

Registered number  
06653373

International Gaucher Alliance Ltd

Report and Accounts

31 December 2019

**International Gaucher Alliance Ltd**  
**Report and accounts**  
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**International Gaucher Alliance Ltd  
Company Information**

**Directors**

Anne-Grethe Lauridsen  
Vesna Aleksovska  
Irena Znidar  
Biljana Jovanović  
Aimee-Kate Bosch  
Christine White  
Diana Pena Aragon  
Kristijan Dimitrov  
Aviva Rosenberg

**Secretary**

Biljana Jovanović

**Accountants**

Numerii Limited  
Park House  
15-23 Greenhill Crescent  
Watford  
Herts  
WD18 8PH

**Registered office**

8 Silver Street  
Dursley  
Gloucestershire  
GL11 4ND

**Registered number**

06653373

**International Gaucher Alliance Ltd**  
**Registered number: 06653373**  
**Directors' Report**

The directors present their report and accounts for the year ended 31 December 2019.

**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 are to:

- improve Gaucher patients' access to optimal diagnosis, treatment and care
- provide a strong voice for Gaucher patients worldwide
- 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 2019 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 our 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.

**Key activities in 2019**

**Humanitarian Aid**

From day one the (then) EGA have pledged to help any Gaucher patient who asks for help wherever they live in the world. Advocating for charitable treatment has always been and will continue to be the IGA's priority.

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Getting access to treatment is just a small part of the process for each patient. The IGA works closely with local patient advocates, patients and their families, doctors and the pharmaceutical industry, bringing everyone together to ensure a confirmed diagnosis, a treating educated doctor, access to correct treatment, linking to patient advocacy in the country if any, and finally a long term relationship so that the patient/family always knows where to go if they need the IGA.

There are three pharmaceutical companies who provide treatment to Gaucher patients who are not able to get access to it in their own countries through their healthcare programmes: Pfizer, Sanofi Genzyme and Takeda. Each company operates their programme in different ways:

**Pfizer:** PfizerCares programme offer the IGA Elelyso to patients on an ad-hoc basis, although once committed the treatment is for as long as the patient needs it. The IGA allocates the treatment using its database. This programme supports patients in Pakistan, Mongolia, Zimbabwe, Rwanda, Afghanistan, Morocco, India, Iran and Botswana.

**Sanofi Genzyme (SGZ):** SGZ current programme is only open to accept applications from paediatric patients. Each patient is assessed by their local medical team and a report sent to their central team for a decision. In 2019 this programme has provided treatment to many patients in Kenya, Rwanda, India, Sudan, Pakistan and has supported fact-finding for patients in Botswana, Lebanon, Qatar, Morocco, Palestine and Uzbekistan regarding diagnostics, finding a treating doctor and liaising with the government.

**Takeda:** Takeda's programme is managed by an independent Medical Expert Committee (MEC) that the IGA sits on as the patient voice. This programme undertakes due diligence in each country to identify the current situation. The IGA feeds into this process using its knowledge of where there are patients with no access to treatment. The programme offers tailored programmes for educating doctors in partnership with other organisations such as FYMCA and the MEC in regions such as North Africa, Central Africa, South America, Caucasus and Central Asia and then opens its programmes to these countries for applications for treatment. 2019 countries are: Kenya, Tunisia, Pakistan, Indonesia, Sudan, Palestine, Botswana, Ghana, Nigeria, Tanzania and Ethiopia.

In 2019, the IGA received 52 direct requests for treatment from 11 countries: Tunisia, Tanzania, Pakistan, Sudan, Kenya, Algeria, Qatar, Rwanda, Iran, India and Morocco. By working closely with Sanofi Genzyme and Takeda the IGA helped to give a future to 37 Gaucher patients as they received donated ERT. Sadly, 8 patients who reached out to the IGA for support died without getting access to the treatment they needed.

**Educating Doctors**

Diagnostics, treatment, clinical care and management all centre around doctors who are educated and know the signs and symptoms, where to get a patient tested, what test to do, how to get access to it, how to assess their disease progression, what treatments are available, and which are best for their patient. As with any rare disease, this is challenging and therefore the IGA has a strong focus on educating doctors and does this through many different channels, which include:

- Gaucher Preceptorship in conjunction with the Takeda humanitarian aid programme in London with doctors from the Takeda charitable access programme.
- North African countries three-day education programme for inherited metabolic disorders that concentrated on signs and symptoms for diagnosis and also understand limitation of access to equipment and medicines. This was run by FYMCA.
- Multi-stakeholder event run by Bioevents (Prof Ari Zimran) in Vienna and Bogota to raise the profile of lysosomal storage disorders.

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- Takeda Gaucher Expert Summit (GES) & Sanofi Genzyme Gaucher Leadership Forum (GLF) to talk about patient advocacy and patient perspectives.
- EWGGD to use this platform to raise the challenges in countries such as Sudan and Pakistan regarding access to treatment.
- Using the IGA's Regional Manager programme to target education programmes in countries where there is little or no understanding of rare diseases and Gaucher and start to build knowledge among doctors.
- Sanofi Genzyme's 5<sup>th</sup> Annual Bone Meeting in Argentina where the IGA's CEO, board member and volunteer hosted a 90-minute workshops on patient perspective on bone health in GD that was delivered in three ways: a presentation, a patient doctor interview and audience participation of identifying what the patient and doctor challenges were to develop a list of priorities for future working.

**IGA's Global Patient nGD Registry**

The neurological manifestations of neuronopathic Gaucher disease (nGD) 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 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.

Phase 1 commenced in January 2019 and lasted 21 weeks to undertake a feasibility study to evaluate development of a patient led global nGD registry. Four pharmaceutical companies responded to participate and fund Phase I: Oxyrane, Pfizer, Prevail and Sanofi Genzyme. Phase 1 included five workstreams:

- Involvement of patients and parents/carers;
- Input of pharmaceutical companies to define how such a registry could work for them in terms of compliance, governance and regulation;
- Involvement of global key opinion leaders in a Delphi process to identify what data
- Designing the technical architecture of the global registry;
- Communication/ engagements and project management.

The outcomes from Phase 1 included recommendations for implementing a global disease registry to meet the needs of all the stakeholders and offer a sustainable business plan to make the registry a viable asset for the patient community. The registry will have three different platforms:

- Clinical data collection at sites as identified in the IGA's phase 1 report
- A patient portal that will collect patient reported outcomes and caregiver outcomes
- Wearable technology that will support the collection of day to day patient functions

In preparation for the launch, when our first sponsor is identified, behind the scenes work is being undertaken so everything is ready to go, including:

- Developing a nGD specific **Patient Reported Outcome** and a caregiver observation.
- Designing how the data will flow from the clinical sites and the patient App.
- Finalising the clinical data fields that will be in the registry and the patient app.

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The registry will be called GARDIAN; Gaucher Registry for Development Innovation and Analysis of Neuronopathic Disease.

**Medicines Development**

One of the goals of the IGA is to position ourselves as the 'Go to' for medicines development to ensure that the patient voice is heard, that the symptoms and disease burden is understood and that new therapies meet the needs of our community.

The IGA works hard to identify, communicate and work in collaboration with companies who have an interest in the development of potential new therapies for Gaucher disease, from pre-clinical to identifying patients for clinical trials and distributing clinical trial reports.

During 2019 the IGA worked with 15 different pharmaceutical companies who are currently interested in Gaucher disease, by:

- Participating in advisory boards
- Developing Protocol design
- Identifying patients for clinical trials
- Developing Patient factsheets and consent forms
- Developing Patient Reported Outcomes (PROs)
- Linking with patients to undertake surveys
- Presenting the patient perspective
- Looking at repurposing medicines

These companies include: Avrobio, Azafaros, Evox, Freeline, Gain, ISU Abxis, JCR, Orphazyme, Oxyrane, Prevail, Pfizer, Relay, Sanofi Genzyme, Smartpharm and Takeda.

The role of the IGA and patient advocacy groups in medicines development has changed significantly with the increased sophistication of patient advocates and there is an expectation that patient advocates understand the science behind the new therapies in order to contribute to the discussions and be an advocate for the whole community thus requiring an in-depth knowledge of the disease, its pathology and different drug mechanisms.

The IGA is also aware of the continuing shortage of medicines to Gaucher patients due to the high cost of current treatments in many parts of the world resulting in patients dying unnecessarily. Therefore, the IGA work with other stakeholders to identify other possible treatment avenues for patients, e.g. the use of bone marrow transplantation (BMT) in Pakistan and repurposed medicines like Ambroxol. The IGA are aware that Ambroxol is being used by some patients across the world, in particular for nGD patients. However, to date no clinical trial, other than the one in Japan for GD 3, has been undertaken to gain enough clinical data to provide safety and efficacy data for GD1 and 3 patients. One of the IGA's goal is to do this with a group of key opinion leaders over the next few years.

**Website development**

In November 2018, a taskforce was set up to develop a new website for the IGA:

Reviewing existing content (to ensure it is accurate, current and easily understandable) and providing 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).

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.

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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.

**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 is obligatory for all existing IGA members to have a code of practice or to adhere to the IGA's code.

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.

**Regional Manager programme**

With the IGA's transformation into a global organization, the regional managers (RM) programme was developed to grow the IGA's footprint and establish local representatives who can be the eyes and ears of the IGA in different countries that have Gaucher patients but do not have any formal patient organization or have many unmet challenges. The positions of regional managers have been taken up on a voluntary basis by young adult Gaucher patients who have participated in the IGA's "Go with Gaucher" programme, which is about empowering and taking forward the next generation of Gaucher advocates.

**The target outcomes of the regional manager programme aligned with other key activities for 2019:**

- Educate doctors
- Create awareness
- Improve diagnostics
- Establish Centers of Excellence
- Develop clinical guidelines
- Collaborate with governments
- Patient advocacy
- Create a database

To accomplish these objectives, the RMs liaise with doctors, patients, pharma, governments and patient groups to identify and address challenges faced by patients in their region.

Marketa Smockova had the opportunity to attend a regional meeting in the Adria region, where she met around 100 patients from the region and learnt about their challenges, providing possible solutions and guidance on how the IGA can help.

Shashank Tyagi, together with Suyog Sathe, arranged an educational meeting in Nepal with the help of Dr. Ashok Vellodi. The meeting was well attended by a large number of local pediatricians and geneticists. Lectures were held in three different cities of Kathmandu, Biratnagar and Dharan. A gathering of patients/families was also organized in Kathmandu to understand their challenges and offer possible solutions.

Patricia Lucki is working with the Health Commission of the Central American Parliament to include rare diseases and genetic diseases in the Central American Health Policy Plan. She plans to set up a meeting with the health ministers, directors of the Social Security Institutes of the eight countries in the region, and the Central American Health Commissioner.

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Adel Kaplan is working on creating a database of patients, doctors, and officials in her region. She plans to give special emphasis to Kazakhstan, whose patient organization has long successfully cooperated with the IGA.

**Some major challenges identified were the lack of diagnostic infrastructure in many countries, lack of government financial support or insurance for treatment, lack of awareness among doctors and lack of clinical guidelines.**

**Gaucher Disease and Comorbidities (Parkinson's)**

One of the focus points in the IGA strategic plan was for us to build up a better understanding of the impact of being diagnosed with a co-morbidity, and by the end of 2023 put in place a structure to support Gaucher patients and families affected by co-morbidities.

The definition of true co-morbidities in relation to Gaucher Disease is as presented in The American Journal of Hematology): Non-Hodgins B-cell Lymphoma/Myeloma and Parkinson's Disease. The project group have taken a multi-phase approach, beginning with Parkinson's Disease, as approximately 8% of carriers of Gaucher Disease risk having Parkinson's Disease and we hope to identify Health Care Providers who are willing to participate in the project.

There is a need to develop educational papers/sessions for Health Care Providers in order to facilitate communication between Gaucher and Parkinson's Disease experts.

The aim of the project is to develop a community for patients and their families with Gaucher Disease and Parkinson's disease and to identify support needed. Therefore, we will reach out based on number of Gaucher/Parkinson's Disease patients in country reports.

**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.

**Older Generation project**

With access to treatment Gaucher patients live longer and many live into retirement age, and the IGA want to identify and map any unmet needs both medical and non-medical for these patients (55 years or older). Questionnaires for patients, IGA member organisations and for doctors/other professionals will be developed and with help from all IGA members will be translated, disseminated and collected. The IGA will publish the findings to raise awareness and provide evidence where relevant.

## **Relations to other organisations**

### **RDI**

As a natural part of being a global organisation the IGA applied and became 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.

### **MetabERN**

MetabERN (European Reference Network for hereditary metabolic disorders) is a network established by the EU to facilitate access to the best available care and address the needs for all patients affected by any IEM. The IGA is involved through participating in the annual meeting and the being connected to the Patient Board. In particular, we follow the Subnetwork focused on lysosomal diseases. Internally we have a work stream who together work to put forward the voice of Gaucher patients and the IGA.

### **Eurordis**

As a Eurordis member the IGA participate in a number of meetings and events, such as the annual members meeting and also the annual seminar of the CEF (Council of Federations).

As a patient representative in the MetabERN, Anne-Grethe Lauridsen has registered as ePAG (European Patient Advocacy Group) with Eurordis and have through this the opportunity to participate in workshops during the annual members meeting, workshops that cover both educational sessions and time for peer-support-talks. Furthermore, Anne-Grethe has participated in Eurordis Open Academy Leadership School that provides an on-line capacity-building programme on leadership, network management, healthcare and research.

### **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 2019, we attended Gaucher Leadership Forum, EWGGD Meeting, WORLD Conference, and there we met with several pharmaceutical companies (also those which have the treatment for Gaucher still in early development), scientists and physicians.

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 1st MSM was organised in 2017 and the 2nd MSM was planned for December 2019, however had to be postponed until 2020. 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.

### **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.

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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.

As a response to the confusion regarding the understanding of what a biosimilar drug is, Sanofi Genzyme organised a round-table meeting ("Biologics and Biosimilarity in Rare Diseases Expert Meeting", 2017) to discuss the understanding and the challenges related to biosimilars and non-comparable biotherapeutics for rare diseases. IGA was invited to actively participate at this meeting. Board member Irena Znidar attended the meeting as IGA representative. A scientific paper titled "The road to biosimilars in rare diseases - ongoing lessons from Gaucher disease" was written and is due to be published in 2020.

**EWGGD representation**

In 2019 the 13th EWGGD workshop was held in Clermont Ferrand in July. As the IGA had their biennial members meeting in Riga in October 2018, only the Board and CEO of the IGA attended the EWGGD meeting, at which we presented on the work of the IGA and unmet needs within the community. We also awarded the IGA award to Dr Aimee Donald for her contribution to expanding the knowledge in neuronopathic Gaucher disease.

The election of the new board under the Chairmanship of Prof. Derralynn Hughes and Vice chairmanship of Prof. Marc Berger has established an ambitious programme of activities designed to move the organisation from a more limited aspiration of organising a meeting once every two years to creating a connected Gaucher community with a full programme of work. Aspirations include the encouragement of research projects, the establishment of preceptorships and to use the EWGGD platform to further encourage mutual collaboration to meet the needs of the Gaucher community.

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.

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.

**International Gaucher Day**

Since the transition from the European Gaucher Alliance to the International Gaucher Alliance, we have worked towards the goal of making International Gaucher Day more accessible to our members. We re-shaped the aims with our membership to try and understand barriers that different membership countries face with regards to the participation in IGD. We also tried to understand what resources they would require to better participate in IGD. For many, a main issue was being able to get their members together to celebrate IGD. It was for these reasons that IGD transitioned from separate awareness days in each country, to a social media based awareness day/campaign. This aimed to incorporate the participation of not only IGA member countries, but pharmaceutical companies, medical professionals and key opinion leaders.

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In 2019 we celebrated our patient's own personal Rare Stars which included parents, caregivers, personal nurses, local physicians and patients themselves. In 2018 the response to the IGD social media campaign was encouraging and by 2019, we saw an even greater response. Interaction and sharing of posts created the awareness we were hoping for and certainly made a name for the IGA in the Rare Disease community.

In addition to our featured Rare Stars, infographics displaying facts and information about Gaucher Disease were shared daily on our social media platforms and we worked towards making these resources available on our website in an editable format, that some members translated into their local languages.

To celebrate and commemorate the day, we had transfer tattoos and encouraged our members to share photos and "selfies" on our social media platforms with these tattoos to help create awareness. They were encouraged to use the hashtags #IGD2019 and #rarebutnotalone.

2019 was a difficult year for the IGA Board with the Chair leaving at short notice in January and our vice chair Vesna Aleksovska stepping up into the role, she has done this successfully with the Board and staff team around her and the IGA have gone from strength to strength.

**Directors**

The following persons served as directors during the year:

- Pascal Niemeyer (resigned 11 February 2019)
- Anne-Grethe Lauridsen
- Vesna Aleksovska
- Irena Znidar
- Biljana Jovanović
- Aimee-Kate Bosch
- Christine White
- Diana Pena Aragon
- Kristiyan Dimitrov
- Manjit Singh (resigned 5 July 2019)
- Aviva Rosenberg (appointed 25 October 2019)

**Directors' interests**

The directors, who are members, guarantee to contribute an amount not exceeding £1 to the assets of the company in the event of a winding up.

**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 24 July 2020 and signed on its behalf.

Vesna Aleksovska  
Director

**International Gaucher Alliance Ltd  
Accountants' Report**

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

You consider that the company is exempt from an audit for the year ended 31 December 2019. 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

Park House  
15-23 Greenhill Crescent  
Watford  
Herts  
WD18 8PH

24 July 2020

**International Gaucher Alliance Ltd  
Income and Expenditure Account  
for the year ended 31 December 2019**

	<b>year ended 31 December 2019 £</b>	<b>17 month period ended 31 December 2018 £</b>
<b>Turnover</b>	380,781	455,013
Cost of sales	(892)	-
<b>Gross surplus</b>	<u>379,889</u>	<u>455,013</u>
Administrative expenses	(301,254)	(431,419)
<b>Operating surplus</b>	<u>78,635</u>	<u>23,594</u>
Interest payable	-	(25)
<b>Surplus before taxation</b>	<u>78,635</u>	<u>23,569</u>
Tax on profit	-	-
<b>Surplus for the financial year</b>	<u><u>78,635</u></u>	<u><u>23,569</u></u>

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**Balance Sheet**

as at 31 December 2019

	Notes	2019 £	2018 £
<b>Fixed assets</b>			
Tangible assets	3	3,586	4,599
		<u>3,586</u>	<u>4,599</u>
<b>Current assets</b>			
Debtors	4	573	149
Cash at bank and in hand		159,740	146,279
		<u>160,313</u>	<u>146,428</u>
<b>Creditors: amounts falling due within one year</b>	5	(3,182)	(68,945)
<b>Net current assets</b>		<u>157,131</u>	<u>77,483</u>
<b>Total assets less current liabilities</b>		<u>160,717</u>	<u>82,082</u>
<b>Net assets</b>		<u>160,717</u>	<u>82,082</u>
<b>Capital and reserves</b>			
Income and expenditure account		160,717	82,082
<b>Members' funds</b>		<u>160,717</u>	<u>82,082</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.

Vesna Aleksovaska

Director

Approved by the board on 24 July 2020

**International Gaucher Alliance Ltd**  
**Statement of Changes in Equity**  
**for the year ended 31 December 2019**

	<b>Profit and loss account £</b>	<b>Total £</b>
<b>At 1 August 2017</b>	58,513	58,513
Surplus for the financial period and total comprehensive income for the financial period	23,569	23,569
<b>At 31 December 2018</b>	<u>82,082</u>	<u>82,082</u>
<b>At 1 January 2019</b>	82,082	82,082
Surplus for the financial year and total comprehensive income for the financial year	78,635	78,635
<b>At 31 December 2019</b>	<u>160,717</u>	<u>160,717</u>

**International Gaucher Alliance Ltd**  
**Notes to the Accounts**  
**for the year ended 31 December 2019**

**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).

***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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***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.

***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.

**International Gaucher Alliance Ltd**  
**Notes to the Accounts**  
**for the year ended 31 December 2019**

***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.

<b>2 Employees</b>	<b>2019</b>	<b>2018</b>
	<b>Number</b>	<b>Number</b>
Average number of persons employed by the company:		
Paid employees	2	-
Volunteer directors	9	10
Total average number of persons employed by the company including volunteer directors	<u>11</u>	<u>10</u>
<b>3 Tangible fixed assets</b>		<b>Plant and machinery etc</b>
		<b>£</b>
<b>Cost</b>		
At 1 January 2019		5,524
Additions		223
At 31 December 2019		<u>5,747</u>
<b>Depreciation</b>		
At 1 January 2019		925
Charge for the year		1,236
At 31 December 2019		<u>2,161</u>
<b>Net book value</b>		
At 31 December 2019		<u>3,586</u>
At 31 December 2018		<u>4,599</u>
<b>4 Debtors</b>	<b>2019</b>	<b>2018</b>
	<b>£</b>	<b>£</b>
Other debtors	573	149
	<u>573</u>	<u>149</u>
<b>5 Creditors: amounts falling due within one year</b>	<b>2019</b>	<b>2018</b>
	<b>£</b>	<b>£</b>
Taxation and social security costs	2,184	-
Other creditors	998	68,945
	<u>3,182</u>	<u>68,945</u>

**International Gaucher Alliance Ltd**  
**Notes to the Accounts**  
**for the year ended 31 December 2019**

**6 Related party transactions**

Jeremy Manuel, a director of the company until his resignation on 15 October 2018, and now Honorary President of the company, is also a director of The Gauchers Association Limited. Tanya Collin-Histed, Chief Executive Officer of the company, is a director of The Gauchers Association Limited. During the year charges were received from The Gauchers Association Limited as follows:

	<b>year ended 31 December 2019</b>	<b>17 month period 31 December 2018</b>
	<b>£</b>	<b>£</b>
Administration fees	1,398	121,123

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

	<b>year ended 31 December 2019</b>	<b>17 month period 31 December 2018</b>
	<b>£</b>	<b>£</b>
Consultancy fees	3,400	-
Administration fees	1,441	-

Directors have made donations of their services to the company during the period to the value of £72,500 (2018: £114,233). Administrative expenses include directors fees for services donated to the company of £72,500 (2018: £114,233) and turnover includes donations by the directors of £72,500 (2018: £114,233) in respect of their services to the company.

**7 Controlling party**

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

**8 Other information**

International Gaucher Alliance Ltd (formerly known as European Gaucher Alliance) is a private company limited by guarantee and has no share capital. The liability of each member in the event of a winding up is limited to £1. The company is incorporated in England. Its registered office is:

8 Silver Street  
Dursley  
Gloucestershire  
GL11 4ND