

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

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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
Kristijan 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.

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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.

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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.

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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.

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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 that 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

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- 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,

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- 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.

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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 Vajevic, 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.

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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.

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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. Eastern 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.

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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 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

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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).

International Gaucher Alliance Limited

Company Registration Number - 06653373

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 (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	<u>293,567</u>	<u>232,709</u>
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	<u>267,491</u>	<u>190,820</u>
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	<u>26,076</u>	<u>41,889</u>
Retained surplus for the financial year	<u>26,076</u>	<u>41,889</u>

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 uncertainties 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.

International Gaucher Alliance Limited

Notes to the Accounts for the year ended 31 December 2021

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
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International Gaucher Alliance Limited

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	-

International Gaucher Alliance Limited

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
	£	£
<i>Included in Legacies and Donations:-</i>		
Donated goods and services	34,325	40,775
	34,325	40,775

Prior Year

	Prior Year Unrestricted Funds	Prior Year Total Funds
	2020	2020
	£	£
<i>Included in Legacies and Donations:-</i>		
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 Number	2020 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

International Gaucher Alliance Limited

Notes to the Accounts for the year ended 31 December 2021

7 Staff costs and emoluments (continued)

	2021 Number	2020 Number
<i>The estimated number of all staff employed as above</i>	<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 :-

	2021 £	2020 £
£60,001 to £70,000	1	-
	<u>1</u>	<u>-</u>

The cost to the charity 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	<u>1,319</u>	<u>1,314</u>

	No	No
<i>Numbers of such staff to whom benefits are accruing :-</i>		
Under money purchase pension schemes	<u>1</u>	<u>1</u>

8 Defined contribution pension schemes

The charity operates a defined contribution pension scheme, the costs of which are shown above.
Any liabilities 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 £
<i>Remuneration payable to trustees or connected persons</i>		
Directors' and volunteers' fees for services donated to the charity	34,325	40,775
Total remuneration	<u>34,325</u>	<u>40,775</u>

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

<i>Current Year</i>	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

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
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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.

International Gaucher Alliance Limited

Notes to the Accounts for the year ended 31 December 2021

12 Tangible fixed assets

<i>Current Year</i>	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

International Gaucher Alliance Limited

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

International Gaucher Alliance Limited

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

International Gaucher Alliance Limited

Notes to the Accounts for the year ended 31 December 2021

21 Details of transfers between funds

<i>The transfers shown in note 19 above are:-</i>	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.
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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.
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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 classssified 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

<i>Current year</i>	Current year Unrestricted Funds 2021 £	Current year Restricted Funds 2021 £	Current year Total Funds 2021 £	Prior Year Total funds 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

<i>Current year</i>	Current year Unrestricted Funds 2021 £	Current year Restricted Funds 2021 £	Current year Total Funds 2021 £	Prior Year Total Funds 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

<i>Current Year</i>	Current year Unrestricted Funds 2021 £	Current year Restricted Funds 2021 £	Current year Total Funds 2021 £	Prior Year Total Funds 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

<i>Current Year</i>	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				
<i>Current Year</i>	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

<i>Current Year</i>	Current year Unrestricted Funds	Current year Restricted Funds	Current year Total Funds	Prior Year Total Funds
	2021	2021	2021	2020
	£	£	£	£
<i>Employee costs not included in direct costs</i>				
Training and welfare - staff	114	85	199	-
Recruitment expenses	171	365	536	-
Entertaining	79	-	79	147
<i>Premises Expenses</i>				
Rent payable under operating leases	2,617	1,943	4,560	4,560
<i>Administrative overheads</i>				
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
Liability 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
<i>Professional fees paid to advisors other than the auditor or examiner</i>				
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
<i>Financial costs</i>				
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

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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

<i>Current Year</i>	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

<i>Current Year</i>	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.

<i>Prior Year</i>	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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