INTERNATIONAL GAUCHER ALLIANCE

England & Wales · Charity number 1192011

Details

Status	Registered
Legal form	Charitable company
Company number	06653373
Registered	2020-10-27
Register	View on the Charity Commission register

Contact

Address	86-90 Paul Street London EC2A 4NE
Phone	01453796402
Email	admin@gaucheralliance.org
Website	www.gaucheralliance.org

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Activities

Objects: THE OBJECTS FOR WHICH THE COMPANY IS ESTABLISHED ARE THE RELIEF OF SICKNESS AND THE PRESERVATION OF HEALTH AMONGST PEOPLE SUFFERING FROM THE RARE GENETICALLY INHERITED CONDITION OF GAUCHER DISEASE WHEREVER THEY ARE IN THE WORLD ("OBJECTS") AND IN DOING SO THE COMPANY WILL: 1.1 COLLECT INFORMATION ON THE LATEST DEVELOPMENTS IN THE UNDERSTANDING, MANAGEMENT AND TREATMENT OF GAUCHER DISEASE AND TO DISSEMINATE SUCH INFORMATION TO ALL PARTIES WHO HAVE AN INTEREST IN GAUCHER DISEASE AND OTHER SIMILAR DISORDERS;1.2 PROVIDE INFORMATION SUPPORT GUIDANCE AND ENCOURAGEMENT TO GROUPS OF INDIVIDUALS REPRESENTING GAUCHER PATIENTS GLOBALLY;1.3 REPRESENT THE INTERESTS OF GAUCHER PATIENTS TO EUROPEAN AND INTERNATIONAL ORGANISATIONS AND BODIES AND TO ENSURE THAT THE VOICE OF THE GAUCHER PATIENT IS HEARD AT ALL TIMES.1.4 ENCOURAGE AND PROMOTE SCIENTIFIC AND MEDICAL RESEARCH INTO GAUCHER DISEASE AND IMPROVED THERAPEUTIC APPROACHES AND TO SEEK TO ENSURE ALL SUCH RESEARCH RECOGNISES THE CENTRALITY OF THE GAUCHER PATIENT.1.5 WORK WITH THE MEDICAL AND SCIENTIFIC COMMUNITY TO DEFINE PRIORITIES IN THE UNDERSTANDING OF GAUCHER DISEASE ITS MANAGEMENT AND TREATMENT.1.6 WORK WITH, FACILITATE, SUPPORT AND ENCOURAGE THE ACTIVITIES OF THE EUROPEAN WORKING GROUP ON GAUCHER DISEASE (EWGGD) AND OTHER ORGANISATIONS OR WORKING GROUPS WITH SIMILAR OBJECTIVES.1.7 BE A FORUM TO ADDRESS ETHICAL ISSUES ARISING FROM THE STUDY OF GAUCHER DISEASE 1.8 ENSURE THAT APPROPRIATE TREATMENT IS AVAILABLE TO ALL PATIENTS WITH GAUCHER DISEASE WHO REQUIRE TREATMENT REGARDLESS OF RACE, CREED, COLOUR ETHNIC ORIGIN OR NATIONAL OR RELIGIOUS BACKGROUND; AND1.9 CARRY OUT ANY OTHER ACTIVITIES THAT ADVANCE THE OBJECTS.

Activities: The IGA is an international umbrella group representing the interest of Gaucher patients and those of non-for-profit Gaucher patient groups as well as rare disease groups throughout the world.

Classification

- **How:** Provides Advocacy/advice/information, Acts As An Umbrella Or Resource Body
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives
- **Who:** Other Charities Or Voluntary Bodies, Other Defined Groups, The General Public/mankind

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Geography

- Albania
- Argentina
- Australia
- Austria
- Belgium
- Bosnia And Herzegovina
- Botswana
- Brazil
- Bulgaria
- Canada
- China
- Colombia
- Croatia
- Czech Republic
- Denmark
- Estonia
- Finland
- France
- Germany
- Greece
- India
- Israel
- Italy
- Japan
- Jordan
- Kazakhstan
- Latvia
- Lithuania
- Luxembourg
- Macedonia
- Mexico
- Moldova
- Mongolia
- Morocco

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- Mozambique
- Netherlands
- New Zealand
- Norway
- Pakistan
- Paraguay
- Poland
- Portugal
- Romania
- Russia
- Slovakia
- Slovenia
- South Africa
- Spain
- Sweden
- Switzerland
- Thailand
- Tunisia
- Turkey
- Ukraine
- United States
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£335,442	£383,772	-	-
2023-12-31	£395,659	£365,122	-	-
2022-12-31	£251,407	£293,233	-	-
2021-12-31	£293,567	£267,491	-	-

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Trustees

Name	Role	Appointed
Aimee-Kate Bosch		2022-05-09
Andre Balzekiene		2024-11-08
Aviva Rosenberg		2019-10-25
Christine White		2024-11-08
Diana Paulina Pena Aragon		2022-01-19
Irena Znidar		2010-10-05
Patricia Lucki Zifonsky		2024-11-08
Raul Chertkoff		2024-11-08
Suyog Sathe		2020-05-23

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INTERNATIONAL GAUCHER ALLIANCE

England & Wales - Charity number 1192011

Accounts

Registered number
06653373

International Gaucher Alliance Limited

Report and Accounts

31 December 2024

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
Suyog Sathe
Francisco Carreiro
Aimeé-Kate Bosch
Diana Paulina Peña Aragón
Raul Chertkoff
Andre Balzekiene
Christine White
Patricia Lucki Zifonsky

Secretary
Patricia Lucki Zifonsky

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 2024, 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 (resigned 8 November 2024)
Kristiyan Dimitrov |(resigned 15 July 2025)
Suyog Sathe
Francisco Carreiro
Aimeé-Kate Bosch
Sara Khan (resigned 8 November 2024)
Diana Paulina Peña Aragón
Raul Chertkoff (appointed 8 November 2024)
Andre Balzekiene (appointed 8 November 2024)
Christine White (appointed 8 November 2024)
Patricia Lucki Zifonsky (appointed 8 November 2024)

All trustees are also members of the charity.

International Gaucher Alliance Limited
Company limited by guarantee registered number: 06653373
Registered charity number: 1192011
Trustees' Annual Report

Objects and activities of the charity

The purposes of the charity

The International Gaucher Alliance (IGA) is an international umbrella group representing the interests of Gaucher patients and not-for-profit patient groups, as well as wider rare disease organisations. Our vision is for a world where all Gaucher patients have access to the treatment and care they need, with the possibility of a cure.

Our mission is to be the global voice for Gaucher patients and their families: empowering members, advocating for research that addresses unmet needs, and taking collective action to improve early diagnosis, treatment, and care. Our strategic imperatives remain focused on improving access, influencing the research agenda, and strengthening the capacity and sustainability of member organisations.

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

In 2024, the IGA continued to strengthen its position as the trusted global voice for the Gaucher community. With patients at the heart of everything we do, our work combined humanitarian support, advocacy, research, and education to ensure that the lived experiences of those affected by Gaucher disease shape international policy, practice, and innovation.

Humanitarian Aid and Patient Support

Requests for help once again underscored the inequities that continue to affect Gaucher patients worldwide. Families and clinicians from 18 countries approached the IGA for support, representing a total of 23 patients. Through charitable access programmes, five patients were approved for treatment, though tragically two patients passed away during the year, one in Malawi and one in India. Several cases remained unresolved by year end, particularly in regions facing political instability or systemic barriers to healthcare.

The IGA worked closely with its partners to respond to these challenges. In Sudan, conflict disrupted supply chains and forced families to flee, resulting in treatment interruptions and patient deaths. The IGA collaborated with Sanofi to relocate two siblings to Saudi Arabia, where they could access care. In Gaza, despite comprehensive efforts with partners including Shaare Zedek Hospital, Sanofi, and Direct Relief, the escalation of conflict meant treatment could not be delivered, though communication with families has been maintained. These cases illustrate both the fragility of access and the vital importance of international solidarity.

Focus on Africa

Africa remained a priority region in 2024. Patients in Ghana, Kenya, Malawi, Sudan, and Zambia received support through humanitarian pathways, while new collaborations were established to address the wider challenges of diagnosis and sustainable care. Working with partners such as Direct Relief, Project HOPE, Takeda, and Sanofi, the IGA advanced plans for an Africa diagnostic roadmap and began laying the groundwork for a regional registry. Building local capacity by partnering with physicians and patient advocates has been central to this effort, ensuring that improvements are durable and context-specific.

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

International Gaucher Alliance Limited
Company limited by guarantee registered number: 06653373
Registered charity number: 1192011
Trustees' Annual Report

The main achievements and performance of the charity during the year

Education and communication continued to be central pillars of our work. The Gaucher Voices podcast grew significantly, offering patients and caregivers a space to share their experiences and reach new audiences. We also hosted a global series of gene therapy webinars, ensuring that patients everywhere had access to clear, accurate, and timely information about clinical trials, with sessions adapted to multiple time zones and translated into several languages.

Our commitment to improving diagnosis was furthered through initiatives such as the Red Flags programme and GD3 registry studies, which deepened understanding of disease prevalence and clinical presentation. The IGA also entered into a pioneering collaboration with SymetryML and GAUCHERITE to explore the use of artificial intelligence in supporting diagnosis and monitoring in low- and middle-income countries.

Collaboration across the rare disease community strengthened through the Global LSD Collaborative, a network of eight international patient organisations working together to address common challenges such as equitable access to treatment and regulatory barriers. In parallel, the IGA launched the Anne-Grethe Lauridsen Memorial Award in honour of a long-standing colleague and advocate, celebrating the contributions of young people to the Gaucher community, with the first award to be presented in 2025.

Research and Publications

The GARDIAN registry continued to expand its role as a cornerstone of global Gaucher research. Data from 26 patients and caregivers were presented at the International Working Group on Gaucher Disease (IWGGD) meeting in Serbia, offering valuable insights into the lived experience of those with neuronopathic Gaucher disease (nGD). A comprehensive Lessons Learnt exercise was carried out during the year, gathering feedback from patients, families, clinicians, and industry partners to refine the platform and enhance engagement.

Further dissemination of research included poster presentations at the European Conference on Rare Diseases (ECRD) and IWGGD, and contributions to peer-reviewed publications exploring transitions in care, gene therapy, and the role of real-world evidence in rare disease research. The IGA's leadership in this space reinforced its reputation as a reliable and respected source of patient-led insight.

Representation at Global Meetings

2024 was marked by a strong presence at international conferences and forums. At the WORLD Symposium in San Diego, the IGA highlighted the persistence of global inequities in Gaucher care, while at the ECRD in Brussels and the IWGGD in Serbia, we presented new data from the GARDIAN registry. Beyond Gaucher-specific events, the IGA contributed to wider rare disease dialogues, including the ASMD Policy Meeting in Milan, the Brains4Brains symposium in Cambridge, and the Aspire Biosciences workshop in London. These engagements underscored the IGA's role as both a disease-specific advocate and a broader thought leader in rare disease policy and research.

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

October 2024 marked another successful celebration of International Gaucher Day (IGD). This year's theme focused on timely diagnosis and equitable access, sharing powerful stories from patients and physicians across different regions of the world. Campaigns were translated into multiple languages and disseminated across digital platforms, ensuring global reach and engagement. IGD continues to be a defining moment for our community each year, uniting voices worldwide in advocacy and solidarity.

Biennial Members' Meeting – Lisbon

In November, the IGA gathered members, Gaucher Leaders, volunteers, clinicians, and partners in Lisbon for our biennial members' meeting, coinciding with the organisation's 30th anniversary. The meeting provided a forum for reflection on three decades of progress, while also launching new initiatives, including preparations for the Youth Council. It was a celebration of community resilience and a reaffirmation of our shared vision for the years ahead.

Volunteer Contribution

The achievements of 2024 would not have been possible without the dedication of our volunteers. From translation and outreach to the delivery of webinars and humanitarian case management, volunteers extended the reach and impact of the IGA's work across continents. Their generosity of time, skill, and commitment remains one of our greatest strengths.

Looking Ahead: 2025 Priorities

As we look to 2025, the IGA is committed to deepening and expanding its impact. The Gaucher Voices podcast will continue to grow, focusing on the experiences of patients living in different parts of the world. A comprehensive information repository on neuronopathic Gaucher disease will be launched, alongside the establishment of a global research network and a community advisory board dedicated to nGD.

Our focus on global equity will remain paramount. We will build on 2024's work in Africa, strengthening collaborations with local and international partners to expand diagnostic services, secure charitable access to treatment, and establish sustainable care networks. In parallel, we will continue work on a position paper on newborn screening, providing advocates and policymakers with a vital tool to argue for earlier detection.

Finally, the IGA will launch its Youth Council, embedding the voices of young people into our structure and decision-making. This initiative will ensure that the next generation of patient leaders is empowered to shape the future of advocacy and support for Gaucher patients. Together, these priorities reflect our ongoing mission to be the global voice of Gaucher patients and to advance a world of equity, access, and hope.

Structure, governance and management of the charity

The methods used to recruit and appoint new charity trustees

The IGA is governed by a Board of Trustees, elected biennially in accordance with the Articles of Association. Trustees are recruited from member organisations, ensuring global representation and lived experience. The Board undertakes annual assessments and maintains a document on trustee competencies to ensure effective governance.

Financial review

The charity's financial position at the end of the year ended 31 December 2024

The financial position of the charity at 31 December 2024 and comparatives for the prior period, as more fully detailed in the accounts, can be summarised as follows:-

	2024 £	2023 £
Net (expense)/income	(48,330)	30,537
Unrestricted funds available for the general purposes of the charity	169,063	201,251
Restricted funds	-	16,142
Total funds	169,063	217,393

Financial review of the position at the reporting date, 31 December 2024

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 £104,358.

During the year the charity's reserves decreased by £48,330 and held reserves of £169,063 at 31 December 2024. 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.

International Gaucher Alliance Limited
Company limited by guarantee registered number: 06653373
Registered charity number: 1192011
Trustees' Annual Report

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.

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 29 September 2025.

Aimeé-Kate Bosch
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 2024

I report to the Trustees on my examination of the financial statements of the charitable company on pages 11 to 22 for the year ended 31 December 2024 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 14.

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

As described on page 7, 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.

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 2024

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.

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

29 September 2025

International Gaucher Alliance Limited
Statement of Financial Activities Including Income and Expenditure Accounts
for the year ended 31 December 2024

	Notes	Unrestricted Funds 2024 £	Restricted Funds 2024 £	Total Funds 2024 £	Total Funds 2023 £
Income					
Donations and legacies		118,846	182,479	301,325	365,855
Charitable activities		34,117	-	34,117	29,804
Total income		152,963	182,479	335,442	395,659
Expenditure					
Charitable activities		208,716	175,056	383,772	365,122
Total expenditure		208,716	175,056	383,772	365,122
Net income/(expenditure) for the year and Movement in total funds for the year	2	(55,753)	7,423	(48,330)	30,537
Other recognised gains/ (losses)					
Total funds at 1 January		201,251	16,142	217,393	186,856
Transfers in /(out)		23,565	(23,565)	-	-
Total funds at 31 December	14	169,063	-	169,063	217,393

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 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		231,396	164,263	395,659	251,407
Expenditure					
Charitable activities		205,216	159,906	365,122	293,233
Total expenditure		205,216	159,906	365,122	293,233
Net income/(expenditure) for the year and Movement in total funds for the year	2	26,180	4,357	30,537	(41,826)
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	201,251	16,142	217,393	186,856

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 2024

	Notes		2024		2023
			£		£
Fixed assets					
Intangible assets	8		6,980		12,216
Tangible assets	9		1,142		2,261
Investments	10		100		100
			8,222		14,577
Current assets					
Debtors	12	51,382		35,147	
Cash at bank and in hand		119,799		204,244	
		171,181		239,391	
Creditors: amounts falling due within one year	13	(10,340)		(36,575)	
Net current assets			160,841		202,816
Total assets less current liabilities			169,063		217,393
Net assets			169,063		217,393
Total funds of the charity					
Restricted Funds		14	-		16,142
Unrestricted Funds		14	169,063		201,251
Total charity funds			169,063		217,393

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.

Aimeé-Kate Bosch
Trustee
Approved by the board on 29 September 2025

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2024

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 2025, 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 uncertainites 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 tht 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

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

	2024	2023
	£	£
This is stated after charging:		
Depreciation and amortisation of owned fixed assets	1,119	1,141
Trustees' and volunteers' remuneration	44,638	53,431
Independent Examiner's remuneration	3,450	3,000
Contributions to pension fund for employees	1,832	1,700

3 Donated goods, services and facilities

	2024	2023
	Unrestricted funds	Unrestricted funds
	£	£
Included in donations and legacies:		
Donated goods and services	44,638	53,431
	44,638	53,431

Directors and volunteers have made donations of their services to the company during the year to the value of £44,638 (2023: £53,431). Administration expenses include directors' and volunteers' fees for services donated to the company of £44,638 (2023: £53,431) and donations and legacies include donations by the directors and volunteers of £44,638 (2023: £53,431) in respect of their services to the company.

4 Staff costs

	2024	2023
	£	£
Wages and salaries excluding trustees and key management personnel	46,011	40,197
Social security costs	8,026	11,769
Other pension costs	1,832	1,700
Salaries and benefits paid to key management personnel	77,496	71,498
Directors' and volunteers' fees for services donated to the charity	44,638	53,431
	178,003	178,595

The cost to the charity of senior management personnel remuneration included the following:	2024	2023
	£	£
Gross wages and Employer's National Insurance contributions	83,312	80,110
Contributions for the provision of money purchase pension	1,321	1,321

	2024	2023
Numbers of such staff to whom benefits are accruing :	Number	Number
Under money purchase pension schemes	1	1

5 Employees

	2024 Number	2023 Number
Average number of full time staff	1	1
Average number of part time staff	2	2
Average total number of staff	3	3

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

	2024 Number	2023 Number
£70,001 to £80,000	1	1

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

	2024 £	2023 £
Remuneration payable to trustees or connected persons		
Directors' and volunteers' fees for services donated to the charity	44,638	53,431

Directors and volunteers have made donations of their services to the company during the year to the value of £44,638 (2023: £53,431). Administration expenses include directors' and volunteers' fees for services donated to the company of £44,638 (2023: £53,431) and donations and legacies include donations by the directors and volunteers of £44,638 (2023: £53,431) in respect of their services to the company.

7 Deferred income - Restricted funds

	2024 Received deferred in year £	2024 Deferred at year end £	2023 Received deferred in year £	2023 Deferred at year end £
Takeda Transitions grant	-	-	-	5,000
Sanofi Outstanding research priorities	-	-	11,000	11,000
	-	-	11,000	16,000

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 2024	24,900
At 31 December 2024	24,900
Amortisation	
At 1 January 2024	12,684
Provided during the year	5,236
At 31 December 2024	17,920
Net book value	
At 31 December 2024	6,980
At 31 December 2023	12,216

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

9 Tangible fixed assets

	Plant and machinery etc £	Total £
Cost		
At 1 January 2024	10,977	10,977
At 31 December 2024	10,977	10,977
Depreciation		
At 1 January 2024	8,716	8,716
Charge for the year	1,119	1,119
At 31 December 2024	9,835	9,835
Net book value		
At 31 December 2024	1,142	1,142
At 31 December 2023	2,261	2,261

10 Investments

	Investments in subsidiary undertakings £	Total £
Cost		
At 1 January 2024	100	100
At 31 December 2024	100	100
Historical cost		
At 1 January 2024	100	
At 31 December 2024	100	

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.

A summary of the unaudited financial statements of the subsidiary is :	2024 £	2023 £
Assets and Funds		
Aggregate amounts of assets /(liabilities)	22,629	3,246
Aggregate amount of funds	22,629	3,246
Profit and Loss		
Turnover	80,788	57,023
Other income	139	1,035
Expenses	(61,544)	(58,670)
Net profit /(loss) for the year after tax	19,383	(612)

The net profit/(loss) of the subsidiary is stated after including intergroup company expenditure of £22,756 (2023 - £28,498).

12 Debtors

	2024 £	2023 £
Amounts owed by group undertakings and undertakings in which the company has a participating interest	6,624	29,894
Other debtors	44,758	5,253
	51,382	35,147

13 Creditors: amounts falling due within one year	2024 £	2023 £
Trade creditors	629	13,231
Deferred Income - Restricted funds	-	16,000
Taxation and social security costs	3,171	3,364
Other creditors	6,540	3,980
	10,340	36,575

14 Movement in Funds	As at 1 January 2024 £	Income £	Expenditure £	Transfers in/(out) £	As at 31 December 2024 £
Restricted funds					
Gene Therapy	60	-	-	(60)	-
Sanofi work programme 2023	10,440	11,000	(6,215)	(15,225)	-
Pfizer funding 2023-24	4,445	-	(4,980)	535	-
Takeda Educating doctors	1,197	-	(1,197)	-	-
Takeda transitions	-	5,000	(4,200)	(800)	-
ISU sponsorship BGM	-	3,979	(3,963)	(16)	-
Eli Lilly work programme 2024	-	15,000	(15,000)	-	-
Eli Lilly BGM sponsorship	-	10,000	(10,016)	16	-
Eli Lilly Educating and Empowering	-	5,000	(5,000)	-	-
Sanofi work programme 2024	-	95,000	(86,984)	(8,016)	-
Pfizer funding 2024	-	37,500	(37,501)	1	-
Total restricted funds	16,142	182,479	(175,056)	(23,565)	-
General fund	201,251	152,963	(208,716)	23,565	169,063
Total unrestricted funds	201,251	152,963	(208,716)	23,565	169,063
Total restricted and unrestricted funds	217,393	335,442	(383,772)	-	169,063

Movement in Funds	As at 1 January 2023 £	Income £	Expenditure £	Transfers in/(out) £	As at 31 December 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	8,569	164,263	(159,906)	3,216	16,142
					-
General fund	178,287	231,396	(205,216)	(3,216)	201,251
Total unrestricted funds	178,287	231,396	(205,216)	(3,216)	201,251
Total restricted and unrestricted funds	186,856	395,659	(365,122)	-	217,393

During the year ended 31 December 2024 transfers were made from unrestricted funds to cover deficits on Pfizer 2023-24 projects and Eli Lilly BGM sponsorship. A transfer was made from the Takeda Transitions fund to unrestricted funds to match costs recognised in unrestricted funds during 2024 related to this funding now paid. Transfers were made from the Sanofi work programme 2023 and 2024 funds to unrestricted funds following agreement with Sanofi to reallocate funds not spent on other IGA work programme projects without restriction. During the year the small brought forward balance on the Gene Therapy restricted fund was re-designated to the general fund as approved by the Trustees.

14 Movement in Funds (continued)

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.

At 31 December 2024 the net assets of £153,356 were analysed between unrestricted funds of £153,356 and restricted funds of £nil.

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.
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 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 2023	Funds held for funds received from Avrobio for funding 2023 work programme.
Eli Lilly work programme 2023	Funds held for funds received from Eli Lilly for funding 2023 work programme.
Takeda Educating doctors	Funds held for funds received from Takeda for Education doctors work.
Takeda transitions	Funds held for funds received from Takeda for Transitions prject.
ISU sponsorship BGM	Funds received from ISUABXIS CO., LTD for sponsorship of the 2024 Biennial General Meeting.
Eli Lilly work programme 2024	Funds held for funds received from Eli Lilly for funding 2024 work programme.
Eli Lilly BGM sponsorship	Funds received from Eli Lilly for sponsorship of the 2024 Biennial General Meeting.
Eli Lilly Educating and Empowering	Funds received from Eli Lilly for sponsorship of Educating and Empowering 2024 Global Advocates conference.
Sanofi work programme 2024	Funds held for funds received from Sanofi for funding 2024 work programme.

15 Related party transactions

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

	2024	2023
	£	£
Administration fees	22,756	28,498

Included in other debtors is £6,624 due from International Gardian Limited (2023:£29,894). Included in other creditors is £601 (2023: £601) owed to The Gauchers Association, Jeremy Manuel, the Honorary President of the Company is a director of The Gauchers Association Limited.

During the year staff costs included £nil (2023:£1,243) relating to 50% of time spent on work done for its subsidiary International Gardian Limited ("IGL"). Administration fees included £nil relating to contractor costs incurred for IGL (2023: £2,367). 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 2024
This schedule does not form part of the statutory accounts

	Total funds 2024 £	Total funds 2023 £
Donations		
Revenue grants and donations from non public bodies	256,687	312,424
Donated goods and services	44,638	53,431
Charitable activities - consultancy fees receivable	34,117	29,804
	335,442	395,659
Expenditure on charitable activities- Grant funding of activities		
Grants made/charitable payments	-	6,658
	-	6,658
Expenditure on charitable activities - Direct spending		
Employee costs:		
Wages and salaries	123,507	111,695
Pensions	1,832	1,700
Employer's NI	8,026	11,769
Travel and subsistence	63,032	53,537
Other direct costs:		
Research	-	2,244
Conferences and Seminars	55,453	-
	251,850	180,945
Expenditure on charitable activities - Support costs		
Employee costs:		
Employee costs:		
Staff training and welfare	1,736	37
Directors' and volunteers' fees	44,638	53,431
Entertaining	258	1,643
	46,632	55,111
Premises costs:		
Rent	1,675	1,440
	1,675	1,440
General administrative expenses:		
Telephone and internet	835	437
Postage	32	14
Stationery and printing	1,942	6,519
Subscriptions	2,910	4,236
Bank charges	925	991
Insurance	1,700	1,200
Equipment expensed	40	1,371
Software	4,401	4,142
Repairs and maintenance	116	114
Depreciation	1,119	1,141
Amortisation of intangible fixed assets	5,235	5,235
Sundry	688	-
Foreign exchange gains and losses	165	6,794
	20,108	32,194

International Gaucher Alliance Limited
Detailed Income and Expenditure
for the year ended 31 December 2024
This schedule does not form part of the statutory accounts

	Total funds 2024 £	Total funds 2023 £
Legal and professional costs:		
Accountancy fees (including Examiner's fee)	9,592	7,518
Consultancy fees	1,685	1,675
Administration recharge (contractor)	12,824	17,646
Advertising and PR	10,560	-
Other legal and professional	28,846	61,935
	63,507	88,774
	383,772	365,122
Total	(48,330)	30,537

INTERNATIONAL GAUCHER ALLIANCE

England & Wales - Charity number 1192011

Accounts

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
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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

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 Aleksovska 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.

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.

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 CEPCAL, "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.

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 improver patients' lives by accelerating rare disease diagnosis and enabling faster, more targeted, access to treatments and management.

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.'
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•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.

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 trails 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.

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.

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), Zubyda 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.

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.

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		231,396	164,263	395,659	251,407
Expenditure					
Charitable activities		205,216	159,906	365,122	293,233
Total expenditure		205,216	159,906	365,122	293,233
Net income/(expenditure) for the year and Movement in total funds for the year	2	26,180	4,357	30,537	(41,826)
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	201,251	16,142	217,393	186,856

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 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		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
			14,577		19,392
Current assets					
Debtors	12	35,147		59,533	
Cash at bank and in hand		204,244		150,731	
		239,391		210,264	
Creditors: amounts falling due within one year	13	(36,575)		(42,800)	
Net current assets			202,816		167,464
Total assets less current liabilities			217,393		186,856
Net assets			217,393		186,856
Total funds of the charity					
Restricted Funds	14		16,142		8,569
Unrestricted Funds	14		201,251		178,287
Total charity funds			217,393		186,856

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 uncertainites 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 tht 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

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

	2023	2022
Numbers of such staff to whom benefits are accruing :	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

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.

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	10,977	10,977
Depreciation		
At 1 January 2023	7,575	7,575
Charge for the year	1,141	1,141
At 31 December 2023	8,716	8,716
Net book value		
At 31 December 2023	2,261	2,261
At 31 December 2022	1,841	1,841

10 Investments

	Investments in subsidiary undertakings £	Total £
Cost		
At 1 January 2023	100	100
At 31 December 2023	100	100
Historical cost		
At 1 January 2023	100	
At 31 December 2023	100	

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.

A summary of the unaudited financial statements of the subsidiary is :	2023 £	2022 £
Assets and Funds		
Aggregate amounts of assets /(liabilities)	3,246	3,858
Aggregate amount of funds	3,246	3,858
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	(612)	10,846

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
	35,147	59,533

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
	36,575	42,800

14 Movement in Funds	As at 1 January 2023 £	Income £	Expenditure £	Transfers in/(out) £	As at 31 December 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	8,569	164,263	(159,906)	3,216	16,142
General fund	178,287	231,396	(205,216)	(3,216)	201,251
Total unrestricted funds	178,287	231,396	(205,216)	(3,216)	201,251
Total restricted and unrestricted funds	186,856	395,659	(365,122)	-	217,393

Movement in Funds	As at 1 January 2022 £	Income £	Expenditure £	Transfers in/(out) £	As at 31 December 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	5,783	122,825	(135,510)	15,471	8,569
General fund	222,899	128,582	(157,723)	(15,471)	178,287
Total unrestricted funds	222,899	128,582	(157,723)	(15,471)	178,287
Total restricted and unrestricted funds	228,682	251,407	(293,233)	-	186,856

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.

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
	395,659	251,407
Expenditure on charitable activities- Grant funding of activities		
Grants made/charitable payments	6,658	-
	6,658	-
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
	180,945	175,789
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
	55,111	48,707
Premises costs:		
Rent	1,440	3,457
	1,440	3,457
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)
	32,194	15,608

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
	88,774	49,672
	365,122	293,233
Total	30,537	(41,826)

IGA final accounts 31 December 2023 v5

Final Audit Report 2024-09-27

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INTERNATIONAL GAUCHER ALLIANCE

England & Wales - Charity number 1192011

Accounts

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

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.

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

•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.

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.

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:

» 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

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)	(41,826)	26,076
Unrestricted funds available for the general purposes of the charity	178,287	222,899
Restricted funds	8,569	5,783
Total funds	186,856	228,682

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

International Gaucher Alliance Limited
Company limited by guarantee registered number: 06653373
Registered charity number: 1192011
Trustees' Annual Report

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.

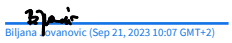
The Trustees are also responsible for the contents of the Trustees' report, and the statutory responsibility of the Independent Examiner in relation to the Trustees' report is limited to examining the report and ensuring that , on the face of the report, there are no material inconsistencies with the 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
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		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
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	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
Statement of Financial Activities Including Income and Expenditure Accounts
for the year ended 31 December 2021

	Notes	Unrestricted Funds 2021 £	Restricted Funds 2021 £	Total Funds 2021 £	Total Funds 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

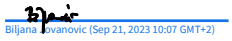
	Notes		2022		2021
			£		£
Fixed assets					
Intangible assets	8		17,451		18,408
Tangible assets	9		1,841		3,789
Investments	10		100		100
			19,392		22,297
Current assets					
Debtors	12	59,533		22,864	
Cash at bank and in hand		150,731		220,505	
		210,264		243,369	
Creditors: amounts falling due within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

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
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 uncertainites 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 tht 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

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

	2022	2021
Numbers of such staff to whom benefits are accruing :	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

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	1	1

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	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.

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		
	31,000	28,848	11,279	11,279

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	24,900
Amortisation	
At 1 January 2022	2,832
Provided during the year	4,617
At 31 December 2022	7,449
Net book value	
At 31 December 2022	17,451
At 31 December 2021	18,408

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

9 Tangible fixed assets

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

10 Investments

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

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.

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

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	-
	59,533	22,864

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
	42,800	36,984

14 Movement in Funds	As at 1 January 2022 £	Income £	Expenditure £	Transfers in/(out) £	As at 31 December 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	5,783	122,825	(135,510)	15,471	8,569
General fund	222,899	128,582	(157,723)	(15,471)	178,287
Total unrestricted funds	222,899	128,582	(157,723)	(15,471)	178,287
Total restricted and unrestricted funds	228,682	251,407	(293,233)	-	186,856

Movement in Funds	As at 1 January 2021 £	Income £	Expenditure £	Transfers in/(out) £	As at 31 December 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	-	161,661	(165,591)	9,713	5,783
General fund	202,606	131,906	(101,900)	(9,713)	222,899
Total unrestricted funds	202,606	131,906	(101,900)	(9,713)	222,899
Total restricted and unrestricted funds	202,606	293,567	(267,491)	-	228,682

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.

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
	251,407	293,567
Expenditure on charitable activities- Grant funding of activities		
Grants made/charitable payments	-	71,979
	-	71,979
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	-
	175,789	111,814
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
	48,707	34,628
Premises costs:		
Rent	3,457	4,560
	3,457	4,560
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
	15,608	20,653

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
	49,672	23,857
	293,233	267,491
Total	(41,826)	26,076

INTERNATIONAL GAUCHER ALLIANCE

England & Wales - Charity number 1192011

Accounts

Company Registration Number - 06653373

The Charity Registration Number is :- 1192011

International Gaucher Alliance Limited

Report and Accounts

31 December 2021

International Gaucher Alliance Limited

Report and accounts for the year ended 31 December 2021

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International Gaucher Alliance Limited
Company Information

Directors
Aviva Fisher Rosenberg
Vesna Aleksovksa (resigned 3 December 2021)
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)
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
8 Silver Street
Dursley
Gloucestershire
GL11 4ND

Registered number
06653373

The Charity Registration Number
1192011

International Gaucher Alliance Limited

Company Registration Number - 06653373

Trustees' Annual Report for the year ended 31 December 2021

The Trustees present their Report and Accounts for the year ended 31 December 2021, which also comprises the Directors' Report required by the Companies Act 2006.

Reference and administrative details

The charity name.

The legal name of the charity is: International Gaucher Alliance Limited.

The charity is also known by its operating name, IGA.

The charity's areas operation and UK charitable registration.

The charity is registered in England & Wales with the Charity Commission in England & Wales (CCEW) with charity number 1192011.

The charity does not operate in any overseas jurisdictions.

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:-

8 Silver Street

Dursley, Gloucestershire

GL11 4ND

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

The Trustees in office on the date the report was approved were:-

Aviva Fisher Rosenberg
Vesna Aleksovksa (resigned 3 December 2021)
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)
Aimeé-Kate Bosch (appointed 9 May 2022)
Sara Khan (appointed 19 January 2022)
Diana Paulina Pena Aragon (appointed 19 January 2022)

All the trustees are also members of the charity.

International Gaucher Alliance Limited

Company Registration Number - 06653373

Trustees' Annual Report for the year ended 31 December 2021

Objects and activities of the charity

The purposes of the charity.

The 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

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 growing and at the end of 2021 the IGA had 57 member organisations, and this number will increase in the next years as the IGA grow our footprint through the Regional Manager programme to ensure no patient is left behind. Together the CEO Tanya Collin-Histed; our staff team Jo McPherson (resigned on 26th April 2021), Angel Jones, Wendy Horrobin (resigned on 4th November 2021), Harry Albright (appointed 19th July 2021) and Vesna Aleksovska (appointed 1st December 2021) work with the IGA board towards achieving our mission – a better quality of life of patients with Gaucher disease. The IGA have and will continue to achieve a better world for Gaucher patients and their families around the globe.

The IGA is a globally recognised well respected organisation and the CEO spends a lot of her time communicating/collaborating with stakeholders to ensure that the patient voice is heard through meetings, presenting at conferences, and securing a place on projects that involve the community. More and more the IGA works as part of collaborations to ensure effective uses of resources, to avoid duplication and to get things done faster.

The CEO's role, with the support of the staff team is to serve the global patient community, to ensure no one ever feels alone, to underpin the work of the IGA, keep the IGA on track, ensure everything is delivered on time to its highest quality and to ensure the IGA have a global voice and remain a well-respected and trusted organisation.

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

International Gaucher Alliance Limited

Company Registration Number - 06653373

Trustees' Annual Report for the year ended 31 December 2021

The main achievements and performance of the charity during the year.

Chief Executive Officer (CEO Report)

Over the past few years, we have seen our membership increase with Australia and New Zealand, Mongolia, Brazil, Columbia, Tunisia, USA Gaucher Community Alliance, Romania (Asociatia Gaucher România), Portugal, Thailand become members and a few new pending applications. This brings our membership up to 57 representing 55 countries.
In October 2020, the IGA became a formal charity registered in England and Wales and this has enabled us to access additional resources but most importantly be recognised for the important work that the IGA does around the globe.

In 2021 we restructured our office team, following the departure of Joanne McPherson, and two new posts were created, communications and & campaigns officer and projects officer, Harry Albright and Wendy Horrobin were appointed, respectively. Later in 2021, Wendy left and Vesna Aleksovska joined as the new projects officer.

In 2021 the Regional Manager programme underwent a review, a few changes in personnel and the launch of a new programme in Africa. The regional manager programme is another excellent example of how the IGA is successfully working with dedicated volunteers to make a difference.

Throughout the global COVID pandemic we have continued to support our community through a series of educational seminars on an array of topics, all in line with the topics we believe are important to our community. These are all now available for our community and other interested persons to watch through the IGA's website.

During the pandemic access to treatment was very challenging and the value of home therapy was raised, the IGA, together with the IWGGD (formerly EWGDD) held several different online meetings about this topic and the IWGGD issued a statement about the benefits of home therapy. Subsequently this topic is now being taken forward to develop guidelines through the IGA and IWGGD working group.

As a global organisation we have worked hard to improve access to our information and webinars with our new Gaucher disease booklet available in 7 languages, and our global GD2 and GD3 registry GARDIAN in 8, plus webinars with subtitles and or simultaneous translation. It is important to recognise that a lot of our translation work is done by our volunteers, for which we are extremely grateful and proud.

There is a lot of potential research in the pipeline for Gaucher disease, for GD1 and finally for GD2 and GD3. Gene Therapy trials are finally here, and we are mindful that we have a responsibility to ensure that our community has the information they need to make the best decisions for them or the person they care for when making decisions about taking part in a clinical trial. The IGA works with all the industry companies involved in Gaucher research and development, being the patient voice and ensuring that they know and understand the community they are involved with, we sit on advisory boards, help protocol design and advice on patient information. Independently we also raise awareness in our community of the opportunity that are out there for new investigational medicines, through webinars and social media posts.

As such a close community, it is always difficult when we lose someone from within our community. In August 2021 Ghislaine Surreal, one of the original 7 members of the EGA passed away and more recently Yoram Muller, one of our board members and dear friends from Israel passed away.

Humanitarian Aid

For more than 28 years the EGA, now IGA has received requests from patients, caregivers, and clinicians from all over the world requesting access to enzyme replacement therapy (ERT) on a charitable basis at no cost to themselves or their government for the medicine, but support for storage and infusions.

The demand has always outstripped the supply and in the early days there was only one company, Genzyme, now Sanofi that had such a programme, today Takeda (formerly Shire) and Pfizer provide ERT on a charitable basis. It is important to recognise that each programme has limitations.

Sanofi: severe paediatric patients only and in some countries, they have had to cap the application for example India and China.

Takeda: open to adults and children, countries are limited though, and a set annual donation.

Pfizer: no formal programme, use IGA database, limited allocation but open to all countries.

The role of the IGA is to receive requests, communicate with the requester, register the request on the IGA charitable database, advocate on behalf of the patient to the various companies, continue communications and then ad hoc emails if there are challenges like late shipment, customs etc

In terms of resource the IGA spend approximately 5 – 10 hours a month on these cases, it is a very important aspect of the support we give to our community.

In the last two years we have seen application from: Afghanistan, Zambia, Ethiopia, Rwanda, Pakistan, India, Sudan, Tanzania, Morocco, Jordan, Nicaragua, Botswana, Qatar, Ghana, Mozambique, Honduras, and Mongolia

Sadly, many patients' pass away whilst waiting for treatment. We are seeing unprecedented numbers in some countries due to increased clinician education and awareness and improvement in diagnostic facilities, however access to treatment is still limited.

What can we do, what are we doing?

Never giving up and accepting the first answer we are given from the companies; we have a responsibility to the patients to fight for them.

Seeking to increase access for adult patients where they are severe

Seeking possible exceptional circumstances where all avenues have been sought

Expanding the number of countries for the Takeda programme added on patient need i.e., Rwanda

Seeking to get an agreed new allocation per annum from Pfizer

Increasing the number of companies providing programmes as new medicines come online.

GARDIAN

The IGA has set up a subsidiary company called International GARDIAN Limited (IGL). The purpose of this new company is to govern the new GD2 and GD 3 (nGD) global registry, known as 'GARDIAN' that we have developed. GARDIAN stands for Gaucher Registry for the Development, Innovation and Analysis of Neuronopathic Disease.

The GARDIAN registry will initially collect patient reported data from patients and caregivers globally. It will be launched in 8 different languages (Arabic, Chinese, English, Japanese, French, German, and Spanish)

IGA, in collaboration with key opinion leaders, has developed a patient reported outcome (PRO) and observer (caregiver) reported outcome (ObsRO) specifically for GD2 and GD 3 for the registry. IGL intends to validate the two new surveys through the registry and then encourage other stakeholders including industry, to use these tools during clinical trials and for other research purposes to use it. At each stage of developing the surveys for the registry we have worked with patients and caregivers to ensure that the questions are understandable, meaningful, and ensure the meaning of words are the same in different languages. As a result of this we have adjusted the surveys.

Gardian will help us to:

- understand the impact of nGD on patients and caregivers.
- improve clinical management
- improve social care and support services
- drive research into new areas of the condition at impact patients
- design more effective and safer medicines -
- identify possible endpoints of importance to patients that can be used in clinical trials

The collection of patients reported data is only phase one. GARDIAN's vision is to be able to collect clinical data, inputted at clinical sites globally.

GARDIAN has been awarded funds by six pharmaceutical and biotech companies. All funding as at this time are donations and medical grants to the registry development.

To maintain the highest standards in ethics, adherence to regulatory standards, data protection, technical capabilities, and legal, the IGL will, once finalised sign an agreement with Cerner Envisa to operate the day-to-day logistics of the registry. However, the registry and all the data are owned by the IGA.

The new company IGL has its own Board of Directors, who are all volunteers.

IGL has developed and translated a variety of tools to help promote and communicate GARDIAN to the global community.

Members of the IIGA staff team are involved in day-to-day operational activities of GARDIAN and include:

- Tanya Collin-Histed: CEO
- Angel Jones: Finance and administration support
- Harry Albright: Communications and Campaigns
- Vesna Aleksovska: Project Officer in charge of the GARDIAN champion programme

Gaucher Disease type 3 Guidelines Supportive and Symptomatic and GD1 guidelines

Both patients and the clinical community recognize that there are international inequalities in access to treatment, clinical care, and supportive services for patients with Gaucher disease (GD). Factors contributing to this include lack of awareness, clinical experience, and knowledge due to diagnostic challenges and the rarity of the condition, inadequate funding for treatment, and the lack of international guidelines.

Initiated jointly by the International Working Group on Gaucher Disease (IWGGD, previously EWGGD and the International Gaucher Alliance (IGA) six working groups (WGs) were established with the aim of developing clinical guidelines in the following areas:

1. **Laboratory working group:** materials and biomarkers assays
2. Gaucher disease diagnostics
    a. Clinical signs and symptoms leading to suspect GD diagnosis
    b. Laboratory diagnosis
    c. Newborn screening
3. Management and monitoring: Gaucher specific treatment and monitoring
4. Additional morbidities: hematological and other malignancies
5. Supportive care
    a. Supportive and symptomatic care, focusing on adults, children, and women-related issues for type 1 and neuronopathic GD
    b. The transition of care from childhood to adulthood and care coordination

c. Patient reported measurement outcomes
d. Self-management
e. Home therapy

6. Ethics

Membership of the WGs is open to global patient advocates and healthcare professionals and has taken place online.

The board of the IWGGD provided overarching governance and methodology. Each WG defined the critical needs for guideline statements, is developing a review of currently available evidence and building consensus around statements to ensure wide adoption. Each WG will understand the need for guidelines to specific problems in the diagnosis and management of GD through surveying our members and affiliated stakeholders.

The Gaucher Disease type 3 Guidelines Supportive and Symptomatic Care is a subgroup of the supportive care and measuring outcomes WG is made up of clinicians and patient advocates. The WG will seek to identify all the healthcare professionals involved in looking after patients with GD 3 and define the symptoms and how to treat and manage. In addition to symptoms, the WG will also review healthcare training and education, and support for patients and caregivers in relation to mental health, information and advice, social care, and education and employment.

This WG is a new subgroup and is in the early stages of writing the guidelines.

All guidelines will be peer reviewed and presented on the IWGGD website.

Since September 2020, all the working groups and sub-groups meet regularly online. So far, the outcomes are the following:

- Drafts of guidelines,
- Drafts of scientific papers (e.g. self-management),
- Surveys sent out to healthcare professionals and to Gaucher patients/representatives (e.g. transition, newborn screening),
- Webinars/workshops for Gaucher community (e.g. ethics).

Working groups will meet again at IWGGD Leiden 2022, where already their interim results would be presented.

Scientific Advisory Committee (SAC)

The purpose of the SAC is to:

· Provide advice to the IGA Board of Directors on scientific and clinical matters for the purposes of the IGA work and collaborations with stakeholders,

· Consider research/study requests received by the IGA and provide guidance to the Board of Directors,

· Contribute to the on-going development of the IGA for the benefit of the global patient community.

In 2021 the IGA held its first SAC meeting. The current members of the SAC cover Australia, Egypt, Europe, Pakistan, Israel, Mexico and USA.

The first meeting was an introduction meeting and to discuss a range of topics for the SAC to discuss over the next two years, these included:

· Gene Therapy for Gaucher disease: Educating our community

o What questions should we be asking the companies to answer to ensure our community understand the risk/benefits

· Medicines procurement – how to balance patients and payer's needs?

o Non comparable/generics/switching to cheapest treatments,

o Lack of patient/clinician say

· Improved diagnosis facilities but no access to treatment – diagnosis is more than just access to treatment but how can we best support the patient and medical community?

· Licensing treatments in countries where this results in charitable access programmes being withdrawn but payers not willing to pay for treatment – do the companies have an obligation here?

· Clinical trials for GD3 patients but with no neurological benefit – should we be challenging this decision?

· Psychiatric support

· Behavioural abnormalities

· Parkinson's disease – research and support

A survey monkey was set up and each member of the SAC was allocated two votes, the top topics were identified for 2022 as.

· Medicines procurement – how to balance patients and payer's needs?
  - o Non comparable/generics/switching to cheapest treatments,
  - o Lack of patient/clinician say

· Improved diagnosis facilities but no access to treatment – diagnosis is more than just access to treatment but how can we best support the patient and medical community?

In addition, it was agreed to have a chair for one year on a rotation, Dr Hagit Baris Feldman is the SAC's chair for 2022/23.

Our Older Generation

The project group (Paul Gujit, Christine White, Kate Teochari, Fernanda Torquati, Biljana Jovanovic) have worked on the Older generation project throughout 2021. The aim of the project is to have a better understanding of the clinical and non-medical needs of our older Gaucher patient community (60 plus) and to improve their lives. The first step in the project will be to send out a questionnaire (in 2022) on the issues and needs of older Gaucher patients. Also, to support IGA member organisations to undertake a piece of research within their patient community to understand their clinical needs and quality of life issues.

The project group has had several online meetings and decided to involve all parties in the project: patients, member organisations and healthcare professionals. The project team thinks that the help of IGA member organisations would be of great importance.

Educational webinars

The IGA continues to support Gaucher community to increase their capacities through education and providing member organisations, patients, families and healthcare professionals with information about all aspects of Gaucher disease. In the regular communication with members and through survey, topics for webinars in 2021 were identified.

1. Wellness for Gaucher disease, two speakers talked about how to improve the everyday lives of Gaucher patients

- Dr Seema Kanwal, a Naturopathic doctor and speaker, talked about maximising patients' well-being.

- Janez Vajevec, an acting coach talked about body and feelings relaxation and demonstrated relaxation and meditation techniques.

2. Bone disease Bone involvement is one of the most prevalent aspects of GD and a major cause of pain, disability, and reduced quality of life.

- Dr Patrick Deegan, MD, FRCP Edin, gave an introduction to bone disease

- Dr Pramod Mistry, MD, PhD, talked about maintaining bone health through generations of Gaucher disease.

3. Mental health, this webinar was open to young Gaucher patients, as a part of the Go with Gaucher project. Dr Stacey J.Feuer, PsyD, talked with young people about mental health and teach them tips and tools for dealing with different issues.

4. Biomarkers- In lysosomal storage diseases such as Gaucher disease, there are several available biological markers that are useful tools in diagnosis that offer objective information about the situation of the disease and in the follow-up to detect early complications and the stability in the response to treatment.

- Professor Maria Fuller- Biomarkers in Gaucher disease,
- Professor Ari Zimran MD LysoGb1 as a key parameter in the management of patients with GD,

5. Fundraising, Speaker Jonah Halper, MPA. Through the lens of personal relationships, Jonah guided attendees through 21st-century donor cultivation and solicitation, and how it relates to our organisations in a world where donors have so many philanthropic options - and much less attention span.

6. nGD – the spectrum, the experience and the therapies The focus of this webinar was on nGD. Three fantastic speakers gave lectures on the following topics:

- The spectrum of nGD and what we know. - Raphael Schiffmann, MD,
- The experience of Ambroxol in nGD, what do we know – professor Ari Zimran,
- New potential therapies for nGD – professor Derralynn Hughes

7. Gene therapy, a Members-only meeting on the topic of Gene therapy for Gaucher disease. The objective of the webinar was to educate IGA members on the different approaches and discuss some of the challenges of Gene Therapy. The main presentation was given by Professor Atul Mehta, and he was available for Q&A afterwards.

Webinars that are for the wider community are uploaded to the IGA YouTube channel, some of them with Spanish subtitles.

Trustees' Annual Report for the year ended 31 December 2021

In 2021, the IGA managed to translate GD booklet and 'What being a member of the IGA means?' to seven languages: Arabic, French, Spanish, Portuguese, Hebrew, Chinese, Russian. With the help of our volunteers, IGA Code of practice is translated to Arabic. All documents are available on the IGA website.

Biennial members meeting report

Every second year IGA members gather for a two-day meeting. Due to the situation with COVID-19 pandemic, the IGA has not been able to organise a face-to-face Biennial members meeting in 2021. It is important to be in regular contact with our membership and meet them often, to act together on our work program, hear their needs, share information and experience. Thus, we are very excited to have face to face members meeting in 2022. Prior to the meeting we ask each of our members to submit a report providing detailed information on the Gaucher community in that country and highlight any major achievements or challenges. This information is then distributed to all member countries for information and helps to structure some of the topics for discussion at the meeting, i.e., formal presentations and workshop themes. In addition to our members, we have invited a few new patient group representatives from non-member countries, as part of the IGA's commitment to becoming a global organisation. The outcomes of the Members meeting help the IGA Board feed in to the IGA's future work programme.

Members meeting report 2021

On 20th of November 2021 the IGA held its members' meeting over Zoom. The meeting was opened by a welcome speech from the chairperson. This was followed by presentations by the IGA board related to different projects part of the organisation's work programme. The floor was then given to our members to share their projects. The meeting took longer than scheduled as people were keen to discuss the different topics that were presented in the Q&A section of the event.

The IGA prepares its work programme and projects based on the needs of the community, so it is really important to keep in touch with its members as this is the only way to make sure our priorities reflect the needs of our community.

Regional managers

The Regional Managers Programme was started as a 12-month pilot project in 2018, and it covered four regions across the world: South Asia (north and south), Eastern Europe and the Balkans, Central America, Caucasus, and Central Asia. The Regional Managers work on improving the awareness of Gaucher disease in their regions and have conducted Continuing Medical Education (CMEs) for healthcare professionals in countries such as Nepal (2019) and a virtual CME on Lysosomal storage disorders in South Asia (2021). The Regional Managers are all volunteers.

In 2021 we reviewed and reformed the IGA Regional Manager Programme. The Regional Managers are the eyes and ears of the IGA 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.

With the review of the program, we decided on 6 regions and started the process of gathering volunteers as Regional Managers with the possibility to expand the program further in the future through cooperation and volunteers:

a. Southeast Asia region (Bangladesh, Bhutan, Indonesia, Myanmar, Maldives, Nepal, N. Korea, Sri Lanka, Timor-Leste): Mugdha Bhagwat, India

b. European region 1 (Armenia, Azerbaijan, Belarus, Georgia, Hungary, Kyrgyzstan, Tajikistan, Turkmenistan, Uzbekistan): Adel Kaplan, Russia

c. European region 2 (Cyprus, Iceland, Kosovo, Liechtenstein, Malta, Monaco, Montenegro)

d. Central America 1 region (Honduras, El Salvador, Nicaragua, Costa Rica, Panama, Belize, Dominican Republic): Patricia Lucki, Guatemala

e. Easter Mediterranean region (Afghanistan, Bahrain, Iran, Iraq, Kuwait, Lebanon, Oman, Qatar, Saudi Arabia, Syria, United Arab Emirates, Yemen): Atif Qureshi, Pakistan

f. African region (Zimbabwe, Rwanda, Tanzania, Namibia, Lesotho, Kenya, Ghana, Ivory Coast): Trudy Nyakambangwe (Zimbabwe) and Roselyn Odero (Nairobi) as Regional Managers, and Iman Tagelsir Mohamed (Sudan) as medical advisor in the team

RDI, Eurordis, MetabERN

IGA participated in different Rare Disease International (RDI) meetings in 2021, such as the meeting in March about universal health care, a policy developed by the UN to improve access to diagnosis, care, and treatment all over the world - no one left behind. All organisations agree that it is essential that Rare Diseases (RD) are included in universal health care, and it is the responsibility of all organisations to advocate for better visibility of RD and more focus on this vulnerable group.

IGA was also a part of the RDI workshops (June, October 2021) about regional hubs development which is different to the European Reference Networks (ERNs) and include countries from all over the world (patient advocates, patient organisations, doctors, researchers, hospitals).

IGA participated also in Council of European Federations (CEF) and Council of National Alliances (CAN) meetings in 2021 organized from EURORDIS, such as discussions with other international organisations about fundraising, and we presented on the IGA Volunteer Programme. There were also presentations and discussion about the pharmaceutical legislation, the United Nations (UN) resolution, COVID 19 vaccination and guidelines, Customer advisory board program, access to orphan drugs, newborn screening and much more.

IGA also had representative attending Europa Bio conferences in 2021. Taking health up a gear: the value of advanced therapies. Focus on availability and costs of therapies and talks about gene therapy. Also: **Pharmaceutical Strategy implementation for continued innovation and delivery around rare and Pediatric diseases. Improving patient access across borders.** Europa bio conference on ERNs - Challenges, achievements, and opportunities.

MetabERN is a European non-profit network established by the European Union (EU) to facilitate access to the best available care and address the needs across the border of all patients and their families affected by inherited metabolic rare diseases. It is driven by the principle of patient-centred care.

Trustees' Annual Report for the year ended 31 December 2021

Volunteer program

The overall goal of the volunteer program: to support the activities of the IGA board to fulfil the mission in the IGA strategy, through the IGA annual work program. It was developed by a volunteer in 2020 for the IGA 2021 work program.

In 2021 IGA has had support from 41 volunteers, and the number is increasing, they gave around 1400 volunteer hours in 2021. Volunteers were involved in 11 projects, and they come from come from 34 different countries (Africa, Argentina, Australia, Belgium, Bulgaria, Canada, China, Croatia, Czechia, Denmark, Egypt, France, Greece, Guatemala, India, Italy, Israel, Lebanon, Mexico, Nairobi, Netherlands, North Macedonia, Pakistan, Portugal, Qatar, Russia, Serbia, Slovenia, South Africa, Sudan, Turkey, United Kingdom, USA, Zimbabwe). Most of the volunteers (around 70%) were recruited through advertisement on social media and some of them were directly invited to join in projects and activities in IGA.

Home therapy

During the COVID pandemic many Gaucher patients' access to their biweekly ERT infusions were interrupted/cancelled due to limited or no access to hospitals due to COVID demands, national lockdowns and personal safety issues. However, before the pandemic, home therapy was recognised as important for a better quality of life for patients and their family

The IGA used International Gaucher Day 2020 to raise awareness of the benefits of home therapy.

In 2021, the IGA started researching with its global community to understand the current provision of home therapy across our membership and how home therapy is organised in each country. Some information is already available in the country reports, however more details are being collected via survey which will be sent out to IGA representatives in early 2022. Eight IGA volunteers participated at the preparation of the survey. The survey results will be evaluated together with the colleagues from IWGGD. We plan to present the results in a form of a scientific paper.

The IGA also works with IWGGD in writing home therapy guidelines which would help our members, patient communities and healthcare professionals at advocating for home therapy in their countries.

Our future plan is to work with other Lysosomal Storage Disorders (LSD) patient groups that use biweekly ERT infusions, to encourage them to collect their own data, to share best practices and to understand the challenges in provision of home therapy. We also plan to work with organisations like RDI, Eurordis and the ERNs on this topic. Another stakeholder in this project will be the pharmaceutical companies who provide Enzyme replacement therapy (ERT), and we will approach them regarding their Summary of product Characteristics (SMPC) for their products and the inclusion of home therapy. In cooperation with the companies, we will seek to gather more information on how they support home treatment.

Home therapy project is in progress and the expected outcomes are the following:

- A world map outlining where home therapy is available
- An understanding of how home therapy is supported in each country
- IWGGD Guidelines on home therapy
- IGA/IWGGD scientific paper on the global home therapy picture, the benefits, the challenges and recommendations for implementing home therapy
- The development of a toolkit to support our community to advocate for home therapy

Trustees' Annual Report for the year ended 31 December 2021

Gaucher Community Perceptions of Gene Therapy as a Treatment Option

The International Gaucher Alliance (IGA) has committed to a multi-step process to fully capture the views and understanding of the Gaucher community's perception of gene therapy (GT) as a treatment for Gaucher. As GT is a new treatment modality for Gaucher, community understanding and education on the option can be a key in the successful recruitment for clinical trials and ultimately the success of a treatment option for the community.

The first step was a series of three 90-minute virtual focus groups held in the Spring of 2021. During the focus groups, individuals responded to survey questions on issues pertaining to gene therapy. To ensure a wide representation, the IGA offered translation services and that was used by two caregivers from Italy and Ukraine. The groups were divided into: individuals living with Gaucher Type 1, parents/caregivers of those with Gaucher Type 2/3, and young adults living with Gaucher Type 3. The IGA engaged UrbanKind Institute to professionally facilitate the focus groups limited to 4-7 individuals to best encourage participation. Each of the seven survey questions were developed by the IGA with assistance from Amsterdam Medical Centre (AMC). The participants received no prior reading or information regarding gene therapy to enable responses to capture the most accurate perceptions of GT.

Several major recurring themes arose from the discussions: understanding GT, risks versus benefits, life limitations, side effects, potential effectiveness of GT, and the decrease of future medical intervention. Differences were most profound within members of a single focus group, possibly related to neurological severity, although there were also differences observed between the groups. Those who had educated themselves on GT and caretakers of individuals with advanced Gaucher were more receptive to participating in a GT clinical trial. These findings will direct future patient education and outreach efforts and inform clinical trial design.

International Gaucher Day; Communication strategy.

The IGA's communications and campaigns work in the past year has been dominated by International Gaucher Day (IGD) and the launch of GARDIAN. For 2021 IGD was once again entirely online, with social media posts focusing on the benefits of early diagnosis. Different channels worked well in different ways. For example, LinkedIn reaches mostly professionals in the rare disease field, and this is a good way to engage with clinicians and researchers. We had huge engagement from pharma companies, with a lot of reacting, sharing, and amplifying in their own posts. Facebook was particularly good for engaging members. Several members and related organisations shared our posts and amplified them with their own. There was also some translation of posts. There was good use of the profile frames as well. Facebook and to a lesser extent Instagram were also good for connecting with individual patients and carers, some of whom shared our posts. Overall, it was a successful campaign, with over 20,000 impressions (the total number of times our posts were seen) across all platforms, up from around 10,000 the year before (which was also all online).

Trustees' Annual Report for the year ended 31 December 2021

The launch of GARDIAN has involved working with various partners to create a communications campaign to publicise the launch. In 2021 we worked on creating an entirely new website, to act both as a portal to the registry and as an information resource about nGD; The website will be launched in 2022. This website will grow and evolve over time with the aim of becoming a "one-stop" shop for all things neuronopathic Gaucher Disease (nGD). Other activities in 2021 have included strengthening our social media presence generally, building on the boost we got from IGD, and improving our monthly newsletter, which continues to gain subscribers. We have also instituted a blog, mainly written by board members and staff, which highlights various aspects of the IGA's work and individual experiences as well Finally, we have developed a new Communications Strategy to help guide the work going forward, in conjunction with the IGA's Strategic Plan. The aim of this strategy is to focus the IGA's communications work on empowering patients and their families worldwide through the provision of comprehensive information about all aspects of Gaucher disease to various stakeholders, including patients themselves, the public and pharmaceutical companies. This will include general information about Gaucher, more specific information aimed at patients to help them manage their condition and improve their lives, and communication with pharmaceutical companies and clinicians to help them understand the unmet needs of patients and their families.

Structure, governance and management of the charity

The methods used to recruit and appoint new charity trustees.

Every 2 years the IGA holds elections to become or remain a trustee of the IGA 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.

Financial review

The charity's financial position at the end of the year ended 31 December 2021

The financial position of the charity at 31 December 2021 and comparatives for the prior period, as more fully detailed in the accounts, can be summarised as follows:-

	2021 £	2020 £
Net income	26,076	41,889
Unrestricted Revenue Funds available for the general purposes of the charity	222,899	202,606
Restricted Revenue Funds	5,783	-
Total Funds	228,682	202,606

International Gaucher Alliance Limited

Company Registration Number - 06653373

Trustees' Annual Report for the year ended 31 December 2021

Financial review of the position at the reporting date, 31 December 2021 .

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 circa £83,400.
During the year the charity's reserves increased by £26,076 and held reserves of £228,682 at 31 December 2021. 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 to see how well the Board are operating and how they can improve from a staff perspective or how other members of the organisation can improve according to the Board of 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
(Senior and Statutory Auditor)
Rayner Essex LLP Chartered Accountants and Statutory Auditors
Faulkner House
Victoria Street
St Albans
AL1 3SE

International Gaucher Alliance Limited

Company Registration Number - 06653373

Trustees' Annual Report for the year ended 31 December 2021

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 Registration Number - 06653373

Trustees' Annual Report for the year ended 31 December 2021

Method of preparation of accounts - Small company provisions

The financial statements are set out on pages 20 to 34.
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 12 October 2022.

Biljana Jovanović
Biljana Jovanović (Oct 13, 2022 23:37 GMT+2)

Biljana Jovanovic
Director and Trustee

International Gaucher Alliance Limited

Report of the Independent Examiner to the Trustees of the charitable company on the accounts for the year ended 31 December 2021

I report to the Trustees on my examination of the financial statements of the charitable company on pages 4 to 23 for the year ended 31 December 2021 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 10.

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

As described on page 16, 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 Accountants and Statutory Auditors, which is 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.

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.

International Gaucher Alliance Limited

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 2021 appears to exceed the sum specified in Section 145(3) of the Act, namely £250000, and that I am qualified to act as Independent Examiner in accordance with that section by virtue of my being a qualified member of 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:-

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;

the financial statements do not accord with those records; or

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;

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.

Signed:- Neil Heyes
Neil Heyes (Oct 14, 2022 13:13 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

This report was signed on 12 October 2022

International Gaucher Alliance Limited - Statement of Financial Activities for the year ended 31 December 2021

Statement of Financial Activities (including the Income and Expenditure Account for the year ended 31 December 2021, as required by the Companies Act 2006)

	Current year Unrestricted Funds	Current year Restricted Funds	Current year Total Funds	Prior Year Total Funds
	2021	2021	2021	2020
	£	£	£	£
Income & Endowments from:				
Donations & 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 on:				
Charitable activities	101,900	165,591	**267,491**	190,820
Total expenditure	**101,900**	**165,591**	**267,491**	**190,820**
Net income for the year	**30,006**	**(3,930)**	**26,076**	**41,889**
Transfers between funds	(9,713)	9,713	**-**	-
Net income after transfers	**20,293**	**5,783**	**26,076**	**41,889**
Net movement in funds	**20,293**	**5,783**	**26,076**	**41,889**
Reconciliation of funds:-				
Total funds brought forward	202,606	-	**202,606**	160,717
Total funds carried forward	**222,899**	**5,783**	**228,682**	**202,606**

A separate Statement of Total Recognised Gains and Losses is not required as this statement includes all recognised gains and losses.

All the prior year transactions were unrestricted items, and no further analysis is required.

All activities derive from continuing operations.

The notes attached on pages 24 to 34 form an integral part of these accounts.

International Gaucher Alliance Limited - Statement of Financial Activities for the year ended 31 December 2021

International Gaucher Alliance Limited - Resources applied in the year ended 31 December 2021 towards fixed assets for Charity use:-

	2021 £	2020 £
Funds generated in the year as detailed in the SOFA	26,076	41,889
Resources applied on functional fixed assets	-	(2,503)
Resources applied on Intangible assets	(2,184)	(19,056)
Other applications of funds	-	-
Net resources available to fund charitable activities	**23,892**	**20,330**

The notes attached on pages 24 to 34 form an integral part of these accounts.

Movements in revenue and capital funds for the year ended 31 December 2021

Revenue accumulated funds

	Unrestricted Funds 2021 £	Restricted Funds 2021 £	Total Funds 2021 £	Last year Total Funds 2020 £
Accumulated funds brought forward	202,606	-	202,606	**160,717**
Recognised gains and losses before transfers	30,006	(3,930)	26,076	41,889
	232,612	**(3,930)**	**228,682**	**202,606**
(From)/To unrestricted revenue funds	(9,713)	9,713	-	-
Closing revenue funds	**222,899**	**5,783**	**228,682**	**202,606**

Summary of funds

	Unrestricted and Designated funds 2021 £	Restricted Funds 2021 £	Total Funds 2021 £	Last Year Total Funds 2020 £
Revenue accumulated funds	222,899	5,783	**228,682**	202,606

The notes attached on pages 24 to 34 form an integral part of these accounts.

International Gaucher Alliance Limited - Statement of Financial Activities for the year ended 31 December 2021

International Gaucher Alliance Limited
Income and Expenditure Account for the year ended 31 December 2021 as required by the Companies Act 2006

	2021 £	2020 £
Income		
Income from operations	293,567	232,709
Gross income in the year including exceptional items	**293,567**	**232,709**
Expenditure		
Charitable expenditure, excluding depreciation and amortisation	225,320	148,593
Depreciation and amortisation	4,846	1,452
Governance costs	37,325	40,775
Total expenditure in the year	**267,491**	**190,820**
Net income before tax in the financial year	**26,076**	**41,889**
Tax on surplus on ordinary activities	-	-
Net income after tax in the financial year	**26,076**	**41,889**
Retained surplus for the financial year	**26,076**	**41,889**

All activities derive from continuing operations

In accordance with the provisions of the Companies Act 2006, the headings and subheadings used in the Income and Expenditure account have been adapted to reflect the special nature of the charity's activities.

The notes attached on pages 24 to 34 form an integral part of these accounts.

International Gaucher Alliance Limited - Balance Sheet as at 31 December 2021

	Notes		2021		2020
			£		£
Fixed assets					
Intangible assets	11		18,408		19,056
Tangible assets	12		3,789		4,637
Investments held as fixed assets	13		100		100
Total fixed assets			22,297		23,793
Current assets					
Debtors	15	22,864		2,002	
Cash at bank and in hand		220,505		180,196	
Total current assets		243,369		182,198	
Creditors: amounts falling due within one year	16	(36,984)		(3,385)	
Net current assets			206,385		178,813
The total net assets of the charity			**228,682**		**202,606**
The total net assets of the charity are funded by the funds of the charity, as follows:-					
Restricted funds					
Restricted Revenue Funds	19	5,783		-	
			5,783		-
Unrestricted Funds					
Unrestricted Revenue Funds	19	222,899		202,606	
			222,899		202,606
Total charity funds			**228,682**		**202,606**

The 'SORP Ref' indicated above is the classification of Balance Sheet items as set out in the formal SORP documents. As required by paragraph 4.60 of the SORP, the brought forward and carried forward funds above have been agreed to the SOFA.

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 charity is subject to Independent Examination under charity legislation, and the report of the Independent Examiner is on page 19.

The 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.

Biljana Jovanović
Biljana Jovanović (Oct 13, 2022 23:37 GMT+2)

Biljana Jovanovic

Trustee

Approved by the board of trustees on 12 October 2022

The notes attached on pages 24 to 34 form an integral part of these accounts.

International Gaucher Alliance Limited

Notes to the Accounts for the year ended 31 December 2021

1 Accounting policies

Policies relating to the production of the accounts.

Basis of preparation and accounting convention

The accounts have been prepared on the accruals basis, under the historical cost convention, and in accordance with the Financial Reporting Standard 102, (effective 1st January 2016) and '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) , effective January 2016, , and in accordance with all applicable law in the charity's jurisdiction of registration, except that the charity has prepared the financial statements in accordance with 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 preference to the previous SORP, the SORP 2005, which has been withdrawn, notwithstanding the fact that the extant statutory regulations, the Charities (Accounts and Reports) Regulations 2008 refer explicitly to the SORP 2005. This has been done to accord with current best practice.

The charity is a public benefit entity.

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 2022, 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 uncertainites about the charity's ability to continue as a going concern.

Policies relating to categories of income and income recognition.

Accounting for deferred income and income received in advance

Where terms and conditions relating to income have not been met or uncertainty exists as to whether the charity can meet any terms or conditions otherwise within its control, income is not recognised but is deferred as a liability until it is probable that the terms or conditions imposed can be met.

Any grant that is subject to performance-related conditions received in advance of delivering the goods and services required by that condition, or is subject to unmet conditions wholly outside the control of the recipient charity, is accounted for as a liability and shown on the balance sheet as deferred income. Deferred income is released to income in the reporting period in which the performance-related or other conditions that limit recognition are met.

When income from a grant or donation has not been recognised due to the conditions applying to the gift not being wholly within the control of the recipient charity, it is disclosed as a contingent asset if receipt of the grant or donation is probable once those conditions are met.

Where time related conditions are imposed or implied by a funder, then the income is apportioned to the time periods concerned,and, where applicable, is accounted for as a liability and shown on the balance sheet as deferred income. When grants are received in advance of the expenditure on the activity funded by them, but there are no specific time related conditions, then the income is not deferred.

Any condition that allows for the recovery by the donor of any unexpended part of a grant does not prevent recognition of the income concerned, but a liability to any repayment is recognised when repayment becomes probable.

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.

Policies relating to expenditure on goods and services provided to the charity.

Recognition of liabilities and expenditure

A liability, and the related expenditure, is recognised when a legal or constructive obligation exists as a result of a past event, and when it is more likely than not that a transfer of economic benefits will be required in settlement, and when the amount of the obligation can be measured or reliably estimated..

Liabilities arising from future funding commitments and constructive obligations, including performance related grants, where the timing or the amount of the future expenditure required to settle the obligation are uncertain, give rise to a provision in the accounts, which is reviewed at the accounting year end. The provision is increased to reflect any increases in liabilities, and is decreased by the utilisation of any provision within the period, and reversed if any provision is no longer required. These movements are charged or credited to the respective funds and activities to which the provision relates.

Policies relating to assets, liabilities and provisions and other matters.

Fixed Asset Investments

Fixed asset investments in quoted shares, traded bonds, investment properties and similar investments are shown initially at cost upon acquisition and at their market value at the balance sheet date at the end of the financial period. Investment properties are not depreciated.

Fixed asset investments in unlisted equities are shown at the balance sheet date at the best estimate of their market value, where practicable. Where valuation techniques are considered unreliable or where, in the opinion of the trustees, the costs outweigh the benefits to the users of the accounts, the investment is included at cost, and a review is undertaken at each year end as to whether the asset should be written down.

All gains on fixed asset investments, whether realised or unrealised, are included in row B4 of the Statement of Financial Activities.

Intangible assets

Website development costs are being written off in equal annual instalments over its estimated economic life of 5 years, which equates to amortisation at 20% straight line.

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	25 % straight line

Notes to the Accounts for the year ended 31 December 2021

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 and provisions

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.

Pensions - defined contribution schemes

The charity operates a defined contribution pension scheme. Contributions are charged to the profit and loss account as they become payable in accordance with the rules of the scheme.

Fund Accounting

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

Restricted funds are subjected to restrictions on their expenditure imposed by the donor or through the terms of an appeal or as implied by law.

There are no endowment funds.

2 Liability to taxation

The company is a registered charity and is not liable to corporation tax on income or gains derived from its charitable activities.

3 Winding up or dissolution of the charity

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.

4 Significance of financial instruments to the charity's position

The charity's financial assets consist of debtors and cash only.

5 Net surplus before tax in the financial year

	2021 £	2020 £
The net surplus before tax in the financial year is stated after charging:-		
Amortisation and depreciation of owned fixed assets	4,846	1,452
Trustees' remuneration	34,325	40,775
Pension costs	1,617	1,786
Independent Examiner's Fee	3,000	-

Notes to the Accounts for the year ended 31 December 2021

6 Donated goods, services and facilities

Current year

	Current year Unrestricted Funds	Prior Year Total Funds
	2021	2020
	£	£
Included in Legacies and Donations:-		
Donated goods and services	34,325	40,775
	34,325	**40,775**

Prior Year

	Prior Year Unrestricted Funds	Prior Year Total Funds
	2020	2020
	£	£
Included in Legacies and Donations:-		
Donated goods and services	40,775	**40,775**
	40,775	**40,775**

Directors have made donations of their services to the company during the year to the value of £34,325 (2020: £40,775). Administration expenses include directors fees for services donated to the company of £34,325 (2020: £40,775) and turnover includes donations by the directors of £34,325 (2020: £40,775) in respect of their services to the company.

7 Staff costs and emoluments

Salary costs

	2021	2020
	£	£
Gross Salaries excluding trustees and key management personnel	39,081	31,235
Employer's National Insurance for all staff	8,889	8,547
Employer's operating costs of defined contribution pension schemes	1,617	1,786
Salaries and benefits paid to key management personnel	60,703	55,821
Directors' and volunteers' fees for services donated to the charity as detailed in note 9	34,325	40,775
Total salaries, wages and related costs	**144,615**	**138,164**

	2021	2020
	Number	Number
The average number of full time staff employed in the year was	**1**	**1**
The average number of part time staff employed in the year was	**2**	**2**
The average number of all staff employed in the year was	**3**	**3**

Notes to the Accounts for the year ended 31 December 2021

7 Staff costs and emoluments (continued)

	2021 Number	2020 Number
The estimated number of all staff employed as above	**3**	3

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

	2021 £	2020 £
£60,001 to £70,000	**1**	-
	1	-

The cost to the chairty of senior management personnel remuneration included the following:

	£	£
Gross wages and Employer's National Insurance contributions	**68,255**	**62,559**
Contributions for the provision of money purchase pension	**1,319**	1,314

	No	No
Numbers of such staff to whom benefits are accruing :-		
Under money purchase pension schemes	**1**	1

8 Defined contribution pension schemes

The charity operates a defined contribution pension scheme, the costs of which are shown above.
Any liabilites and assets associated with the scheme are shown under debtors and creditors.

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

	2021 £	2020 £
Remuneration payable to trustees or connected persons		
Directors' and volunteers' fees for services donated to the charity	34,325	40,775
Total remuneration	**34,325**	**40,775**

Directors and volunteers have made donations of their services to the company during the year to the value of £34,325 (2020: £40,775). Administration expenses include directors' and volunteers' fees for services donated to the company of £34,325 (2020: £40,775) and turnover includes donations by the directors and volunteers of £34,325 (2020: £40,775) in respect of their services to the company.

International Gaucher Alliance Limited

Notes to the Accounts for the year ended 31 December 2021

10 Deferred income - Restricted funds

Current Year	Received deferred in year	Deferred at year end
	£	£
Pfizer work programme	2,136	2,136
International Working Group on Gaucher Disease	9,143	9,143
Total	11,279	11,279

10 Deferred income - Restricted funds (continued)

	2021	2020
	£	£
These deferrals are included in creditors	11,279	-

The deferrals included in creditors relate to 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.

11 Intangible Fixed Assets

	2021	2020
	£	£
Goodwill:		
Cost		
At 1 January 2021	19,056	-
Additions	2,184	19,056
At 31 December 2021	**21,240**	**19,056**
Amortisation		
Provided during the year	2,832	-
At 31 December 2021	**2,832**	**-**
Net book value	**18,408**	**19,056**

Website development costs are being written off in equal annual instalments over its estimated economic life of 5 years, which equates to amortisation at 20% straight line.

Notes to the Accounts for the year ended 31 December 2021

12 Tangible fixed assets

Current Year	Plant & Machinery
	£
Cost	
At 1 January 2021	8,250
Additions	1,166
At 31 December 2021	**9,416**
Depreciation	
At 1 January 2021	3,613
Charge for the year	2,014
At 31 December 2021	**5,627**
Net book value	
At 31 December 2021	**3,789**
At 31 December 2020	**4,637**

13 Investments held as fixed assets

	Investments in subsidiaries
	£
Carrying values of investments	
At 1 January 2021	100
At 31 December 2021	**100**
Analysis between fair value and historical cost	
Investments as above held at historical cost, less any write down	100

Notes to the Accounts for the year ended 31 December 2021

14 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.

A summary of the unaudited financial statements of the subsidiary is :-

	2021 £	2020 £
Assets and Funds		
Aggregate amounts of liabilities	(6,988)	(2,902)
Aggregate amount of funds	(6,988)	(2,902)
Profit and Loss		
Turnover	509,511	-
Expenses	(513,597)	(3,002)
Net loss for the year after tax	**(4,086)**	**(3,002)**

The net profit of the subsidiary is stated after including intergroup company expenditure of £20,862 (2020 - £2,102)

Amounts owing to and from the subsidiary are shown in the notes relating to creditors and debtors.

15 Debtors

	2021 £	2020 £
Amounts owed by group undertakings and undertakings in which the charity has a participating interest	22,864	2,002

16 Creditors: amounts falling due within one year

	2021 £	2020 £
Accruals	22,812	568
Deferred Income - Restricted funds	11,279	-
PAYE, NIC VAT and other taxes	2,519	2,420
Other creditors	374	397
	36,984	**3,385**

Notes to the Accounts for the year ended 31 December 2021

17 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:

	2021	2020
	£	£
Administration fees	1,104	497

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	10,400	4,416
The Gauchers Association Limited Administration fees	1,343	197
International Gardian Limited Administration fees	20,862	2,102

During the year staff costs included £3,308 relating to 50% of time spent on work done for its subsidiary International Gardian Limited ("IGL"). This amount has not been recharged to IGL as the charity agreed to fund 50% of staff time period spent on IGL work for a period of 2 years from July 2021.

18 Particulars of how particular funds are represented by assets and liabilities

At 31 December 2021	**Unrestricted funds**	**Restricted funds**	**Total Funds**
	£	£	£
Intangible Assets	18,408	-	**18,408**
Tangible Fixed Assets	3,789	-	**3,789**
Investments held as fixed assets	100	-	**100**
Current Assets	226,307	17,062	**243,369**
Current Liabilities	(25,705)	(11,279)	**(36,984)**
	222,899	**5,783**	**228,682**

At 1 January 2021	**Unrestricted funds**	**Restricted funds**	**Total Funds**
	£	£	£
Intangible Assets	19,056	-	**19,056**
Tangible Fixed Assets	4,637	-	**4,637**
Investments held as fixed assets	100	-	**100**
Current Assets	182,198	-	**182,198**
Current Liabilities	(3,385)	-	**(3,385)**
	202,606	**-**	**202,606**

International Gaucher Alliance Limited

Notes to the Accounts for the year ended 31 December 2021

19 Change in total funds over the year as shown in Note 18 , analysed by individual funds

	Funds brought forward from 2020	Movement in funds in 2021	Transfers between funds in 2021	Funds carried forward to 2022
		See Note 20	See Note 21	
	£	£	£	£
Unrestricted and designated funds:-				
Unrestricted Revenue Funds	202,606	30,006	**(9,713)**	**222,899**
Total unrestricted and designated funds	**202,606**	**30,006**	**(9,713)**	**222,899**
Restricted funds:-				
Eurordis Funding	-	1,619	(1,619)	**-**
Gene Therapy	-	60	-	**60**
Sanofi work programme	-	(10,693)	10,693	**-**
Access to Medicines Africa	-	(24)	24	**-**
Pfizer work programme	-	5,723	-	**5,723**
IWGDD	-	(615)	615	**-**
Total restricted funds	**-**	**(3,930)**	**9,713**	**5,783**
Total charity funds	**202,606**	**26,076**	**-**	**228,682**

20 Analysis of movements in funds over the year as shown in Note 19

	Income	Expenditure	Movement in funds
	2021	2021	2021
	£	£	£
Unrestricted and designated funds:-			
Unrestricted Revenue Funds	131,906	(101,900)	**30,006**
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)**
	293,567	**(267,491)**	**26,076**

Notes to the Accounts for the year ended 31 December 2021

21 Details of transfers between funds

The transfers shown in note 19 above are:-	2021
	£
To/(from) Unrestricted Revenue Funds in accordance with the accounting policy 'Accounting for capital grants and fixed asset funds'.	(9,713)
To/(from) Restricted Revenue Funds	9,713
Net transfers	-

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 as detailed in note 19.

22 The purposes for which the funds as detailed in note 19 are held by the charity are:-

Unrestricted and designated funds:-

Unrestricted Revenue Funds	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.

Restricted funds:-

Eurordis Funding	Funds held for 2020 work programme funded by Eurordis.
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	Funds held for funds received from Pfizer for funding 2021 work programme.

22 The purposes for which the funds as detailed in note 19 are held by the charity are (continued):

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.

23 Ultimate controlling party

The charity is under the control of its legal members.

Every member of the charity is obliged to contribute such amount as may be required not exceeding £10 to the assets of the company in the event of its being wound up while he or she is a member, or within one year after he or she ceases to be a member.

International Gaucher Alliance Limited

Detailed analysis of income and expenditure for the year ended 31 December 2021 as required by the SORP 2015

This analysis is classsified by conventional nominal descriptions and not by activity.

24 Donations, Grants and Legacies

	Current year Unrestricted Funds 2021 £	Current year Restricted Funds 2021 £	Current year Total Funds 2021 £	Prior Year Total Funds 2020 £
Revenue grants and donations from non public bodies				
Gift Aid Donations from subsidiaries	2,612	1,619	**4,231**	4,259
International Working Group on Gaucher Disease	-	3,048	**3,048**	-
Orphayme	8,000	-	**8,000**	8,000
Avrobio	21,125	-	**21,125**	11,820
Prevail	9,988	-	**9,988**	4,988
Freeline	-	5,000	**5,000**	-
Sanofi	-	56,537	**56,537**	12,629
Takeda	40,000	71,955	**111,955**	47,000
Pfizer	-	23,502	**23,502**	75,000
GAIN	-	-	**-**	4,993
Centogene	-	-	**-**	6,500
SCD	-	-	**-**	10,000
Total private sector revenue grants	**81,725**	**161,661**	**243,386**	**185,189**

	Current year Unrestricted Funds 2021 £	Current year Restricted Funds 2021 £	Current year Total Funds 2021 £	Prior Year Total Funds 2020 £
Donated goods and services				
Directors' and volunteers' donation of services	34,325	-	**34,325**	40,775
Total donated goods and services	**34,325**	**-**	**34,325**	**40,775**
Total Donations, Grants and Legacies				
Total Donations, Grants and Legacies	**116,050**	**161,661**	**277,711**	**225,964**

International Gaucher Alliance Limited

Detailed analysis of income and expenditure for the year ended 31 December 2021 as required by the SORP 2015

25 Income from charitable activities - Trading Activities

Current year	Current year Unrestricted Funds	Current year Restricted Funds	Current year Total Funds	Prior Year Total funds
	2021	2021	2021	2020
	£	£	£	£
Primary purpose and ancillary trading				
Consultancy fees receivable	15,856	-	**15,856**	6,745
Total Primary purpose and ancillary trading	**15,856**	**-**	**15,856**	**6,745**

26 Total Income from charitable activities

Current year	Current year Unrestricted Funds	Current year Restricted Funds	Current year Total Funds	Prior Year Total Funds
	2021	2021	2021	2020
	£	£	£	£
Total income from charitable trading	15,856	-	**15,856**	6,745
Total from charitable activities	**15,856**	**-**	**15,856**	**6,745**

27 Expenditure on charitable activities - Direct spending

Current Year	Current year Unrestricted Funds	Current year Restricted Funds	Current year Total Funds	Prior Year Total Funds
	2021	2021	2021	2020
	£	£	£	£
Gross wages and salaries - charitable activities	40,836	58,948	**99,784**	**87,056**
Employers' NI - Charitable activities	3,669	5,220	**8,889**	**8,547**
Defined contribution pension costs - charitable activities	656	961	**1,617**	**1,786**
Travel and Subsistence - Charitable Activities	988	-	**988**	**23,100**
Miscellaneous Purchases	25	-	**25**	**49**
Total direct spending	**46,174**	**65,129**	**111,303**	**120,538**

International Gaucher Alliance Limited

Detailed analysis of income and expenditure for the year ended 31 December 2021 as required by the SORP 2015

28 Expenditure on charitable activities- Grant funding of activities

Current Year	Current year Unrestricted Funds	Current year Restricted Funds	Current year Total Funds	Prior Year Total Funds
	2021	2021	2021	2020
	£	£	£	£
Grants made to organisations	-	71,979	**71,979**	-
Total grantmaking costs	**-**	**71,979**	**71,979**	**-**

Breakdown of Grants made to organisations

Current Year	Current year Unrestricted Funds	Current year Restricted Funds	Current year Total Funds
	2021	2021	2021
	£	£	£
Grant to FYMCA Medical Ltd	-	71,979	71,979
	-	**71,979**	**71,979**

A grant was made to FYMCA Medical Ltd regarding the Capacity Building in Africa Project as part of the Takeda Charitable Access Programme.

International Gaucher Alliance Limited

Detailed analysis of income and expenditure for the year ended 31 December 2021 as required by the SORP 2015

29 Support costs for charitable activities

Current Year	Current year Unrestricted Funds	Current year Restricted Funds	Current year Total Funds	Prior Year Total Funds
	2021	2021	2021	2020
	£	£	£	£
Employee costs not included in direct costs				
Training and welfare - staff	114	85	**199**	**-**
Recruitment expenses	171	365	**536**	**-**
Entertaining	79	-	**79**	**147**
Premises Expenses				
Rent payable under operating leases	2,617	1,943	**4,560**	**4,560**
Administrative overheads				
Telephone, fax and internet	731	343	**1,074**	**1,466**
Postage	47	35	**82**	**93**
Stationery and printing	(1,799)	269	**(1,530)**	**2,800**
Membership subscriptions	2,177	1,315	**3,492**	**3,384**
Equipment expenses	98	73	**171**	**244**
Software licences and expenses	2,429	1,542	**3,971**	**5,400**
Liabilty and contents insurance	1,190	883	**2,073**	**1,683**
Sundry expenses	3,456	2,565	**6,021**	**(2,375)**
Admin recharge	994	805	**1,799**	**4,954**
Professional fees paid to advisors other than the auditor or examiner				
Accountancy fees other than examination or audit fees	1,128	837	**1,965**	**1,272**
Consultancy fees	1,574	1,685	**3,259**	**1,566**
Other legal and professional	389	13,445	**13,834**	**2,326**
Financial costs				
Bank charges	224	229	**453**	**535**
Depreciation & Amortisation in total for	2,782	2,064	**4,846**	**1,452**
Total support costs - Current Year	**18,401**	**28,483**	**46,884**	**29,507**
				-

All the expenditure in the prior year was unrestricted.

International Gaucher Alliance Limited

Detailed analysis of income and expenditure for the year ended 31 December 2021 as required by the SORP 2015

30 Other Expenditure - Governance costs

Current Year	Current year Unrestricted Funds	Current year Restricted Funds	Current year Total Funds	Prior Year Total Funds
	2021	2021	2021	2020
	£	£	£	£
Independent Examiner's fees	3,000	-	**3,000**	**-**
Trustees' remuneration	34,325	-	**34,325**	**40,775**
Total Governance costs	**37,325**	**-**	**37,325**	**40,775**

All the expenditure in the prior year was unrestricted.

31 Total Charitable expenditure

Current Year	Current year Unrestricted Funds	Current year Restricted Funds	Current year Total Funds	Prior Year Total Funds
	2021	2021	2021	2020
	£	£	£	£
Total direct spending	46,174	65,129	**111,303**	**120,538**
Total grantmaking costs	-	71,979	**71,979**	**-**
Total support costs	18,401	28,483	**46,884**	**29,507**
Total Governance costs	37,325	-	**37,325**	**40,775**
Total charitable expenditure	**101,900**	**165,591**	**267,491**	**190,820**

All the expenditure in the prior year was unrestricted.

Prior Year	Prior Year Unrestricted Funds	Prior Year Restricted Funds	Prior Year Total Funds
	2020	2020	2020
	£	£	£
Total direct spending	120,538	-	**120,538**
Total support costs	29,507	-	**29,507**
Total Governance costs	40,775	-	**40,775**
Total charitable expenditure	**190,820**	**-**	**190,820**

21-12-31 International Gaucher Alliance final accounts FULL v5 final

Final Audit Report 2022-10-14

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