

Registered number
06653373

International Gaucher Alliance Limited

Report and Accounts

31 December 2022

Registered Charity Number 1192011
Company Registration Number 06653373

International Gaucher Alliance Limited
Report and accounts
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International Gaucher Alliance Limited Company Information

Trustees

Aviva Fisher Rosenberg
Irena Znidar
Biljana Jovanovic
Kristiyan Dimitrov
Suyog Sathe
Dr Yoram Muller (resigned 22 March 2022)
Francisco Carreiro (appointed 9 May 2022)
David Ohana (appointed 9 May 2022, resigned 13 February 2023)
Aimeé-Kate Bosch (appointed 9 May 2022)
Sara Khan (appointed 19 January 2022)
Diana Paulina Pena Aragon (appointed 19 January 2022)

Secretary

Kristiyan Dimitrov

Independent Examiner

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

Registered office

86-90 Paul Street
London
EC2A 4NE

Registered Charity Number 1192011

Registered Name of the Charity International Gaucher Alliance Limited

Company Registration Number 06653373

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

The Trustees present their Report and Accounts for the year ended 31 December 2022, which also comprises the Directors' Report required by the Companies Act 2006.

Reference and administrative details

Legal structure of the charity

The charity is constituted as a company limited by guarantee, registered under the Companies Acts . The governing document of the charity is the Memorandum and Articles of Association establishing the company under company legislation.

There are no restrictions in the governing documents on the operation of the Charity or on its investment powers other than those imposed by Charity Law.

By operation of law, all trustees are directors under the Companies Act 2006 and all directors are trustees under Charities legislation and have responsibilities, as such, under both company and charity legislation.

The trustees are all individuals.

The principal operating address of the charity is:

86-90 Paul Street

London

EC2A 4NE

The registered office of the charity for Companies Act purposes is the same as the operating address shown above.

The Trustees who served during the year were:

Aviva Fisher Rosenberg

Irena Znidar

Biljana Jovanovic

Kristiyan Dimitrov

Suyog Sathe

Francisco Carreiro (appointed 9 May 2022)

Aimeé-Kate Bosch (appointed 9 May 2022)

Sara Khan (appointed 19 January 2022)

Diana Paulina Pena Aragon (appointed 19 January 2022)

Dr Yoram Muller (resigned 22 March 2022)

David Ohana (appointed 9 May 2022, resigned 13 February 2023)

All trustees are also members of the charity.

Objects and activities of the charity

The purposes of the charity

The International Gaucher Alliance Limited ("IGA") is an international umbrella group representing the interest of Gaucher patients and those of not-for-profit Gaucher patient groups as well as rare disease groups throughout the world.

The IGA's vision is 'A world where all Gaucher patients have access to the treatment and care they need and there is a possibility of a cure'.

The IGA has the mission to be the global voice for Gaucher patients and their families:

- to empower its members
- to advocate on behalf of Gaucher patients to ensure that the Gaucher research agenda is focused on patients' unmet needs
- to take collective action to address challenges Gaucher patients worldwide face in accessing early diagnosis and optimal treatment and care

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The IGA's Strategic imperatives seek to achieve a strong voice for Gaucher patients through collaboration and partnership.

- improve Gaucher patients' access to optimal diagnosis, treatment and care
- influence the Gaucher research agenda so that it's focused on addressing key unmet needs
- support member organisations to be more effective and sustainable

The main activities undertaken in relation to those purposes during the year

The IGA is a patient-led international organisation that has become the 'go to' global voice for over 90% of the Gaucher community and has built its reputation through listening to and delivering outcomes that have impacted on patients and their carers' lives.

In 2022 the IGA welcomed two new Members to the IGA with Peru and Argentina joining, making our membership 58 countries. Together the CEO Tanya Collin-Histed; our staff team Angel Jones, Harry Albright and Vesna Aleksovska work with the IGA Board towards achieving our mission – a better quality of life for patients with Gaucher disease and a better world for them and their families. This is achieved through communicating/collaborating globally with stakeholders to ensure that the patient voice is heard and at the heart of all decisions and actions via meetings, conferences, and other projects.

In 2022 the IGA held a members' meeting representatives and volunteers face to face and virtually in Rotterdam, the Netherlands. It was a wonderful experience to finally, after all challenges and difficulties with the COVID pandemic, meet with our dear friends who work alongside us to achieve our goals.

The IGA Board of Directors are all volunteers and give their time tirelessly to improve patient outcomes, and break down barriers across the world, increase standards of care and gain a better understanding of unmet needs through patient centred projects, collaborative working groups, educational webinars, and scientific meetings.

2022 saw new clinical trials for Gene Therapy, and with a number of different mechanisms it is important to ensure that the patient community truly understands Gene Therapy, its possible opportunities, and the challenges. The IGA is working collaboratively to develop an educational programme for our community.

The focus of International Gaucher Day 2022 was the management of Gaucher Disease, focusing on the whole person beyond treatment for the physical symptoms.

Recognising our global role and responsibility, in 2022 we strived to provide translations of our work in many areas including webinars and during our biennial meetings and surveys; we commit to continue this and, going forward, will be providing more languages in partnership with our volunteer translators and Member organisations.

The Trustees confirm that they have had regard to the guidance issued by the Charity Commission on public benefit.

The main achievements and performance of the charity during the year

VOLUNTEER PROGRAMME AND TRANSLATIONS

Our new Projects Officer reorganised and streamlined the Volunteer Programme, bringing new people on board and ensuring that their time was used effectively, leading to a year-on-year increase in time volunteered, and increased output in areas such as translations.

Expanding our volunteer programme has helped us reach more people in different parts of the world, including by translating documents and supporting our regional managers.

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At the end of 2022, 45 volunteers from 40 different countries were involved in over 11 projects (almost all IGA projects in 2022 had volunteers working on them). They collectively volunteered for 2083 hours in total. Our volunteers were recruited through advertisements on social media, conferences, and events, and some of them were invited by other volunteers, staff, or board members.

Thanks to volunteers we were able to translate many materials into Arabic, Spanish, French, German, Japanese, Chinese – and with that to reach out to families and patients around the world.

Volunteer activity also included the home therapy project, the older generation project, Regional Manager Programme, GD1 guidelines, the self-management working group, switching, and monitoring of patients, non-comparable and biosimilar medicines, GARDIAN recruitment (through webinars, translation and sharing of materials), development of the new 2024-2029 IGA strategy, Scientific Advisory Committee, and the development of neuronopathic guidelines for care and support.

REGIONAL MANAGER PROGRAMME

Reviewing and reforming the IGA Regional Manager (RM) Programme continued with the process of recruiting volunteers to support the RMs. The RMs were able to gather a lot of information from many different countries that will help us in the realisation of activities in 2023. Now we are equipped with the necessary knowledge to move forward and do more in the countries where there are no patient groups or organisations but Gaucher patients.

The Regional Managers are the eyes and ears of the IGA and are responsible for working closely with key stakeholders such as patients, patient associations, doctors, industry, and policymakers; exploring and identifying new development opportunities; and identifying and addressing challenges faced by Gaucher patients in the region. A big part of the regional manager programme is to help improve diagnosis. We ended the year with RMs in Southeast Asia, the European regions¹ and 2, the Central America 1 region, the Eastern Mediterranean region, and the African region.

WORKING GROUPS

In 2022 Members of the Board, staff and volunteers participated in the following working groups on behalf of the IGA -

- International Working Group on Gaucher Disease (IWGGD)
- Supportive care Global Alliance for Rare Diseases (GARD)
- Eurordis Digital Advisory Group (DAG)
- Rare Disease International (RDI)
- Global Access Working Group
- Eurordis Screen4Care patient advisory
- Board Member of the Medical Expert Committee (MEC) - Takeda's Charitable Access Programme
- Gaucher Outcome Survey steering committee – Takeda

PUBLICATIONS

The IGA co-authored/was involved in the publications of the following reports, presentations, papers, and posters:

- Transformative effect of a Humanitarian Program for individuals affected by rare diseases: building support systems and creating local expertise: Orphanet – IGA CEO co-author, publication
- Patient centered guidelines for the laboratory diagnosis of Gaucher disease type 1: Orphanet – Jasenka Wagner co-author, publication

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- Findacure, now Beacon, February 2022: Building an international patient group: achieving a global reach with limited resources – poster
- Lysosomal Storage Disorders, A practical Guide, Atul B. Mehta and Bryan Winchester, 2nd Edition, 2022: Patients' Perspective; Chapter, pp.299- 307 – IGA CEO co-author, publication
- European Conference on Rare Disease (ECRD): Harnessing the power of patients: Developing and validating the Neuronopathic Gaucher Disease Patient Reported Outcomes(nGD-PRO) and Observer Reported Outcomes(nGD-ObsRO) to measure HRQoL in patients with Gaucher Disease Type 2 and Type 3 – poster
- Creation of the GARDIAN patient registry for neuronopathic Gaucher Disease Type 2 and Type 3: A collaborative approach – poster
- Global Genes: Creation of the GARDIAN patient registry: A collaborative approach to address the unmet needs of patients with neuronopathic Gaucher disease type 2 and type 3 – poster
- Understanding patient and parent/caregiver perceptions on gene therapy in Gaucher disease: an international survey: Freeline, Pfizer, Avrobio

ISPOR-The Professional Society for Health Economics and Outcomes Research:

- Addressing unmet needs of patients with neuronopathic Gaucher Disease Type 2 and Type 3: Creation of the GARDIAN patient registry – poster
- Patient Involvement in the Development of Outcomes Measures Specific to Neuronopathic Gaucher Disease Type 2 and Type 3 to Assess HRQoL Over the Disease Journey – poster

ISPOR-The Professional Society for Health Economics and Outcomes Research:

- Addressing unmet needs of patients with neuronopathic Gaucher Disease Type 2 and Type 3: Creation of the GARDIAN patient registry – poster
- Patient Involvement in the Development of Outcomes Measures Specific to Neuronopathic Gaucher Disease Type 2 and Type 3 to Assess HRQoL Over the Disease Journey – poster

International Working Group on Gaucher Disease biennial meeting:

- GARDIAN -presentation
- Procurement of treatment for Gaucher disease – presentation

NGD GUIDELINES

In conjunction with the IWGGD, the IGA are part of a working group that are developing a supportive care paper for neuronopathic Gaucher disease (nGD) which will be published on the IWGGD website, shared globally, and translated into several languages by the IGA.

HUMANITARIAN AID

In 2022, the IGA received requests for assistance to access treatment from patients, family members and doctors in the following countries: Afghanistan, Cuba, Ethiopia, Ghana, India, Jordan, Kenya, Morocco, Mozambique, Peru, Qatar, Mongolia, Sudan, Venezuela, Palestine, Rwanda, and Zimbabwe.

Sadly, there are a number of cases that have still not been resolved; this is due to several different challenges, including:

- The country of residence is not covered by certain company programmes
- There is a maximum quota per country, and this has been reached
- There is a challenge with treating adults due to eligibility
- Access into the country is restricted due to war and/or political challenges
- The process of getting free treatment into a country is lengthy and challenging

This includes patients in Afghanistan, Ghana, India (12), Jordan (4), Peru, Venezuela, Zimbabwe (2), Mongolia.

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Approved – 18 patients: India (7), Kenya (2), Morocco (2), Mozambique, Qatar (2), Sudan (2), Rwanda, Palestine

Deaths – sadly two patients lost their lives. One was very ill, and treatment did not reach the patient in time. In this case, access to diagnosis and awareness was essential; in the other case the patient died of another cause unrelated to Gaucher disease and had been doing very well on treatment. These patients were from India and Ethiopia.

In process – These cases are being processed and we anticipate that these patients will have access to treatment in 2023. Cuba (1), India (2)

Ukraine – The IGA were in touch with the Gaucher patient group in Ukraine after the war started and supported the companies that were treating patients to ensure access was still available to patients, either in Ukraine or to where they were now living.

The IGA works collaboratively with the three pharmaceutical companies that provide charitable treatment to Gaucher patients.

These are:

- Takeda Charitable programme: through the Medical Expert Committee (MEC) programme (the IGA is a member of the MEC) in 2022 a total of 35 patients was approved from Ethiopia, Kenya, Pakistan, Tanzania, Tunisia, and Sudan
- PfizerCares: seven patients approved with a further 3 in the pipeline (included in the figures above).
- Sanofi ICAP: 11 patients approved for treatment (included in the figures above). Please note that this figure only includes those patients referred to Sanofi by the IGA to their programme and therefore does not represent the total number of other Gaucher patients that were approved by ICAP through other channels. These patients were from India and Ethiopia.

NON-COMPARABLE MEDICINES FOR GAUCHER DISEASE - A POSITION STATEMENT

The IGA began work to agree a position on non-comparable medicines for Gaucher disease on an international scale. This statement is the results of anxieties from our members and Gaucher patients and their families globally that are faced with being switched to a non-comparable medicine for their Gaucher disease after being on a licensed medicine for many years. This positioning statement outlines the International Gaucher Alliance's (IGA) stance in relation to the use of 'intended copies' of enzyme replacement therapy (ERT) medicines as a treatment for Gaucher disease. These 'copies' are also known as non-comparables (the term used in this statement), due to the fact that they have not been directly compared to the original medicine in a clinical trial setting.

STRATEGIC PLAN

A working group was set up to develop the IGA's Strategic Plan for the next five years (2024-2029). This included a member's survey and input from other community stakeholders including clinicians and representatives from the pharmaceutical industry. This included looking at whether we need to update our mission and objectives.

COMMUNICATIONS STRATEGY

A new website was brought online, incorporating new systems to make communications easier, including new ways of collating Country Reports, to collect data from our Members and Regional Managers to give us a much better understanding of challenges, unmet need, and access to care and treatment. We also improved the system for Humanitarian Aid requests.

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INTERNATIONAL GAUCHER DAY

Our 2022 campaign focused on a holistic approach to diagnosis and treatment with the theme Body Mind Soul Managing Your Gaucher Disease.

We shared the stories of patients from around the world, both in social media posts and in videos

We also shared the views of clinicians and others working in the field.

We made a total of 37 Facebook posts and another on 27 Instagram. We sent 26 Tweets and made 16 LinkedIn posts. We also shared videos in different languages. Members and partners also posted, both original posts on the theme and using our templates, with some translating the messages into their languages

IGA CELEBRATES 25 YEARS of IGA CEO BEING A PATIENT ADVOCATE

On Friday 18 November, the UK Gauchers Association and the IGA held receptions for IGA CEO Tanya Collin-Histed to celebrate her 25th anniversary of being a patient advocate for Gaucher patients around the world.

The UK GA event was a lunch attended by around 20 people, where Tanya was presented with an engraved fountain pen.

The IGA held a reception in the afternoon with people attending virtually from around the world as well as in person. Tanya received an engraved vase and a book of photos and reminiscences contributed by around 100 people from all over the world. Attendees including patients, carers, health care providers, researchers, and representatives of pharmaceutical companies spoke, paying tribute to Tanya and her accomplishments over the years.

BIENNIAL MEETING

On the weekend of 6-8 May, the IGA held its first Biennial Members meeting since the COVID pandemic in Rotterdam in the Netherlands. This was held as part of our empowerment through information and education project.

Over 40 people from around 30 countries, most in-person with a few online, attended. It was clear how happy people were to once again be able to meet face-to-face, something that hadn't happened since 2018.

This was an opportunity for Members of the IGA to connect, give and receive updates on their work and the work of the IGA, take part in workshops and hear presentations from pharma companies and others working in the rare disease field. Dr Lucy McKay from Medics for Rare Diseases gave a presentation on her organisation's work, and Barbara Sjouke MD PhD from the Amsterdam University Medical Centre spoke about gene therapy. Takeda, Sanofi, Freeline and Prevail shared the industry perspectives.

The meeting also gave recognition to the volunteers who serve the IGA in many capacities, including the Regional Managers and others who work so hard on our behalf.

OLDER GENERATION

The IGA cares about the older generation of people living with Gaucher disease. Most of this generation, irrespective of the type of Gaucher they have and older than 60, acquired consequences (physical, emotional, social etc) of the disease before the new treatments or without. The IGA sent out a survey to our member organisations analysed the data. Preliminary outcomes of the survey are as follows: the basics:

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» 58 IGA member organisations were invited to respond ,23 IGA member organisations responded (40 %).

» 13 answered that they have no idea about the unmet clinical or non-medical needs of the older generation in their country, the rest didn't answer.

The second survey towards individuals is now in the process of translating to several languages.

Older Gaucher patients are defined as those of 60 years and older, irrespective of their GD type.

The needs don't limit themselves to medical issues, but also include issues like social ones. The survey for patients will be online in 11 languages.

GARDIAN

Gaucher Registry for Development, Innovation and Analysis of Neuronopathic disease (GARDIAN)

In 2020 the IGA set up a company called International GARDIAN Limited (IGL). IGL is wholly owned by the IGA, therefore the global Gaucher community will own and govern a global patient registry for Types 2 and 3 Gaucher disease.

GARDIAN will benefit patients and caregivers by increasing the understanding of the impact of the neurological manifestations of the disease, improve access to and achieve a timely diagnosis, inform better care, and support, and enable better targeted research and the development of better safer treatments.

GARDIAN was launched on April 25th, 2022, and is available in 8 languages UK English, US English, Arabic, Japanese, Chinese, German, Spanish, and French.

GARDIAN was presented at various meetings and conferences during 2022:

- 3 webinars in Spanish (Peru, Argentina, Mexico), September – October 2022
- Gaucher family meeting, Italy, October 2022
- Gaucher family meeting, Canada, November 2022
- Central America forum on reference centres for rare diseases, November 2022
- LSD conference, Panama, October 2022
- Gaucher family meeting, Denmark, November 2022
- Gaucher Community Alliance family meeting, USA, October 2022
- Genetic Rare Immune Disorders Symposium, USA, October 2022
- Global Genes conference, September 2022 ISPOR, November 2022
- Rare disease conference, Austria, December 2022
- Webinars for UK, Egypt, Argentina, Spain, Mexico, Peru, Japan

To support the launch and take GARDIAN forward we have:

Appointed Tanya Collin-Histed as CEO to support the work of the IGL Board.

Formed a Scientific Advisory Board (SAB) to advise the Board of Directors of IGL on scientific and clinical matters, consider and approve research and data requests and contribute to the on-going development of GARDIAN for the benefit of the global patient community. The SAB met for the first time on the 29th of September.

Formed a Pharmaceutical Industry Working Group to regulate the relationship with pharmaceutical and biotech industries, define rules for sponsorship opportunities, define access and scope of access to non-identifiable, aggregated data stored and managed by GARDIAN and approve and/or partner with these organizations for scientific publication aligned with the main objectives of GARDIAN. The PIWG met for the first time on the 30th of November and has a membership from 7 companies: Avrobio, Freeline, Gain, Pfizer, Prevail, Sanofi and Takeda

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Formed the community working group to:

- Identify areas of research that GARDIAN could support that remain an unmet need for patients and caregivers and make recommendations to the Scientific Advisory Board.
- Be the voice of the patient and caregiver on GARDIAN, providing feedback on GARDIAN's accessibility, community value and understanding of the registry and its purpose
- Empower patients and families to engage with and drive the direction of research and scientific advancement on nGD.
- Identify how GARDIAN can best provide feedback to the community on its activities and make recommendations to the Strategic Planning & Registry Development.
- Review the GARDIAN website content and make recommendations for its development

IN 2023 WE WILL CONTINUE TO:

Revise our Strategic Plan for the next five years to ensure that our values, vision, and mission remain relevant and that our activities and campaigns are effective, that we are serving our Members and Gaucher patients and caregivers around the world in the best way possible, and that we continue to improve the visibility and knowledge of Gaucher disease. In 2022 we consulted our community and other stakeholders, and in 2023 a working group will create a revised document for 2024 to 2029 based on the feedback.

Hold a Go with Gaucher symposium for young adult Gaucher patients, from IGA Member organizations, giving them a unique opportunity to meet their peers and develop their skills.

Continue our work with the older generation of Gaucher patients to have a better understanding of their clinical and non-medical needs and to detect unmet needs and improve their situation where we can.

Develop Best Practice switching and monitoring guidelines, in cooperation with the International Working Group on Gaucher Disease (IWGGD), that can be used by patients to take to their clinicians to ensure that if they are made to switch to a new medication this is done in the best and safest way possible for the patient.

Expand International Gaucher Day, with a theme based around diagnosis which will include a keynote lecture on the theme and a video to be broadcast on the day.

Structure, governance and management of the charity

The methods used to recruit and appoint new charity trustees

Every 2 years the IGA holds board elections in line with our Articles of Association. 8 weeks prior to each Biennial General Meeting a statement is sent to our Member organisations from around the globe which includes the number of vacancies on the board, a list of existing council members offering themselves for re-election, a nomination form for new candidates, a form of personal resume for completion by candidates, notification of the closing date for nominations which shall be at least 28 days after the date of despatch of the documents and a summary of the requirements for a valid nomination. If the number of nominations exceeds the number of vacancies an election will be held at the Biennial meeting to determine the successful candidates via secret ballot. By recruiting trustees from our member organisations only, we ensure that they are already engaged, knowledgeable on our work programmes and have experience that will be beneficial to their work as a Trustee.

International Gaucher Alliance Limited**Company limited by guarantee registered number:****06653373****Registered charity number: 1192011****Trustees' Annual Report****Financial review*****The charity's financial position at the end of the year ended 31 December 2022***

The financial position of the charity at 31 December 2022 and comparatives for the prior period, as more fully detailed in the accounts, can be summarised as follows:-

	2022	2021
	£	£
Net income /(expense)	<u>(41,826)</u>	<u>26,076</u>
Unrestricted funds available for the general purposes of the charity	178,287	222,899
Restricted funds	8,569	5,783
Total funds	<u>186,856</u>	<u>228,682</u>

Financial review of the position at the reporting date, 31 December 2022

The trustees consider the financial performance by the charity during the year to have been satisfactory.

Specific changes in fixed assets are detailed in the notes to the accounts.

Policies on reserves

The Board of Trustees of the International Gaucher Alliance have agreed a general fund reserves policy of maintaining reserves equivalent to no less than six months of 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 £100,857.

During the year the charity's reserves decreased by £41,826 and held reserves of £186,856 at 31 December 2022. The level of reserves is above the minimum level of reserves required under the agreed reserves policy.

We have also adopted a document on trustee competencies, and we undertake annual Board assessments, the results form part of an on-going training and development programme for the trustees.

Availability and adequacy of assets of each of the funds

The board of trustees is satisfied that the charity's assets in each fund are available and adequate to fulfil its obligations in respect of each fund.

Details of The Independent Examiner

Neil Heyes FCA - Independent Examiner

(Senior and Statutory Auditor)

Rayner Essex LLP Chartered Accountants

Faulkner House

Victoria Street

St Albans

AL1 3SE

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Statement of the Directors Trustees' Responsibilities

The charity's trustees are responsible for the preparation of the accounts in accordance with the terms of the Companies Act 2006, the Charities Act 2011 and the Charities (Accounts and Reports) Regulations 2008. Notwithstanding the explicit requirement in the extant statutory regulations, the Charities (Accounts and Reports) Regulations 2008, to prepare the financial statements in accordance with the SORP 2005, in view of the fact that the SORP 2005 has been withdrawn, the Trustees determined to interpret this responsibility as requiring them to follow current best practice and prepare the accounts according to the FRS 102 SORP (Statement of Recommended Practice for Accounting and Reporting by Charities) 2015, (as amended by the Bulletin issued in October 2018 and applicable to all accounting periods beginning on or after 1st January 2019), (The SORP).

In particular, the Companies Act 2006 and charity law require the Board of Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity as at the end of the financial year and of the surplus or deficit of the charity. In preparing those financial statements the Board is required to :-

- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business;
- state whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements;

The law requires that the trustees must not approve the accounts unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the surplus or deficit of the charity for the year.

The Trustees are also responsible for maintaining adequate accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which are sufficient to show and explain the charity's transactions and enable them to ensure that the financial statements comply with the Companies Act 2006 and comply with regulations made under the Charities Act. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are also responsible for the contents of the Trustees' report, and the statutory responsibility of the Independent Examiner in relation to the Trustees' report is limited to examining the report and ensuring that, on the face of the report, there are no material inconsistencies with the figures disclosed in the financial statements.

Method of preparation of accounts - Small company provisions

The financial statements have been prepared implementing the FRS 102 SORP (Statement of Recommended Practice for Accounting and Reporting by Charities) 2015, (as amended by the Bulletin issued in October 2018 and applicable to all accounting periods beginning on or after 1st January 2019), (The SORP), and in accordance with the Financial Reporting Standard 102, (effective 1st January 2016).

These financial statements have 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 of trustees on 19 September 2023.


Biljana Jovanovic (Sep 21, 2023 10:07 GMT+2)

Biljana Jovanovic
Trustee Director

International Gaucher Alliance Limited

Report of the Independent Examiner Report to the Trustees of the charitable company on the accounts for the year ended 31 December 2022

I report to the Trustees on my examination of the financial statements of the charitable company on pages 14 to 22 for the year ended 31 December 2022 which have been prepared in accordance with the Charities Act 2011 (the Act) and with the Financial Reporting Standard 102, (effective 1st January 2016) as modified by FRS 102 SORP (Statement of Recommended Practice for Accounting and Reporting by Charities) 2015, (as amended by the Bulletin issued in October 2018 and applicable to all accounting periods beginning on or after 1st January 2019), (The SORP), published by the Charity Commission in England & Wales (CCEW), and under the historical cost convention and the accounting policies set out on page 17.

Respective responsibilities of the Trustees and the Independent Examiner and the basis of the report

As described on page 11, you, the charitable company's Trustees, who are also the Directors of the Company for the purposes of Company law, are responsible for the preparation of the financial statements in accordance with the Companies Act 2006, the Charities Act 2011 and all other applicable law and with United Kingdom Generally Accepted Accounting Practice, applicable to smaller entities, and for being satisfied that the financial statements give a true and fair view.

The Trustees consider that the audit requirement of Section 144(1) of the Charities Act 2011 (the Act) does not apply, and that there is no requirement in the memorandum and articles of the charity for the conducting of an audit, and that the accounts do not require an audit in accordance with Part 16 of the Companies Act 2006 and that no member or members have requested an audit pursuant to Section 476 of the Companies Act 2006. As a consequence, the Trustees have elected that the financial statements be subject to independent examination.

Having satisfied myself that the financial statements are not required to be audited under any legal provision, or otherwise, and are eligible for independent examination, it is my responsibility to:

- a) examine the financial statements of the charity under Section 145 of the Act;
- b) follow the applicable procedures in the Directions given by the Charity Commission under section 145(5)(b) of the Act.

Basis of independent examiner's statement and scope of work undertaken

Since the charitable company's gross income exceeded £250,000, the charitable company's examiner must be a member of a body listed in section 145 of the Act. I confirm that I am qualified to undertake the examination because I am an authorised member of one of the listed bodies.

I report in respect of my examination of the charity's financial statements carried out under s145 of the Act. In carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act setting out the duties of an independent examiner in relation to the conducting of an independent examination. An independent examination includes a review of the accounting records kept by the charitable company and of the accounting systems employed by the charitable company and a comparison of the financial statements presented with those records. It also includes consideration of any unusual items or disclosures in the financial statements, and seeking explanations from you, as Trustees, concerning such matters. The purpose of the examination is to establish as far as possible that there have been no breaches of charity legislation and that, on a test basis of evidence relevant to the amounts and disclosures made, the financial statements comply with the SORP.

The procedures undertaken do not provide all the evidence that would be required in an audit, and information supplied by the Trustees in the course of the examination is not subjected to audit tests or enquiries and does not cover all the matters that an auditor would consider in arriving at an opinion. The planning and conduct of an audit goes beyond the limited assurance that an independent examination can provide.

International Gaucher Alliance Limited

Report of the Independent Examiner Report to the Trustees of the charitable company on the accounts for the year ended 31 December 2022

Consequently, I do not express an audit opinion on the view given by the financial statements, and in particular, I express no opinion as to whether the financial statements give a true and fair view of the affairs of the charity, and my report is limited to the matters set out in the statement below.

I planned and performed my examination so as to satisfy myself that the objectives of the independent examination are achieved and before finalising the report I obtained written assurances from the Trustees of all material matters.

Independent examiner's statement, report and opinion

Subject to the limitations upon the scope of my work as detailed above, I have completed my examination and can confirm that:

The accounts of this charitable company are not required to be audited under Part 16 of the Companies Act 2006;

The gross income of the charitable company in the year ended 31 December 2022 appears to exceed the sum specified in Section 145(3) of the Act, namely £250,000, and that I am qualified to act as Independent Examiner in accordance with that section by virtue of my being a qualified member of Rayner Essex LLP Chartered Accountants and Statutory Auditors;

This is a report in respect of an examination carried out under 145 of the Act and in accordance with Directions given by the Charity Commission under section 145(5)(b) of the Act which may be applicable;

and that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 386 of the Companies Act 2006 and section 130 of The Charities Act 2011;
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in section 396 of the Companies Act 2006 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;
4. have not been prepared in accordance with the methods and principles set out in the FRS 102 SORP (Statement of Recommended Practice for Accounting and Reporting by Charities) 2015, (as amended by the Bulletin issued in October 2018 and applicable to all accounting periods beginning on or after 1st January 2019), (The SORP).

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 financial statements to be reached.

Neil Heyes
Neil Heyes (Sep 22, 2023 14:47 GMT+1)

Neil Heyes FCA - Independent Examiner
(Senior and Statutory Auditor)

for and on behalf of:

Rayner Essex LLP Chartered Accountants and Statutory Auditors

Faulkner House

Victoria Street

St Albans

AL1 3SE

19 September 2023

International Gaucher Alliance Limited
Statement of Financial Activities Including Income and Expenditure Accounts
for the year ended 31 December 2022

	Notes	Unrestricted Funds 2022 £	Restricted Funds 2022 £	Total Funds 2022 £	Total Funds 2021 £
Income					
Donations and legacies		118,718	122,825	241,543	277,711
Charitable activities		9,864	-	9,864	15,856
Total income		<u>128,582</u>	<u>122,825</u>	<u>251,407</u>	<u>293,567</u>
Expenditure					
Charitable activities		157,723	135,510	293,233	267,491
Total expenditure		<u>157,723</u>	<u>135,510</u>	<u>293,233</u>	<u>267,491</u>
Net income/(expenditure) for the year and Movement in total funds for the year	2	<u>(29,141)</u>	<u>(12,685)</u>	<u>(41,826)</u>	<u>26,076</u>
Other recognised gains/ (losses)					
Total funds at 1 January		222,899	5,783	228,682	202,606
Transfers in /(out)		(15,471)	15,471	-	-
Total funds at 31 December	11	<u>178,287</u>	<u>8,569</u>	<u>186,856</u>	<u>228,682</u>

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

International Gaucher Alliance Limited
Statement of Financial Activities Including Income and Expenditure Accounts
for the year ended 31 December 2021

	Notes	Unrestricted Funds	Restricted Funds	Total Funds	Total Funds
		2021 £	2021 £	2021 £	2020 £
Income					
Donations and legacies		116,050	161,661	277,711	225,964
Charitable activities		15,856	-	15,856	6,745
Total income		131,906	161,661	293,567	232,709
Expenditure					
Charitable activities		101,900	165,591	267,491	190,820
Total expenditure		101,900	165,591	267,491	190,820
Net income/(expenditure) for the year and Movement in total funds for the year	2	30,006	(3,930)	26,076	41,889
Total funds at 1 January		202,606	-	202,606	160,717
Transfers in /(out)		(9,713)	9,713	-	-
Total funds at 31 December		222,899	5,783	228,682	202,606

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

International Gaucher Alliance Limited**Registered number:** 06653373**Balance Sheet****as at 31 December 2022**

	Notes	2022 £	2021 £
Fixed assets			
Intangible assets	8	17,451	18,408
Tangible assets	9	1,841	3,789
Investments	10	100	100
		<u>19,392</u>	<u>22,297</u>
Current assets			
Debtors	12	59,533	22,864
Cash at bank and in hand		150,731	220,505
		<u>210,264</u>	<u>243,369</u>
Creditors: amounts falling due within one year	13	(42,800)	(36,984)
Net current assets		<u>167,464</u>	<u>206,385</u>
Total assets less current liabilities		<u>186,856</u>	<u>228,682</u>
Net assets		<u>186,856</u>	<u>228,682</u>
Total funds of the charity			
Restricted Funds	14	8,569	5,783
Unrestricted Funds	14	178,287	222,899
Total charity funds		<u>186,856</u>	<u>228,682</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.



Biljana Jovanovic (Sep 21, 2023 10:07 GMT+2)

Biljana Jovanovic

Trustee

Approved by the board on 19 September 2023

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2022

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 (SORP), 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. As such the charity has taken advantage of the exemption available not to present a Cash Flow statement. International Gaucher Alliance Limited meets the definition of a public benefit entity under FRS 102.

Departure from the Charities (Accounts and Reports) Regulations 2008

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following SORP 2015 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 (SORP 2005) which has since been withdrawn.

Going concern

The charitable activities are entirely dependent on continuing grant aid and voluntary donations. As a consequence, the going concern basis is dependent on the future flow of these uncertain funding streams. Accordingly, the Trustees have obtained forecasts and, after reviewing the financial forecasts for future periods to 31 December 2023, the Trustees are satisfied that, at the time of approving the financial statements, it is appropriate to adopt the going concern basis in preparing the financial statements. Other than these matters, the Trustees are not aware of any material uncertainties about the charity's ability to continue as a going concern.

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.

Donated services

Donated services and facilities are included in the accounts on the basis of the value of the gift to the charity.

All donated services and facilities are recognised as donation income when received, (provided the value of the gift can be measured reliably) and recognised as an expense with an equivalent value.

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.

Fixed Asset Investments

Interests in subsidiaries, associates and jointly controlled entities are initially measured at cost and subsequently measured at cost less any accumulated impairment losses. The investments are assessed for impairment at each reporting date and any impairment losses or reversals of impairment losses are recognised immediately in profit or loss.

Intangible fixed assets

Website development costs are being written off in equal annual instalments over its estimated economic life of 5 years.

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:

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2022

Plant and machinery

over 4 years

Debtors

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

Creditors

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

Pensions

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

2 Net income/(expenditure) for the year	2022	2021
	£	£
This is stated after charging:		
Depreciation and amortisation of owned fixed assets	1,949	4,846
Trustees' and volunteers' remuneration	48,045	34,325
Independent Examiner's remuneration	3,000	3,000
Contributions to pension fund for employees	1,680	1,617

3 Donated goods, services and facilities	2022	2021
	Unrestricted funds	Unrestricted funds
	£	£
Included in donations and legacies:		
Donated goods and services	48,045	34,325
	48,045	34,325

Directors and volunteers have made donations of their services to the company during the year to the value of £48,045 (2021: £34,235). Administration expenses include directors' and volunteers' fees for services donated to the company of £48,045 (2021: £34,235) and donations and legacies include donations by the directors and volunteers of £48,045 (2021: £34,325) in respect of their services to the company.

4 Staff costs	2022	2021
	£	£
Wages and salaries excluding trustees and key management personnel	42,144	39,081
Social security costs	10,964	8,889
Other pension costs	1,680	1,617
Salaries and benefits paid to key management personnel	64,265	60,703
Directors' and volunteers' fees for services donated to the charity	48,045	34,325
	167,098	144,615

The cost to the charity of senior management personnel remuneration included the following:	2022	2021
	£	£
Gross wages and Employer's National Insurance contributions	72,603	68,255
Contributions for the provision of money purchase pension	1,321	1,319

Numbers of such staff to whom benefits are accruing :	2022	2021
	Number	Number
Under money purchase pension schemes	1	1

5 Employees	2022	2021
	Number	Number
Average number of full time staff	1	1
Average number of part time staff	2	2
Average total number of staff	3	3

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2022

5 Employees (continued)

The number of employees whose emoluments including taxable benefits but excluding employer's pension contributions fall into the following bands were :

	2022 Number	2021 Number
£60,001 to £70,000	<u>1</u>	<u>1</u>

6 Remuneration and payments to volunteers and to Trustees and persons connected with them

	2022 £	2021 £
Remuneration payable to trustees or connected persons		
Directors' and volunteers' fees for services donated to the charity	<u>48,045</u>	<u>34,325</u>

Directors and volunteers have made donations of their services to the company during the year to the value of £48,045 (2021: £34,235). Administration expenses include directors' and volunteers' fees for services donated to the company of £48,045 (2021: £34,235) and donations and legacies include donations by the directors and volunteers of £48,045 (2021: £34,325) in respect of their services to the company.

7 Deferred income - Restricted funds

	2022 Received deferred in year £	2022 Deferred at year end £	2021 Received deferred in year £	2021 Deferred at year end £
Pfizer work programmes 2021 and 2022-23	26,000	20,800	2,136	2,136
International Working Group on Gaucher Disease	-	3,048	9,143	9,143
Takeda Transitions grant	5,000	5,000		
	<u>31,000</u>	<u>28,848</u>	<u>11,279</u>	<u>11,279</u>

Deferred income is included in creditors and comprises funding specified by the funders as relating to specific periods and represent those parts of restricted funds which relate to periods subsequent to the accounting year end and are treated as grants in advance.

8 Intangible fixed assets

Website development costs:

Cost

At 1 January 2022	21,240
Additions	3,660
At 31 December 2022	<u>24,900</u>

Amortisation

At 1 January 2022	2,832
Provided during the year	4,617
At 31 December 2022	<u>7,449</u>

Net book value

At 31 December 2022	<u>17,451</u>
At 31 December 2021	<u>18,408</u>

Website development costs are being written off in equal annual instalments over its estimated economic life of 5 years.

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2022

9 Tangible fixed assets

	Plant and machinery etc £	Total £
Cost		
At 1 January 2022	9,416	9,416
At 31 December 2022	<u>9,416</u>	<u>9,416</u>
Depreciation		
At 1 January 2022	5,627	5,627
Charge for the year	1,948	1,948
At 31 December 2022	<u>7,575</u>	<u>7,575</u>
Net book value		
At 31 December 2022	<u>1,841</u>	<u>1,841</u>
At 31 December 2021	<u>3,789</u>	<u>3,789</u>

10 Investments

	Investments in subsidiary undertakings £	Total £
Cost		
At 1 January 2022	100	100
At 31 December 2022	<u>100</u>	<u>100</u>
Historical cost		
At 1 January 2022	100	
At 31 December 2022	<u>100</u>	

11 Subsidiary companies

The name of the subsidiary undertaking is International Gardian Limited, registered in England & Wales with company number 12658731.

The aggregate amount of the holding company's investment in its subsidiary is £100, which represents 100% of the issued ordinary share capital of the subsidiary. The subsidiary is controlled by the holding company by virtue of the power to appoint directors to the board of the subsidiary.

The subsidiary's activities relate to those of the holding company in that the subsidiary is a trading enterprise engaging in trades similar to the charitable activities of the holding company.

	2022 £	2021 £
A summary of the unaudited financial statements of the subsidiary is :		
Assets and Funds		
Aggregate amounts of assets /(liabilities)	3,858	(6,988)
Aggregate amount of funds	<u>3,858</u>	<u>(6,988)</u>
Profit and Loss		
Turnover	152,657	509,511
Expenses	(141,811)	(513,597)
Net profit /(loss) for the year after tax	<u>10,846</u>	<u>(4,086)</u>

The net profit of the subsidiary is stated after including intergroup company expenditure of £15,962 (2021 - £20,862).

12 Debtors

	2022 £	2021 £
Amounts owed by group undertakings and undertakings in which the company has a participating interest	17,964	22,864
Other debtors	41,569	-
	<u>59,533</u>	<u>22,864</u>

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2022

13 Creditors: amounts falling due within one year

	2022	2021
	£	£
Deferred Income - Restricted funds	28,848	11,279
Taxation and social security costs	2,914	2,519
Other creditors	11,038	23,186
	<u>42,800</u>	<u>36,984</u>

14 Movement in Funds

	As at 1			Transfers	As at 31
	January	Income	Expenditure	in/(out)	December
	2022	£	£	£	2022
	£				£
Restricted funds					
Gene Therapy	60	-	-	-	60
Sanofi work programme	-	71,447	(82,425)	14,252	3,274
Pfizer work programme 2021	5,723	-	(5,763)	40	-
Pfizer work programme 2022-23		7,337	(2,102)	-	5,235
IWGDD	-	6,041	(7,220)	1,179	-
Avrobio	-	20,000	(20,000)	-	-
Freeline	-	18,000	(18,000)	-	-
Total restricted funds	<u>5,783</u>	<u>122,825</u>	<u>(135,510)</u>	<u>15,471</u>	<u>8,569</u>
General fund	222,899	128,582	(157,723)	(15,471)	178,287
Total unrestricted funds	<u>222,899</u>	<u>128,582</u>	<u>(157,723)</u>	<u>(15,471)</u>	<u>178,287</u>
Total restricted and unrestricted funds	<u>228,682</u>	<u>251,407</u>	<u>(293,233)</u>	<u>-</u>	<u>186,856</u>
Movement in Funds					
	As at 1			Transfers	As at 31
	January	Income	Expenditure	in/(out)	December
	2021	£	£	£	2021
	£				£
Restricted funds					
Eurordis Funding	-	1,619	-	(1,619)	-
Gene Therapy	-	5,000	(4,940)	-	60
Sanofi work programme	-	56,537	(67,230)	10,693	-
Access to Medicines Africa	-	71,955	(71,979)	24	-
Pfizer work programme	-	23,502	(17,779)	-	5,723
IWGDD	-	3,048	(3,663)	615	-
Total restricted funds	<u>-</u>	<u>161,661</u>	<u>(165,591)</u>	<u>9,713</u>	<u>5,783</u>
General fund	202,606	131,906	(101,900)	(9,713)	222,899
Total unrestricted funds	<u>202,606</u>	<u>131,906</u>	<u>(101,900)</u>	<u>(9,713)</u>	<u>222,899</u>
Total restricted and unrestricted funds	<u>202,606</u>	<u>293,567</u>	<u>(267,491)</u>	<u>-</u>	<u>228,682</u>

During the year ended 31 December 2022 transfers were made from unrestricted funds to cover deficits on the Sanofi work programme, Pfizer work programme 2021 and IWGDD restricted funds.

During the year ended 31 December 2021 transfers were made from unrestricted funds to cover deficits on the Sanofi work programme and IWGDD restricted funds and to re-allocate expenditure incurred in the year ended 31 December 2020 relating to Eurordis restricted funding received in the year.

At 31 December 2022 the net assets of £186,856 were analysed between unrestricted funds of £178,287, and restricted funds of £8,569.

The purposes for which the funds are held by the charity are:

Unrestricted funds:

General fund

These funds are held for the meeting the objectives of the charity, and to provide reserves for future activities, and, subject to charity legislation, are free from all restrictions on their use.

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2022

14 Movement in Funds (continued)

Restricted funds:

Gene Therapy	Funds received from Freeline for funding Gene Therapy work.
Sanofi work programme	Funds held for funds received from Sanofi for funding 2021 work programme.
Access to Medicines Africa	Funds received for Takeda for Access to Medicines Africa project.
Pfizer work programme 2021	Funds held for funds received from Pfizer for funding 2021 work programme.
Pfizer work programme 2022-23	Funds held for funds received from Pfizer for funding 2022-23 work programme.
IWGDD	Funds held for funds received from International Working Group on Gaucher Disease to support promotion and recruitment of patients and caregivers to the nGD registry.
Avrobio	Funds held for funds received from Avrobio for patient education / support.
Freeline	Funds held for funds received from Freeline for specified projects relating to improving patient access.

15 Related party transactions

Jeremy Manuel, the Honorary President of the Company and Tanya Collin- Histed, the Chief Executive Officer of the Company are both directors of The Gauchers Association Limited. During the year charges were received from the Gauchers Association Limited as follows:

	2022	2021
	£	£
Administration fees	1,138	1,104

During the year the company has recharged costs to the Gauchers Association Limited and to its subsidiary International Gardian Limited as follows:

The Gauchers Association Limited Consultancy fees	4,800	10,400
The Gauchers Association Limited Administration fees	552	1,343
International Gardian Limited Administration fees	15,962	20,862

At 31 December 2022 included in other creditors is £601 (2021: £ nil) owed to The Gauchers Association, and included in amounts receivable from Group undertakings is £17,964 due from International Gardian Limited (2021: £22,864)

During the year staff costs included £2,486 (2021:£3,308) relating to 50% of time spent on work done for its subsidiary International Gardian Limited ("IGL"). Administration fees included £4,733 relating to contractor costs incurred for IGL (2021: £355). These amounts have not been recharged to IGL as the charity agreed to fund 50% of staff and contractor time spent on IGL work for a period of 2 years from July 2021.

16 Controlling party

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

17 Other information

International Gaucher Alliance 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.

If upon winding up or dissolution of the charity there remain any assets, after the satisfaction of all debts and liabilities, the assets represented by the accumulated fund shall be transferred to some other charitable body or bodies having similar objects to the charity.

As a charity, tax exemption applies to income arising and expended on its charitable activities.

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:
86-90 Paul Street
London
EC2A 4NE

International Gaucher Alliance Limited
Detailed Income and Expenditure
for the year ended 31 December 2022

This schedule does not form part of the statutory accounts

	Total funds 2022 £	Total funds 2021 £
Donations		
Revenue grants and donations from non public bodies	193,498	243,386
Donated goods and services	48,045	34,325
Charitable activities - consultancy fees receivable	9,864	15,856
	<u>251,407</u>	<u>293,567</u>
Expenditure on charitable activities- Grant funding of activities		
Grants made/charitable payments	-	71,979
	<u>-</u>	<u>71,979</u>
Expenditure on charitable activities - Direct spending		
Employee costs:		
Wages and salaries	106,409	99,784
Pensions	1,680	1,617
Employer's NI	10,964	8,889
Temporary staff and recruitment	-	536
Travel and subsistence	47,750	988
Other direct costs:		
Research	7,198	-
Conferences and Seminars	1,788	-
	<u>175,789</u>	<u>111,814</u>
Expenditure on charitable activities - Support costs		
Employee costs:		
Employee costs:		
Staff training and welfare	357	224
Directors' and volunteers' fees	48,045	34,325
Entertaining	305	79
	<u>48,707</u>	<u>34,628</u>
Premises costs:		
Rent	3,457	4,560
	<u>3,457</u>	<u>4,560</u>
General administrative expenses:		
Telephone and internet	887	1,074
Postage	47	82
Stationery and printing	1,215	(1,531)
Subscriptions	3,460	3,492
Bank charges	597	452
Insurance	1,300	2,073
Equipment expensed	298	-
Software	6,551	3,970
Repairs and maintenance	559	171
Depreciation	1,949	2,014
Amortisation of intangible fixed assets	4,617	2,832
Foreign exchange gains and losses	(5,872)	6,024
	<u>15,608</u>	<u>20,653</u>

International Gaucher Alliance Limited
Detailed Income and Expenditure
for the year ended 31 December 2022

This schedule does not form part of the statutory accounts

	Total funds 2022 £	Total funds 2021 £
Legal and professional costs:		
Accountancy fees (including Examiner's fee)	5,838	4,965
Consultancy fees	1,440	3,259
Administration recharge (contractor)	19,596	1,799
Other legal and professional	22,798	13,834
	<u>49,672</u>	<u>23,857</u>
	<u>293,233</u>	<u>267,491</u>
Total	<u>(41,826)</u>	<u>26,076</u>