

Registered number
06653373

International Gaucher Alliance Limited

Report and Accounts

31 December 2023

Registered Charity Number 1192011
Company Registration Number 06653373

International Gaucher Alliance Limited
Report and accounts
Contents

	Page
Reference and administrative details of the charity	1
Trustees' Annual Report	2-13
Independent Examiner's Report	14-15
Statement of Financial Activities	16
Statement of Financial Activities prior year	17
Balance sheet	18
Notes to the accounts	19-24

International Gaucher Alliance Limited Company Information

Trustees

Aviva Fisher Rosenberg
Irena Znidar
Biljana Jovanovic
Kristiyan Dimitrov
Suyog Sathe
Francisco Carreiro
Aimeé-Kate Bosch
Sara Khan
Diana Paulina Pena Aragon

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 2023, 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

Aimeé-Kate Bosch

Sara Khan

Diana Paulina Pena Aragon

David Ohana (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

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

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.

Together the CEO Tanya Collin-Histed; our staff team Angel Jones, Harry Albright, Vesna Aleksovskaja and Madeline Stoodley 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.

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.

In 2023 the International Gaucher Alliance's work reflected our dedication to advancing disease awareness, research, and support initiatives to enhance the lives of individuals and families affected by Gaucher disease.

Founded in 1994, the International Gaucher Alliance has been at the forefront of advocating for Gaucher community worldwide.

In 2023, the IGA held a "Go with Gaucher" meeting with many lectures, workshops and educational sessions for young people living with the disease. This meeting ended with the creation of a Youth Council initiative, that will be launched in 2024.

The IGA Strategic Plan 2024-2029 was developed with our community and stakeholders and outlines our priorities for the next five years.

Educational empowerment remains an important part of our advocacy, exemplified by our insightful and impactful webinars. This year The IGA had a series of webinars on the topics of Gene therapy clinical trials and clinical trials for new treatment options for the GD3 community. These webinars were organised in different time zones worldwide, so there were separate webinars for each part of the world with interpretation into four languages relevant to each region.

A significant highlight in our calendar is the annual celebration of International Gaucher Day (IGD), a momentous occasion where our global community unites to raise awareness of Gaucher disease, share stories of resilience, and advocate for improved access to diagnosis and care. This year, the IGA launched a movie *The Power of Knowledge in a Timely Diagnosis – Building a Better Future*, in which families and physicians in different parts of the world speak about their diagnostic journeys to raise awareness of the importance of the power of knowledge in a timely diagnosis.

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

In 2024 the Regional Manager programme becomes the Global Gaucher Connect Programme (GGCP) and our Regional Managers are now Gaucher Leaders (GL). The GLs are the eyes and ears of the IGA in countries where there is not a patient organisation, and are responsible for working closely with key stakeholders in the Gaucher community 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.

Integral to our success is the dedication of the participants in our volunteer program, passionate individuals who tirelessly contribute their time, skills and compassion to better the lives of those affected by Gaucher disease. As The IGA reflect on the milestones of 2023, The IGA express our deepest gratitude to our dedicated volunteers, whose passion and hard work have elevated the International Gaucher Alliance to new heights. Together, The IGA continue to pave the way for a brighter future for Gaucher patients and families.

A final note is to reflect on the ongoing challenges faced globally by our community with patients and families displaced by war, or where there are a lack of access to treatment and care through political changes and challenges, as well as a lack of awareness of the needs of our community. The IGA has worked and will continue to work tirelessly for these patients and their families wherever they are in the world.

The IGA has built up strong relationships based on respect and trust with all of the stakeholders and companies we work with, and we work very hard to support patients in a transparent manner.

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

In 2023 the IGA was supported by 79 volunteers. The IGA have been recruiting further volunteers to work on new projects. Volunteers came from 47 different countries (Argentina, Australia, Belgium, Botswana, Brazil, Bulgaria, Canada, China, Croatia, Czechia, Denmark, Egypt, France, Greece, Guatemala, India, Italy, Israel, Japan, Kenya, Lebanon, Lithuania, Malawi, Mexico, Mozambique, Nepal, Netherlands, Nicaragua, North Macedonia, Pakistan, Peru, Poland, Portugal, Qatar, Romania, Russia, Rwanda, Serbia, Slovenia, South Africa, Sudan, Sweden, Turkey, Uganda, United Kingdom, USA, Zimbabwe) and were involved in around 12 projects.

POSITION ON NON-COMPARABLES

The IGA issued a non-comparable position statement in June 2023. The position statement outlines the IGA's stance in relation to the use of 'intended copies' of enzyme replacement therapy (ERT) medicines as a treatment for Gaucher disease, advocating for safe and effective. 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. In October the International Working Group in Gaucher Disease (IWGGD) and IGA issued a consensus document on switching and monitoring best practice. Born from concerns raised with the IGA by patients and patient organisations regarding being faced with switching enzyme replacement therapy due to payers' decisions around the procurement of treatment, the consensus document lists the points that decision makers should consider prior to approving a new medicine purely on economic grounds.

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

CHARITABLE ACCESS TO MEDICINES

The IGA have always pledged to help any Gaucher patient that asks us for help wherever they live in the world, therefore advocating for charitable treatment has always been and will remain our priority. Despite there being three licensed enzyme replacement therapies (ERT) and two substrate reduction therapies (SRT) available for the treatment of the visceral manifestations of the disease, sadly, there are still hundreds of patients around the world without access to treatment. There were direct requests received for support to access treatment to IGA from 17 countries: Botswana, Cuba, Gaza, Ethiopia, India, Kenya, Mongolia, Nepal, Philippines, Rwanda, Singapore, Uganda, Venezuela and Zambia. 9 requests were approved, 1 patient died before treatment could be found, and 9 cases remained unresolved: Jordan (4), Nepal (1), Afghanistan (1), Botswana (2), Singapore (1).

GLOBAL GAUCHER CONNECT (REGIONAL MANAGER) PROGRAMME

The IGA worked to re-organise and rebrand its Regional Manager (RM) programme ahead of a relaunch in 2024. The RMs improved awareness of Gaucher disease, including finding participants for the IGD video and co-ordinating local filming, as well as organising related events, including in Nepal and Botswana. They organised educational webinars for Africa, Asia, Europe and Central America, attended by over 2000 people (most of them medical professionals). RMs were in regular communication with medical professionals, researchers, volunteers and patient organizations to raise awareness of the work of the IGA. They also helped with the translation of materials which are shared in hospitals, Doctors' offices, conferences and other places where the Gaucher community gathers.

Two Regional Managers report:

Patricia Lucki:

2023 has been a busy year for IGA in Central America. We started projects of health and registries in Guatemala, while advertising GARDIAN. We worked with other associations in other countries, in rising awareness of rare diseases and the need of neonatal screening, including lysosomal diseases.

As we partner with CEPICAL, "Colaborativa para las Enfermedades Poco Frecuentes en el Caribe y América Latina", we have been involved in the organisation of the 2024 Regional Congress, with a working group that will focus on Gaucher Disease in the region.

We started the process of distributing leaflets about GD in paediatric congresses and emergencies of hospitals, while we participate as speaker in some of them.

Finally, we are doing our best effort to support patients in countries where there are no associations or where their migration or political conditions do not allow them to receive treatment. We look forward to seeing more progress in such a complex situation.

Andre Balzekiene:

In 2023 I was the Regional Manager for Europe where my countries of interest vary from Iceland or Cyprus to Belarus or Uzbekistan. Since these countries do not have local Gaucher associations, my main goal is to find out if there are any Gaucher patients living there, and what are the laws and treatments for this or other rare diseases. Trying to reach out and find medical professionals or government officials to reply to your email often seems like a mission to the unknown land and I am very happy every time I receive a reply. I've made contact!

I also helped to organize a webinar for raising awareness on Gaucher disease among health professionals. It was my first job at the IGA, and I was happy to be part of it.

The biggest highlight of 2023 was the first-time opportunity to participate in a regional meeting of patients and medical professionals in Croatia. It was an amazing possibility to get to know other patients, meet the doctors, and discover the latest clinical data. The greatest thing on this volunteer journey is the family-like feeling you get along the way.

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

EDUCATING AND EMPOWERING MEMBERS

The IGA continued to organise educational sessions in order to support Gaucher community to increase their capacities. These included: Substrate reduction therapy: What we need to know? held for the Balkans region in Croatian, with interpretation to English. Webinars on Gene therapy for Europe, Asia and the Americas were held in different time zones and interpreted into various languages. Webinars on the GD3 Venglustat trial. Three webinars were held in different time zones for European, Asian and Americas region, also interpreted into various languages.

THE IGA'S PARTICIPATION IN WORKING GROUPS:

- Avrobio's GD3 Advisory Board to educate Avrobio on the GD3 global community to support the development of their GD3 GT clinical trial.
- Sanofi's GD3 Burden of Illness study – member of the Expert Review Group
- Member of the HTAi Rare Disease Interest Group and
- participating in:
 - WG 2 'Characterising Rare Diseases'
 - WG 3 'New paradigms for evidence generation and interpretation that takes into account the complexity of rare diseases including relevant value assessment frameworks'.
- Member of Eurordis Patient Advisory Board for the Screen4Care which offers an innovative research approach to accelerate rare disease diagnosis, based on two central pillars: genetic newborn screening and digital technologies.
- Member of GARDaccess (gardaccess.org)
- Member of RDI 'Identifying the socio-economic burden of rare disease in low middle income countries' project.
- On the advisory board of the European Haematology Association (EHA)
- Member of the RDI Global Access working group
- IWGD working group on Epilepsy in GD3
- IWGGD working Group on the use of Ambroxol for Gaucher patients, developing a best practice paper.
- Member of Eurordis Digital Advisory Group
- Member of the Gaucher Outcome Survey (GOS) steering committee for Takeda
- Attendance at the monthly C-Path for Lysosomal Disorders consortium meetings
- Member of the Medical Expert Committee (MEC) -Takeda's charitable Access programme.
- Member of the Mendelian Patient Involvement Initiative is a pilot project funded by an AI award by the National Institute of Health and Care Research (NIHR) that looks at how data centric tech could improve patients' lives by accelerating rare disease diagnosis and enabling faster, more targeted, access to treatments and management.

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

THE IGA'S PRESENCE AT GLOBAL MEETINGS:

- WORLD Symposium, Jan 2023, Orlando Florida.
 - The 3rd International Conference on Lysosomal Diseases (Med-Lysosomal2023), April, London – Presentation topic: 'Recruiting patients for Gene Therapy clinical trials', is very concerning.
 - Sanofi's Gaucher Leadership Forum, June, Copenhagen – Presentation topic: Gaucher Disease, an advanced but unfinished progress. Setting the path to accelerate Gaucher and ASMD patients' journey.
 - IWGGD 10 May – Presentation topic: IGA Position Statement on Non-Comparables
 - HTAi Adelaide, Australia June – Presentation topics: Rare Disorders. Is the Lack of Effect in a Patient-Reported Outcome, Reflecting no Benefit? Developing a HTAi Rare Diseases Interest Group (RDIG) - Patients' Perspective
 - Biosimilar medicines conference meeting, May Presentation topic: 'Gaucher disease and remaining challenges.
 - Sanofi's Rare Disease Registries Patient Council Presented a poster: 'A rare partnership: community and industry collaboration to shape the impact of real-world evidence on the rare disease ecosystem.'
 - The Society for the Study of Inborn Errors of Metabolism (SSIEM) Annual Symposium, Jerusalem.
 - The Regional Gaucher Meeting, Zagreb, organised by Croatian, Serbian, North Macedonian and Slovenian Gaucher Associations.
 - Eurordis General Assembly – 17 May
 - 2nd Symposium Recent Advances & Rare Overview, 26-27 February, Ponte Delgada, Portugal
 - EURORDIS Council of European Federations Meeting – 12-13 December, Brussels Belgium.
-
- Sanofi's Rare Disease Registries Patient Council Presented a poster: 'A rare partnership: community and industry collaboration to shape the impact of real-world evidence on the rare disease ecosystem.'
 - The Society for the Study of Inborn Errors of Metabolism (SSIEM) Annual Symposium, Jerusalem.
 - The Regional Gaucher Meeting, Zagreb, organised by Croatian, Serbian, North Macedonian and Slovenian Gaucher Associations.
 - Eurordis General Assembly – 17 May
 - 2nd Symposium Recent Advances & Rare Overview, 26-27 February, Ponte Delgada, Portugal
 - EURORDIS Council of European Federations Meeting – 12-13 December, Brussels Belgium.

IMPACT OF WAR

In Sudan Gaucher patients and their families have been displaced, treatment in the country destroyed. Avenues to get treatment into Sudan remain very challenging and impossible for periods of time. Sadly, many Gaucher patients have died, and others have been without treatment for months. Some patients have managed to travel to other countries to access treatment and clinical care. The IGA in partnership with Direct Relief (the distributor for the Takeda charitable access programme) and Sanofi have worked closely together on this with clinicians and patients/families.

In Gaza communication with patients has broken down and a new patient planning to be seen at the Shaare Zedek hospital in Israel for support has not been able to.

Some patients remain in Ukraine and are receiving treatment and care, others have gone to other countries. In late 2023 a new patient with suspected Gaucher disease approached the IGA for help and together with Dr Andrea Dardis, Italy, this patient is being supported.

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

OTHER SUPPORT TO PATIENTS AND FAMILIES

Requests for support were received from Sweden, Peru, Iran, Egypt, Pakistan, Sudan, Ukraine, South Africa, Morocco, Turkey, India and France and included:

- Relocation and link to clinical expert
- Relocation and access to medicines
- Access to diagnostic services
- Prescribed medicines not arriving in country.
- Access to care and medicines through war displacement
- Support for further information into different disease issues and links to experts
- Challenges with access to medicines through Government budget reductions
- Issues with Insurance coverage for medicines

GENE THERAPY

In 2022 the IGA made a commitment to educate the international Gaucher community on Gene Therapy and embarked on a series of activities, in 2023 The IGA achieved the following:

- Manuscript: January 2023 saw the publication in Orphanet of the IGA's international survey that sought to understand patient and parent and caregiver perceptions on gene therapy in Gaucher disease.
- Website: Launched a gene therapy web page to enable the community to be able to easily understand the similarities and differences in the current clinical trials for Type 1 Gaucher disease.
- Educational webinars: hosted a series of regional website on the current clinical trials for Type 1 Gaucher disease to ensure equity of access in different time zones and languages. These webinars are available on the IGA's YouTube Channel.
- Educational Awareness of Clinical trials: hosted a series of regional website on the current clinical trials for Type 3 Gaucher disease to ensure equity of access in different time zones and languages. These webinars are available on the IGA's YouTube channel

STRATEGIC PLAN 2024-2029

In 2023, the IGA worked collaboratively with many stakeholders in the Gaucher community to develop its new Strategic Plan for the five years from 2024. This plan sets out a bold new vision for the IGA's work, aiming to cement its reputation as the go-to international organisation representing and advocating for Gaucher patients and their carers.

INTERNATIONAL GAUCHER DAY

The main event for International Gaucher Day (IGD) in 2023 was the video, The Power of Knowledge in a Timely Diagnosis – Building a Better Future.

The IGA shared the video on Facebook and Instagram. The IGA also uploaded it to YouTube and shared it on LinkedIn. As of the end of 2023, the English version of the video had reached 1,600 people on Instagram, 2,000 on Facebook and had been viewed 264 times on YouTube. The video subtitles were also translated into Spanish (released on 1 October), Serbian and Portuguese, the other two languages used in the video, followed later in the month, with Macedonian, French, Hindi, Chinese, Russian and Arabic added a few days later.

An accompanying leaflet for the video in Afrikaans, Arabic, English, Spanish, French, Croatian, Latvian, Macedonian, Ndebele, Portuguese, Russian, Shona, Tsonga, Xhosa and Zulu versions is available on the website.

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

The IGA also made all of the social media posts available for download, including Word templates that people could download and use with translated text.

The IGA made fewer social media posts this year as we wanted the video to be the focus. The IGA took quotes from each of the video participants to make the posts. We made a total of 14 Facebook posts. Total post reach was 3,780. Total engagement was 571. We also made 14 Instagram posts. Total post reach was 3,866. There were 821 likes. We made 13 LinkedIn posts. There were 3,180 impressions and 99 reactions.

GARDIAN

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

About 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.

February saw the first GARDIAN multistakeholder meeting, bringing together 30 attendees from the registries scientific advisory board, pharma Industry working group and members of the IGL board of Trustees.

July saw the publication in Orphanet of 'A global neuronopathic Gaucher disease registry (GARDIAN): a patient-led initiative'.

December 2023, the Gaucher Community Alliance, and IGA teamed up to host a virtual focus group ,featuring 12 participants, including parents, caregivers, and individuals living with neuronopathic Gaucher disease (nGD. The session aimed to explore the awareness and utilization of the GARDIAN registry platform, and to develop strategies to enhance participation among the target demographic.

Participated in a two-day workshop on establishing a community governed patient registry and offered learnings from GARDIAN. The workshop was hosted by European Health Data & Evidence Network (EHDEN), a member of the GARDIAN team.

GARDIAN was presented at various meetings and conferences during 2023, including:

Poster: WORLD 2023 poster: GARDIAN 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.

Meetings:

IWGGD, May 2023, GARDIAN registry for GD2 and GD3

European Human Genetic Society (EHSG), Glasgow, June 11-13, Presentation topic: Engaging patients in clinical trials endpoints: A Gaucher Disease Registry perspective

GO WITH GAUCHER ISTANBUL

The IGA successfully hosted its fourth Go with Gaucher (GwG) conference in Istanbul, Türkiye, from November 10th to 12th.

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

The conference was specifically designed for young adult Gaucher patients aged 18-30, offering them a unique opportunity to connect with fellow patients worldwide and gain deeper insights into Gaucher through expert-led lectures on crucial topics.

Attended by over 15 patients representing Europe, the Americas, and Asia, the conference featured expert talks covering various pertinent subjects. These included recent advancements in Gaucher disease research and treatment, managing mental health during significant life transitions while coping with Gaucher disease, transitioning between different therapies, the significance of diet and nutrition for Gaucher patients, engaging in the Gaucher community through advocacy, and the impact of Gaucher disease on pregnancy.

Esteemed speakers such as Prof. Derralynn Hughes (Royal Free London NHS; Chair, IWGGD), Zubya Azzam (Rareminds), Dr. Mehmet Balci (Istanbul University), Gidon Goodman (Gaucher patient and President of the Gaucher Association of Australia and New Zealand), and Elizabeth Morris (Clinical Nurse Specialist, Cambridge University Hospital) shared their expertise. Moreover, participants courageously shared their poignant and inspiring personal narratives of living with Gaucher during the patient monologues session. The event left a profound impact on the attendees, many of whom expressed how it was a life-changing experience for them.

IN 2024 WE INTEND TO:

- Celebrate 30 years of advocating on behalf of the Global Gaucher community with various events including a 'fire side chat' looking back over the past 30 years.
- Hold our biennial members meeting in November in Lisbon, Portugal and invite our Gaucher leaders and volunteers to join us.
- Launch the GARDIAN dashboard to share some of the data captured in the nGD patient reported registry.
- Continue our work with the older generation of Gaucher patients to better understand their clinical and non-medical needs and seek ways in which to address unmet needs where they exist.
- Understanding the community's position on Newborn Screening, providing a position paper that will be a tool for patients and advocates to address the issue in their own country.
- Provide a series of podcasts on different aspects of Gaucher disease e.g. gene therapy, pregnancy, switching to an oral therapy, transition, mental health.
- Continue to grow our Global Gaucher Connect (formerly Regional Manager programme) in Africa, Central America, Southeast Asia, Eastern Mediterranean and European regions.
- Seek to work in collaboration with other stakeholders to develop a patient registry in Africa.
- Continue to ensure access to information and our services by providing translation and interpretation in as many languages as possible.
- Through the 2023 Go with Gaucher symposium, to work with the young adults to develop a Youth Council for the IGA. This will create the opportunity to have young people involved in the IGA structure, and their perspective in the work of IGA.

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

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.

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.

Financial review

The charity's financial position at the end of the year ended 31 December 2023

The financial position of the charity at 31 December 2023 and comparatives for the prior period, as more fully detailed in the accounts, can be summarised as follows:-

	2023 £	2022 £
Net income /(expense)	30,537	(41,826)
Unrestricted funds available for the general purposes of the charity	201,251	178,287
Restricted funds	16,142	8,569
Total funds	217,393	186,856

Financial review of the position at the reporting date, 31 December 2023

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 £102,298.

During the year the charity's reserves increased by £30,537 and held reserves of £217,393 at 31 December 2023. 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.

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011

Trustees' Annual Report

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

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.

International Gaucher Alliance Limited

Company limited by guarantee registered number:

06653373

Registered charity number: 1192011


Trustees' Annual Report

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 27 September 2024.


Biljana Jovanovic (Sep 27, 2024 14:43 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 2023

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 2023 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 2023

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 2023 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 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

27 September 2024

International Gaucher Alliance Limited
Statement of Financial Activities Including Income and Expenditure Accounts
for the year ended 31 December 2023

	Notes	Unrestricted Funds 2023 £	Restricted Funds 2023 £	Total Funds 2023 £	Total Funds 2022 £
Income					
Donations and legacies		201,592	164,263	365,855	241,543
Charitable activities		29,804	-	29,804	9,864
Total income		<u>231,396</u>	<u>164,263</u>	<u>395,659</u>	<u>251,407</u>
Expenditure					
Charitable activities		205,216	159,906	365,122	293,233
Total expenditure		<u>205,216</u>	<u>159,906</u>	<u>365,122</u>	<u>293,233</u>
Net income/(expenditure) for the year and Movement in total funds for the year	2	<u>26,180</u>	<u>4,357</u>	<u>30,537</u>	<u>(41,826)</u>
Other recognised gains/ (losses)					
Total funds at 1 January		178,287	8,569	186,856	228,682
Transfers in /(out)		(3,216)	3,216	-	-
Total funds at 31 December	14	<u>201,251</u>	<u>16,142</u>	<u>217,393</u>	<u>186,856</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 2022

	Notes	Unrestricted Funds	Restricted Funds	Total Funds	Total Funds
		2022 £	2022 £	2022 £	2021 £
Income					
Donations and legacies		118,718	122,825	241,543	277,711
Charitable activities		9,864	-	9,864	15,856
Total income		128,582	122,825	251,407	293,567
Expenditure					
Charitable activities		157,723	135,510	293,233	267,491
Total expenditure		157,723	135,510	293,233	267,491
Net income/(expenditure) for the year and Movement in total funds for the year	2	(29,141)	(12,685)	(41,826)	26,076
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	14	178,287	8,569	186,856	228,682

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 2023**

	Notes	2023 £	2022 £
Fixed assets			
Intangible assets	8	12,216	17,451
Tangible assets	9	2,261	1,841
Investments	10	100	100
		<u>14,577</u>	<u>19,392</u>
Current assets			
Debtors	12	35,147	59,533
Cash at bank and in hand		<u>204,244</u>	<u>150,731</u>
		239,391	210,264
Creditors: amounts falling due within one year	13	(36,575)	(42,800)
Net current assets		<u>202,816</u>	<u>167,464</u>
Total assets less current liabilities		<u>217,393</u>	<u>186,856</u>
Net assets		<u>217,393</u>	<u>186,856</u>
Total funds of the charity			
Restricted Funds	14	16,142	8,569
Unrestricted Funds	14	201,251	178,287
Total charity funds		<u>217,393</u>	<u>186,856</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 27, 2024 14:43 GMT+2)

Biljana Jovanovic

Trustee

Approved by the board on 27 September 2024

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2023

1 Accounting policies

Basis of preparation

The accounts have been prepared under the historical cost convention and in accordance with the Statement of Recommended Practice (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:

Plant and machinery over 4 years

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2023

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	2023	2022
	£	£
This is stated after charging:		
Depreciation and amortisation of owned fixed assets	1,141	1,949
Trustees' and volunteers' remuneration	53,431	48,045
Independent Examiner's remuneration	3,000	3,000
Contributions to pension fund for employees	1,700	1,680

3 Donated goods, services and facilities	2023	2022
	Unrestricted funds	Unrestricted funds
	£	£
Included in donations and legacies:		
Donated goods and services	53,431	48,045
	53,431	48,045

Directors and volunteers have made donations of their services to the company during the year to the value of £53,431 (2022: £48,045). Administration expenses include directors' and volunteers' fees for services donated to the company of £53,431 (2022: £48,045) and donations and legacies include donations by the directors and volunteers of £53,431 (2022: £48,045) in respect of their services to the company.

4 Staff costs	2023	2022
	£	£
Wages and salaries excluding trustees and key management personnel	40,197	42,144
Social security costs	11,769	10,964
Other pension costs	1,700	1,680
Salaries and benefits paid to key management personnel	71,498	64,265
Directors' and volunteers' fees for services donated to the charity	53,431	48,045
	178,595	167,098

The cost to the charity of senior management personnel remuneration included the following:	2023	2022
	£	£
Gross wages and Employer's National Insurance contributions	80,110	72,603
Contributions for the provision of money purchase pension	1,321	1,321

Numbers of such staff to whom benefits are accruing :	2023	2022
	Number	Number
Under money purchase pension schemes	1	1

5 Employees	2023	2022
	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 2023

5 Employees (continued)

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

	2023 Number	2022 Number
£60,001 to £70,000	-	1
£70,001 to £80,000	1	-

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

	2023 £	2022 £
Remuneration payable to trustees or connected persons		
Directors' and volunteers' fees for services donated to the charity	53,431	48,045

Directors and volunteers have made donations of their services to the company during the year to the value of £53,431 (2022: £48,045). Administration expenses include directors' and volunteers' fees for services donated to the company of £53,431 (2022: £48,045) and donations and legacies include donations by the directors and volunteers of £53,431 (2022: £48,045) in respect of their services to the company.

7 Deferred income - Restricted funds

	2023 Received deferred in year £	2023 Deferred at year end £	2022 Received deferred in year £	2022 Deferred at year end £
Pfizer work programme 2022-23	-	-	26,000	20,800
International Working Group on Gaucher Disease	-	-	-	3,048
Takeda Transitions grant	-	5,000	5,000	5,000
Sanofi Outstanding research priorities	11,000	11,000	-	-
	11,000	16,000	31,000	28,848

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 2023	24,900
At 31 December 2023	24,900

Amortisation

At 1 January 2023	7,449
Provided during the year	5,235
At 31 December 2023	12,684

Net book value

At 31 December 2023	12,216
At 31 December 2022	17,451

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 2023

9 Tangible fixed assets

	Plant and machinery etc £	Total £
Cost		
At 1 January 2023	9,416	9,416
Additions	1,561	1,561
At 31 December 2023	<u>10,977</u>	<u>10,977</u>
Depreciation		
At 1 January 2023	7,575	7,575
Charge for the year	1,141	1,141
At 31 December 2023	<u>8,716</u>	<u>8,716</u>
Net book value		
At 31 December 2023	<u>2,261</u>	<u>2,261</u>
At 31 December 2022	<u>1,841</u>	<u>1,841</u>

10 Investments

	Investments in subsidiary undertakings £	Total £
Cost		
At 1 January 2023	100	100
At 31 December 2023	<u>100</u>	<u>100</u>
Historical cost		
At 1 January 2023	100	
At 31 December 2023	<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.

	2023 £	2022 £
A summary of the unaudited financial statements of the subsidiary is :		
Assets and Funds		
Aggregate amounts of assets /(liabilities)	3,246	3,858
Aggregate amount of funds	<u>3,246</u>	<u>3,858</u>
Profit and Loss		
Turnover	57,023	152,657
Other income	1,035	-
Expenses	(58,670)	(141,811)
Net profit /(loss) for the year after tax	<u>(612)</u>	<u>10,846</u>

The net profit/(loss) of the subsidiary is stated after including intergroup company expenditure of £28,894 (2022 - £15,962).

12 Debtors

	2023 £	2022 £
Amounts owed by group undertakings and undertakings in which the company has a participating interest	29,894	17,964
Other debtors	5,253	41,569
	<u>35,147</u>	<u>59,533</u>

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2023

13 Creditors: amounts falling due within one year

	2023	2022
	£	£
Trade creditors	13,231	-
Deferred Income - Restricted funds	16,000	28,848
Taxation and social security costs	3,364	2,914
Other creditors	3,980	11,038
	<u>36,575</u>	<u>42,800</u>

14 Movement in Funds

	As at 1			Transfers	As at 31
	January	Income	Expenditure	in/(out)	December
	2023	£	£	£	2023
	£				£
Restricted funds					
Gene Therapy	60	-	-	-	60
Sanofi work programme 2022	3,274	4,405	(3,274)	(4,405)	-
Pfizer work programme 2022-23	5,235	20,800	(26,423)	388	-
IWGDD	-	3,048	(3,610)	562	-
Avrobio 2023	-	10,000	(10,000)	-	-
Eli Lilly work programme 2023	-	30,000	(30,000)	-	-
Sanofi work programme 2023	-	64,000	(60,231)	6,671	10,440
Pfizer funding 2023-24	-	25,000	(20,555)	-	4,445
Takeda Educating doctors	-	7,010	(5,813)	-	1,197
Total restricted funds	<u>8,569</u>	<u>164,263</u>	<u>(159,906)</u>	<u>3,216</u>	<u>16,142</u>
General fund	178,287	231,396	(205,216)	(3,216)	201,251
Total unrestricted funds	<u>178,287</u>	<u>231,396</u>	<u>(205,216)</u>	<u>(3,216)</u>	<u>201,251</u>
Total restricted and unrestricted funds	<u>186,856</u>	<u>395,659</u>	<u>(365,122)</u>	<u>-</u>	<u>217,393</u>

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 2022	-	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>

During the year ended 31 December 2023 transfers were made from unrestricted funds to cover deficits on projects within the Sanofi work programme 2023, Pfizer work programme 2022 and IWGDD restricted funds. Funds were transferred to the Sanofi work programme in 2022 from unrestricted funds of £14,252 to cover anticipated deficits on projects in 2022. Of this amount, £4,405 was transferred back to unrestricted funds on completion of projects in 2023 when it was identified that final deficits on those projects were lower than anticipated.

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

At 31 December 2023 the net assets of £217,393 were analysed between unrestricted funds of £201,251 and restricted funds of £16,142.

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 2023

14 Movement in Funds (continued)

Restricted funds:

Gene Therapy	Funds received from Freeline for funding Gene Therapy work.
Sanofi work programme 2022	Funds held for funds received from Sanofi for funding 2022 work programme.
Sanofi work programme 2023	Funds held for funds received from Sanofi for funding 2023 work programme.
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.
Pfizer work programme 2023-24	Funds held for funds received from Pfizer for funding 2023-24 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.
Avrobio 2023	Funds held for funds received from Avrobio for funding 2023 work programme.
Freeline	Funds held for funds received from Freeline for specified projects relating to
Eli Lilly work programme 2023	Funds held for funds received from Eli Lilly for funding 2023 work programme.

15 Related party transactions

Jeremy Manuel, the Honorary President of the Company is a director of The Gauchers Association Limited. During the year charges were received from the Gauchers Association Limited as follows:

	2023	2022
	£	£
Administration fees	-	1,138

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
The Gauchers Association Limited Administration fees	-	552
International Gardian Limited Administration fees	28,498	15,962

At 31 December 2023 included in other creditors is £601 (2022: £601) owed to The Gauchers Association, and included in amounts receivable from Group undertakings is £29,894 due from International Gardian Limited (2022: £17,964)

During the year staff costs included £1,243 (2022: £2,486) relating to 50% of time spent on work done for its subsidiary International Gardian Limited ("IGL"). Administration fees included £2,367 relating to contractor costs incurred for IGL (2022: £4,733). 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 2023

This schedule does not form part of the statutory accounts

	Total funds 2023 £	Total funds 2022 £
Donations		
Revenue grants and donations from non public bodies	312,424	193,498
Donated goods and services	53,431	48,045
Charitable activities - consultancy fees receivable	29,804	9,864
	<u>395,659</u>	<u>251,407</u>
Expenditure on charitable activities- Grant funding of activities		
Grants made/charitable payments	6,658	-
	<u>6,658</u>	<u>-</u>
Expenditure on charitable activities - Direct spending		
Employee costs:		
Wages and salaries	111,695	106,409
Pensions	1,700	1,680
Employer's NI	11,769	10,964
Travel and subsistence	53,537	47,750
Other direct costs:		
Research	2,244	7,198
Conferences and Seminars	-	1,788
	<u>180,945</u>	<u>175,789</u>
Expenditure on charitable activities - Support costs		
Employee costs:		
Employee costs:		
Staff training and welfare	37	357
Directors' and volunteers' fees	53,431	48,045
Entertaining	1,643	305
	<u>55,111</u>	<u>48,707</u>
Premises costs:		
Rent	1,440	3,457
	<u>1,440</u>	<u>3,457</u>
General administrative expenses:		
Telephone and internet	437	887
Postage	14	47
Stationery and printing	6,519	1,215
Subscriptions	4,236	3,460
Bank charges	991	597
Insurance	1,200	1,300
Equipment expensed	1,371	298
Software	4,142	6,551
Repairs and maintenance	114	559
Depreciation	1,141	1,949
Amortisation of intangible fixed assets	5,235	4,617
Foreign exchange gains and losses	6,794	(5,872)
	<u>32,194</u>	<u>15,608</u>

International Gaucher Alliance Limited
Detailed Income and Expenditure
for the year ended 31 December 2023

This schedule does not form part of the statutory accounts

	Total funds 2023 £	Total funds 2022 £
Legal and professional costs:		
Accountancy fees (including Examiner's fee)	7,518	5,838
Consultancy fees	1,675	1,440
Administration recharge (contractor)	17,646	19,596
Other legal and professional	61,935	22,798
	<u>88,774</u>	<u>49,672</u>
	<u>365,122</u>	<u>293,233</u>
Total	<u>30,537</u>	<u>(41,826)</u>









IGA final accounts 31 December 2023 v5

Final Audit Report

2024-09-27

Created:	2024-09-27
By:	Lisa Davis (compliance@numerii.co.uk)
Status:	Signed
Transaction ID:	CBJCHBCAABAALfyENLbrB9kC9KF5UOAntK3MIC1CJI7C

"IGA final accounts 31 December 2023 v5" History

-  Document created by Lisa Davis (compliance@numerii.co.uk)
2024-09-27 - 12:40:04 PM GMT
-  Document emailed to Biljana Jovanovic (biljana@gaucheralliance.org) for signature
2024-09-27 - 12:40:10 PM GMT
-  Email viewed by Biljana Jovanovic (biljana@gaucheralliance.org)
2024-09-27 - 12:42:03 PM GMT
-  Document e-signed by Biljana Jovanovic (biljana@gaucheralliance.org)
Signature Date: 2024-09-27 - 12:43:23 PM GMT - Time Source: server
-  Document emailed to Neil Heyes (nmh@rayneressex.com) for signature
2024-09-27 - 12:43:24 PM GMT
-  Email viewed by Neil Heyes (nmh@rayneressex.com)
2024-09-27 - 3:14:30 PM GMT
-  Document e-signed by Neil Heyes (nmh@rayneressex.com)
Signature Date: 2024-09-27 - 3:15:50 PM GMT - Time Source: server
-  Agreement completed.
2024-09-27 - 3:15:50 PM GMT



Adobe Acrobat Sign