

Registered number
04468323

The Gauchers Association Limited (a Company Limited by Guarantee)

Report and Accounts

30 June 2023

Registered Charity Number 1095657

Company Registration Number 04468323

The Gauchers Association Limited (a Company Limited by Guarantee)
Report and accounts
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The Gauchers Association Limited (a Company Limited by Guarantee)
Company Information

Directors

| | |
|--|-----------|
| D A Brown | Chairman |
| J H Manuel OBE | |
| E J Lew | Secretary |
| T Collin-Histed (resigned 16 October 2022) | |
| J Cox (resigned 16 October 2022) | |

Accountants

Rayner Essex LLP Chartered Accountants
Faulkner House
Victoria Street
St Albans
AL1 3SE

Bankers

CAF Bank Limited
25 Kings Hill Avenue
Kings Hill
West Malling
Kent
ME19 4LJ

Solicitors

Manuel Swaden
340 West End Lane
London
NW6 1LN

Registered office

86-90 Paul Street
London
EC2A 4NE

Registered number

04468323

The Gauchers Association Limited (a Company Limited by Guarantee)
Registered number: 4468323
Directors' Report

The directors present their report and accounts for the year ended 30 June 2023.

Structure, Governance and Management

Governing Document

The Gauchers Association Limited is a company limited by guarantee incorporated on 24 June 2002 and was registered as a charity on 28 January 2003. The company was formed under a Memorandum of Association that established its objects and powers and is governed by its Articles of Association. In the event of the company being wound up members are required to contribute an amount not exceeding £10.

Recruitment and Appointment of Directors

The Directors of the charitable company ("the charity") are its trustees for the purposes of charity law and throughout this report are collectively referred to as the Trustees. The Articles of Association require the members of the company to elect from their number a Board of Directors consisting of at least three persons, but with no maximum. The Directors may select one of their number to act as Chair. One third of the Trustees are required to retire from office at the Annual General Meeting and elections for their reappointment or to appoint others as directors are held at that time. The Trustees have the power to appoint a member as a director to fill a vacancy or as an additional director.

Executive Committee

The general management of the affairs of the company is directed by an Executive Committee. The Trustees must retire by rotation, and can then be re-appointed, at the annual general meeting with sufficient notice having been given to the members. New trustees can also be proposed for appointment at the annual general meeting, again subject to the relevant notice to members.

The Executive Committee meets at least five times a year and is responsible for the strategic direction and policy of the charity. At present the Committee is constituted of the 3 Trustees.

Organisational Structure

The trustees govern the general policy of the Association, and meet not less than four times during the year. There are no sub-committees. The day-to-day business of the Association is managed by the Trustees and the Operations and Communications Coordinator.

Trustees Induction and Training

All of the trustees either have Gaucher disease or have the disease in their family and are already familiar with the work of the charity. All Trustees are either founder members or volunteers who have worked for the charity before being nominated as a Trustee.

Before becoming a Trustee, members are encouraged to attend a number of Executive Committee meetings to familiarise themselves with the work of the charity and the areas in which it operates.

Each new Trustee is invited to a meeting jointly led by the existing Trustees and the Chief Executive of the charity, which covers:

1. The obligations of Management Committee members.
2. The main documents which set out the operational framework for the charity including the Memorandum and Articles of Association.
3. Resources and the current financial position as set out in the latest published accounts.
4. Future plans and objectives.

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Directors' Report

A Question & Answer pack has been prepared drawing information from various Charity Commission publications signposted through the Commission's guide "the Essential Trustee" as a follow up to these sessions. This is provided to all new trustees along with the Memorandum and Articles and the latest financial statements. Feedback from new trustees about their induction has been positive.

Risk Management

The Trustees have considered the major risks to which the charity is exposed and have reviewed those risks and established systems and procedures to manage those risks. A formal review of the charity's risk management processes is undertaken on an annual basis.

Objectives and Activities

The Gauchers Association is the only registered UK charity providing support to individuals and families affected by Gaucher Disease, acting as the centre point for the Gaucher community working alongside medical professionals, scientists and the pharmaceutical industry to meet our aims:

1. To support those individuals and their families affected by Gaucher disease through our patient and family advocacy service and our counselling service.
2. To provide information to patients and families regarding all aspects of Gaucher disease.
3. To advocate on behalf of patients and families to ensure access to appropriate treatment and specialised care through the Centres of Excellence in the UK.
4. To promote research into the causes; effects and treatments for the three types of Gaucher disease.
5. To raise awareness and promote education in the medical profession of Gaucher disease to improve diagnosis and the impact of the condition on patients and families lives.

Board members/ Staff

The following persons served as directors during the year:

D A Brown Chairman

J H Manuel OBE

E J Lew Secretary

T Collin-Histed (resigned 16 October 2022)

J Cox (resigned 16 October 2022)

After 13 years of service, Sarah Allard, the Association's Operations Manager, left the Association on 5th August 2022. A huge thank you to Sarah for her dedication and commitment to UK Gaucher patients and their families for well over a decade.

Following her earlier resignation as CEO, Tanya Collin-Histed stepped down from her role as a trustee of the Association in October 2022 to focus on her work with the International Gaucher Alliance. Tanya also ceased her consultancy work for the Association where she provided representation in key areas with the NHS, pharmaceutical companies and LSD Collaborative in particular.

In January 2023, Su Simons was appointed to the role of Operations and Communications Coordinator.

Strategic Plan

The Association started a strategic plan review using the services of Kathy Redmond at Redmond Consulting in May 2021. The objectives of the review were to agree the Gauchers Association's core purpose, identify how the Association can be a more effective and sustainable organisation and develop a medium term strategic plan to ensure the Association delivers on its core purpose. In the wake of Sarah Allard's resignation and Tanya Collin-Histed stepping down from her role as a trustee and consultant to the Association, and the subsequent need to re-organise the Association's day to day operations, this review was put on hold.

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Directors' Report

Advocacy Service

The Association has continued its advocacy partnership with the MPS Society Advocacy Team. This new service is promoted regularly in our e-news bulletins, on our website and through social media. The clinical teams at each specialist centre are also aware of the service. Areas of support have included:

1. PIP Appeal
2. Benefits claims
3. DLA application
4. Student finance
5. Referral for specialist treatment
6. Emotional support

Mental Health Service

The Association has also continued its partnership with Rare Minds, supporting the Gaucher community with a dedicated counselling service. The service is available to all adult Gaucher patients and their carers. Referrals can be made through contacting the Association direct or through the specialist centres.

We have two dedicated counsellors who are available to help with the psychological and emotional challenges of living with a rare disease including:

1. Diagnosis, living with a rare disease and managing treatment
2. Relationships, with family, friends, and healthcare professionals
3. Loneliness and isolation
4. Work and education worries
5. Emotional needs
6. Bereavement
7. Day to day life

Family Fun Day

This event has not been held since 2019 due to Covid 19 but a fun day at Warwick Castle is planned for October 2023 to coincide with International Gaucher Day.

National Highly Specialised LSD Service

Gaucher Centres and National Specialised Services

We would like to thank all the clinicians, the Clinical Nurse Specialists, and the teams at each of the centres for their continued advice and support to the Association and their dedication to Gaucher patients, especially throughout the Covid-19 Pandemic. The national service provides our members with the very best clinical management and treatment. The adult centres work with the paediatric centres in helping patient transition from childhood to adulthood.

LSD Expert Advisory Group (EAG) / Patient Professional Partnership Network

A representative of the Association historically sat on the EAG and attended bi-annual meetings with representatives from each of the LSD centres in England (and Wales as an observer) and the NHS England (NHSE) Commissioning staff to discuss clinical management, guidelines, research, treatment options and other issues associated with the National Highly Specialised LSD Service. In 2019, NHS England Commissioners took the decision to call a halt to the LSD EAG, as it no longer had a place in the NHSE structure, nor the ability to produce officially recognised decisions on policy or funding. The main meeting between commissioners, providers and patient groups was replaced with an annual clinical audit meeting.

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The UK LSD Collaborative through consultation with the NHSE Commissioners and the Clinical Teams at each of the national centres, have determined that there is support for the continuation of such a forum and that it could be better served as an externally facilitated entity. The proposal is that the UK LSD Collaborative take forward this valuable initiative as a Patient Professional Partnership Network (PPPN) that continues to bring together clinicians, scientists and patient organisation representatives in England, Wales, Scotland and Northern Ireland, with a view to making a key contribution to the future of clinical care and treatment for LSD patients. The network will be facilitated and funded through the Collaborative and meetings will be held virtually. The first meeting will take place in early 2024.

National Homecare Framework for LSDs Services

Four companies now provide homecare services to the LSD Homecare Framework being Healthcare at Home, Lloyds Pharmacy, Pharmaxo, and Healthnet Homecare. The Homecare Framework was reviewed in early 2023 and a new framework agreement is now in place until June 2027.

Rare Diseases Framework

In January 2021 the UK Government published a policy paper reviewing and updating the UK Rare Disease Framework across the 4 nations of the United Kingdom. 4 Key priority areas have been identified being: helping patients get a final diagnosis faster; increasing awareness of rare diseases among healthcare professionals; better coordination of care; improving access to specialist care, treatments and drugs. All 4 nations will develop action plans which will set out how priorities identified will be addressed. These actions plans will be developed, alongside the rare disease community to ensure commitments developed are actionable and measurable. England published their action plan on 28th February 2022 (Rare Disease Day), Northern Ireland published on 22 March, Wales published on 16th June 2022 and Scotland is still in development.

The Association continues to collaborate with other organisations (LSD Collaborative & Genetic Alliance UK) on this policy.

Wales

The Association attend meetings held by the Welsh Health Specialised Services Committee (WHSSC) and Genetic Alliance Wales to ensure that the Association have an input into policy development on access to medicines and shape service provision for Gaucher patients.

In April 2023, the Association submitted a consultation response to the WHSCC in relation to an assessment of imiglucerase (Cerezyme®) for the treatment of Gaucher disease type 1 and 3.

Gaucher Disease in Europe and Other Parts of the World

The Gauchers Association is a founding member of the International Gaucher Alliance (IGA) (formally the European Gaucher Alliance), a collaboration of patient representative groups around Europe and the World which now has 57 members. The Association Trustees represent the UK Gauchers Association, by working alongside the IGA, attending meetings and participating in events. Gauchers Association Trustee, Jeremy Manuel, is it's honorary President.

Fundraising and Awareness

The Association continues to use Just Giving, as well as Paypal and CAF Donate, which enables members and supporters to donate funds online. Members are encouraged and supported to use this method for sponsorship for all fundraising activities including the London Marathon, annual subscriptions and individual member activities and continues to be very successful.

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The 2023 London Marathon took place on Sunday 23rd April with the Association being represented by seven runners raising £13,740. Runners also took part in the Belfast and Paris marathons raising a further £14,810 on behalf of the Association.

The Association raised over £450 through Facebook donation facilities year ending June 2023.

Other member fundraising activities include birthday celebrations, in memories, workplace social events, cycling and hikes.

The Association is extremely grateful to all its members who continue to support the charity, through fundraising events, regular donations and individual donations.

Neuronopathic Gaucher Disease Type 3

Patient and Family Conference 2023

In April 2023, the Association hosted their 10th nGD family conference at Wyboston Lakes Bedfordshire, the first conference since Covid-19. This event was held over a full weekend and was attended by 14 families from throughout the UK as well as a family from Italy. Presentation topics included; the GARDIAN registry, association of visual loss with nGD, behavioural issues with nGD, genotyping and progression of disease, potential new therapies and several powerful and emotional personal stories. The children all enjoyed a full packed activities program. On Saturday evening families enjoyed a gala dinner with the opportunity to meet old friends and new. On Sunday morning parents and adult patients enjoyed a selection of giant pub games.

Genzyme GD 3 clinical trial (LEAP)

This global clinical trial looking into Genzyme's new oral therapy for adult type 3 patients is ongoing, and participants are receiving an intervention or being examined. Enrollment has now started for a follow on LEAP 2 trial. The Association works closely with Sanofi Genzyme and the UK clinicians to support this project.

GARDIAN neuronopathic Gaucher disease Registry

On 25th April 2022 the International Gaucher Alliance launched the first patient led registry for people with neuronopathic Gaucher disease (type 2 and 3) called GARDIAN.

1. GARDIAN is a registry to improve disease understanding, management and support for patients with GD2 & GD3.
2. GARDIAN is a research platform to provide evidence-based data for advancing disease management, designing safer treatments and improving patient outcomes.
3. GARDIAN is patient-led and owned by the IGA as a global community to drive research and ensure we all work together with researchers and pharmaceutical companies to have one disease registry.

The UK Gauchers Association have supported the registry and encourage as many patients as possible and carers to register and will continue to promote and help families with this.

Research

General

The Association has given several small grants to research projects over the past few years. These projects have carried out important research and, in most cases, have gone on to use the results to lever additional funds or identify further areas of research that need to be taken forward. In addition to giving grants, members of the Association support others as a stakeholder in collaborative grant applications through time and links with patients and their families.

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Gaucherite

Jeremy Manuel on behalf of the GA together with the eight specialist LSD Centres in the UK, the Association continues to partner with the Gaucherite study. Recruitment to the project includes data from 85 per cent of all UK Gaucher patients and the results continue to be analysed to stratify patients by the nature of their disease with the aim of better targeting therapy interventions.

Through the year consideration has been given for access to material for research and to the data collected. There are a considerable number of papers that have been prepared and are in preparation based on analysis of data collected which will be of real value to the Gaucher community both in the UK and Globally. There remains much detail that needs to be analysed.

Funding streams continue to be investigated to ensure the longevity of the study and maintenance of the Biobank as well as discussions over the longevity of the data collected and the study.

Rapsodi - Gaucher families helping find a cure for Parkinson's

The Association continues to support the research being undertaken at the Royal Free Hospital into the link between Gaucher disease and Parkinson's disease by encouraging patients and their families to support the study through our news bulletins and direct mailings and website. The Association worked with the team at the Royal Free on the development of the online portal which remains up and running and is the main tool that captures all the patient data, including working for the site and a video on how to use the portal.

Susan Lewis Memorial Fund

Susan Lewis was a founder of both the UK Gauchers Association and the European Gaucher Alliance (EGA). Following her death in 2007 the Gauchers Association established the Susan Lewis Memorial Award to provide grants and bursaries to doctors and other healthcare professionals from developing countries (particularly Eastern Europe) to allow them to travel to the UK Centres of Excellence to undertake mentoring and educational programmes in the treatment and management of Gaucher disease. The Award was subsequently extended to support healthcare professionals attending educational events around the world.

In February 2022 the Association received an application for funding from FYMCA Medical Ltd, a medical education company, to support their pilot study 'Building capacity in Africa'. The aim of this project is to illustrate that African countries can work together to establish a rare diseases diagnostic network. The following countries were selected:

Botswana, Ghana, Kenya, Mozambique, Namibia, Nigeria, Sudan, Tanzania and Uganda

These countries have already trained rare disease physicians and are able to access the already existing transport infrastructure of private pathology groups and are therefore ideal sample collection sites.

The funding request was approved unanimously by the Board of Trustees for £15,000 in provision for a full written report to be published in our e-news bulletin. This was the final funding application from the Susan Lewis Memorial Fund, hence closing the fund.

Additional New Treatments for Gaucher Disease

Sanofi Genzyme's small molecule for type III Gaucher disease (LEAP / LEAP 2 Mono) – See above

ELIKIDS - Safety and efficacy of Eliglustat with or without Imiglucerase in paediatric patients with Gaucher disease Type 1 and Type 3. This is a global clinical trial, recruitment for which in the UK started in 2019.

Freeline's gene therapy for Gaucher disease Type 1 (Galileo-1) – this is a global clinical trial with one of the trial centres in the UK. The trial is expected to be fully enrolled by mid-24.

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Directors' Report

Managing Information and Communication

GDPR

The Association continue to review their processes and practices to ensure compliance with the new General Data Protection Regulation (GDPR) which has now come into effect and replaces the Data Protection Act (1998). By making this change we ensure to only contact our members and supporters in ways they have chosen and we will be able to communicate more effectively. All information and responsibilities are available from our website.

The Association continues to supply up to date information on the telephone, by mail and through our website and Social Media platforms. The Association continues to produce a regular e-news bulletin sent out to families, doctors and other interested parties worldwide. Our news bulletin is sent to over 250 people worldwide.

Database

The Association operates a secure Members database which was last updated through our GDPR implementation in May 2018.

Website

The Association's website allows regular e-news alerts to our members (if they choose) to ensure they are kept up to date with the latest news and developments in the Gaucher field. The Association is planning to overhaul the website as a key project for 2024.

Social Media

The Association have an active Facebook and posts updates with interesting articles on new projects, research updates, current political issues etc. On Facebook we have over 1000 followers.

Rare Disease Day 2023

The Association supported this event through their Social Media channels by sharing infographics and posts.

International Gaucher Day 2022

The Association joined many Associations' around the world to celebrate International Gaucher Day (IGD) on 1st October 2022. IGD is the brainchild of the International Gaucher Alliance (IGA). The aim is to raise international awareness of Gaucher disease and the slogan remains 'Rare but not alone'.

UK LSD Collaborative Group

The patient organisations for those affected by LSDs work collaboratively within the umbrella of the 'LSD Patient Organisation Collaborative' to work and lobby on behalf of LSD patients and their families in the UK.

The LSD Collaborative has now become a formal legal entity in its own right with registered charitable status.

The group is made up of representatives from the Association of Glycogen Storage Disease, Batten Disease Family Association, the Gauchers Association, the Society for Mucopolysaccharide Diseases, the Niemann Pick Disease Group UK, Krabbe and CATS (Tay Sachs), MLD Support UK (Metachromatic Leukodystrophy) & Metabolic Support UK, Pompe UK and Cystinosis Foundation UK. As part of this collaboration, the Gauchers Association has undertaken to jointly promote and share understanding of their diseases to advance standards of care and to enhance the well-being of those affected.

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The LSD Collaborative continues to be a recognised forum and provides the expert patient perspective to NHS England in respect of procurement of Enzyme Replacement Therapy and Home Care and the approval of new therapies coming to the market. It also has a representative on the Metabolic Clinical Reference Group (CRG) of NHS England, RDAG, ABPI Patient Council, Genetic Alliance PEG, Rare Disease Forum, Genomics England.

Meeting with LSD Centres

As part of the LSD Collaborative commitment to strengthen communications with the LSD Centres (see above), the Collaborative meet with the nine (including the Evelina) national centres in Manchester, Birmingham, Cambridge and London. All minutes of these meetings are sent to NHS England.

Newborn Screening

In 2020 ArchAngel MLD Trust brought together 13 principal rare disease patient organisations, including the Gauchers Association, plus Genetic Alliance UK, in order to form a new UK New Born Screening (NBS) Collaborative, representing over 500 rare diseases and thousands of patients. A high-profile campaign calling for change was launched in 2020 with the important support of Nickie Aiken MP. The Collaborative developed a number of key policy changes which would allow for the appropriate and efficient expansion of the NBS programme in direct response to the Rare Disease Framework launched by the Department of Health & Social Care (DHSC) in 2021.

In February 2022, the DHSC published the England Rare Disease Action Plan containing an important commitment to improving newborn screening, in line with the key policy changes which the Collaborative had called for. The Collaborative will continue to work with the DHSC on the detail of the above promises at every opportunity and to raise awareness for the expansion of the NBS programme in the UK.

Medics4RareDiseases (M4RD)

The Association continues to collaborate and support the vital work carried out by this organisation. In 2021 the Association supported the joint initiative of M4RD and Beacon's Student voice, being an essay writing competition. Charities are partnered with a medical student to share information and stories enabling students to write and submit an essay, therefore raising awareness of Rare Diseases within medical students' education.

Financial Review

The Board of Trustees of the Gaucher's Association have agreed a general fund reserves policy of maintaining reserves equivalent to no less than one years' annual operating costs below which a meeting of the Trustees would be convened to formally discuss the issue. This policy currently reflects a minimum level of reserves of circa £80,000.

During the year the charity's reserves increased by £23,344 and held reserves of £204,730 at 30 June 2023. The level of reserves is above the minimum level of reserves required under the agreed reserves policy.

Small company provisions

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

This report was approved by the board on 21 March 2024 and signed on its behalf.

Daniel Brown

Daniel Brown (Mar 21, 2024 09:59 GMT)

D A Brown
Director

The Gauchers Association Limited (a Company Limited by Guarantee)

Independent Examiner's Report to the Trustees of The Gauchers Association Limited (A Company Limited by Guarantee) for the year ended 30 June 2023

I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2023, which are set out on pages 11 to 15.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ("the 2006 Act").

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

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

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

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



Neil Heyes FCA
(Senior Statutory Auditor)
for and on behalf of
Rayner Essex LLP Chartered Accountants
Accountants and Statutory Auditors
Faulkner House
Victoria Street
St Albans
AL1 3SE

21 March 2024

The Gauchers Association Limited (a Company Limited by Guarantee)
Statement of Financial Activities Including Income and Expenditure Accounts
for the year ended 30 June 2023

| | Notes | Unrestricted Funds | Restricted Funds | Total Funds 2023 £ | Total Funds 2022 £ |
|--|-------|-----------------------|---------------------|--------------------------|--------------------------|
| Income | | | | | |
| Income from other trading activities | | 51,898 | - | 51,898 | 15,837 |
| Income from donations and legacies | | | | | |
| Donations | | 14,190 | 38,510 | 52,700 | 36,842 |
| Subscriptions | | - | - | - | 899 |
| Gift Aid tax | | 3,073 | - | 3,073 | 3,510 |
| Interest and investment income | | | | | |
| Interest receivable | | 2,005 | 21 | 2,026 | 125 |
| Total income | | 71,166 | 38,531 | 109,697 | 57,213 |
| Expenditure | | | | | |
| Expenditure on raising funds | | 3,018 | 1,665 | 4,683 | 3,729 |
| Expenditure on charitable activities | | | | | |
| Grants | | - | - | - | 15,525 |
| Conference | | - | 24,203 | 24,203 | 148 |
| Information and publications | | - | - | - | 3,406 |
| Charitable payments | | - | 22,450 | 22,450 | - |
| Managing and administering the charity | | 31,054 | 3,963 | 35,017 | 61,050 |
| Total expenditure | | 34,072 | 52,281 | 86,353 | 83,858 |
| Movement in total funds for the year | | | | | |
| Net (expenditure) / income for the year | 2 | 37,094 | (13,750) | 23,344 | (26,645) |

The Gauchers Association Limited (a Company Limited by Guarantee)
Registered number: 04468323
Charity Balance Sheet
as at 30 June 2023

| | Notes | 2023 £ | 2022 £ |
|---|-------|-----------|-----------|
| Fixed assets | | | |
| Tangible assets | 4 | - | 105 |
| | | - | 105 |
| Current assets | | | |
| Debtors | 5 | 3,386 | 2,222 |
| Cash at bank and in hand | | 210,719 | 206,174 |
| | | 214,105 | 208,396 |
| Creditors: amounts falling due within one year | 6 | (9,375) | (27,115) |
| Net current assets | | 204,730 | 181,281 |
| Total assets less current liabilities | | 204,730 | 181,386 |
| Net assets | | 204,730 | 181,386 |
| Funds of the charity | | | |
| Unrestricted funds | 7 | 155,465 | 118,371 |
| Restricted funds | 7 | 49,265 | 63,015 |
| Total charity funds | | 204,730 | 181,386 |

The directors are satisfied that the company is entitled to exemption from the requirement to obtain an audit under section 477 of the Companies Act 2006.

The members have not required the company to obtain an audit in accordance with section 476 of the Act.

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

The accounts have been prepared and delivered in accordance with the special provisions applicable to companies subject to the small companies regime. The profit and loss account has not been delivered to the Registrar of Companies.

Daniel Brown
Daniel Brown (Mar 21, 2024 09:59 GMT)

D A Brown
Director
Approved by the board on 21 March 2024

The Gauchers Association Limited (a Company Limited by Guarantee)
Notes to the Accounts
for the year ended 30 June 2023

1 Accounting policies

Basis of preparation

The accounts have been prepared under the historical cost convention and in accordance with the Statement of Recommended Practice, Accounting and Reporting by Charities and FRS 102, The Financial Reporting Standard applicable in the UK and Republic of Ireland (as applied to small entities by section 1A of the standard) and the Companies Act 2006.

Fund Accounting

Funds held by the charity are either:

Unrestricted funds are available for the use at the discretion of the trustees in furtherance of the general objectives of the charity.

Designated funds are unrestricted funds earmarked by the trustees for a particular purpose.

Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of appeal.

Income

Income received from subscriptions, donations, Gift Aid Tax and activities is measured at the fair value of the consideration received or receivable. Income is recognised when the charity has entitlement to the funds, any performance conditions attached the item of income have been met, it is probable that the income will be received and the amount can be reliably measured. Accruals are made for monies received on fund generating activities that were held during the financial year but received after the financial year end up to the date these financial statements were approved by the trustee/directors. Income received in advance of the provision of services is deferred until the criteria for income recognition are met.

Government and other grants for the purpose of giving immediate financial support with no future related costs, are recognised under the accrual model as income in the period in which it becomes receivable.

Expenditure

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that a settlement will be required and the amount of the obligation can be measured reliably. Resources expended are included in the Statements of Financial Activities on an accrual basis, inclusive of any VAT which cannot be recovered. Where applicable they have been charged directly to the funds and activities to which they relate.

Tangible fixed assets

Tangible fixed assets are measured at cost less accumulative depreciation and any accumulative impairment losses. Depreciation is provided on all tangible fixed assets, other than freehold land, at rates calculated to write off the cost, less estimated residual value, of each asset evenly over its expected useful life, as follows:

| | |
|---------------------|--------------------|
| Plant and machinery | over 3 to 10 years |
|---------------------|--------------------|

Debtors

Short term debtors are measured at transaction price (which is usually the invoice price), less any impairment losses for bad and doubtful debts. Loans and other financial assets are initially recognised at transaction price including any transaction costs and subsequently measured at amortised cost determined using the effective interest method, less any impairment losses for bad and doubtful debts.

Creditors

Short term creditors are measured at transaction price (which is usually the invoice price). Loans and other financial liabilities are initially recognised at transaction price net of any transaction costs and subsequently measured at amortised cost determined using the effective interest method.

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Notes to the Accounts
for the year ended 30 June 2023

Pensions

Contributions to defined contribution plans are expensed in the period to which they relate.

| 2 Net income/(expenditure) for the year | 2023 £ | 2022 £ |
|--|-------------------|-------------------|
| This is stated after charging: | | |
| Depreciation of owned fixed assets | 105 | 105 |
| Independent Examiner's remuneration | 2,700 | 2,700 |
| Contributions to pension fund for employees | 189 | 696 |
| | <hr/> | <hr/> |
| This is stated after crediting: | | |
| Donations from trustees | 400 | 3,099 |
| | <hr/> | <hr/> |

No employee received emoluments more than £60,000.
No key management personnel were paid a salary in the year.

| 3 Employees | 2023 Number | 2022 Number |
|---|------------------------|------------------------|
| Part-time directors | 3 | 6 |
| Other part-time staff | 1 | 2 |
| Average number of persons employed by the company | 4 | 8 |
| | <hr/> | <hr/> |

| 4 Tangible fixed assets | Plant and machinery etc £ |
|--------------------------------|--|
| Cost | |
| At 1 July 2022 | 7,564 |
| At 30 June 2023 | <hr/> 7,564 |
| Depreciation | |
| At 1 July 2022 | 7,459 |
| Charge for the year | 105 |
| At 30 June 2023 | <hr/> 7,564 |
| Net book value | |
| At 30 June 2023 | <hr/> - |
| At 30 June 2022 | <hr/> 105 |

| 5 Debtors | 2023 £ | 2022 £ |
|------------------|-------------------|-------------------|
| Trade debtors | - | 806 |
| Other debtors | 3,386 | 1,416 |
| | <hr/> 3,386 | <hr/> 2,222 |

The Gauchers Association Limited (a Company Limited by Guarantee)
Notes to the Accounts
for the year ended 30 June 2023

| 6 Creditors: amounts falling due within one year | 2023 | 2022 |
|---|--------------|---------------|
| | £ | £ |
| Trade creditors | 570 | 240 |
| Taxation and social security costs | 166 | - |
| Other creditors | 8,639 | 26,875 |
| | <u>9,375</u> | <u>27,115</u> |

| 7 Movement in funds | As 1 July | Income | Transfer | Expenditure | As 30 June |
|--|--------------------|--------------------|-----------------|--------------------|--------------------|
| | 2022 | | | | 2023 |
| | £ | £ | £ | £ | £ |
| <u>Restricted Funds</u> | | | | | |
| Alan Gordon Memorial Fund | 1,977 | 21 | - | 14 | 1,984 |
| Neuronopathic Fund | 22,233 | 14,150 | - | 27,201 | 9,182 |
| Patient and Family Worker Support Fund | 30,288 | 10,060 | - | 14,969 | 25,379 |
| LSD Collaborative Fund | 2,299 | - | - | 1,607 | 692 |
| Susan Lewis Memorial Fund | 355 | - | - | - | 355 |
| Improving Communications | 3,823 | 5,000 | - | 950 | 7,873 |
| Rare Minds Mental Health | 2,040 | 9,300 | - | 7,540 | 3,800 |
| Total restricted funds | <u>63,015</u> | <u>38,531</u> | <u>-</u> | <u>52,281</u> | <u>49,265</u> |
| General fund | <u>118,371</u> | <u>71,166</u> | <u>-</u> | <u>34,072</u> | <u>155,465</u> |
| Total unrestricted funds | <u>118,371</u> | <u>71,166</u> | <u>-</u> | <u>34,072</u> | <u>155,465</u> |
| Total funds | <u>181,386</u> | <u>109,697</u> | <u>-</u> | <u>86,353</u> | <u>204,730</u> |

8 Related party transactions

Jeremy H Manuel and Tanya Collin-Histed were Honorary President and Chief Executive Officer of the International Gaucher Alliance Limited ("IGA"). During the year ended 30 June 2023 the company charged the IGA £767 (2022: £1,522) for the provision of administration services. As at 30 June 2023 included in trade debtors is £nil (2022: £806) and included in other debtors is £601 (2022: £333) due from IGA.

Included in other debtors at 30 June 2023 is £254 receivable from D Brown.

During the year the IGA received payment of £1,406 (2022: £8,400) for consultancy services provided to the charity.

The total amount of expenses waived by trustees during the year was £nil (2022: £nil).

9 Controlling party

The company is limited by guarantee and is under the control of its directors as a body.

10 Other information

The Gauchers Association Limited (a Company Limited by Guarantee) is a private company limited by guarantee and incorporated in England. It has no share capital. The liability of each member in the event of a winding up is limited to £10. Its registered office is:

86-90 Paul Street
London
EC2A 4NE

An Independent Examination has been carried out on the accounts. There were no matters of concern arising as a result of the Examination.










Gauchers Association final accounts 30 June 2023 v7

Final Audit Report

2024-03-21

| | |
|-----------------|--|
| Created: | 2024-03-21 |
| By: | Lisa Davis (compliance@numerii.co.uk) |
| Status: | Signed |
| Transaction ID: | CBJCHBCAABAAsyquQnxZyHxSAmCVvy-jLd9Z4EqsYPV2 |

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