.

There are no immediate financial concerns, although the length of lockdown and the continuing pandemic may cause some concern, Nerve Tumours UK is still currently on track to meet its long-term financial targets.

The continued rollout of core services throughout the period is an excellent reflection of the combined efforts and dedication of the Specialist Advisors, our members, supporters, head office staff and Medical Advisory Board during this unprecedented time. The Trustees are very grateful for the exceptionally hard work which has been put into the charity.

Structure, Governance and Management

Nerve Tumours UK is a Charitable Company, limited by guarantee, incorporated on 30 June 1999, and registered as a charity on 5th January 2000 (previously 284653 registered 1982) with a membership base. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required by the adopted Constitution to contribute an amount not exceeding £1.

The directors of the company are also charity trustees for the purposes of charity law, and under the company's Articles are known as members of the Board of Trustees. The Board of Trustees meets at least four times a year and is responsible for the strategic direction and policy of the charity and appointing auditors to ensure financial compliance. Medical input is given via our Medical Advisory Board, a representative of which sits on the Board of Trustees.

Medical Background

The charity's membership is mostly drawn from families affected by NF. There are two types of NF. NF1 affects 1 in every 2,500 people worldwide, which means that there are more than 25,000 in the UK; NF2 is much rarer, with 1 in 35,000 affected worldwide (1,000 in the UK). An affected person of either sex has a 1 in 2 (50:50) chance of passing the altered (abnormal) gene on to their children. However, everyone has a risk of having an affected child because 50% of all those affected by NF are the first person in their family to be so affected.

NF1 is a hugely variable condition, which has the potential to develop a large number of complications. Some people with NF1 only having skin involvement, but potential complications include: specific learning difficulties and behavioural problems - which affects about 60% of all people with NF1; high blood pressure (hypertension); curvature of the spine (scoliosis); malformation of the long bones (below the knee and below the elbow) (pseudarthrosis); large benign skin tumours (plexiform neurofibromas); tumours on the nerves of sight (optic glioma); internal, spinal and brain tumours – which are usually benign however 10-15% of people will develop a malignant tumour related to their NF1. The most significant issues for people with NF1 is that the occurrence of these complications cannot be predicted even within families. Many people with NF1 also have low self-esteem and this can cause problems forming friendships, which leads to isolation.

NF2 causes consistently more problems than NF1, and it has an increased risk of developing brain tumours. Although these tumours are benign, the position in which they grow can cause major problems. The most common site is on the hearing and balance nerves causing problems with deafness and coordination. The sense of isolation from deafness onset in adulthood can be immense. People with NF2 may also develop spinal cord tumours, with their own significant complications.

Neurofibromatosis is an unpredictable and variable genetic condition that can affect all people regardless of gender, race or age. During their lifetime, patients may see a wide range of health and social care professionals, both in community and hospital settings. The Specialist Advisors act as a point of reference for families helping them navigate through routine planned events and at times of crisis. Essentially, their role is to help people to learn to live with their diagnosis of neurofibromatosis and to equip them with the knowledge of when, where, and how to seek help, if necessary.

As a multi-system condition, NF has an impact on many areas of people's lives, not just health. The Specialist Advisors take a lead role in liaison and advocacy with health, education, and social services to support the quality and continuity of care for families affected by NF. They seek to develop a service that is professional, timely and responsive to need. Their setting may be clinical, visiting families at home or telephone contact. The quality of the relationships they establish is critical to their effectiveness and may continue over many years.

Financial Review

Income Generating Activities

During the period the charity had income resources of £397,174 and a total expenditure of £390,589 resulting in net resources of £6,584.

Our head office team have continued to develop innovative virtual fundraising ideas. Our membership and supporters have once again worked hard this year generating new and fantastic fundraising events, and we are extremely grateful for all their continued support. This has provided the charity with new and diverse funding streams that can hopefully be harnessed for years to come.

Investment Policy

The charity's funds have been invested in short-term deposits this financial year. We continue to review this position as we are aware of the need to ensure all income potential is maximised with minimum risk.

We have given careful consideration as to how we can make our reserves generate an income for the charity and have considered a number of options and informal advice. At present, given the current rate of return, the costs involved in investing, and the inherent risk, we have continued to elect to hold the reserves in a mixture of fixed term deposits with our bankers. However, we will continue to monitor all other options available.

Reserves Policy

Reserves are needed to bridge the gap between the spending and receiving of income and to cover unplanned emergency expenditure. The trustees consider £500,000 is the ideal level of reserves, and being sufficient unrestricted reserves to fund the Specialist Advisor network for a minimum of twelve months due to the number of multi year contractual commitments, and the charity's administrative and operating costs for at least six months.

The trustees consider that adequate resources continue to be available to fund the activities of the Charity for the foreseeable future. The trustees are of the view that the charity is a going concern.

Key Expenditure Areas

The key areas of expenditure continue to be the operational costs of the Specialist Advisor network. Each year, we aim to raise sufficient funds to maintain the twelve months' reserves. If the charity provides further funding for the Specialist Advisor network, this expenditure, and the required reserves, is likely to increase.

Public Benefit

All our charitable activities focus on improving the lives of those affected by Neurofibromatosis and are undertaken to further our charitable purposes for public benefit. The Trustees have regard to the Charity Commission's guidance on the need for charities to deliver a public benefit and have complied with the duty in section 17(2) of the Charities Act 2011.

Recruitment, Appointment & Induction of Board of Trustees

Under the requirements of the Memorandum and Articles of Association, the one-third longest standing members of the Board of Trustees shall retire or put themselves forward for re-election at the next Annual General Meeting. The maximum time a trustee can remain in post is nine years, although that time may be extended for a short period by the Board on an exceptional basis.

The Board of Trustees seeks to recruit a diverse mix of business, medical and patient expertise, there is no requirement for a Board member to have any direct or indirect experience of NF. Our new Trustees are also required to undergo DBS checks. All Trustees, upon election, meet with the Chair to discuss and agree specific requirements of the role.

Statement of Trustees responsibilities

The Trustees, who are also the directors of the Neurofibromatosis Association for the purpose of company law, are responsible for preparing the Trustees Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company Law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Board of Trustees is responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time that the financial statements comply with the Companies Act 2006. The Board of Trustees is also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Members of the Board of Trustees

Members of the Board of Trustees, who are directors for the purpose of company law, and trustees for the purpose of charity law, who served during the year and up to the date of this report, are set out on page 1.

Independent Examiners

The charity's trustees consider that an audit is not required for this year and that an independent examination is needed. Accordingly, David Howard Chartered Accountants, a firm of accountants specialising in charity accounts, have reviewed the following financial statements.

Small company provisions

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

Approved by the Board of Trustees on 07 March 2022 and signed on its behalf by:

Michael Fry
Chair of the Board of Trustees

Richard Goode
Vice Chair & Company Secretary

Independent Examiner's report to the trustees of The Neurofibromatosis Association (Nerve Tumours UK)

I report on the accounts of the company for the year ended 31st October 2021, which are set out on pages 8 to 17.

Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under Part 16 of The Companies Act 2006, section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10(1)(a) to (c) of the Charities Accounts (Scotland) Regulations 2006 ("The 2006 Regulations") and that an independent examination is needed. The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Association on Chartered Certified Accountants and it is my responsibility to:

- examine the accounts under section 145 of the Charities Act 2011 and under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission and is in accordance with Regulations 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:
(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 386 of the Companies Act 2006 and section 44(1)(a) of the 2005 Act; and
- to prepare accounts which accord with the accounting records, comply with the accounting requirements under Section 396 of the Companies Act 2006, section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations
- which are consistent with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities (SORP FRS102)

have not been met; or
(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Philip Lane FCCA
Fellow of the Association of Chartered Certified Accountants
For and on behalf of David Howard Chartered Accountants
1 Park Road
Hampton Wick
Kingston Upon Thames
Surrey
KT1 1AS

Date: 7/3/2022

Statement of Financial Activities (including Income & Expenditure Accounts) for the Year ended 31 October 2021

	Notes	Unrestricted funds 2021 £	Restricted funds 2021 £	Total funds 2021 £	Total funds 2020 £
Incoming Resources from Generated Funds					
Donations & Legacies	2	184,059	124,000	308,059	201,694
Income from Charitable Activities	2	88,463	596	89,059	122,969
Investment Income	2	56		56	573
Incoming Resources from Charitable Activities		**272,577**	**124,596**	**397,174**	**325,236**
Other Incoming Resources		-	-	-	-
Total Income		**272,577**	**124,596**	**397,174**	**325,236**
Expenditure	4				
Cost of raising funds		94,940	-	94,940	109,359
Expenditure on charitable activities		163,146	132,503	295,649	221,365
Total Resources Expended		**258,086**	**132,503**	**390,589**	**330,724**
Net Income (Expenditure)		**14,491**	**(7,907)**	**6,584**	**(5,488)**
Reconciliation of funds					
Total funds brought forward		456,706	87,856	544,562	550,050
Net movement in funds for the year		14,491	(7,907)	6,584	(5,488)
Total funds carried forward		**471,197**	**79,949**	**551,146**	**544,562**

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing operations.

Balance sheet as at 31 October 2021

		2021	2020
		£	£
Tangible fixed assets	10	1,283	479
Current assets			
Debtors	11	1,769	15,029
Cash at bank and in hand		685,944	605,031
		687,713	620,059
Creditors : amounts falling due within one year	12	137,850	75,977
Net current assets		**549,863**	**544,082**
Net assets		**551,146**	**544,562**
Analysis of net assets between funds			
Unrestricted funds	13	471,197	456,706
Restricted funds	13	79,949	87,856
Total funds		**551,146**	**544,562**

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 October 2021 relating to small companies.

The trustees have not required the charitable company to obtain an audit of its financial statements for the year ended 31 October 2021 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of accounts.

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies and with the Financial Reporting Standard for Smaller Entities (effective January 2019).

Approved by the Board of Trustees on 07 March 2022 and signed on its behalf by:

Michael Fry
Chair of The Board of Trustees

Richard Goode
Vice Chair & Company Secretary

Company Registration No. 03798407
Charity Registration No. 1078790
Scottish Charity Register No. SC045051

1. Accounting policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the year and the preceding year.

a) Basis of accounting

The financial statements comply with the Charities Act 2011, the Companies Act 2006, Trustee Investment (Scotland) Act 2005, the charities Accounts (Scotland) Regulations 2006 (as amended), the Memorandum and Articles of Association, and the Charities Statement of Recommended Practice ("Charities SORP") (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland; FRS 102) effective from 1 January 2019.

The Neurofibromatosis Association meets the definition of a public benefit entity under FRS 102.

The Charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the Charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

b) Fund accounting

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the Charity, and
- Restricted funds are subjected to restrictions on their expenditure imposed by the donor.

c) Incoming resources

All incoming resources are included in the statement of financial activities when the charity is entitled to the income, and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

- Income from donations and legacies is received by way of grants, donations, fundraising and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant,
- The value of services provided by volunteers has not been included in these accounts,
- Income from charitable activities are accounted for when earned, and
- Income resources from grants, where related to performance and specific deliverables, are accounted for as the charity earns the right to consideration by its performance.
- There has been a change in the accounting policy for Lifetime Subscriptions from 2010/11. Henceforth income resources from lifetime subscriptions will be fully accounted for in the year in which the subscription is registered.

d) Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

- Costs of raising funds comprise the costs associated with attracting voluntary income, and also include governance costs. These include those costs associated with meeting the constitutional and statutory requirements of the charity and include the independent examiner fees and costs linked to the strategic management of the charity.
- Expenditure on charitable activities comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- All costs are allocated between expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resource.
- Depreciation: Assets are written off over two years on the straight line basis of depreciation.

e) Fixed Assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Individual fixed assets costing £250 or more are capitalised at cost.
Depreciation: the value of each asset is written off over two years, on a straight-line basis.

f) Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. Thus the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

2. Incoming Resources from Generated Funds

	Unrestricted funds 2021 £	Restricted funds 2021 £	Total funds 2021 £	Total funds 2020 £
a) Donations & Legacies				
Donations and gifts	32,937	-	32,937	28,807
Events	57,982	-	57,982	39,828
Gift Aid	10,849	-	10,849	13,377
Grants (note 3)	17,067	123,700	140,767	69,700
Legacies	59,427	300	59,727	43,888
Subscriptions	5,797	-	5,797	6,095
	184,059	124,000	308,059	201,694
b) Income from Charitable Activities				
Fundraising	83,718	596	84,314	116,941
Goods for Sale	4,745		4,745	6,028
	88,463	596	89,059	122,969
c)Investment Income				
Interest	56	-	56	573
	272,577	**124,596**	**397,174**	**325,236**

3. Grants

	Unrestricted funds 2021 £	Restricted funds 2021 £	Total funds 2021 £	Total funds 2020 £
The Peter Sowerby Foundation		15,000	15,000	-
The Peacock Trust	5,000	-	5,000	5,000
The Childwick Charitable Trust		15,000	15,000	-
The Three Oaks Trust		10,000	10,000	10,000
The Norman Family Charitable Trust		500	500	750
The Baron Davenport Charity		1,000	1,000	700
The Schon Charitable Trust	1,650		1,650	1,200
The Sir James Rolls Charitable Trust		1,000	1,000	-
The Eveson Charitable Trust		4,000	4,000	4,000
The Hilary Awdry Charitable Trust		1,000	1,000	500
The James Tudor Foundation			-	5,000
The Sobell Foundation		10,000	10,000	10,000
The AstraZeneca PLC		30,000	30,000	-
The Hospital Saturday Fund		2,000	2,000	-
The Alan Boswell Group Charitable Trust		10,000	10,000	2,000
The Roger & Jean Jefcoate Trust			-	10,000
The Dixie Rose Findlay Charitable Trust		2,000	2,000	4,000
The Ardwick Charitable Trust		200	200	400
The Pears Foundation		10,000	10,000	-
The Joseph Hopkins Charitable Foundation		1,000	1,000	1,000
The Gaia Foundation			-	3,000
The Hadrian Trust		1,000	1,000	-
The PF Edwards Charitable Trust	2,000		2,000	2,000
The Coral Samuel Charitable Trust		3,000	3,000	-
AW & CS Fenwick Charitable Trust			-	150
The February Foundation		3,000	3,000	-
The John Avins Trust			-	1,000
The Sir Jules Thorn Charitable Trust		1,000	1,000	1,000
The Roger & Douglas Turner Trust		2,000	2,000	2,000
The Thomas J Horne Memorial Trust	5,000		5,000	-
The BCH 1971 Charitable Trust		1,000	1,000	-
Genetic Disorders UK	3,417		3,417	-
The Sheffield Town Trust			-	2,000
The Morrisons Foundation			-	1,000
The Anson Charitable Trust			-	3,000
	17,067	**123,700**	**140,767**	**69,700**

4. Resources Expended

	Cost of raising funds				Charitable activities		
	Events	Voluntary income	Trusts	Governance	Information and meetings	NSA's and helpline	Total
Costs directly allocated to activities							
Independent Auditors Fee	-	-	-	1,620	-	-	1,620
Independent Auditors Fee for other works	-	-	-	808	-	-	808
Events	28,638	-	-	-	-	-	28,638
Fundraising	-	24,392	22,327	-	-	-	46,719
Newsletters and information	-	-	-	-	112,006	-	112,006
NSA's	-	-	-	-	-	132,128	132,128
Research	-	-	-	-	-	-	-
Trustee and committee meetings	-	-	-	907	-	-	907
	28,638	24,392	22,327	3,335	112,006	132,128	322,826
Support costs allocated to activities							
Staff costs	3,381	3,017	5,562	1,890	22,503	5,028	41,380
Consultancy/Professional Fees	-	-	-	-	-	-	-
Depreciation	189	169	311	106	1,257	281	2,312
Premises	1,442	1,287	2,372	807	9,597	2,144	17,650
Printing, postage and stationery	175	156	287	98	1,162	260	2,136
IT, telephone and fax	350	312	576	196	2,330	521	4,285
Other	-	-	-	-	-	-	-
	5,536	4,940	9,107	3,098	36,849	8,233	67,763
	34,174	29,332	31,434	6,433	148,855	140,361	390,589

Staff Cost	Allocation based on time spent on activities
Premises Costs	Allocation based on staff costs
Depreciation	Allocation based on premises costs
It, etc	Allocation based on staff costs

5. Net Incoming Resources for the Year

This is stated after charges:	2021 £	2020 £
Depreciation	2312	944
Independent Audit Fee	1620	1560
	3932	2504

6. Staff costs and numbers

	2021 £	2020 £
Salaries and wages	184,914	169,321
Social security costs	11,117	9,344
Pension costs	3,691	3,416
	199,723	**182,082**

No employees received emoluments of more than £50,000. The Association operates a pension scheme for its employees as currently required. Costs have increased due to staff turnover and payment for Lead Specialist Advisor services throughout the pandemic period.

The average number of employees during year, calculated on the basis of full-time equivalents, was as follows:

	2021	2020
CEO		
Membership Secretary		
IT/Information	1.5	1.6
Fundraising	2.3	2.3
Administration and support	0.4	0.4
Change manager		
Development managers	0.8	0.7
	5.0	**5.0**

7. Trustee remuneration

No members of the Board of Trustees received any remuneration during the year; and no travel costs were reimbursed during the year (last year, £192.69 was reimbursed to one member of the Board of Trustees).

8. Related party transactions

There were no Related Party Transactions during the year. No Trustee, or other person related to the Association, had any personal interest in any transaction.

9. Taxation

As a charity, The Neurofibromatosis Association is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or s256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the Association.

10. Tangible fixed assets

	2021 £	2020 £
Cost		
As at 1 November	5,498	4,538
Additions	3,115	960
Removal of fully depreciated assets		
As at 31 October	8,613	5,498
Accumulated depreciation		
As at 1 November	5,019	4,075
Charge for the year	2,312	944
Removal of fully depreciated assets		
As at 31 October	7,331	5,019
Net book value		
As at 1 November	479	463
As at 31 October	**1,283**	**479**

11. Debtors

	2021 £	2020 £
Debtor Control Account	(89)	76
Rent Deposit	-	
Other debtors	-	
Prepayments	1,858	14,953
	1,769	**15,029**

12. Creditors: amounts falling due within one year

	£	£
Trade Creditors	42,946	20,434
Taxation	-	4,474
Lottery Grant	10,000	10,000
Other Creditors	-	2,658
Accruals and deferred income	84,905	38,412
	137,850	**75,977**

13. Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds
	£	£	£
Tangible fixed assets	1,283	-	1,283
Current assets	607,764	79,949	687,713
Current liabilities	137,850	-	137,850
	471,197	**79,949**	**551,146**

14. Movement in funds

	At 1 November 2020	Incoming Resources	Outgoing Resources	At 31 October 2021
Restricted Funds				
Support Groups	3,744	-	-	3,744
Research/NSA's	67,256	124,596	132,503	59,349
Website/Platform	-	-	-	-
CWT Camps	5	-	-	5
NF2 Activities	16,851	-	-	16,851
	87,856	124,596	132,503	79,949
Unrestricted Funds	456,706	272,577	258,086	471,197
Total Funds	**544,562**	**397,174**	**390,589**	**551,146**

Purposes of Restricted Funds

Support Groups:	This grant is for the funding of support groups in various parts of the country
Research/NSA's:	Donations made to be spent on Research/ Specialist Advisor Network.
CWT Camps:	Donations restricted to spend on camps for children
NF2 activities:	Donations made specifically for the running of the NF2 activities each year

15. Financial commitments

At 31 October 2021, the charity had annual commitments under non-cancellable operating leases, following rent renegotiations, as follows:

	2021
	£
Expiry date:	
Not later than one year	5,833
Later than one year and not later than five years	-
	5,833

THE NEUROFIBROMATOSIS ASSOCIATION

England & Wales - Charity number 1078790

Accounts

The Neurofibromatosis Association

Report of the Board of Trustees

Year ended 31 October 2020

Charity Registration Number 1078790
Scottish Charity Registration Number SC045051
Company Registration Number 3798407

The Neurofibromatosis Association
Report and financial statements
Year ended 31 October 2020

Reference and administrative information

Charity Name:	The Neurofibromatosis Association
Charity Registration Number:	1078790
Scottish Charity Registration Number:	SC045051
Company Registration Number:	3798407
Charity Working Name:	Nerve Tumours UK
Registered office and operational address:	44 Coombe Lane West Wimbledon London SW20 0LA
Telephone:	020 8439 1234
Fax:	020 8439 1200
E-mail address:	info@nervetumours.org.uk
Website address:	www.nervetumours.org.uk

Nerve Tumours UK

(Nerve Tumours UK is the working name of The Neurofibromatosis Association. Prior to 01 November 2018, the working name was The Neuro Foundation.)

Board of Trustees
The current Board of Trustees is:

Michael Fry (Chair)
Dr. Timothy Corn
Emily Owen
Stewart Lee
Richard Goode (Vice Chair)
Professor Rosalie Ferner
Jonathan Bruce
Rohan Chanmugam

Senior Management Personnel
The trustees delegate day-to-day management of the charity to:
Karen Cockburn, Charity Director

Patrons
Gillian Anderson

Independent Examiners
David Howard Chartered Accountants
1 Park Road
Hampton Wick
Kingston - upon - Thames
Surrey
KT1 4AS

Bankers
National Westminster Bank Plc
5 Market Place
Kingston - upon - Thames
Surrey
KT1 1VX

Board of Trustees Report for the Year Ended 31 October 2020

Objectives and Activities

The charity's vision is "To improve the lives of those affected by neurofibromatosis".

"Nerve Tumours UK" is a working name for the charity, which retains its legal name "The Neurofibromatosis Association".

To allow the charity to deliver its vision of helping to improve the lives of those affected by Neurofibromatosis (NF), it works in collaboration with the Highly Specialised Commissioning Services, formerly the National Commissioning Group (NCG) funded service.

The mission for the charity is to "Enable people concerned about Neurofibromatosis to find solutions appropriate to them by increasing awareness, and by providing support and information on Neurofibromatosis".

The charity delivers its mission through five services to members, supporters and beneficiaries. It endeavours to:

- **Inform** — We provide accurate, relevant and up to date information that explains the conditions of NF1 and NF2, the implications, challenges and opportunities, in language understood by all.
- **Advise** — We provide practical and emotional advice to help people find the best services and support available. We enable people to make choices about how they approach and live with neurofibromatosis.
- **Advocate** — We aim to increase knowledge, awareness and understanding of NF, and will campaign for change in areas we believe will improve the lives of those affected by neurofibromatosis.
- **Connect** — We take a pivotal role in bringing together groups of people interested in neurofibromatosis to maximise the support and information available to them.
- **Fund** — We make funds available for small projects to bodies and patient groups where we believe it will make a difference.

The charity works with the following groups to achieve its mission:

- Patients and carers
- Families with neurofibromatosis
- The medical community
- NF Specialist Network of Nurses and Advisors
- The research community (particularly The Nerve Tumours UK Medical Advisory Board)
- Supporters
- Volunteers
- Other charities

Achievements and Performance

Although hindered by the Covid-19 pandemic for the latter 9 months of the financial year, the charity has continued to concentrate on its central five services again this year. The pandemic did not detract from working to strengthen and develop our core support structures to ensure that we can continue to provide the best possible support and information to anyone affected by NF. However, during this period, our services were under increased demand, and so we reorganised to provide extra helpline hours. Other services were provided virtually or by telephone consultation.

Impact of Covid-19 on Charity Services & Finances

We fund a unique and vital service, which is not provided by other organisations. Our services were particularly important for people diagnosed with NF and their carers. Many people with NF are vulnerable and often isolated. They have been immensely distressed by the current situation, as some of their complications may make them more susceptible to catching Covid-19. Many have had to shield. The effect on the broader group of people with NF has been that the work of many genetics and neurology clinics has been significantly reduced as staff have been redeployed to critical and Covid-19 services. In response, we extended our helpline availability and rolled out virtual services to ensure that we can continue to reach and support our beneficiaries. We are acutely aware of the potential impact on mental health both for our beneficiaries and our staff.

We do not receive statutory or local funding, and the bulk of the charity's income has been from charitable giving and monies raised from events. Nearly all events were either postponed or cancelled this year, which has had a significant adverse effect on our income streams. We were able to access some emergency funding to alleviate a small percentage (10%) of lost income but have not benefitted from any significant funding. This is because most emergency funding has been targeted at small local charities.

We continue to fundraise as much as possible with new innovative and virtual schemes. Our decision was not to furlough our staff as we needed all staff members to resource to maintain services and to continue fundraising initiatives remotely. Our assessment is that our strategy has been appropriate and has minimised our deficit this year.

Regrettably, the uncertainty caused by the pandemic has forced us to delay or rethink our development plans. For example, agreements to fill vacancies in four existing regions, were delayed for six months. This has meant that some patients and families, who had previously benefitted from our community-based support were not able to access the same level of support. The effect of this lower level of available support was compounded by the issues concerning NF and Covid-19. The charity focussed on managing every item of expenditure, where feasible and this has significantly reduced our expenditure. For example, design & production of literature has been brought back in house, and office rent has been reduced by 30% per annum.

As we fund a network of Specialist NF Nurses and Advisors (Specialist Advisors), our policy requires us to maintain 12 months of reserves. Although the charity reacted very quickly to the current situation, and we consider that we minimised the impact on our operations, we were, nevertheless required to draw down from reserves. As the pandemic continues, we may require further draw down in the months to come. However, at this time, we are confident that we will continue to maintain our reserves policy.

Plans for Future Sustainability

The pandemic has forced us to reconsider our strategic plan, which had been close to adoption. The Board has implemented a strategy group to look at how we can continue to provide our services, in a post Covid world. We expect to publish our strategic plan in advance of the 2021 AGM.

Our focus is on how we can streamline our services, co-ordinate our work with partners and improve the education of the medical profession. Our aim is to ensure that people are able to access advice and support as effectively and efficiently as possible, not only from the charity. The charity has adopted new ways of working, including virtual clinics. Although online services are not practical for all (for example. patients with cognitive impairment and learning issues), we anticipate that improved online connectivity and familiarity may lead to reduced delivery costs and greater efficiency. Post pandemic, we expect that a balance of online and in person delivery will allow the charity to provide services to more people.

Specialist Advisors

The charity will continue to maintain its Specialist Advisors and will seek to identify areas of the country where we can work with the NHS to make joint appointments.

The charity currently funds a network of nine Specialist Advisors across the country, supporting posts in Newcastle (2), Birmingham (2), Plymouth, Liverpool, Southampton, Sheffield and Wales. Two Specialist Advisors provide the Nerve Tumours UK national helpline on a part time basis, which provides advice and connects people affected by

NF with relevant practical help, either in their community, or in clinic. There is currently a vacancy based in Leeds, covering the West Yorkshire & Humberside region, and we expect this post to be filled shortly. Each post supports between 500 – 3,560 patients per year working via clinics, home visits, schools, advisory services and telephone consultation.

The role of Specialist Advisors is very diverse. We have had excellent feedback from the families supported by our Specialist Advisors. It is plain to see that for those families, the support they receive from the charity and our Specialist Advisors is pivotal in helping them to cope with NF. We anticipate that supporting the Specialist Advisors network will continue to be a key role for Nerve Tumours UK.

Over 60% of patients with NF1 will have learning difficulties. However, public awareness of NF is low. Our experience is that this can lead to some people with NF struggling at school, with inappropriate, or non-existent support. Nerve Tumours UK offers a schools' advisory service, iNForm, staffed by our Specialist Advisors. Where engaged, the team works closely with teachers, supporting tailored learning plans, and suggesting mechanisms for enhancing the child's experience at school. Even during the pandemic, we have found that we can still operate iNForm effectively, albeit virtually.

Nerve Tumours UK continues to offer an extensive range of literature and information, for lay people and professionals. Our literature is widely used by medical teams across the country. Our leaflets and pamphlets are subject to constant review and update. Medical professionals are also invited to use the Nerve Tumours UK national helpline.

As a result of the pandemic, the Nerve Tumours UK Head Office ream has worked exceptionally hard this period. Key workstreams have included the development of our website, in particular the sections on government Covid-19 advice, mental health and research.

We have seen a surge in activity on our website, and this has greatly increased our interactions and the support available to the community. Facebook coverage and engagement has continued to grow. Over 64,500 people are reached organically each month and our page views are up by 295%. Our website achieves an average of 38,000 users per month, with 63,562 in December 2020 alone. Nerve Tumours UK's Twitter reach continues to grow steadily with 1,352 followers. Our tweets make an average of 80,333 impressions per month. Our Instagram reach is also increasing, we now have 1,695 followers.

The number of subscribers to the Nerve Tumours UK newsletter has increased to 2,592, more than double last year's count. We continue our membership of a number of other social and marketing branches eg. MeetUp groups, to directly target our challenge events outside the community, and at 166 members, we are reaching a wider audience than before. On World NF Awareness Day in May 2020, despite lockdown, total social media posts on the respective NF1 and NF2 Days led to the highest peak of activities across social media and the web during the year.

We also continue to seek to develop and strengthen our institutional partnerships with organisations such as The Small Charities Coalition, Embracing Complexity, Genetic Alliance, Genetic Disorders UK, etc., and have started planning for conferences, events and outreach in 2021.

There are no immediate financial concerns, although the length of lockdown and the continuing pandemic may cause some concern, Nerve Tumours UK is still currently on track to meet its long-term financial targets.

The continued rollout of core services throughout the period is an excellent reflection of the combined efforts and dedication of the Specialist Advisors, our members, supporters, head office staff and Medical Advisory Board during this unprecedented time. The Trustees are very grateful for the exceptionally hard work which has been put into the charity.

Structure, Governance and Management

Nerve Tumours UK is a Charitable Company, limited by guarantee, incorporated on 30 June 1999 and registered as a charity on 5th January 2000 (previously 284653 registered 1982) with a membership base. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required by the adopted Constitution to contribute an amount not exceeding £1.

The directors of the company are also charity trustees for the purposes of charity law, and under the company's Articles are known as members of the Board of Trustees. The Board of Trustees meets at least four times a year and is responsible for the strategic direction and policy of the charity. Medical input is given via our Medical Advisory Board, a representative of which sits on the Board of Trustees.

Medical Background

The charity's membership is mostly drawn from families affected by NF. There are two types of NF. NF1 affects 1 in every 2,500 people worldwide, which means that there are more than 25,000 in the UK; NF2 is much rarer, with 1 in 35,000 affected worldwide (1,000 in the UK). An affected person of either sex has a 1 in 2 (50:50) chance of passing the altered (abnormal) gene on to their children. However, everyone has a risk of having an affected child because 50% of all those affected by NF are the first person in their family to be so affected.

NF1 is a hugely variable condition, which has the potential to develop a large number of complications. Some people with NF1 only having skin involvement, but potential complications include: specific learning difficulties and behavioural problems - which affects about 60% of all people with NF1; high blood pressure (hypertension); curvature of the spine (scoliosis); malformation of the long bones (below the knee and below the elbow) (pseudarthrosis); large benign skin tumours (plexiform neurofibromas); tumours on the nerves of sight (optic glioma); internal, spinal and brain tumours – which are usually benign however 10-15% of people will develop a malignant tumour related to their NF1. The most significant issues for people with NF1 is that the occurrence of these complications cannot be predicted even within families. Many people with NF1 also have low self-esteem and this can cause problems forming friendships, which leads to isolation.

NF2 causes consistently more problems than NF1, and it has an increased risk of developing brain tumours. Although these tumours are benign, the position in which they grow can cause major problems. The most common site is on the hearing and balance nerves causing problems with deafness and coordination. The sense of isolation from deafness onset in adulthood can be immense. People with NF2 may also develop spinal cord tumours, with their own significant complications.

Neurofibromatosis is an unpredictable and variable genetic condition that can affect all people regardless of gender, race or age. During their lifetime, patients may see a wide range of health and social care professionals, both in community and hospital settings. The Specialist Advisors act as a point of reference for families helping them navigate through routine planned events and at times of crisis. Essentially, their role is to help people to learn to live with their diagnosis of neurofibromatosis and to equip them with the knowledge of when, where and how to seek help, if necessary.

As a multi-system condition, NF has an impact on many areas of people's lives, not just health. The Specialist Advisors take a lead role in liaison and advocacy with health, education and social services to support the quality and continuity of care for families affected by NF. They seek to develop a service that is professional, timely and responsive to need. Their setting may be clinical, visiting families at home or telephone contact. The quality of the relationships they establish is critical to their effectiveness and may continue over many years.

Financial Review

Income Generating Activities

Our head office team, with their innovative virtual fundraising ideas, our membership and supporters have once again worked hard this year generating new and fantastic fundraising events, and we are extremely grateful for all their continued support. This has provided the charity with new funding streams that can hopefully be harnessed for years to come.

Investment Policy

The charity's funds have been invested in short-term deposits this financial year. We continue to review this position as we are aware of the need to ensure all income potential is maximised with minimum risk.

We have given careful consideration as to how we can make our reserves generate an income for the charity and have considered a number of options and informal advice. At present, given the current rate of return, the costs involved in investing, and the inherent risk, we have elected to hold the reserves in a mixture of fixed term deposits with our bankers. However, we will continue to monitor all other options available.

Reserves Policy

It is Nerve Tumours UK policy to hold sufficient unrestricted reserves to fund the Specialist Advisor network for a period of at least twelve months, and the charity's administrative and operating costs for at least six months.

Key Expenditure Areas

The key areas of expenditure continue to be the operational costs of the Specialist Advisor network. Each year, we aim to raise sufficient funds to maintain the twelve months' reserves. If the charity provides further funding for the Specialist Advisor network, this expenditure, and the required reserves is likely to increase.

Public Benefit

All our charitable activities focus on improving the lives of those affected by Neurofibromatosis and are undertaken to further our charitable purposes for public benefit. The Trustees have regard to the Charity Commission's guidance on the need for charities to deliver a public benefit and have complied with the duty in section 17(2) of the Charities Act 2011.

Recruitment, Appointment & Induction of Board of Trustees

Under the requirements of the Memorandum and Articles of Association, the one-third longest standing members of the Board of Trustees shall retire or put themselves forward for re-election at the next Annual General Meeting. The maximum time a trustee can remain in post is nine years, although that time may be extended for a short period by the Board on an exceptional basis.

The Board of Trustees seeks to recruit a diverse mix of business, medical and patient expertise, there is no requirement for a Board member to have any direct or indirect experience of NF. Our new Trustees are also required to undergo DBS checks. All Trustees, upon election, meet with the Chair to discuss and agree specific requirements of the role.

Responsibilities of the Board of Trustees

Company law requires the Board of Trustees to prepare financial statements for each financial year, which give a true and fair view of the state of the affairs of the charitable company as at the balance sheet date, and of its

incoming resources and application of resources, including income and expenditure, for the financial year. In preparing those financial statements, the Board of Trustees has followed best practice and:

- Selected suitable accounting policies and then applied them consistently;
- Made judgments and estimates that are reasonable and prudent;
- Prepared the financial statements on the going concern basis unless it was inappropriate to assume that the company will continue on that basis; and
- Are responsible for the maintenance and integrity of the corporate and financial information included on the company's website.

The Board of Trustees is responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time that the financial statements comply with the Companies Act 2006. The Board of Trustees is also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Members of the Board of Trustees

Members of the Board of Trustees, who are directors for the purpose of company law, and trustees for the purpose of charity law, who served during the year and up to the date of this report, are set out on page 1.

Independent Examiners

The charity's trustees consider that an audit is not required for this year and that an independent examination is needed. Accordingly, David Howard Chartered Accountants, a firm of accountants specialising in charity accounts, have reviewed the following financial statements.

Small company provisions

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

Approved by the Board of Trustees on 22 March 2021 and signed on its behalf by:

Michael Fry
Chair of The Board of Trustees

Richard Goode
Trustee & Company Secretary

Independent Examiner's report to the trustees of The Neurofibromatosis Association (Nerve Tumours UK)

I report on the accounts of the company for the year ended 31st October 2020, which are set out on pages 8 to 17.

Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts in accordance with the terms of the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended). The trustees consider that an audit is not required for this year under Part 16 of The Companies Act 2006, section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10(1)(a) to (c) of the Charities Accounts (Scotland) Regulations 2006 ("The 2006 Regulations") and that an independent examination is needed. The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Association on Chartered Certified Accountants and it is my responsibility to:

- examine the accounts under section 145 of the Charities Act 2011 and under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission and is in accordance with Regulations 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:
(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 386 of the Companies Act 2006 and section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and
- to prepare accounts which accord with the accounting records, comply with the accounting requirements of the Companies Act 2006, section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations
- which are consistent with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities

have not been met; or
(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Philip Lane FCCA
Fellow of the Association of Chartered Certified Accountants
For and on behalf of David Howard Chartered Accountants
1 Park Road
Hampton Wick
Kingston Upon Thames
Surrey KT1 1AS
Date: 22/3/21

Statement of Financial Activities (including Income & Expenditure Accounts) for the Year ended 31 October 2020

	Notes	Unrestricted funds 2020 £	Restricted funds 2020 £	Total funds 2020 £	Total funds 2019 £
Incoming Resources from Generated Funds					
Donations & Legacies	2	154,844	46,850	201,694	332,898
Income from Charitable Activities	2	116,256	6,713	122,969	133,396
Investment Income	2	573		573	1,069
Incoming Resources from Charitable Activities		**271,673**	**53,563**	**325,236**	**467,362**
Other Incoming Resources		-	-	-	-
Total Income		**271,673**	**53,563**	**325,236**	**467,362**
Expenditure	4				
Cost of raising funds		109,359	-	109,359	128,208
Expenditure on charitable activities		166,347	55,018	221,365	295,322
Total Resources Expended		**275,706**	**55,018**	**330,724**	**423,530**
Net Income (Expenditure)		**(4,033)**	**(1,455)**	**(5,488)**	**43,832**
Reconciliation of funds					
Total funds brought forward		460,739	89,311	550,050	506,218
Net movement in funds for the year		(4,033)	(1,455)	(5,488)	43,832
Total funds carried forward		**456,706**	**87,856**	**544,562**	**550,050**

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing operations.

The statement of the financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

Balance sheet as at 31 October 2020

	2020 £	2019 £
Tangible fixed assets	479	463
Current assets		
Debtors	15,029	15,078
Cash at bank and in hand	605,031	582,851
	620,059	597,929
Creditors : amounts falling due within one year	75,977	48,341
Net current assets	**544,082**	**549,587**
Net assets	**544,562**	**550,050**
Analysis of net assets between funds		
Unrestricted funds	456,706	460,740
Restricted funds	87,856	89,311
Total funds	**544,562**	**550,050**

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 October 2020 relating to small companies. No member of the company has deposited a notice, pursuant to section 476 of the Companies Act 2006, requiring an audit of these financial statements.

The trustees acknowledge their responsibilities for ensuring that the charity keeps accounting records which comply within section 386 of the Act and for preparing of financial statements which give a true and fair view of the state of the affairs of the company as at the end of the financial year and of its incoming resources and application of resources, including its income and expenditure for the financial year in accordance with the requirements of sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company.

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

Approved by the Board of Trustees on 22 March 2021 and signed on its behalf by:

Michael Fry
Chair of The Board of Trustees

Richard Goode
Trustee & Company Secretary

Company Registration No. 03798407
Charity Registration No. 1078790
Scottish Charity Register No. SC045051

1. Accounting policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the year and the preceding year.

a) Basis of accounting

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in The UK and Republic of Ireland (FRS 102) (effective 01 January 2019) – (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in The UK and Republic of Ireland (FRS 102) and the Companies Act 2006. The Neurofibromatosis Association meets the definition of a public benefit entity under FRS 102.

The principal accounting policies adopted in the preparation of the financial statements are set out below.

b) Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

c) Fund accounting

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the Charity, and
- Restricted funds are subjected to restrictions on their expenditure imposed by the donor.

d) Incoming resources

All incoming resources are included in the statement of financial activities when the charity is entitled to the income, and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

- Income from donations and legacies is received by way of grants, donations, fundraising and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant,
- The value of services provided by volunteers has not been included in these accounts,
- Income from charitable activities are accounted for when earned, and
- Income resources from grants, where related to performance and specific deliverables, are accounted for as the charity earns the right to consideration by its performance.
- Income from charitable activities also includes income derived from goods sold via the online shop and this is below the small trading tax exemption.
- There has been a change in the accounting policy for Lifetime Subscriptions from 2010/11. Henceforth income resources from lifetime subscriptions will be fully accounted for in the year in which the subscription is registered.

e) Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

- Costs of raising funds comprise the costs associated with attracting voluntary income, and also include governance costs. These include those costs associated with meeting the constitutional and statutory requirements of the charity and include the independent examiner fees and costs linked to the strategic management of the charity.
- Expenditure on charitable activities comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- All costs are allocated between expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resource.
- Depreciation: Assets are written off over two years on the straight line basis of depreciation.

f) Fixed Assets
Individual fixed assets costing £250 or more are capitalised at cost.
Depreciation: the value of each asset is written off over two years, on a straight-line basis.

g) Online Shop
The income from the on-line shop is derived from the sale of Christmas Cards and branded merchandise.

2. Incoming Resources from Generated Funds

	Unrestricted funds 2020 £	Restricted funds 2020 £	Total funds 2020 £	Total funds 2019 £
a) Donations & Legacies				
Donations and gifts	28,807	-	28,807	32,249
Events	39,828	-	39,828	111,451
Gift Aid	13,377	-	13,377	21,681
Grants	22,850	46,850	69,700	96,400
Legacies	43,888	-	43,888	65,311
Subscriptions	6,095	-	6,095	5,806
	154,844	46,850	201,694	332,898
b) Income from Charitable Activities				
Fundraising	110,228	6,713	116,941	124,459
Goods for Sale	6,028		6,028	8,937
	116,256	6,713	122,969	133,396
c)Investment Income				
Interest	573	-	573	1069

3. Grants

	Unrestricted funds 2020 £	Restricted funds 2020 £	Total funds 2020 £	Total funds 2019 £
The VTCT Foundation			-	25,000
The Peacock Trust	5,000	-	5,000	5,000
The Childwick Charitable Trust			-	12,000
The Three Oaks Trust		10,000	10,000	10,000
The Norman Family Charitable Trust		750	750	1,000
The Baron Davenport Charity		700	700	700
The Schon Charitable Trust	1,200		1,200	950
The Sir James Rolls Charitable Trust			-	1,000
The Eveson Charitable Trust		4,000	4,000	4,000
The Hilary Awdry Charitable Trust	500		500	1,000
The James Tudor Foundation		5,000	5,000	5,000
The Sobell Foundation		10,000	10,000	10,000
The Hospital Saturday Fund			-	2,000
The Alan Boswell Group Charitable Trust	2,000		2,000	-
The Roger & Jean Jefcoate Trust	10,000		10,000	-
The Dixie Rose Findlay Charitable Trust		4,000	4,000	-
The Ardwick Charitable Trust		400	400	500
The W&M Morris Charitable Trust			-	500
The Joseph Hopkins Charitable Foundation		1,000	1,000	500
The Gaia Foundation	3,000		3,000	3,000
The Hey Smile Foundation			-	1,000
The PF Charitable Trust		2,000	2,000	2,000
The EIG Foundation			-	1,000
AW & CS Fenwick Charitable Trust	150		150	-
The Lloyds Bank Foundation			-	500
The John Avins Trust		1,000	1,000	1,000
The Sir Jules Thorn Charitable Trust		1,000	1,000	750
The Roger & Douglas Turner Trust		2,000	2,000	3,000
The Thomas J Horne Memorial Trust			-	5,000
The Sheffield Town Trust		2,000	2,000	-
The Morrisons Foundation	1,000		1,000	-
The Anson Charitable Trust		3,000	3,000	-
	22,850	**46,850**	**69,700**	**96,400**

4. Resources Expended

	Cost of raising funds				Charitable activities		
	Events	Voluntary income	Trusts	Governance	Information and meetings	NSA's and helpline	Total
Costs directly allocated to activities							
Independent Auditors Fee	-	-	-	1,560	-	-	1,560
Independent Auditors Fee for other works	-	-	-	743	-	-	743
Events	44,275	-	-	-	-	-	44,275
Fundraising	-	17,488	21,927	-	-	-	39,415
Newsletters and information	-	-	-	-	76,817	-	76,817
NSA's	-	-	-	-	-	96,913	96,913
Research	-	-	-	-	-	-	-
Trustee and committee meetings	-	-	-	982	-	-	982
	44,275	17,488	21,927	3,285	76,817	96,913	260,705
Support costs allocated to activities							
Staff costs	5,248	2,900	5,968	2,668	17,039	4,682	38,506
Consultancy/Professional Fees	589	325	670	299	1,912	525	4,320
Depreciation	129	71	146	65	417	115	943
Premises	2,829	1,563	3,217	1,438	9,185	2,524	20,756
Printing, postage and stationery	155	86	177	79	505	139	1,141
IT, telephone and fax	593	328	675	302	1,926	529	4,352
Other	-	-	-	-	-	-	-
	9,544	5,272	10,853	4,852	30,983	8,514	70,019
	53,819	22,760	32,780	8,137	107,800	105,428	330,724

Staff Cost	Allocation based on time spent on activities
Premises Costs	Allocation based on staff costs
Depreciation	Allocation based on premises costs
It, etc	Allocation based on staff costs

5. Net Incoming Resources for the Year

This is stated after charges:	2020	2019
	£	£
Depreciation	944	1048
Independent Audit Fee	1560	1476
	2504	2524

6. Staff costs and numbers

	2020	2019
	£	£
Salaries and wages	169,321	156,431
Social security costs	9,344	8,295
Pension costs	3,416	2,519
	182,082	**167,245**

No employees received emoluments of more than £50,000. The Association operates a pension scheme for its employees as currently required. Costs increased due to bringing back certain projects and services in house, as overall, this meant a significant saving.

The average number of employees during year, calculated on the basis of full-time equivalents, was as follows:

	2020	2019
CEO		
Membership Secretary		
IT/Information	1.6	1.6
Fundraising	2.3	2.3
Administration and support	0.4	0.4
Change manager		
Development managers	0.7	0.7
	5.0	**5.0**

7. Trustee remuneration

No members of the Board of Trustees received any remuneration during the year. Travel costs amounting to £192.69 (last year, £135.65) were reimbursed to 1 (last year, 1) member of the Board of Trustees.

8. Related party transactions

There were no Related Party Transactions during the year. No Trustee, or other person related to the Association, had any personal interest in any transaction.

9. Taxation

As a charity, The Neurofibromatosis Association is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or s256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the Association.

10. Tangible fixed assets

	2020 £	2019 £
Cost		
As at 1 November	4,538	9,066
Additions	960	927
Removal of fully depreciated assets		5,455
As at 31 October	5,498	4,538
Accumulated depreciation		
As at 1 November	4,075	8,482
Charge for the year	944	1,048
Removal of fully depreciated assets		5,455
As at 31 October	5,019	4,075
Net book value		
As at 1 November	463	584
As at 31 October	**479**	**463**

11. Debtors

	2020 £	2019 £
Debtor Control Account	76	520
Rent Deposit	-	-
Other debtors	-	-
Prepayments	14,953	14,558
	15,029	**15,078**

12. Creditors: amounts falling due within one year

	2020 £	2019 £
Trade Creditors	20,434	12,906
Taxation	4,474	3,088
Lottery Grant	10,000	-
Other Creditors	2,658	3,783
Accruals and deferred income	38,412	28,564
	75,977	**48,341**

13. Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds
	£	£	£
Tangible fixed assets	479	-	479
Current assets	532,203	87,856	620,059
Current liabilities	75,977	-	75,977
	456,705	**87,856**	**544,562**

14. Movement in funds

	At 1 November 2019	Incoming Resources	Outgoing Resources	At 31 October 2020
Restricted Funds				
Support Groups	3,744	-	-	3,744
Research/NSA's	68,711	53,563	55,018	67,256
Website/Platform	-	-	-	-
CWT Camps	5	-	-	5
NF2 Activities	16,851	-	-	16,851
	89,311	53,563	55,018	87,856
Unrestricted Funds	460,739	271,673	275,706	456,706
Total Funds	**550,050**	**325,236**	**330,724**	**544,562**

Purposes of Restricted Funds

Support Groups:	This grant is for the funding of support groups in various parts of the country
Research/NSA's:	Donations made to be spent on Research/ Specialist Advisor Network.
CWT Camps:	Donations restricted to spend on camps for children
NF2 activities:	Donations made specifically for the running of the NF2 activities each year

15. Financial commitments

At 31 October 2020 the charity had annual commitments under non-cancellable operating leases as follows:

	2020
	£
Expiry date:	
Not later than one year	11,667
Later than one year and not later than five years	8,750
	20,417