

**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
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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



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- 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.

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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



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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 compiled 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.



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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.



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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



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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.



**The Neurofibromatosis Association
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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**

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

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.

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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



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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.

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

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



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

**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					
Cost of raising funds	4	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.

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

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
		<u>768,252</u>	<u>734,547</u>
Creditors : amounts falling due within one year	12	113,554	88,214
Net current assets		<u>654,698</u>	<u>646,333</u>
Net assets		<u>656,018</u>	<u>648,617</u>
Analysis of net assets between funds			
Unrestricted funds	13	627,337	626,491
Restricted funds	13	28,681	22,126
Total funds		<u>656,018</u>	<u>648,617</u>

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



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

Statement of Cashflows for the year ended 31 October 2025

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

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

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.

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

- 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.

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

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
	<hr/> 354,303	118,353	472,656	<hr/> 402,954
b) Income from Charitable Activities				
Fundraising	52,123	1,730	53,853	71,163
	<hr/> 52,123	1,730	53,853	<hr/> 71,163
c) Investment Income				
Interest	28,902	-	28,902	13,314

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

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

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

4. Expenditure

£	Cost of raising funds				Charitable activities			Total
	Events	Voluntary income	Trusts	Governance	Information and meetings	Helpline & Clinical Support	Specialist NF Nurses	
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

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

5. Net Incoming Resources for the Year

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

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
	<u>277,030</u>	<u>237,497</u>

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
	<u>5.7</u>	<u>5.0</u>

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.



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

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	<u>18,846</u>	<u>16,205</u>
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	<u>17,526</u>	<u>13,921</u>
Net book value		
As at 1 November	2,284	757
As at 31 October	<u>1,320</u>	<u>2,284</u>

11. Debtors

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

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
	<u>113,554</u>	<u>88,214</u>

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

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
	<u>627,337</u>	<u>28,681</u>	<u>656,018</u>

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 Unaudited	Incoming Resources	Outgoing Resources	At 31 October 2025
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
	<u>22,126</u>	<u>120,083</u>	<u>113,526</u>	<u>28,681</u>
Unrestricted Funds	626,491	435,329	434,483	627,337
Total Funds	<u>648,617</u>	<u>555,411</u>	<u>548,010</u>	<u>656,018</u>

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	<u>7,000</u>
	<u>19,000</u>



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

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	<u>7,634</u>	<u>(76,478)</u>

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.

