

Registered number
06653373

International Gaucher Alliance Limited

Report and Accounts

31 December 2020

International Gaucher Alliance Limited
Report and accounts
Contents

	Page
Company information	1
Directors' report	2-9
Accountants' report	10
Profit and loss account	11
Balance sheet	12
Statement of changes in equity	13
Notes to the accounts	14-17

**International Gaucher Alliance Limited
Company Information**

Directors

Aviva Risher Rosenberg
Vesna Aleksovksa
Irena Znider
Biljana Jovanovic
Kristijan Dimitrov
Suyog Sathe
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Secretary

Kristijan Dimitrov

Accountants

Numerii Limited
William Old Centre
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Registered office

8 Silver Street
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Registered number

06653373

International Gaucher Alliance Limited
Registered number: 06653373
Directors' Report

The directors present their report and accounts for the year ended 31 December 2020.

Principal activities

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 IGA is growing and at the end of 2020 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, Sandra Zarina and Angel Jones, 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 organization and the CEO spends a lot of her time communicating 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 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.

International Gaucher Alliance Limited
Registered number: 06653373
Directors' Report

Key activities in 2020

Gaining Charitable status

On the 27th of October 2020, the IGA became a registered charity. Since its inception, the IGA has been a not-for-profit organisation. This new charity status recognises the valuable work that the IGA does and demonstrates our commitment and values as we continue to serve the needs of our global community

Charitable access

We have always pledged to help any Gaucher patient that asks us for help wherever they live in the world, therefore advocating for charitable treatment has always been and will remain our priority. Despite there being three licensed enzyme replacement therapies (ERT) and two substrate reduction therapies (SRT) available for the treatment of the visceral manifestations of the disease, sadly, there are still hundreds of patients around the world without access to treatment.

In 2020, we received requests for treatment from 11 countries such as Afghanistan, Honduras, India, Jordan, Kenya, Morocco, Mozambique, Pakistan, Senegal, South Africa, Sudan. By working closely with Sanofi Genzyme, Pfizer and Takeda we helped to give a future to 31 Gaucher patients as they received donated ERT. Sadly, 15 patients who reached out to us for support died without getting access to the treatment they needed. At the end of 2020 we have 13 cases still unresolved on our database. One of the challenges we face in supporting the community is that there is very little access available to adult patients through charitable access programmes. This is an area we need to address in collaboration with our members and other stakeholders. Sadly, there are many more other patients suffering without treatment across the world and therefore the IGA will continue to provide the much-needed support.

Covid-19

In 2020 one of the biggest challenges faced by patients across the World was the global pandemic. We hosted a webinar with the European Working Group on Gaucher Disease (EWGGD) to learn more about the effects of coronavirus in Gaucher disease and to coordinate data collection, attended by over 100 participants including physicians, EWGGD colleagues, patients and patient advocates and industry representatives. Situational reports from countries across Europe were given and patient concerns were discussed. The IGA and pharmaceutical representatives were given the opportunity to speak, and questions were raised by patients and patient advocates.

Throughout the pandemic we have continued to share best practices and updates, offering support to patient groups where needed. One of the challenges that the COVID-19 situation has brought to Gaucher patients is receiving their fortnightly enzyme replacement therapy (ERT) infusions. The EWGGD published a statement recommending home therapy wherever possible and a webinar was hosted in May led by patient group representatives from Italy and Greece who have both been successful in lobbying their governments to authorise home therapy. The purpose of this meeting was to share best practice regarding home therapy and answer additional questions.

International Gaucher Alliance Limited
Registered number: 06653373
Directors' Report

International Gaucher Day (IGD)

IGD is an important part of our strategy at IGA as it helps to raise awareness of Gaucher disease and our community. Our 2020 campaign focussed on the challenges Gaucher patients are facing during the COVID-19 pandemic and our aim was to improve patients' quality of life by advocating for home therapy. On 1st October we were able to reach almost 4000 people on Twitter: almost 2500 people on Instagram and over 4000 people on Facebook. We hosted a webinar which was attended by 60 participants from around the world and included an interview with a GD patient and her partner conducted by a clinical nurse from the UK. Our keynote speaker was Prof Derralynn Hughes, the chair of the EWGGD presented the EWGGD's statement on home therapy and we were once again joined by two patient group representatives from Italy and Greece who shared their experiences of advocating for home therapy in their countries. The video has also been viewed over 120 times from our YouTube channel.

Introducing GARDIAN

The neurological manifestations of neuronopathic Gaucher disease (nGD), type 2 and type 3, remain a high unmet need. Currently available medicines address the systemic manifestations of the disease, but no intervention to date has successfully penetrated the central nervous system to halt neurological disease.

Therefore, the IGA has invested in the development of a patient led global disease registry to support a better understanding of the natural history of the disease, correlate global phenotypes and genotypes, validate new endpoints/outcomes and to generate a data source that can be used for both regulatory and Health Technology Assessments evaluation of current and emerging treatments for nGD.

Gaucher Registry for Development, Innovation and Analysis of Neuronopathic disease (GARDIAN). Neuronopathic Gaucher disease (nGD) has an unfulfilled need, but with an increasing number of pharmaceutical companies now seeking to develop potential investigational treatment options; it brings hope to many patients & families.

2020 saw a step forward in the development of GARDIAN:

- We developed a new nGD specific PRO (patient reported outcome) and ObsRO (observer reported outcome), that will be validated through the registry and owned by the IGA.
- We held an advisory board of key opinion leaders in the nGD world to advise on clinical data collection.
- We established a new company called International GARDIAN Ltd (IGL), owned by the IGA to govern GARDIAN.
- We appointed a Board of Directors to the IGL including representatives of; caregivers, clinicians, business (pharma and non-pharma), and patient advocacy.
- We secured funding to establish phase one of GARDIAN that will provide a non-site-based patients and carers reported outcomes and the specific nGD PRO and ObsRO that will be translated into 7 languages that will be accessible via an app or website.

Educational Webinars

The IGA continues to support its members to boost their capacities through education and providing them with information about all aspects of Gaucher disease. Following an assessment of training needs, we identified topics that were of importance for our community and during September and October we offered a series of online educational webinars. These meetings were primarily for Gaucher patients and families but were open to the wider Gaucher community including clinicians and pharma representatives.

International Gaucher Alliance Limited
Registered number: 06653373
Directors' Report

The webinars were conducted in a 'town hall' format which meant that there was lots of time for discussion and for participants to ask questions and share their experiences.

- **Gaucher & Parkinson's disease:** We were joined by three panellists: Prof Ari Zimran, Prof Per Svenningsson and Dr Marco Baptista who gave presentations and discussed this key topic. Margaret Giuliani from France moderated the session.
- **EWGGD GD1 guidelines:** The first joint EWGGD/IGA event to develop International type I Gaucher disease clinical management guidelines. Dr Derralynn Hughes and Prof Magy Abdel Wahab hosted the meeting. Prof Chris Hendriksz presented challenges with diagnosis and clinical management in Africa.
- **IGD home therapy:** The focus of the IGD2020 campaign was home therapy, given many challenges that patients face when they had to go to a hospital, especially due to pandemic. We were joined by a clinical nurse, a patient and a carer who all shared their experiences of home therapy. There was also the opportunity to ask questions of Prof Derralynn Hughes, chair of the EWGGD and two patient group representatives who had advocated for home therapy in their countries.
- **Ex vivo gene therapy for type I Gaucher disease:** Focused on the developments in AVROBIO's lentiviral gene therapy. AVROBIO's Chief Scientific Officer, Chris Mason, was our key speaker and Prof Timothy Cox from Addenbrooke's moderated this session.
- **AAV based gene therapy:** Focused on AAV-based gene therapy and Prevail's approach for neuronopathic Gaucher disease. Eriene Wasef, Medical Director at Prevail was our key speaker.

All webinars were recorded and available on YouTube and on the IGA website to view.

Multi-stakeholder meeting (MSM)

The representatives of the IGA are regularly present at different scientific meetings and conferences which are always a good opportunity to get in contact with or continue our collaboration with different stakeholders interested into Gaucher disease (GD). In 2020 we attended at presented at more than 6 virtual international symposiums. Reaching an audience of and developing relationships with pharmaceutical companies (also those which have the treatment for Gaucher still in early development), scientists, physicians, and patients.

As a global organisation we see all stakeholders involved or interested in Gaucher disease as 'a community' and therefore came to the idea that for the best outcome for Gaucher patients, these different stakeholders should come together and collaborate. So, the Multi-stakeholder meeting was born, with a purpose to explore how to enhance collaboration between different stakeholders of the Gaucher community.

The goal is the development of standardised clinical guidelines. The registered MSM participants were from several different countries, representing a global geographical spread and stakeholder groups; key-opinion leaders in GD, scientists, European Medicines Agency, the pharmaceutical industry, patients, and patient advocates. In 2020 the IGA proposed to the EWGGD that we collaborate to form these guidelines.

Clinical Guidelines for Gaucher disease type 1

Clinical guidelines for GD1 is a joint project with the EWGGD which started in September 2020. The European Working Group on Gaucher Disease (EWGGD) is a non-profit network established to promote clinical and basic research into Gaucher disease for the ultimate purpose of improving the lives of patients with this disease; it brings together clinicians, scientists and patients in an open forum for discussion on all aspects of the condition.

International Gaucher Alliance Limited
Registered number: 06653373
Directors' Report

During EWGGD meeting (October 2020), four working groups were established:

1. Diagnosis
2. Treatment and monitoring
3. Comorbidities
4. Outcomes that are important to patients and universal issues related to GD.

These working groups consist of physicians, researchers, and patient representatives.

There are several sub-groups within each working group, e.g., there are four sub-groups in WG4:

- 4.1 Supportive and symptomatic care
- 4.2 Care coordination and transition
- 4.3 Measuring outcomes
- 4.4 Self-management

The members of each sub-group/working group have regular meetings and they prepare the guidelines concerning the topic each group covers, and that will contribute to the international patient centric guidelines for GD1 which will be published on the EWGGD's website.

Biennial online members meeting

Due to the situation with COVID-19 pandemic, the IGA was not able to convene a face-to-face members meeting in 2020. However, we recognize the importance of regular contact and meetings with our membership to enable us to act on our work program, hear their needs and to share information and experiences and so we organised online members meetings. The IGA online General Meeting was held in May and was a formal meeting with office and board reports being presented. The new IGA board which was elected came into office after this meeting. After the formal meeting, Prof Pramod Mistry and Tanya Collin-Histed gave an update on ongoing clinical trials and Dr Derralynn Hughes updated on EWGGD, including COVID-19.

With the same COVID challenges, the face-to-face biennial EWGGD did not take place, therefore the held an online congress in October. Following this we held a series of online members meeting. These took place on Mondays and Thursdays during the two last weeks of October. On Mondays, the meetings were open for our members only and the IGA board and staff team presented key projects and activities. Representatives from Canada, Japan, Romania, South Africa, Turkey, USA, Mongolia, and Israel presented their work, shared experiences, successes but also challenges and concerns. This session was very important and there was a lot of support, understanding, new ideas and good vibes. There was also a very interesting presentation from Orphazyme, giving an update on Arimoclomol. On Thursdays we held educational sessions which our members had shown an interest in learning more about: New-born screening (speakers Dr Juanita Navarette, Mexico and Dylan Simon, USA, moderated by Aviva Rosenberg) and Digital health technology (Daniel Lewi, Aparito, Michael Shapiro -Barr and Kathleen Coolidge, Backpack Health and Shelby Chamberlain, Patient Discovery). These meetings were open for all interested attendees and were recorded and available on YouTube. All sessions were translated in real-time to Spanish to reach a wider audience.

Website development

In November 2018, a taskforce was set up to develop a new website for the IGA. The purpose of the taskforce was to review existing content (to ensure it is accurate, current and easily understandable) and provide new content such as: patient stories, nGD registry, best practice sharing, patient group training, clinical studies and scientific papers. It was also agreed that IGA would source 'real' images for the website where possible to avoid using stock images. Two new features on the website will be to subscribe to the IGA's newsletter and to make online donations using the Stripe payment platform (as part of our fundraising strategy).

International Gaucher Alliance Limited
Registered number: 06653373
Directors' Report

A major improvement to the site will also be to add our membership database on to the backend (securely) so that each member association is able to access and update their own data. Long term there will also be the function to submit membership applications and to complete biennial reports online

Our new website will be more interactive and focussed on the needs of our visitors which are: to describe the types of Gaucher disease and treatments available; how to access treatment; how to find a local patient association; and clinical research.

The majority of the work for the new website was completed in 2020 and the launch date was set for 2021.

Supporting members

The IGA continue to support our member organisations to be more effective and sustainable and undertook an analysis of all country reports to identify current activities, capacities, issues, similarities/differences between regions and their needs. We have identified training needs and six topics were chosen for a series of town hall webinars.

In the past two years, board members also offered help to members in the process of adopting a Code of practice with pharmaceutical companies. As all of us need to act independently and transparently, from the beginning of 2020, it became obligatory for all existing IGA members to have a code of practice or to adhere to the IGA's code, within 6 months of joining the IGA.

Each board member is a contact person for several member organisations with a task to be in touch and to be there for any issue. The IGA board members also wish to attend member's national meetings, to represent the IGA and keep members updated.

Fundraising strategy

Since 2018 the IGA is a globally operating organisation and has begun an exciting new phase of growth which calls for the creation of a more structured, diverse and more entrepreneurial approach to the fundraising development within the organization. It was also acknowledged that in the last years it has become more and more difficult to secure the funds from the pharmaceutical companies (usual IGA's funding avenue) and therefore the IGA board has recognized the need to diversify the funding sources to increase the organisation's independency. For that purpose, in 2018 it was decided to hire a fundraising project manager to research opportunities for possible sources of funding.

The IGA has started to enlarge and strengthen its current fundraising development infrastructure with a focus on the researching of potential funders, communication with them as well as the process of building a relationship with potential funders. Within our fundraising strategy we have also developed and approved an "Ethical Statement on Donations/Sponsorships" in which we have outlined in a more detailed way the ethical principles regarding the acceptance/non-acceptance of the funds from different sources. In 2020 the board reviewed the effectiveness of the funds invested and funds attracted through our fundraising role. Due to the lack of fundraising received in the two years of the post It was decided that we no longer had the resources to maintain this post against its incomings. Going forward the IGA are exploring new ways to utilize the resources we already have to invest more time and efforts into fundraising strategies.

International Gaucher Alliance Limited
Registered number: 06653373
Directors' Report

Relations to other organisations
Rare Disease International (RDI)

As a natural part of being a global organisation the IGA are a member of the RDI. Rare Diseases International is the global alliance of people living with a rare disease of all nationalities across all rare diseases. RDI's mission is to be a strong common voice on behalf of rare disease patients around the world, to advocate for rare diseases as an international public health priority and to represent its members and enhance their capacities. Our CEO Tanya Collin-Histed is the IGA representative in this forum, where a number of IGA member organisations also are represented.

Biosimilars

As biosimilars are becoming a hot topic in the rare disease world, the IGA started to educate its members about them two years ago including a presentation at our 2018 biennial meeting on what biosimilars are. More information was made available via the IGA's newsletters.

Still, a confusion exists among several physicians and patients around the world and the term 'biosimilar' is not consistently used – the same term 'biosimilar' carries different meanings in different countries.

The IGA co-authored/was involved in the publications of the following reports, papers and posters: »
The road to biosimilars in rare diseases - ongoing lessons from Gaucher disease, published in March 2020 issue of American Journal of Haematology (Am J Hematol. 2020; 95:233-237):
Guillermo Drelichman, Gilberto Castañeda-Hernández, Muhlis Cem Ar, Marta Dragosky, Ricardo Garcia, Howard Lee, Sergey Moiseev, Majid Naderi, Hanna Rosenbaum, Irena Žnidar, Andrés Felipe Zuluaga, Selena Freisens, Pramod K. Mistry.

EWGGD representation

Alongside our clinical guidelines for GD1 project, in 2020 we provided evidence to the Ministry of Health in Ukraine on the procurement tenders for treatments for rare diseases, including Gaucher disease to express patient's great anxiety on switching of treatments annually. By working with the European Working Group on Gaucher Disease (EWGGD) we are seeking to develop a statement that would highlight the challenges, backed up with research and data on this approach to help treating physicians, patients, and patient groups to have discussions with governments who are thinking about adopting this approach. The IGA presented at EWGGD virtual congress and spoke about Our older generation, Development of the nGD PRO for GARDIAN co-presented with Elin Haf Davies; Regional Manager Programme co-presented with Dr Ashok Vellodi and we also highlighted collaborative projects, including the development of the GD1 guidelines with Prof Chris Hendrickzs

The IGA is supporting the EWGGD with their social media profile and regular newsletter publication.

Communications strategy

Communication is a fundamental tool for an international organization like the IGA, keeping in constant contact with our members and stakeholders is of vital importance for our work to advance and to achieve goals. This is done through newsletters, emails, social media platform and our website. Each Board director is responsible for the care of some member countries with which it (the board) has more direct communication.

International Gaucher Alliance Limited
Registered number: 06653373
Directors' Report

As the IGA continues to expand new members come from all parts of the world and we are aware that using English as our main language is and will be a challenge for some parts of the world. It is very important to the IGA that our members fully understand the messages we send and the information that we share. Likewise, it is important that our members are given the opportunity to make themselves understood, that they can share information with the IGA and its members that is fully understood.

Directors

The following persons served as directors during the year:

Aviva Risher Rosenberg
Vesna Aleksovska
Irena Znider
Biljana Jovanovic
Kristiyan Dimitrov
Suyog Sathe (appointed 23 May 2020)
Dr Yoram Muller (appointed 23 May 2020)
Anne-Grethe Lauridsen (resigned 9 November 2020)
Aimee - Kate Bosch (resigned 23 May 2020)
Christine White (resigned 23 May 2020)
Paulina Pena Aragon (resigned 23 May 2020)

Small company provisions

This report has 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 on 31 July 2021 and signed on its behalf.



V Aleksovska
Director

**International Gaucher Alliance Limited
Accountants' Report**

**Accountants' report to the directors of
International Gaucher Alliance Limited**

You consider that the company is exempt from an audit for the year ended 31 December 2020. You have acknowledged, on the balance sheet, your responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of accounts. These responsibilities include preparing accounts that give a true and fair view of the state of affairs of the company at the end of the financial year and of its profit or loss for the financial year.

In accordance with your instructions, we have prepared the accounts which comprise the Profit and Loss Account, the Balance Sheet, the Statement of Changes in Equity and the related notes from the accounting records of the company and on the basis of information and explanations you have given to us.

We have not carried out an audit or any other review, and consequently we do not express any opinion on these accounts.

Numerii Limited
Accountants

William Old Centre
Ducks Hill Road
Northwood
HA6 2NP

31 July 2021

**International Gaucher Alliance Limited
Income and Expenditure Account
for the year ended 31 December 2020**

	2020	2019
	£	£
Turnover	232,709	380,781
Cost of sales	-	(892)
Gross profit	<u>232,709</u>	<u>379,889</u>
Administrative expenses	(190,820)	(301,254)
Operating profit	<u>41,889</u>	<u>78,635</u>
Surplus before taxation	<u>41,889</u>	<u>78,635</u>
Tax on surplus	-	-
Surplus for the financial year	<u><u>41,889</u></u>	<u><u>78,635</u></u>

International Gaucher Alliance Limited

Registered number: 06653373

Balance Sheet

as at 31 December 2020

	Notes	2020 £	2019 £
Fixed assets			
Website development	3	19,056	-
Tangible assets	4	4,637	3,586
Investments	5	100	-
		<u>23,793</u>	<u>3,586</u>
Current assets			
Debtors	6	2,002	573
Cash at bank and in hand		<u>180,196</u>	<u>159,740</u>
		182,198	160,313
Creditors: amounts falling due within one year			
	7	(3,385)	(3,182)
Net current assets		<u>178,813</u>	<u>157,131</u>
Net assets		<u>202,606</u>	<u>160,717</u>
Capital and reserves			
Income and expenditure account		202,606	160,717
Members' funds		<u>202,606</u>	<u>160,717</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.



V Aleksovska
Director

Approved by the board on 31 July 2021

International Gaucher Alliance Limited
Statement of Changes in Equity
for the year ended 31 December 2020

	Profit and loss account	Total
	£	£
At 1 January 2019	82,082	82,082
Surplus for the financial year and total comprehensive income for the financial year	78,635	78,635
At 31 December 2019	<u>160,717</u>	<u>160,717</u>
At 1 January 2020	160,717	160,717
Surplus for the financial year and total comprehensive income for the financial year	41,889	41,889
At 31 December 2020	<u>202,606</u>	<u>202,606</u>

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2020

1 Accounting policies

Basis of preparation

The accounts have been prepared under the historical cost convention and in accordance with 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).

The Company applied for Charitable status during the year and was registered as a Charity with the Charities Commission on 27 October 2020. The Registered Charity number is 1192011 . Charity accounts will be prepared for the year ended 31 December 2021.

Turnover

Income from donations and sponsorship is measured at the fair value of the consideration received or receivable. Income is recognised when the company has entitlement to the funds, any performance conditions attached the item of income have been met, and it is probable that the income will be received.

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
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Investments

Investments in subsidiaries, associates and joint ventures are measured at cost less any accumulated impairment losses. Listed investments are measured at fair value. Unlisted investments are measured at fair value unless the value cannot be measured reliably, in which case they are measured at cost less any accumulated impairment losses. Changes in fair value are included in the profit and loss account.

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.

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2020

Taxation

A current tax liability is recognised for the tax payable on the taxable profit of the current and past periods. A current tax asset is recognised in respect of a tax loss that can be carried back to recover tax paid in a previous period. Deferred tax is recognised in respect of all timing differences between the recognition of income and expenses in the financial statements and their inclusion in tax assessments. Unrelieved tax losses and other deferred tax assets are recognised only to the extent that it is probable that they will be recovered against the reversal of deferred tax liabilities or other future taxable profits. Deferred tax is measured using the tax rates and laws that have been enacted or substantively enacted by the reporting date and that are expected to apply to the reversal of the timing difference, except for revalued land and investment property where the tax rate that applies to the sale of the asset is used. Current and deferred tax assets and liabilities are not discounted.

Foreign currency translation

Transactions in foreign currencies are initially recognised at the rate of exchange ruling at the date of the transaction. At the end of each reporting period foreign currency monetary items are translated at the closing rate of exchange. Non-monetary items that are measured at historical cost are translated at the rate ruling at the date of the transaction. All differences are charged to profit or loss.

Pensions

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

2 Employees	2020 Number	2019 Number
Paid employees	3	2
Volunteer directors	8	9
Average number of persons employed by the company	<u>11</u>	<u>11</u>

3 Website Development	£
Cost	
Additions	19,056
At 31 December 2020	<u>19,056</u>
Amortisation	
At 31 December 2020	<u>-</u>
Net book value	
At 31 December 2020	<u>19,056</u>

The above comprises costs incurred to date on the building of the organisation's website. Once completed the cost will be spread over the economic useful life of the asset.

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2020

4 Tangible fixed assets

	Plant and machinery etc £
Cost	
At 1 January 2020	5,747
Additions	<u>2,503</u>
At 31 December 2020	<u>8,250</u>
Depreciation	
At 1 January 2020	2,161
Charge for the year	<u>1,452</u>
At 31 December 2020	<u>3,613</u>
Net book value	
At 31 December 2020	<u>4,637</u>
At 31 December 2019	<u>3,586</u>

5 Investments

	Investments in subsidiary undertakings £
Cost	
Additions	100
At 31 December 2020	<u>100</u>
Historical cost	
At 31 December 2020	<u>100</u>

6 Debtors

	2020 £	2019 £
Amounts owed by group undertakings and undertakings in which the company has a participating interest	2,002	-
Other debtors	-	573
	<u>2,002</u>	<u>573</u>

7 Creditors: amounts falling due within one year

	2020 £	2019 £
Taxation and social security costs	2,420	2,184
Other creditors	965	998
	<u>3,385</u>	<u>3,182</u>

International Gaucher Alliance Limited
Notes to the Accounts
for the year ended 31 December 2020

8 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:

	2020	2019
	£	£
Administration fees	497	1,398

During the year the company has recharged costs to the Gauchers Association Limited as follows:

	2020	2019
	£	£
Consultancy fees	4,416	3,400
Administration fees	197	1,441

Directors have made donations of their services to the company during the year to the value of £40,775 (2019: £72,500). Administration expenses include directors fees for services donated to the company of £40,775 (2019: £72,500) and turnover includes donations by the directors of £40,775 (2019: £72,500) in respect of their services to the company.

During the year the Company made an Investment in a Limited company, International Gardian Limited ("IGL"). During the year the company made payments on behalf of IGL amounting to £2,102

9 Controlling party

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

10 Other information

International Gaucher Alliance Limited is a private company limited by guarantee and incorporated in England. Its registered office is:

8 Silver Street
Dursley
Gloucestershire
GL11 4ND

International Gaucher Alliance Limited
Detailed profit and loss account
for the year ended 31 December 2020

This schedule does not form part of the statutory accounts

	2020	2019
	£	£
Sales		
Sales	<u>232,709</u>	<u>380,781</u>
Cost of sales		
Purchases	<u>-</u>	<u>892</u>
Administrative expenses		
Employee costs:		
Wages and salaries	87,056	79,946
Directors' salaries	40,775	72,500
Pensions	1,786	1,761
Employer's NI	8,547	8,218
Staff training and welfare	-	400
Travel and subsistence	21,112	54,812
Entertaining	147	599
	<u>159,423</u>	<u>218,236</u>
Premises costs:		
Rent	4,560	3,600
Light and heat	1,988	5,948
	<u>6,548</u>	<u>9,548</u>
General administrative expenses:		
Telephone and internet	1,466	1,269
Postage	93	877
Stationery and printing	2,800	12,935
Subscriptions	3,384	2,798
Bank charges	535	527
Insurance	1,683	1,503
Equipment expensed	75	112
Software	5,400	12,288
Repairs and maintenance	170	173
Depreciation	1,452	1,235
Sundry expenses	(2,326)	2,930
	<u>14,732</u>	<u>36,647</u>
Legal and professional costs:		
Accountancy fees	1,272	1,692
Consultancy fees	6,519	33,649
Other legal and professional	2,326	1,482
	<u>10,117</u>	<u>36,823</u>
	<u>190,820</u>	<u>301,254</u>