

Registered number
4468323

The Gauchers Association Limited (A company limited by guarantee)

Report and Accounts

30 June 2020

Registered Charity Number 1095657
Company Registration Number 4468323

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
M Collin (resigned 17 September 2019)
J Cox (appointed 17 September 2019)

Independent Examiner

Rayner Essex LLP Chartered Accountants
Tavistock House South
Tavistock Square
London
WC1H 9LG

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

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The Gauchers Association Limited (A company limited by guarantee)

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Directors' Report

The directors present their report and accounts for the year ended 30 June 2020.

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 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.

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4. Future plans and objectives.

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 which is translated into Spanish and Russian.
6. Hold a conference every two years.

Board Members / Staff

James Cox was elected to become a Director and Trustee of the Gauchers Association.

Madeline Collin resigned from being a Director and Trustee of the Gauchers Association to join the staff team as Project Coordinator.

Claire Bickley was employed as the new Patient and Family Support Worker from September 2019, working 18.5 hours per week.

Covid-19

In March 2020, due to the Covid-19 global pandemic and pursuant to UK Government Guidance, the Gauchers Association closed the office with all staff working remotely from home. Due to the nature of project work for Madeline Collin, the Trustees unanimously agreed to place her on furlough until further notice pursuant to the Covid-19 Government Furlough Scheme. The Trustees agreed that there would be no further face to face meetings throughout 2020 and that this would be reviewed in early 2021.

Throughout and beyond the national lockdown, Claire Bickley, supported by Sarah Allard and Tanya Collin-Histed, was in close contact with vulnerable members (who were advised to shield to protect their health) via telephone and online Zoom meetings on a regular basis. Claire Bickley continues to do this.

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The Association, as a member of the LSD Collaborative, and in collaboration with Metabolic Support UK and BIMDG, hosted a series of 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.

Restructure of the Gauchers Association

The restructuring of the Association was completed in September 2019 to realise targeted savings of approximately £16,800 per annum for the Association in light of the ever-increasing financial difficulties faced by small charities and the difficulties in fund raising. The process was led by former Chief Executive Officer, Jane Jones, alongside the Board of Trustees.

The new structure (i) removed the post of Chief Executive Officer and Information and Communications Officer and created a new role of Operations Manager to be supported and supervised by the Chair of Trustees; (ii) retained the role of Patient and Family Support Worker but on the basis a reduced number of hours per week (18.5 vs 25); (iii) outsourced work to the International Gaucher Alliance for strategic work with the Specialist Centres, the Lysosomal Storage Disorder Collaborative and other healthcare providers at two days per month.

In addition, the post of Project Coordinator (for which Maddie Collin was subsequently recruited) was created on a fixed term contract for a 12 month period to complete projects for which funding had been obtained in the previous financial year as follows: Type 1 GD education meetings; updated Type 2 GD information booklet; and produce a short awareness raising film.

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:

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

Maturing Community

Through unrestricted funding the Association completed a research project looking into the changing needs of our maturing community and how the Association can best meet their needs. The results were published in October 2019. The publication is available as a hardcopy booklet or to download as a PDF from the Association website.

The outcomes from the published report are being used to help shape the future of the Patient and Family Support Service.

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Family Education Weekend

In June 2019 we hosted our second family education weekend at Conkers Adventure and Discovery Centre in Derbyshire. The sun shone throughout the whole weekend for our 11 families who joined us, including both type 1 and type 3 Gaucher disease.

We must thank former Patient & Family Support Worker Helen Whitehead who worked hard to bring this event together, working with families and each of the paediatric specialist centres to ensure each Gaucher family were invited to attend. Thank you to Gauchers Association Trustee Tanya Collin-Histed for giving up her Saturday by joining us and spending time talking to all families and sharing her story, experiences and knowledge.

Family Quote' We cannot thank you all enough for the superb weekend, you guys are fantastic'.

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. 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, Gauchers 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 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 Service

The new National Homecare Framework meetings commenced in October 2018; the adjudication process was carried out up until February 2019 with four companies now providing Homecare 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.

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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 Gauchers 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 Gauchers Association, by working alongside the IGA, attending meetings and participating in events.

Fundraising & 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, Great North Run, annual subscriptions and individual member activities and continues to be very successful.

In April 2020 the Virgin London Marathon was postponed until October 2020 due to Covid-19. The Association had five runners registered and this has a huge effect on fundraising, the marathon being the biggest fundraising event in the year for the Association. The five Golden Bond places for 2020 will be deferred over the next 3 years. The next London Marathon event will be held in October 2021 before returning to April 2022.

The Association held their 8th London to Cambridge charity 60 mile bike ride in September 2019 with over 72 riders registered to participate raising over £12,800. The Association would like to say a big thank you to all our wonderful volunteers, without whom it would not be possible.

The Association raised over £145 through Smile Amazon year ending June 2020.

The Association raised over £1,711 through Facebook donation facilities year ending June 2020.

Other member fundraising activities include birthday celebrations, in memories, workplace social events and half marathons.

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

Neuronopathic Gaucher Disease Type 3

Empowering young type 3 GD patients to shape the future

This project is funded through a grant from Great Ormond Street Hospital.

In July 2017 the group of type 3 young adults all travelled to London and took part in a river cruise along the river Thames, organised by Patient & Family Support Worker Helen Whitehead. This event offers the opportunity for the group to meet together, share experiences and offer a support network. The Empowerment Project is supported by Dr Derralyyn Hughes and Clinical Nurse Specialist Niamh Finnegan from the Royal Free Hospital.

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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 continue on a regular basis throughout 2020; enabled by funding received by National Lottery Community Fund.

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 has now ceased recruiting for the phase II trial. However 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, the Association continues to partner, along with the eight specialist LSD Centres in the UK the Gaucherite project. Recruitment to the project includes 85 per cent of all UK Gaucher patients and the results continues 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 is now 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.

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Gene Therapy for the treatment of Gaucher disease

Researchers, including Dr's Simon Waddington, Ahad Rahim and Guilia Massaro have successfully prevented the development of a fatal neurodegenerative disorder, Gaucher disease, using fetal gene therapy, in mice. The study, published in Nature Medicine highlights the potential of using this approach to combat lethal neurodegenerative diseases affecting newborns. 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 Gauchers 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 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 total 3 awards were made in 2019 and 2020. 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.

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.

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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.

Business Plan

The last Strategic Business Plan was agreed by the Board in early 2017. The Business plan should be reviewed and updated by Trustees in 2020/2021.

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 879 followers; Twitter was activated in January 2018 and has 169 active followers.

Rare Disease Day 2019

The Association supported this event through their Social Media channels and website sharing facts about Gaucher disease.

International Gaucher Day 2019

The Association joined many Associations' around the world to celebrate International Gaucher Day (IGD) on 1st October 2018. 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'.

In the UK, the Association asked our members to celebrate IGD by sharing their pictures with us wearing their IGD temporary tattoos along with sharing the Rare Star social media posts. As ever we encourage our members to get involved through their personal social media channels to raise awareness of Gaucher disease.

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 Gauchers Association, the Society for Mucopolysaccharide Diseases, the Niemann Pick Disease Group UK, Krabbe and CATS (Tay Sachs). 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.

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.

NICE / NHS Consultation

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 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.

Medics4RareDiseases (M4RD)

The Association's Director Tanya Collin-Histed, stood down as the vice chair of M4RD in January 2020 but the LSD collaborative are still involved in supporting and promoting the work of M4RD.

Project Coordinator, Maddie Collin became an Ambassador for M4RD. Part of her role, will be promoting the work of M4RD through social media, blogging and videos; She will also be attending regular meetings, as well as their annual symposium

Financial Review

The Board of Trustees of the Gauchers 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 £21,883 and held reserves of £207,573 at 30 June 2020. The level of reserves is above the minimum level of reserves required under the agreed reserves policy.

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There was a deficit on the Patient & Family Support Fund of £6,847 at 30 June 2020 (2019 deficit: £9,207). This has arisen because a fund provider ceased to provide funds during 2019. The deficit has been temporarily supported by the surplus on the general fund. Subsequent to the year end the Patient & Family Support Fund has been fully funded and brought back into surplus.

There was a deficit on the LSD Collaborative Fund of £751 at 30 June 2020 (£2019: surplus £2,262). This has arisen due to timing of receipt of funding. Subsequent to the year end the LSD Collaborative Fund has been brought back into surplus.

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 26 March 2021 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 2020

I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2020, which are set out on pages 13 to 19.

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.

Stephen Jacobs FCA
Rayner Essex LLP Chartered Accountants
Chartered Accountants
Tavistock House South
Tavistock Square
London
WC1H 9LG

26 March 2021

The Gauchers Association Limited (A company limited by guarantee)
Statement of Financial Activities Including Income and Expenditure Accounts
for the year ended 30 June 2020

| | Notes | Unrestricted Funds 2020 £ | Restricted Funds 2020 £ | Total Funds 2020 £ | Total Funds 2019 £ |
|---|-------|------------------------------------|----------------------------------|-----------------------------|-----------------------------|
| Income | | | | | |
| Income from other trading activities | | 24,833 | 28,620 | 53,453 | 33,683 |
| Income from donations and legacies | | | | | |
| Donations | | 50,712 | 19,405 | 70,117 | 136,224 |
| Subscriptions | | 778 | - | 778 | 870 |
| Gift Aid tax | | 6,416 | - | 6,416 | 6,192 |
| Interest and investment income | | | | | |
| Interest receivable | | 263 | 50 | 313 | 245 |
| Other income | 2 | 15,193 | - | 15,193 | - |
| Total income | | 98,195 | 48,075 | 146,270 | 177,214 |
| Expenditure | | | | | |
| Expenditure on raising funds | | 6,846 | - | 6,846 | 13,190 |
| Expenditure on charitable activities | | | | | |
| Grants | | - | 11,960 | 11,960 | 20,969 |
| Conference | | 1,585 | 21,226 | 22,811 | - |
| Information and publications | | 626 | - | 626 | 438 |
| Managing and administrating the charity | | 65,267 | 16,877 | 82,144 | 151,832 |
| Total expenditure | 3 | 74,324 | 50,063 | 124,387 | 186,429 |
| Movement in total funds for the year | | | | | |
| Net income /(expenditure) for the year | | 23,871 | (1,988) | 21,883 | (9,215) |

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

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**Balance Sheet
as at 30 June 2020**

| | Notes | 2020 | 2019 |
|---|--------------|----------------|----------------|
| | | £ | £ |
| Fixed assets | | | |
| Tangible assets | 5 | 316 | 72 |
| | | <u>316</u> | <u>72</u> |
| Current assets | | | |
| Debtors | 6 | 903 | 1,939 |
| Cash at bank and in hand | | 210,648 | 209,835 |
| | | <u>211,551</u> | <u>211,774</u> |
| Creditors: amounts falling due within one year | 7 | (4,294) | (26,156) |
| Net current assets | | <u>207,257</u> | <u>185,618</u> |
| Total assets less current liabilities | | <u>207,573</u> | <u>185,690</u> |
| Net assets | | <u>207,573</u> | <u>185,690</u> |
| Funds of the charity | | | |
| Unrestricted Funds | 8 | 164,852 | 140,981 |
| Restricted Funds | 8 | 42,721 | 44,709 |
| Total charity funds | | <u>207,573</u> | <u>185,690</u> |

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.

A Bloom
Director

Approved by the board on 26 March 2021

The Gauchers Association Limited (A company limited by guarantee)
Notes to the Accounts
for the year ended 30 June 2020

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 |
|---------------------|--------------------|

The Gauchers Association Limited (A company limited by guarantee)
Notes to the Accounts
for the year ended 30 June 2020

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.

Pensions

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

2 Other income

| | 2020 | 2019 |
|--------------|---------------|-------------|
| | £ | £ |
| Grant income | 15,193 | - |
| | <u>15,193</u> | <u>-</u> |

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

3 Net income /(expenditure) for the year

| | 2020 | 2019 |
|---|--------------|---------------|
| | £ | £ |
| This is stated after charging: | | |
| Depreciation of owned fixed assets | 177 | 266 |
| Independent Examiner's remuneration | 2,000 | 1,920 |
| Contributions to pension fund for employees | 884 | 2,579 |
| Remuneration of key management personnel | <u>9,618</u> | <u>57,387</u> |
| This is stated after crediting: | | |
| Donations from trustees | <u>2,300</u> | <u>2,055</u> |

No employee received emoluments more than £60,000.

4 Employees

| | 2020 | 2019 |
|---|-------------|-------------|
| | Number | Number |
| Part-time directors | 6 | 5 |
| Other part-time staff | 2 | 5 |
| Average number of persons employed by the company | <u>8</u> | <u>10</u> |

In the year ended 30 June 2019 other part-time staff included 2.5 employees subcontracted to the International Gaucher Alliance Limited until December 2018. The costs of subcontracted employees were recharged to the International Gaucher Alliance Limited until December 2018.

The Gauchers Association Limited (A company limited by guarantee)
Notes to the Accounts
for the year ended 30 June 2020

5 Tangible fixed assets

| | Plant and machinery etc £ |
|-----------------------|--|
| Cost | |
| At 1 July 2019 | 7,143 |
| Additions | 421 |
| At 30 June 2020 | <u>7,564</u> |
| Depreciation | |
| At 1 July 2019 | 7,071 |
| Charge for the year | 177 |
| At 30 June 2020 | <u>7,248</u> |
| Net book value | |
| At 30 June 2020 | <u>316</u> |
| At 30 June 2019 | <u>72</u> |

| 6 Debtors | 2020 | 2019 |
|------------------|-------------|--------------|
| | £ | £ |
| Other debtors | 903 | 1,939 |
| | <u>903</u> | <u>1,939</u> |

| 7 Creditors: amounts falling due within one year | 2020 | 2019 |
|---|--------------|---------------|
| | £ | £ |
| Trade creditors | 240 | 150 |
| Taxation and social security costs | 482 | 1,279 |
| Other creditors | 3,572 | 24,727 |
| | <u>4,294</u> | <u>26,156</u> |

The Gauchers Association Limited (A company limited by guarantee)
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| 8 Movement in Funds | <u>As 1 July</u> <u>2019</u> £ | <u>Income</u> £ | <u>Expenditure</u> £ | <u>As 30 June</u> <u>2020</u> £ |
|--------------------------------|--------------------------------------|--------------------|-------------------------|---------------------------------------|
| <u>Restricted Funds</u> | | | | |
| Research Fund | 353 | - | - | 353 |
| Alan Gordon Memorial Fund | 12,097 | 18 | 14 | 12,101 |
| Neuronopathic Fund | 9,305 | 30,620 | 21,284 | 18,641 |
| Julia Fund | 1,004 | - | - | 1,004 |
| Patient and Family Worker | (9,207) | 15,470 | 13,110 | (6,847) |
| LSD Collaborative Fund | 2,262 | 560 | 3,573 | (751) |
| Susan Lewis Memorial Fund | 27,879 | 32 | 12,034 | 15,877 |
| Improving Communications | 1,016 | 1,375 | 48 | 2,343 |
| Total restricted funds | 44,709 | 48,075 | 50,063 | 42,721 |
| General fund | 140,981 | 98,195 | 74,324 | 164,852 |
| Total unrestricted fund | 140,981 | 98,195 | 74,324 | 164,852 |
| Total funds | 185,690 | 146,270 | 124,387 | 207,573 |

The deficit on the Patient & Family Support Fund of £6,847 at 30 June 2020 (2019 deficit: £9,207) has arisen because a fund provider ceased to provide funds during 2019. The deficit has been temporarily supported by the surplus on the general fund. Subsequent to the year end the Patient & Family Support Fund has been fully funded and brought back into surplus.

The deficit on the LSD Collaborative Fund of £751 at 30 June 2020 (£2019: surplus £2,262) has arisen due to timing of receipt of funding. Subsequent to the year end the LSD Collaborative Fund has been brought back into surplus.

| 9 Other financial commitments | 2020 £ | 2019 £ |
|--|------------------|------------------|
| Total future minimum payments under non-cancellable operating leases | - | 5,880 |

10 Related party transactions

Jeremy H Manuel and Tanya Collin-Histed were also directors of the International Gaucher Alliance Limited ("IGA") until 15 October 2018, and after that date were Honorary President and Chief Executive Officer of the IGA. During the year ended 30 June 2020 the company charged the IGA £276 (2019: £70,387) for the provision of administration services.

During the year Tanya Collin-Histed received payment of £600 (2019: £800) for consultancy services she provided to the charity. During the year the IGA received payment of £4,014 (2019 £nil) for consultancy services provided to the charity.

The total amount of expenses waived by trustees during the year was £nil (2019: £nil).

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11 Controlling party

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

12 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