

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**  
**Contents**

	<b>Page</b>
Reference and administrative details of the charity	1
Trustees' Annual Report	2-8
Independent Examiner's Report	9-10
Statement of Financial Activities	11
Statement of Financial Activities prior year	12
Balance sheet	13
Notes to the accounts	14-20

## **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.

## **International Gaucher Alliance Limited**

**Company limited by guarantee registered number:**

**06653373**

**Registered charity number: 1192011**

### **Trustees' Annual Report**

#### **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.

## 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*

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.

**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 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	Restricted Funds	Total Funds	Total Funds
		2024	2024	2024	2023
		£	£	£	£
<b>Income</b>					
Donations and legacies		118,846	182,479	301,325	365,855
Charitable activities		34,117	-	34,117	29,804
<b>Total income</b>		152,963	182,479	335,442	395,659
<b>Expenditure</b>					
Charitable activities		208,716	175,056	383,772	365,122
<b>Total expenditure</b>		208,716	175,056	383,772	365,122
<b>Net income/(expenditure) for the year and Movement in total funds for the year</b>	2	(55,753)	7,423	(48,330)	30,537
<b>Other recognised gains/ (losses)</b>					
Total funds at 1 January		201,251	16,142	217,393	186,856
Transfers in /(out)		23,565	(23,565)	-	-
<b>Total funds at 31 December</b>	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	Restricted Funds	Total Funds	Total Funds
		2023	2023	2023	2022
		£	£	£	£
<b>Income</b>					
Donations and legacies		201,592	164,263	365,855	241,543
Charitable activities		29,804	-	29,804	9,864
<b>Total income</b>		231,396	164,263	395,659	251,407
<b>Expenditure</b>					
Charitable activities		205,216	159,906	365,122	293,233
<b>Total expenditure</b>		205,216	159,906	365,122	293,233
<b>Net income/(expenditure) for the year and Movement in total funds for the year</b>	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	-	-
<b>Total funds at 31 December</b>	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 £
<b>Fixed assets</b>			
Intangible assets	8	6,980	12,216
Tangible assets	9	1,142	2,261
Investments	10	100	100
		<u>8,222</u>	<u>14,577</u>
<b>Current assets</b>			
Debtors	12	51,382	35,147
Cash at bank and in hand		119,799	204,244
		<u>171,181</u>	<u>239,391</u>
<b>Creditors: amounts falling due within one year</b>	13	(10,340)	(36,575)
<b>Net current assets</b>		<u>160,841</u>	<u>202,816</u>
<b>Total assets less current liabilities</b>		<u>169,063</u>	<u>217,393</u>
<b>Net assets</b>		<u>169,063</u>	<u>217,393</u>
<b>Total funds of the charity</b>			
Restricted Funds	14	-	16,142
Unrestricted Funds	14	169,063	201,251
<b>Total charity funds</b>		<u>169,063</u>	<u>217,393</u>

The directors are satisfied that the company is entitled to exemption from the requirement to obtain an audit under section 477 of the Companies Act 2006.

The members have not required the company to obtain an audit in accordance with section 476 of the Act.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of accounts.

The accounts have been prepared and delivered in accordance with the special provisions applicable to companies subject to the small companies regime. The profit and loss account has not been delivered to the Registrar of Companies.

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 uncertainties about the charity's ability to continue as a going concern.

***Fund Accounting***

Funds held by the charity are either:

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

Designated funds are unrestricted funds earmarked by the trustees for a particular purpose.

Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of appeal.

***Income***

Income received from subscriptions, donations, Gift Aid Tax and activities is measured at the fair value of the consideration received or receivable. Income is recognised when the charity has entitlement to the funds, any performance conditions attached the item of income have been met, it is probable that the income will be received and the amount can be reliably measured. Accruals are made for monies received on fund generating activities that were held during the financial year but received after the financial year end up to the date these financial statements were approved by the trustee/directors. Income received in advance of the provision of services is deferred until the criteria for income recognition are met.

***Donated services***

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

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

***Expenditure***

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that a settlement will be required and the amount of the obligation can be measured reliably. Resources expended are included in the Statements of Financial Activities on an accrual basis, inclusive of any VAT which cannot be recovered. Where applicable they have been charged directly to the funds and activities to which they relate.

***Fixed Asset Investments***

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

***Intangible fixed assets***

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



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

***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.

<b>2 Net income/(expenditure) for the year</b>	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
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

<b>3 Donated goods, services and facilities</b>	<b>2024</b>	<b>2023</b>
	<b>Unrestricted funds</b>	<b>Unrestricted funds</b>
	<b>£</b>	<b>£</b>
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.

<b>4 Staff costs</b>	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
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:

	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
Gross wages and Employer's National Insurance contributions	83,312	80,110
Contributions for the provision of money purchase pension	1,321	1,321

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

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

**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	<u>3</u>	<u>3</u>

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	<u>1</u>	<u>1</u>

**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	<u>44,638</u>	<u>53,431</u>

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
	<u>-</u>	<u>-</u>	<u>11,000</u>	<u>16,000</u>

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

**8 Intangible fixed assets**

Website development costs:

**Cost**

At 1 January 2024	24,900
At 31 December 2024	<u>24,900</u>

**Amortisation**

At 1 January 2024	12,684
Provided during the year	5,236
At 31 December 2024	<u>17,920</u>

**Net book value**

At 31 December 2024	<u>6,980</u>
At 31 December 2023	<u>12,216</u>

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

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

**9 Tangible fixed assets**

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

**10 Investments**

	<b>Investments in subsidiary undertakings £</b>	<b>Total £</b>
<b>Cost</b>		
At 1 January 2024	100	100
At 31 December 2024	<u>100</u>	<u>100</u>
<b>Historical cost</b>		
At 1 January 2024	<u>100</u>	
At 31 December 2024	<u>100</u>	

**11 Subsidiary companies**

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

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

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

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

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

**12 Debtors**

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

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

**13 Creditors: amounts falling due within one year**

	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
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
	<u>10,340</u>	<u>36,575</u>

**14 Movement in Funds**

	<b>As at 1</b>			<b>Transfers</b>	<b>As at 31</b>
	<b>January</b>	<b>Income</b>	<b>Expenditure</b>	<b>in/(out)</b>	<b>December</b>
	<b>2024</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>2024</b>
	<b>£</b>				<b>£</b>
<b>Restricted funds</b>					
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	-
<b>Total restricted funds</b>	<u>16,142</u>	<u>182,479</u>	<u>(175,056)</u>	<u>(23,565)</u>	<u>-</u>
General fund	201,251	152,963	(208,716)	23,565	169,063
<b>Total unrestricted funds</b>	<u>201,251</u>	<u>152,963</u>	<u>(208,716)</u>	<u>23,565</u>	<u>169,063</u>
<b>Total restricted and unrestricted funds</b>	<u>217,393</u>	<u>335,442</u>	<u>(383,772)</u>	<u>-</u>	<u>169,063</u>

**Movement in Funds**

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

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.

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

**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 project.
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.

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

**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*

	<b>Total funds 2024 £</b>	<b>Total funds 2023 £</b>
<b>Donations</b>		
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
	<u>335,442</u>	<u>395,659</u>
<b>Expenditure on charitable activities- Grant funding of activities</b>		
Grants made/charitable payments	-	6,658
	<u>-</u>	<u>6,658</u>
<b>Expenditure on charitable activities - Direct spending</b>		
<b>Employee costs:</b>		
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
<b>Other direct costs:</b>		
Research	-	2,244
Conferences and Seminars	55,453	-
	<u>251,850</u>	<u>180,945</u>
<b>Expenditure on charitable activities - Support costs</b>		
<b>Employee costs:</b>		
Employee costs:		
Staff training and welfare	1,736	37
Directors' and volunteers' fees	44,638	53,431
Entertaining	258	1,643
	<u>46,632</u>	<u>55,111</u>
<b>Premises costs:</b>		
Rent	1,675	1,440
	<u>1,675</u>	<u>1,440</u>
<b>General administrative expenses:</b>		
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
	<u>20,108</u>	<u>32,194</u>

**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*

	<b>Total funds 2024 £</b>	<b>Total funds 2023 £</b>
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
	<u>63,507</u>	<u>88,774</u>
	<u>383,772</u>	<u>365,122</u>
Total	<u>(48,330)</u>	<u>30,537</u>