

Registered number  
04468323

The Gauchers Association Limited (A Company Limited by Guarantee)

Report and Accounts

30 June 2021

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 |
| A Bloom         | Treasurer |
| T Collin-Histed |           |
| J Cox           |           |

**Independent Examiner**

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**

8 Silver Street  
Dursley  
Gloucestershire  
GL11 4ND

**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 2021.

**Structure, Governance and Management**

**Governing Document**

The Gaucher's 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 has been directed by an Executive Committee which consists of not less than five or more than 20 members. The members of the Executive Committee are elected by the members at the Annual General Meeting of the company to remain in office until the conclusion of the next Annual General Meeting. The Trustees of the company shall be ex-officio members of the Executive Committee.

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 has 8 members from a variety of backgrounds relevant to the work of the charity.

**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 Chairman, Treasurer and Chief Executive.

**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 Trustee is invited to a meeting jointly led by the Chairman of the Executive Committee 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.

## **The Gauchers Association Limited (A Company Limited by Guarantee)**

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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 objects of the charity are:-

1. to relieve the need of sufferers from Gaucher disease.
2. to promote research into Gaucher disease and to publish the useful results of such research.

The Charity aims to:

1. Provide information about Gaucher disease and keep families and medical advisers up to date with latest developments.
2. Encourage the availability of treatment including enzyme replacement therapy.
3. Actively encourage and raise funds for medical research.
4. Publish a biannual newsletter, which is sent to over 1300 readers worldwide.
5. Maintain an up to date website on [www.gaucher.org.uk](http://www.gaucher.org.uk) which is translated into Spanish and Russian.
6. Hold a conference every two years.

### **Board Members / Staff**

Madeline Stoodley (nee Collin) Project Coordinator commenced maternity leave on 23<sup>rd</sup> June 2021.

Claire Bickley Patient and Family Support Worker from February 2020 has been supporting the Gaucher community on a consultation basis for 5 hours per week.

### **Covid-19**

The Covid-19 global pandemic has continued to affect the working pattern for staff at the Gaucher's Association, with remote working from home; the office reopened in April 2021. Going forward staff can continue to work remotely away from the office when necessary. Madeline Stoodley returned to work from Furlough for one day per week before commencing maternity leave in June 2021.

The Trustees agreed to continue with no further face to face meetings, however, review this on a quarterly basis; including Executive Board Meetings which have been held remotely via Zoom.

Throughout and beyond the national lockdowns, Claire Bickley, supported by Sarah Allard and Tanya Collin-Histed, was in close contact with vulnerable members via telephone and online Zoom meetings on a regular basis.

The Association, as a member of the LSD Collaborative, and in collaboration with Metabolic Support UK and BIMDG, have hosted further Covid-19 related webinars offering our members the opportunity to join online to hear the latest advice and information from clinicians as well as the chance to ask questions.

## **The Gauchers Association Limited (A Company Limited by Guarantee)**

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### **Directors' Report**

#### **3-5 Year Strategic Plan**

The Association started a 3-5 year strategic plan review using the services of Kathy Redmond at Redmond Consulting in May 2021. The Association are extremely grateful to Kathy for offering her consulting services on a Pro Bono basis. The objectives of the review are to agree the Gauchers Association's core purpose, identify how the Association can be a more effective and sustainable organisation and develop a strategic plan for 2022-2024 to ensure the Gauchers Association delivers on its core purpose. The review process has been informed by internal and external stakeholder interviews which were managed by Kathy Redmond. The strategic plan is expected to be finalised in early 2022.

#### **Advocacy Service**

##### **Patient & Family Support Worker**

The Association provides a dedicated Patient & Family Support service that provides support and advice to meet the non-medical needs of the Gaucher community in England, Scotland & Wales. Types of support provided are:

1. Dedicated telephone helpline
2. Advice on welfare, disability and employment benefits
3. Advice and support on educational issues
4. Advice on housing and equipment
5. Supporting patients and families with benefit court tribunals
6. Employment advice with curriculum vitae support
7. Attending hospital appointments with patients at their request and hospital specific Gaucher clinics
8. Attending hospital Gaucher clinics to meet patients and family members and talk to them about the Association
9. Emotional support

Due to Covid-19 our Patient & Family Support Worker has worked remotely away from the office and continues to do so with no face to face meetings. Our service is currently accessed via email, telephone, Facebook and online meeting platforms (Zoom, Microsoft Teams).

#### **Family Education Weekend**

Due to Covid-19 we have not been able to host this event since 2019. Since the start of the pandemic, Claire Bickley, PFSW, along with Sarah Allard, hosted a small number of online family get togethers giving families the opportunity for a safe space to talk and come together whilst setting activities for the children to take part in and share. We hope to revisit this much needed event in 2022.

#### **Type 1 GD Educational Meetings**

In 2019 the Association published their Insight from Gaucher patients aged 45 years and over in the UK. The outcomes from this report resulted in a series of small face to face meetings across the UK being organised for our GD1 community. Due to the Covid-19 Pandemic these meetings were cancelled; however, we hosted three online educational webinars between November-December 2020. Topics covered were Oral therapies (cerdelga), homecare and social care and the links between Parkinson's and Gaucher disease. We are grateful to Clinical Nurse Specialist, Elizabeth Morris, Patient & Family Support Worker Claire Bickley and Professor Derralynn Hughes for all giving their time to present on these topics as well as answering questions from our GD1 community.

**The Gauchers Association Limited (A Company Limited by Guarantee)**  
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**Directors' Report**

**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 treatment. The adult centres work with the paediatric centres in helping patient transition from childhood to adulthood.

**LSD Expert Advisory Group (EAG)**

As patient representative, Gaucher's Association Trustee Tanya Collin-Histed sits on the EAG and attends bi-annual meetings with representatives from each of the LSD centres in England (and Wales as an observer) and the NHS England 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 (NHSE) 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 will be the annual clinical audit meeting.

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.

**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 is due for review in 2021 however, there is an option to extend for a further 2 years.

**Rare Diseases Framework**

On 9<sup>th</sup> 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. Each nation will aim to publish the action plans in 2021. The Association have been collaborating with other organisations (LSD Collaborative & Genetic Alliance UK) on this policy.

## **The Gauchers Association Limited (A Company Limited by Guarantee)**

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### **Directors' Report**

#### **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.

#### **Gaucher Disease in Europe and Other Parts of the World**

The Gaucher's Association is one of the founding members 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 Gaucher's Association, by working alongside the IGA, attending meetings and participating in events. UK Gaucher's Association Trustee, Tanya Collin-Histed is the CEO of the IGA.

#### **Fundraising and Awareness**

The Association continues to use the Just Giving and Virgin Money Giving sites, 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.

The postponed October 2020 Virgin London Marathon was adapted to a virtual event only; the Association offered all 5 Golden Bond runners the opportunity to take part in this, with just one runner participating raising over £1,500. The cancellation of this event has had a huge effect on fundraising as the marathon is the biggest fundraising event in the year for the Association. The five Golden Bond places from 2020 will be deferred until April 2023. The next London Marathon to take place will be October 2021, followed by October 2022, before returning to April 2023 where the Association will have a bumper team of 10 Golden Bond runners.

The Association raised over £253 through Smile Amazon year ending June 2021.

The Association raised over £2,100 through Facebook donation facilities year ending June 2021.

Other member fundraising activities include birthday celebrations, in memories, workplace social events 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**

##### **Empowering Young Type 3 GD Patients to Shape the Future**

Since March 2020 at the beginning of the UK Government Lockdown, Patient & Family Support Worker, Claire Bickley has been meeting with this group of type 3 adults online via Zoom for regular get togethers, offering the opportunity to meet and chat in a safe environment. These meetings have continued; enabled by funding received by National Lottery Community Fund.



## **The Gauchers Association Limited (A Company Limited by Guarantee)**

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### **Directors' Report**

#### **NGD Educational Webinars**

Due to the Covid-19 Pandemic the Association were unable to host their bi-annual nGD family conference; however, the Association felt it necessary to host a series of online educational webinars to keep our nGD community informed and educated to be able to make informed choices for future potential clinical trials. Topics included - introducing the concept of clinical trials for nGD, gene therapy trials, oral therapy trials and driving research. The Association would like to thank Dr Simon Jones, Dr Aimee Donald, Dr Stewart Rust, Professor Rob Wynn, Professor Ian Kamaly-Asl, Professor Derrallynn Hughes and Trustee Tanya Collin-Histed for designing the webinars.

#### **Facebook**

Through the Patient & Family Support Worker, the group continue to be active on the private Facebook group, as a further communication tool between the group and the Association.

#### **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, but potential participants are not currently being recruited or enrolled. The Association works closely with Sanofi Genzyme and the UK clinicians to support this project.

#### **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.

##### **Gaucherite**

Through our Board member Jeremy Manuel and along with the eight specialist LSD Centres in the UK, the Association continues to partner with the Gaucherite project. Recruitment to the project includes 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.

Jeremy Manuel chairs the management committee of the study and through the year consideration has been given for access to material in the Biobank for research and to the data collected. Documents prepared over the last period include: (i) the approved Data Management Plan (ii) the Data Access Policy (iii) the comprehensive Data Dictionary. There are a considerable number of papers in the pipeline based on analysis of data collected which will be of real value to the Gaucher community.

Funding streams are still being investigated to ensure the longevity of the project.

##### **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. Tanya Collin-Histed 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. Throughout Covid-19 the Association supported the Rapsodi team by promoting and facilitating an online webinar within the Gaucher community.

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**Gene Therapy for the Treatment of Gaucher Disease**

PRV-GD2-101 is an open-label, Phase 1/2, multicentre study to evaluate the safety and efficacy of single-dose PR001 in infants diagnosed with Type 2 Gaucher disease (GD2). For each patient, the study will be approximately 5 years in duration. During the first 12 months after dosing, patients will be evaluated for the effects of PR001 on safety, tolerability, immunogenicity, biomarkers, and efficacy. Patients will be followed up for an additional 4 years to monitor safety and changes on selected biomarkers and clinical outcomes.

Researchers, including Dr Simon Waddington, Dr Ahad Rahim and Dr Guilia Massaro have successfully prevented the development of a fatal neurodegenerative disorder, Gaucher disease, using foetal gene therapy, in mice. The study, published in Nature Medicine highlights the potential of using this approach to combat lethal neurodegenerative diseases affecting new-borns. The contract with Apollo came to an end in late 2019 and we are aware that a company has acquired the rights to take this forward. No public information is available but the Association are in contact with the new company and will continue to support this investigational medicine to get to patients.

The Gaucher's Association has been involved in this project since 2009 and remains involved to seek to bring a potential cure for nGD.

**Susan Lewis Memorial Fund**

Susan Lewis was a founder of both the UK Gaucher's Association and the European Gaucher Alliance (EGA). Following her death in 2007 the Gaucher's 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.

No awards were made throughout 2020/2021; mainly due to the Covid-19 pandemic and meetings all being hosted online or postponed. All recipients of a Susan Lewis Memorial Award are required to write a piece for our news bulletins to inform our members why they attended the meeting, what they learnt and how that can be translated back in the UK for patients and their families with Gaucher disease and other Lysosomal Storage Disorders.

**New Treatments for Gaucher Disease**

**Sanofi Genzyme's Small Molecule for Type III Gaucher Disease (LEAP)** - see above

**ELIKIDS** - Safety and efficacy of Eliglustat with or without Imiglucerase in paediatric patients with Gaucher disease (GD) type 1 and type 3

This is a global clinical trial that is now open and enrolment planned; the UK expects to open 3 study sites (London, Birmingham and Manchester) later this year and recruitment in the UK started in 2019.

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**Directors' Report**

**Gene Therapy for Gaucher Disease** - see above

**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 monthly e-news bulletin sent out to families, doctors and other interested parties worldwide. For those members without access to email we continue to produce a bi-monthly hard copy newsletter sent by mail. 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. This will be repeated in 2023.

**Website**

The Association's website is updated regularly. The site 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.

**Social Media**

The Association have an active Facebook and Twitter account and posts updates with interesting articles on new projects, research updates, current political issues etc. On Facebook we have 939 followers; Twitter was activated in January 2018 and has 259 active followers.

**Rare Disease Day 2020**

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

**International Gaucher Day 2020**

The Association joined many Associations' around the world to celebrate International Gaucher Day (IGD) on 1<sup>st</sup> October 2020. IGD is the brainchild of the International Gaucher Alliance. The aim is to raise international awareness of Gaucher disease and the slogan remains 'Rare but not alone'.

Due to the Covid-19 Pandemic the event was held online only with no materials or merchandise being produced. The 2020 theme was 'Homes not hospitals' improving patients quality of life by campaigning for homecare. The UK Gaucher's Association produced an online news bulletin sharing information on UK Homecare services and personal stories as well as producing a recorded interview between Clinical Nurse Specialist Niamh Finnegan from the Royal Free Hospital, London and Gaucher patient Maddie Collin with her fiancé Callum Stoodley sharing their homecare journey to become independent.

## **The Gauchers Association Limited (A Company Limited by Guarantee)**

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### **Directors' Report**

#### **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 group is made up of representatives from the Association of Glycogen Storage Disease, Batten Disease Family Association, the Gaucher's 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. As part of this collaboration, the Gaucher's 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.

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.

#### **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 five national centres in Manchester, Birmingham, Cambridge and London. All minutes of these meetings are sent to NHS England.

#### **Formulation of the LSD Collaborative**

In 2020 the LSD Collaborative started procedures to become a formal organisation, by reaching out to their membership and stakeholders. The UK Gaucher's Association being a member of the Collaborative have attended online meetings and Tanya Collin-Histed being the Association representative is involved with the steering group. The Trustees from the Association are fully supporting this initiative. Legal work is still in process.

#### **Annual NHSE CQUIN**

In November 2020 the annual CQUINN meeting was held online in which 45 participants attended from NHSE, all 8 LSD HSS centres and the LSD Collaborative. The Collaborative had the first hour and presented on formulation of the LSD Collaborative, LSD Annual patient survey, mental health and the PPPN.

Each of the 8 centres then presented a report on COVID, restoration of services, audit on targets, mortality and morbidity, patient engagement and succession planning.

NHSE undertook a Peer Review of LSD HSS centres and the report plus a presentation was given to the group.

#### **NICE / NHS Consultation Meeting**

NICE are currently undergoing a process and methods review. The purpose of the review is to optimise NICE's evaluation methods to support the ambition of the NHS to provide high quality care that offers good value to patients and to the NHS. The Review is of particular interest to rare disease groups as this is likely to impact the decision making processes in relation to treatments for rare conditions.

The review aims to look at how uncertainty – for example with the available evidence or the assumptions made within economic modelling - is explored or quantified, and what can be done to try and reduce that uncertainty. It also is seeking to look at how quality of life is incorporated into economic analyses and consider Technology-specific issues (for example, addressing the challenges of evaluating the new generation of treatments that have been developed according to their genetic make-up rather than where they originate in the body).

## **The Gauchers Association Limited (A Company Limited by Guarantee)**

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The Association have been involved in the process by attending educational meetings and have made a formal submission to the ongoing consultation.

Originally, a six week public consultation on proposed changes was scheduled for Summer 2020 with publication of an updated NICE manual expected in December 2020. Instead a public consultation on changes to NICE's methods will now begin in November 2020 and separate consultation on changes to NICE's processes will be launched in February 2021. This will then be followed by a stakeholder consultation on a draft updated programme manual for such assessments in June 2021 and NICE anticipates that its final programme manual will be published in September 2021.

#### **Annual Patient Survey**

The LSD annual patient survey was distributed to all patients and carers and through the clinical centres.

All centres will receive their own data and each patient groups their own disease cohort responses in addition to the complete report.

#### **New Born Screening**

Trustee Tanya Collin-Histed has joined the working group being led by ArkAngel Trust to review the current New Born Screening Criteria (Wilson and Young Criteria) used in the UK. The working group seek to review and propose a new method. The ArkAngel Trust are working with Nickie Aiken MP who is seeking for a review and the NBSC list and also supporting the current governments Early Years Review.

#### **Medics4RareDiseases (M4RD)**

Whilst Trustee Tanya Collin-Histed no longer sits of the board for M4RD; the Association continues to collaborate and support the vital work carried out by this organisation. In 2020 the Association supported the joint initiative of m4RD and Findacure'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 £458 and held reserves of £208,031 at 30 June 2021. 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 18 March 2022 and signed on its behalf.



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 2021**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2021, which are set out on pages 13 to 18.

#### **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

18 March 2022

**The Gauchers Association Limited (A Company Limited by Guarantee)**  
**Statement of Financial Activities Including Income and Expenditure Accounts**  
**for the year ended 30 June 2021**

|  | Notes    | Unrestricted<br>Funds<br>2021<br>£ | Restricted<br>Funds<br>2021<br>£ | Total Funds<br>2021<br>£ | Total Funds<br>2020<br>£ |
|--|----------|------------------------------------|----------------------------------|--------------------------|--------------------------|
| <b>Income</b>                                  |          |                                    |                                  |                          |                          |
| <b>Income from other trading activities</b>    |          | 2,655                              | -                                | 2,655                    | 53,453                   |
| <b>Income from donations and legacies</b>      |          |                                    |                                  |                          |                          |
| Donations                                      |          | 29,287                             | 33,190                           | 62,477                   | 70,117                   |
| Subscriptions                                  |          | 1,052                              | -                                | 1,052                    | 778                      |
| Gift Aid tax                                   |          | 1,609                              | -                                | 1,609                    | 6,416                    |
| <b>Interest and investment income</b>          |          |                                    |                                  |                          |                          |
| Interest receivable                            |          | 19                                 | 2                                | 21                       | 313                      |
| <b>Other income</b>                            | <b>2</b> | 3,013                              | -                                | 3,013                    | 15,193                   |
| <b>Total income</b>                            |          | <b>37,635</b>                      | <b>33,192</b>                    | <b>70,827</b>            | <b>146,270</b>           |
| <b>Expenditure</b>                             |          |                                    |                                  |                          |                          |
| <b>Expenditure on raising funds</b>            |          | 2,099                              | -                                | 2,099                    | 6,846                    |
| <b>Expenditure on charitable activities</b>    |          |                                    |                                  |                          |                          |
| Grants   |          | -                                  | 465                              | 465                      | 11,960                   |
| Conference                                     |          | 75                                 | 371                              | 446                      | 22,811                   |
| Information and publications                   |          | 53                                 | 157                              | 210                      | 626                      |
| Managing and administering the charity         |          | 60,244                             | 6,905                            | 67,149                   | 82,144                   |
| <b>Total expenditure</b>                       | <b>3</b> | <b>62,471</b>                      | <b>7,898</b>                     | <b>70,369</b>            | <b>124,387</b>           |
| <b>Movement in total funds for the year</b>    |          |                                    |                                  |                          |                          |
| <b>Net (expenditure) / income for the year</b> |          | <b>(24,836)</b>                    | <b>25,294</b>                    | <b>458</b>               | <b>21,883</b>            |

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

**The Gauchers Association Limited (A Company Limited by Guarantee)**  
**Registered number:** 04468323  
**Balance Sheet**  
**as at 30 June 2021**

|   | Notes | 2021<br>£ | 2020<br>£ |
|---|-------|-----------|-----------|
| <b>Fixed assets</b>                                   |       |           |           |
| Tangible assets                                       | 5     | 210       | 316       |
|   |       | 210       | 316       |
| <b>Current assets</b>                                 |       |           |           |
| Debtors   | 6     | 1,580     | 903       |
| Cash at bank and in hand                              |       | 208,916   | 210,648   |
|   |       | 210,496   | 211,551   |
| <b>Creditors: amounts falling due within one year</b> | 7     | (2,675)   | (4,294)   |
| <b>Net current assets</b>                             |       | 207,821   | 207,257   |
| <b>Total assets less current liabilities</b>          |       | 208,031   | 207,573   |
| <b>Net assets</b>                                     |       | 208,031   | 207,573   |
| <b>Funds of the charity</b>                           |       |           |           |
| Unrestricted funds                                    | 8     | 140,016   | 164,852   |
| Restricted funds                                      | 8     | 68,015    | 42,721    |
| <b>Total charity funds</b>                            |       | 208,031   | 207,573   |

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.

*Andrew Bloom*  
Andrew Bloom (Mar 18, 2022 12:11 GMT)

A Bloom  
Director  
Approved by the board on 18 March 2022



**The Gauchers Association Limited (A Company Limited by Guarantee)**  
**Notes to the Accounts**  
**for the year ended 30 June 2021**

**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, including those from the Government job retention scheme, 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.

**The Gauchers Association Limited (A Company Limited by Guarantee)**  
**Notes to the Accounts**  
**for the year ended 30 June 2021**

**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.

**Pensions**

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

**2 Other income**

|              | <b>2021</b>  | <b>2020</b>   |
|--------------|--------------|---------------|
|              | <b>£</b>     | <b>£</b>      |
| Grant income | 3,013        | 15,193        |
|              | <u>3,013</u> | <u>15,193</u> |

Grant income includes grants received under the Coronavirus Job Retention Scheme of £3,012 (2020: £2,223), a local authority small business grant of £nil (2020: £10,000) and other grants of £nil (2020: £2,970).

**3 Net income / (expenditure) for the year**

|   | <b>2021</b>  | <b>2020</b>  |
|---|--------------|--------------|
|   | <b>£</b>     | <b>£</b>     |
| This is stated after charging:              |              |              |
| Depreciation of owned fixed assets          | 106          | 177          |
| Independent Examiner's remuneration         | 2,000        | 2,000        |
| Contributions to pension fund for employees | 836          | 884          |
| Remuneration of key management personnel    | -            | 9,618        |
|   | <u>-</u>     | <u>9,618</u> |
| This is stated after crediting:             |              |              |
| Donations from trustees                     | 2,887        | 2,300        |
|   | <u>2,887</u> | <u>2,300</u> |

No employee received emoluments more than £60,000.

No key management personnel were paid a salary in the year.

**4 Employees**

|   | <b>2021</b>   | <b>2020</b>   |
|---|---------------|---------------|
|   | <b>Number</b> | <b>Number</b> |
| Part-time directors                               | 6             | 6             |
| Other part-time staff                             | 2             | 2             |
| Average number of persons employed by the company | <u>8</u>      | <u>8</u>      |

**5 Tangible fixed assets**

|                       | <b>Plant and machinery etc<br/>£</b> |
|-----------------------|--------------------------------------|
| <b>Cost</b>           |                                      |
| At 1 July 2020        | 7,564                                |
| Additions             | -                                    |
| At 30 June 2021       | <u>7,564</u>                         |
| <b>Depreciation</b>   |                                      |
| At 1 July 2020        | 7,248                                |
| Charge for the year   | 106                                  |
| At 30 June 2021       | <u>7,354</u>                         |
| <b>Net book value</b> |                                      |
| At 30 June 2021       | <u>210</u>                           |
| At 30 June 2020       | <u>316</u>                           |

**The Gauchers Association Limited (A Company Limited by Guarantee)**  
**Notes to the Accounts**  
**for the year ended 30 June 2021**

|   |              |              |
|---|--------------|--------------|
| <b>6 Debtors</b>  | <b>2021</b>  | <b>2020</b>  |
|   | <b>£</b>     | <b>£</b>     |
| Other debtors   | 1,580        | 903          |
|   | <u>1,580</u> | <u>903</u>   |
| <b>7 Creditors: amounts falling due within one year</b> | <b>2021</b>  | <b>2020</b>  |
|   | <b>£</b>     | <b>£</b>     |
| Trade creditors   | 264          | 240          |
| Taxation and social security costs                      | 222          | 482          |
| Other creditors   | 2,189        | 3,572        |
|   | <u>2,675</u> | <u>4,294</u> |

|                                 |                         |                      |                        |                           |                          |
|---------------------------------|-------------------------|----------------------|------------------------|---------------------------|--------------------------|
| <b>8 Movement in Funds</b>      | <b><u>As 1 July</u></b> | <b><u>Income</u></b> | <b><u>Transfer</u></b> | <b><u>Expenditure</u></b> | <b><u>As 30 June</u></b> |
|                                 | <b><u>2020</u></b>      |                      |                        |                           | <b><u>2021</u></b>       |
|                                 | <b>£</b>                | <b>£</b>             |                        | <b>£</b>                  | <b>£</b>                 |
| <u>Restricted Funds</u>         |                         |                      |                        |                           |                          |
| Research Fund                   | 353                     | -                    | (353)                  | -                         | -                        |
| Alan Gordon Memorial Fund       | 12,101                  | 1                    | -                      | 14                        | 12,088                   |
| Neuronopathic Fund              | 18,641                  | 2,900                | -                      | 988                       | 20,553                   |
| Julia Fund                      | 1,004                   | -                    | (1,004)                | -                         | -                        |
| Patient and Family Worker       | (6,847)                 | 21,815               | 1,357                  | 2,398                     | 13,927                   |
| LSD Collaborative Fund          | (751)                   | 5,050                | -                      | 3,200                     | 1,099                    |
| Susan Lewis Memorial Fund       | 15,877                  | 1                    | -                      | 14                        | 15,864                   |
| Improving Communications        | 2,343                   | 3,425                | -                      | 1,284                     | 4,484                    |
| <b>Total restricted funds</b>   | <u>42,721</u>           | <u>33,192</u>        | <u>-</u>               | <u>7,898</u>              | <u>68,015</u>            |
| General fund                    | <u>164,852</u>          | <u>37,635</u>        | <u>-</u>               | <u>62,471</u>             | <u>140,016</u>           |
| <b>Total unrestricted funds</b> | <u>164,852</u>          | <u>37,635</u>        | <u>-</u>               | <u>62,471</u>             | <u>140,016</u>           |
| <br>Total funds                 | <br><u>207,573</u>      | <br><u>70,827</u>    | <br><u>-</u>           | <br><u>70,369</u>         | <br><u>208,031</u>       |

**9 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 2021 the company charged the IGA £1,530 (2020: £276) for the provision of administration services.

During the year Tanya Collin-Histed received payment of £nil (2020: £600) for consultancy services she provided to the charity. During the year the IGA received payment of £8,800 (2020: £4,014) for consultancy services provided to the charity.

The total amount of expenses waived by trustees during the year was £nil (2020: £nil).

**10 Controlling party**

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

**The Gauchers Association Limited (A Company Limited by Guarantee)**  
**Notes to the Accounts**  
**for the year ended 30 June 2021**

**11 Other information**

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

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

Its registered office is:  
8 Silver Street  
Dursley  
Gloucestershire  
GL11 4ND











# 30-06-21 Gauchers Association final accounts final

Final Audit Report

2022-03-21

|                 |  |
|-----------------|--|
| Created:        | 2022-03-18                                   |
| By:             | L Davis (compliance@numerii.co.uk)           |
| Status:         | Signed                                       |
| Transaction ID: | CBJCHBCAABAABnJhbawGLk9BfLRs4Q5W81L6ahThZFkO |

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