IGA INTERNATIONAL GAUCHER ALLIANCE
Driven by passion for patients

International advocacy for Gaucher patients since 1994

CELEBRATING
30
YEARS
of patient
advocacy

Impact Report 2024

IGA's Biennial Members Meeting, Lisbon, November 2024

www.gaucheralliance.org

Registered Charity Number: 1192011

Table of contents

About the IGA
Page 03

Our Impact in 2024: Stories of Change
Pages 04

Driving Change Worldwide: 2024 Highlights
Pages 05-08

Biennial General Meeting
Pages 09-10

International Gaucher Day
Page 11

Global Collaborative Effort for Gaucher Disease: A Step Towards Improving Healthcare
Page 12

Financial Report
Page 13

In 2025 we commit to Advancing Patient Support & Research Globally
Page 14

A message from the CEO and Chair of the IGA

As we reflect on 2024, a landmark year marking the 30th anniversary of the International Gaucher Alliance (IGA), we are filled with immense pride and gratitude for the progress we've made together.

This year was a powerful reminder of what can be achieved through commitment, collaboration, and community. From launching our first-ever International Gaucher Day Lecture to introducing the Anne-Grethe Lauridsen Award—honouring Anne-Grethe's tireless dedication to supporting young Gaucher patients—2024 was a year defined by both legacy and innovation.

We strengthened our efforts to improve diagnosis, educate healthcare professionals, and support and fight for access to treatment through working with the companies charitable access programmes, across the globe but especially in areas of huge unmet needs. Our biennial Members Meeting in Lisbon brought our global network together once again, sparking inspiration, dialogue, and renewed energy for the path ahead.

Another proud milestone was our involvement in the establishment of the Global LSD Collaborative, where the IGA has played a central role in fostering cross-disease cooperation to improve outcomes for patients worldwide.

Everything we've achieved this year is rooted in our unwavering dedication to making the world a better place for Gaucher patients and their families. That dedication is brought to life every day by our extraordinary team, our passionate members, and our trusted collaborators.

Our strength lies in our unity—our ability to listen, to lead, and to stand together. The recognition, respect, and visibility the IGA continues to earn across the rare disease community is a testament to this shared purpose.

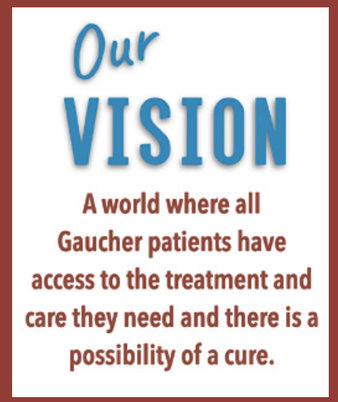
As we look ahead, we remain grounded in our mission and inspired by our global community. Thank you for standing with us.

Aimeé-Kate Bosch (CHAIR)

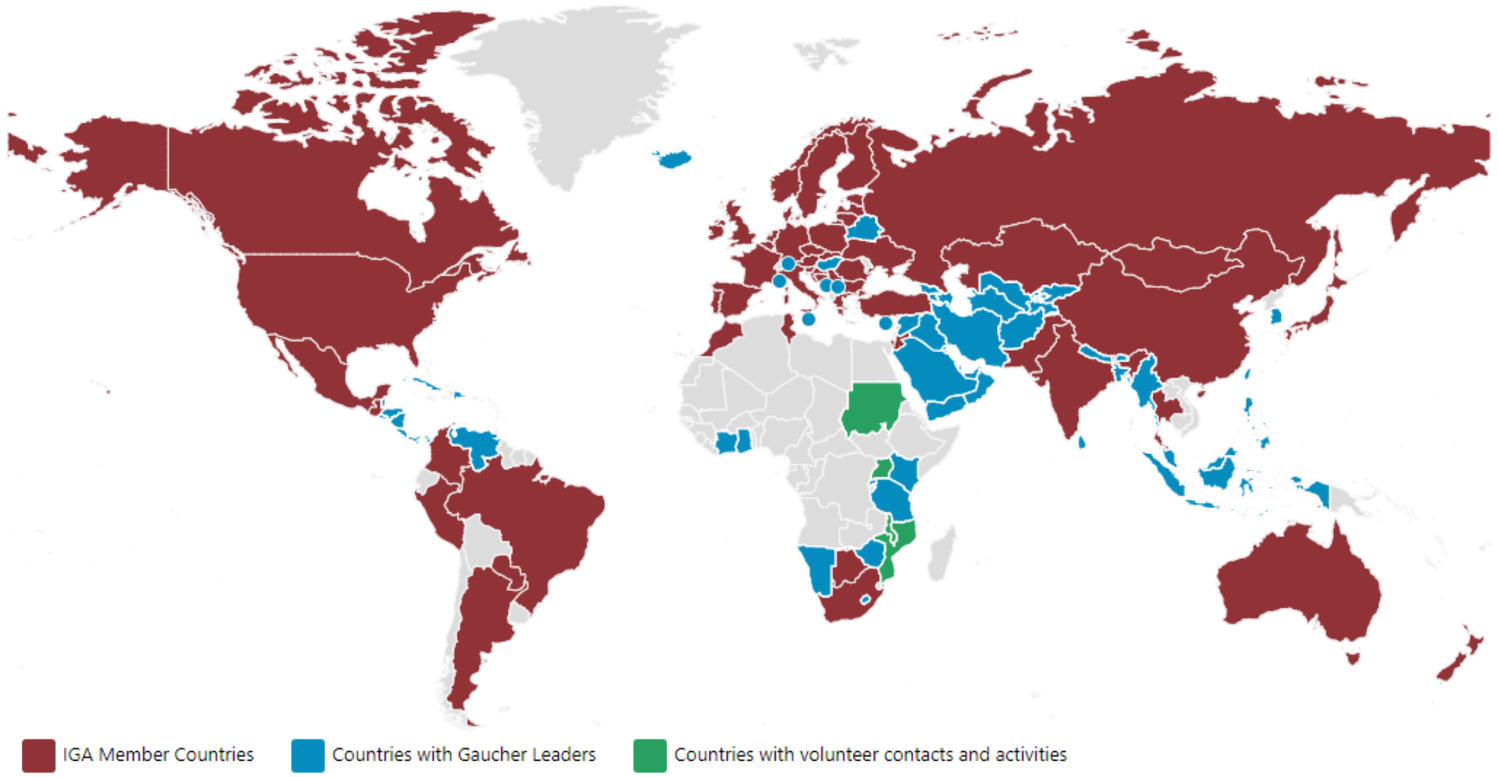
Tanya Collin-Histed (CEO)

The IGA

The IGA is a patient-led international organisation that has become the ‘go to’ global voice for over **90%** of the Gaucher community (see map) and has built its reputation through listening to and delivering outcomes that have impacted patients and their carers’ lives.



Our Global Reach



The impact IGA is making globally is remarkable, and I am proud to play even a small role in advancing its mission. It’s motivating to know that our collective efforts are making a tangible difference globally and more so in the region. I look forward to another productive year of collaboration and positive change!

Roselyn Odero, Gaucher Leader, Kenya

"Collaborating with the IGA´s on projects worldwide is a privilege and an honour. I know we will continue working together in 2025... and beyond!"

Carolina Toneloto, IGA volunteer, Brazil

Our Impact in 2024: Stories of Change

IWGGD collaboration

Educational webinars

Charitable access to treatment

International Collaboration

Global Gaucher Connect Programme

Gaucher voices podcast

International Gaucher Day

Over 100 volunteers

Africa newsletter

Driving Change Worldwide: 2024 Highlights

CHARITABLE ACCESS TO MEDICINES

Countries: Patients/caregivers from 18 countries reached out to the IGA for support to access treatment for Gaucher disease, a total of 23 patients.
Requests came from Armenia, Cuba, Ecuador, Gaza, Ghana, India, Iran, Malawi, Mongolia, Morocco, New Zealand, Pakistan, Peru, Sri Lanka, Turkmenistan, Sudan, Kenya and Zambia

Approved: 5 through Sanofi ICAP and PfizerCares.

Deaths: 2 Malawi and India

Unresolved cases: India (2), Jordan (4), Afghanistan (1), Botswana (2), Nepal (1), Singapore (1)

Company Charitable programmes: Takeda 27; PfizerCares India (2); Sanofi (3)

The Sanofi ICAP approved additional patients' access to Cerezyme through their charitable programme; the two cases stated here were applications that the IGA supported directly.

This video outlines our efforts in the Humanitarian Aid area

IMPACT OF WAR

Sadly, the war in Sudan has displaced many patients, and it has taken a considerable amount of time to get treatment back into the country. We are aware of at least two patients who died during this time. The IGA, in partnership with Sanofi, supported the relocation of two siblings to Saudi Arabia where they had family to receive treatment. The IGA has been in constant communication with many of these families to ensure that they are aware of what is happening regarding treatment and access.

A new patient who contacted the IGA just before the start of the war has reconnected with the IGA in late 2024 and we are now working to support this patient. Three siblings from Gaza contacted our colleagues at Shaare Zedek Hospital in Israel asking for support. The IGA, Shaare Zedek, Sanofi and Direct Relief worked with other international colleagues to get treatment in Gaza. Sadly, although all the paperwork had been completed, the war meant that we were not able to get into the country. Communication with the siblings is ongoing and we are committed to supporting them.

SUPPORT TO PATIENTS AND FAMILIES

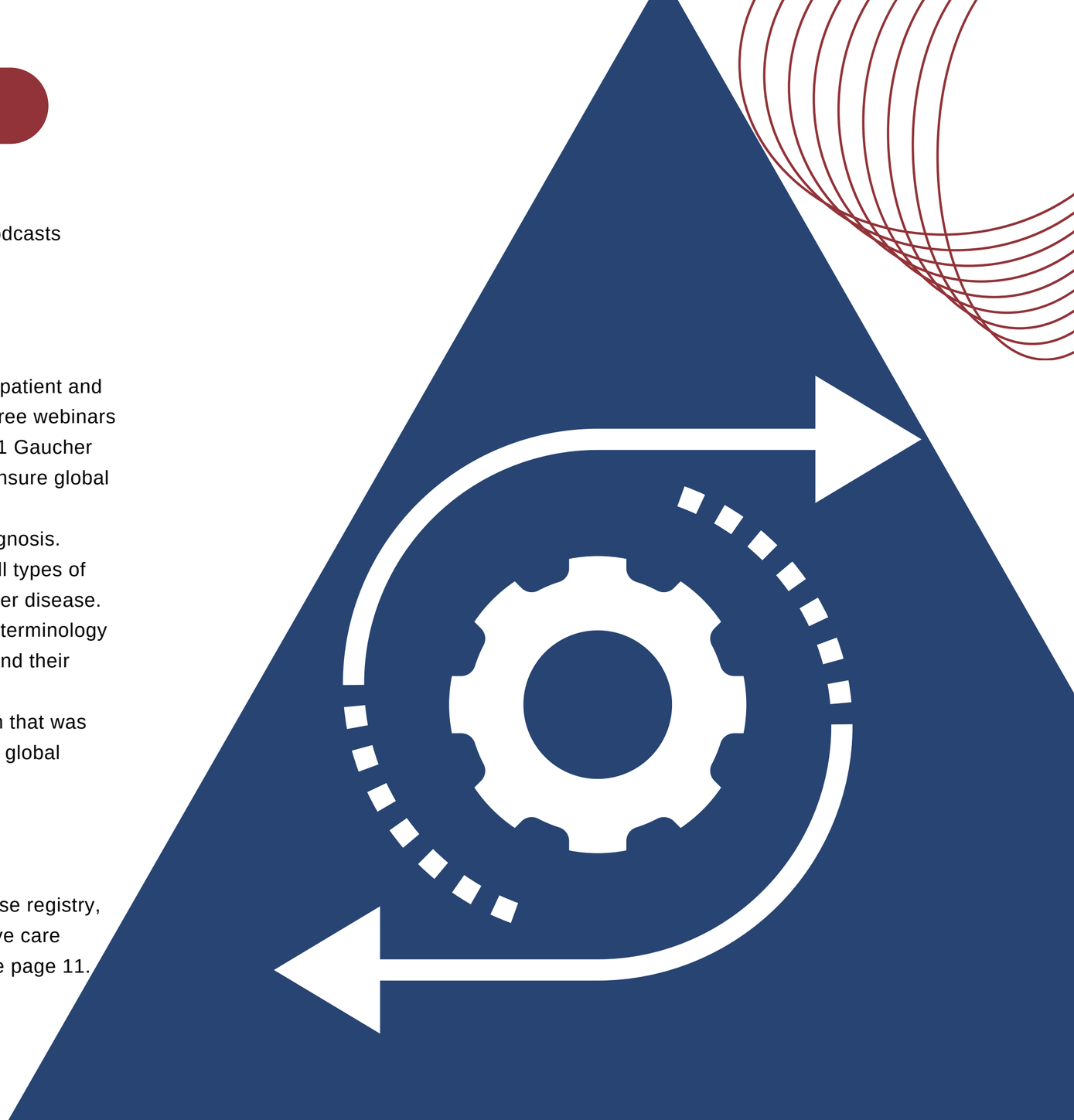
Requests for support were received from Sweden, the UK, Iran, Peru, Turkey, Rwanda, Zimbabwe, Sri Lanka, Egypt, Tunisia, Mozambique and Argentina and included:

- Access to expert advice on GD2 issues
- Information about research into GD2
- Access to expert clinical advice on seizures
- Access to expert clinical advice on bone disease and treatment
- Advice on how to treat GD3 behavioural issues
- Advice on persistent chest infections
- Advice on additional monitoring due to treatment delay due to shortage
- Advice on pregnancy
- Access to diagnostic testing
- Disruption in treatment due to Government funding
- Access to financial support to travel to treatment centre

Driving Change Worldwide: 2024 Highlights

Global Awareness: Our 2024 Educational Impact

- **The Gaucher Voices podcast channel** was launched in 2024. There are currently three podcasts available with more planned every six to eight weeks:
  Gene Therapy Trials – The Patient's Perspective
  Switching from Enzyme Replacement Therapy to Substrate Reduction Therapy
  Pregnancy and Gaucher disease – what you need to consider
- **Gene Therapy educational webinars**: In line with the IGA's publication on 'Understanding patient and parent perceptions on gene therapy in Gaucher disease: an international survey' we held three webinars to update our community on interim data from two gene therapy trials for patients with type 1 Gaucher disease. These were held in different time zones and with access to various languages to ensure global access.
- **Red Flags**: The IGA identified a need to identify common "red flags" that are barriers to diagnosis. Working with 67Health, we designed a survey to help understand barriers to diagnosis for all types of Gaucher disease. The data collected will help improve services for people living with Gaucher disease. The IGA will use it to inform recommendations to speed up diagnosis and develop common terminology to improve communication between people living with Gaucher disease, types 1, 2, and 3, and their healthcare practitioners.
- **GD3 Prevalence**: A new GD3 research network was set up to look at accelerating research that was most important to patients and their families, to be more inclusive and to have a much more global overview of the study. The goals and vision for the project are:
  - Fostering collaboration amongst different stakeholders looking to accelerate research.
  - Looking to address unmet needs and ultimately improve patient outcomes.
  - Making sure that we are inclusive and everything that we do is patient-centred.
- **Sri Lanka registry**: The IGA is collaborating with partners to establish a national rare disease registry, including GD, to: understand prevalence, identify treatment and management needs; improve care through education and awareness; and advocate for policy changes using registry data. See page 11.



Global LSD COLLABORATION

Tanya Collin-Histed, IGA CEO, is one of the four founding members of the Global LSD Collaborative. Eight Global/International patient organisations representing Gaucher, MPS, Fabry, Niemann-Pick, GM1& GM2, Pompe, Sanfilippo and Alpha Mannosidosis have pledged to work together for patient benefit. Based on each group's challenges, and areas of work, a priority list of key areas for our work programme was developed, and four working groups were established:

- Achieving a global reach
- Charitable access to treatment
- Regulatory challenges in different countries.
- Clinically meaningful endpoints.

The Collaborative was featured in the winter edition of Rare Revolution Magazine. tiny.cc/lsdrrm

WORLDWIDE ENGAGEMENT - SHARING EXPERTISE, DRIVING SOLUTIONS

- First face-to-face **Global LSD Collaborative meeting**, Monday 5th February ahead of the WORLD symposium meeting in San Diego.
- **Acid Sphingomyelinase Deficiency (ASMD) Policy Meeting**, Milan 12/13th January. IGA's CEO Tanya Collin-Histed and Honorary President Jeremy Manuel were invited to share their experience of 30 years advocating for the treatment of Gaucher disease with the ASMD community in preparation for the licensing/access of a new enzyme replacement therapy for ASMD.
- **WORLD Symposium, San Diego** 3-9 February: Tanya Collin-Histed, IGA CEO was invited to take part in a panel event and present on: Patient Advocate and Carer Perspective: Persistent Global Inequity Despite 30 years of Progress.' The IGA also presented a poster.
- **European Conference on Rare Diseases (ECRD),** organised by Eurordis, Brussels, May 2024. Poster. Read a report on our web page.
- **International Working Group on Gaucher Disease (IWGGD)**, Serbia, May 2024. Presented on GARDIAN with poster presentation.
- **Aparito's 10th Anniversary** celebration in London to present on the GARDIAN registry.
- **Brains 4 Brains meeting** in Cambridge, UK on 9-11 September.
- **Aspire Biosciences:** London 28th November. A one-day workshop, with patient groups, a clinical expert and a group of research companies all looking to find new treatments for unaddressed and rare diseases through nurturing partnerships between patient groups and companies.

COLLABORATIONS WITH INDUSTRY

The IGA works in partnership with all companies that seek to bring new research and possible future treatments to the global Gaucher community. Our activities include reviewing patient information, having input on clinical study protocols, advice on the global community, linking to clinical experts, sitting on advisory boards, educating personnel and the wider community, hosting focus groups and much more, all within the relevant compliance codes. In 2024, the IGA had active partnerships with **14 different companies**.

Driving Change Worldwide: 2024 Highlights

KEY FINDINGS PRESENTED

WORLD symposium: Home Therapy poster; Self-Management poster

European Conference for Rare Diseases: Global Gaucher Connect Programme poster

SCIENTIFIC CONTRIBUTIONS

- Transition of patients with Gaucher disease type 1 from Paediatric to adult care: results from two international surveys of patients and health care professionals
- A rare partnership: patient community and industry collaboration to shape the impact of real-world evidence on the rare disease ecosystem

EXPERT COLLABORATIONS AND ADVISORY ENGAGEMENTS

- Member of Sanofi's GD3 Burden of Illness study – member of the Expert Review Group
- Patient representative on the HTAi Rare Disease Interest Group steering committee
- Member of Rare Disease International (RDI) Essential Medicines List working group. This WG aims to facilitate the understanding of the WHO Model Essential medicines as a tool to improve access to medicines and improve how rare disease medicines are assessed.
- Member of Eurordis Patient Advisory Board (PAB) for the Screen4Care. Screen4Care offers an innovative research approach to accelerate rare disease diagnosis, which is based on two central pillars: genetic newborn screening and digital technologies.
- On the advisory board of the European Haematology Association (EHA)
- Member of Eurordis Digital Advisory Group. The group provides advice to EURORDIS on all aspects of digital health policies and procedures, with the mission of recognising and acting upon opportunities for people living with rare diseases.
- Member of the Gaucher Outcome Survey (GOS) steering committee for Takeda
- Consortium member of C-Path for Lysosomal Disorders consortium meetings
- Member of the Medical Expert Committee (MEC) - Takeda's charitable Access programme
- Member of the Mendelian Patient Involvement Initiative, a pilot project funded by an AI award by the National Institute of Health and Care Research (NIHR) that looks at how data-centric tech could improve patients' lives by accelerating rare disease diagnosis and enabling faster, more targeted, access to treatments and management.

IGL INTERNATIONAL GARDIAN LIMITED
THE GLOBAL NEURONOPATHIC GAUCHER DISEASE REGISTRY

GARDIAN

Gaucher **R**egistry for **D**evelopment, **I**nnovation &
Analysis of **N**euronopathic **D**isease

Owned by the IGA, GARDIAN is a global registry created to improve disease understanding, management and support for patients living with GD2 and GD3 (nGD). It is a research platform to provide evidence-based data for advancing disease management, designing safer treatments and improving patient outcomes.

Dashboard: On 20 May at the IWGGD meeting in Serbia, International GARDIAN Ltd presented data collected from April 2022 to April 2024 from the first 26 neuronopathic Gaucher disease (nGD) patients and parents/caregivers. You can read the summary of key results.

A Lessons Learnt exercise was conducted amongst patients and caregivers in the registry, and the various other stakeholders involved in GARDIAN to collect feedback on aspects such as ease of use, clarity, motivation, consultation, challenges, timelines promotion effectiveness, advertising visibility and user experience.

Posters

European Conference on Rare Diseases (ECRD): Characteristics of patients with Type 3 Gaucher disease (GD3) and use of medical devices and supportive services

International Working Group on Gaucher Disease: Characteristics and symptoms of patients with Neuronopathic Gaucher disease

Biennial General Meeting - Lisbon November 2024

The IGA held its Biennial General Meeting from 9-10 November in Lisbon, Portugal. IGA members from 31 countries gathered for two days of learning, sharing and celebration as the IGA marked its 30th anniversary.

The meeting started with a welcome from the IGA Chair and the President of the Portuguese Lysosomal Disease Association. Members were then shown a video about the IGA's involvement in charitable access to medicines.

This was followed by a presentation from Prof. Derralynn Hughes from the International Working Group on Gaucher Disease (IWGGD). Prof. Hughes discussed the founding and history of the IWGGD, its current activities and plans for the future.

After a break, our CEO Tanya Collin-Histed launched the annual Anne-Grethe Lauridsen Memorial Award which will celebrate and encourage young individuals who have made a meaningful difference in the lives of Gaucher patients and their families through their dedication, innovation, and compassion. Anne-Grethe was a Danish patient advocate who died in 2023. Our new Board Chair Aimeé-Kate Bosch presented the first annual Anne-Grethe Lauridsen Memorial Award to Anne-Grethe's husband, Kurt. Aimeé-Kate was one of the young people who benefitted from the Go with Gaucher programme, attending two events. She is one of several people from those early events who now serve on our Board, a testament to Anne-Grethe's legacy. Aimeé-Kate said, “Anne-Grethe had a unique gift for engaging with younger patients in a way, that was both empowering and deeply impactful. It is no wonder that her Go with Gaucher programme has inspired so many to become involved with the IGA. Many participants became IGA volunteers, regional managers, and even board members. Anne-Grethe had an extraordinary ability to uplift and empower each person. She was always willing to listen, making people feel heard, understood, and validated. Her guidance was a constant source of strength for all who were fortunate enough to work with her.” The first award will be made in 2025.

Biennial General Meeting - Lisbon November 2024

Then came a feedback session asking members how the IGA can better support them, and how we can help them support their members. The session was led by Aimeé-Kate Bosch, Board member Andre Balzekiene, and IGA Communications and Campaigns Officer Harry Albright.

Next was a "speed sharing" session led by Board member Paulina (Pali) Peña Aragón. This involved breaking into small groups and answering a series of questions about different experiences of various Gaucher-related topics. Pali blew a kazoo to signal that it was time to move on to the next question.

After this, there were member soapbox and poster sessions, a chance for associations to highlight the work they have been doing recently.

On Saturday evening, the IGA hosted a dinner celebrating its 30th anniversary. The highlight was traditional Portuguese entertainment performed by a group of medical students organised by Portuguese Board member Francisco Carreiro.

The formal Biennial General Meeting business was conducted on Sunday morning. This was followed by a video about the IGA's Global Gaucher Connect Programme. This was followed by a session on the importance of data in rare diseases, led by IGA Honorary President Jeremy Manuel, featuring rare disease experts Sheela Upadhyaya and Elin Haf Davis of Aparito.

Next was a presentation by Zubyda Azzam, UKCP Accredited Specialist Counsellor from Rare Minds, about the importance of mental health resilience for people working in patient advocacy. In the afternoon, members participated in focus groups looking at unmet care and patient centred research needs.

The final session involved a panel from the pharmaceutical industry. In a twist to the usual process, each Pharma rep asked the members two questions (rather than the panel being questioned). This provided a good opportunity for representatives of the industry to hear from patient representatives about their views and concerns.
You can read the report of the focus group sessions and the industry panel.

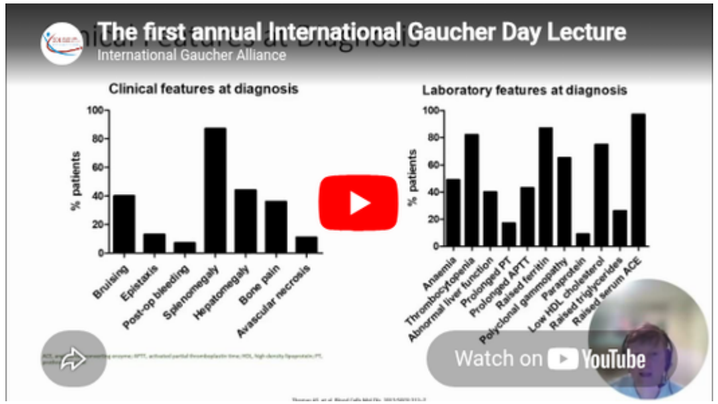
International Gaucher Day

The annual International Gaucher Day (IGD) celebrations took place on Tuesday 1 October and included the launch of a video looking at the IGA's past and future.

We also launched a social media campaign using shorter videos by the 16 people who contributed to the main video. These videos and other information about Gaucher disease can be found on our dedicated web page.

This year marked the International Gaucher Alliance's 30th anniversary, and we also featured a longer video, launched earlier in September, a "Fireside Chat" in which three people who were involved from the start discuss the history of the IGA and its impact on the world of patient advocacy.

IGD 2024 marked the launch of the IGA's first annual IGD Lecture, which was given by Prof. Derralynn Hughes, who speaks about her recollections of the past 30 years, with a look to the future and what remains a challenge.



A massive thank you to everyone who took part in this year's International Gaucher Day celebrations.

By sharing posts and stories you helped to raise awareness of Gaucher disease. Greater awareness leads to better outcomes for patients and helps the IGA to advocate on their behalf.

If you missed any of our videos, visit our webpage to watch them.

Global Collaborative Effort for Gaucher Disease: A Step Towards Improving Healthcare

What is happening in Africa?

- **Strong Network**: We have member organisations in South Africa, Botswana, Tunisia, and Morocco.
- **Dedicated Leaders**: Trudy and Roselyn are Gaucher Leaders who support patients and families in Zimbabwe, Rwanda, Tanzania, Namibia, Lesotho, Kenya, Ghana, and Ivory Coast.
- **Active Volunteers**: Volunteers from Mozambique, Sudan, Egypt, South Africa, Rwanda, Kenya, Botswana, Malawi, and Namibia provide invaluable support.
- **Patient Reach**: We have identified patients in Algeria, Botswana, Egypt, Ethiopia, Ghana, Tanzania, Tunisia, Kenya, Morocco, Mozambique, Niger, Rwanda, South Africa, Sudan, and Uganda. We are actively seeking information on patients in other countries.
- **Doctor networks**: IWGGD, A Rare Cause, Kenya, Ethiopia, Sudan, Egypt, Zimbabwe, ASPAE (African Society for Paediatric and Adolescent Endocrinology), Mozambique.

Raising awareness in Kenya

In December 2024 our Gaucher Leader Roselyn Odero organised a meeting for families and doctors in Nairobi. The meeting aimed to:

- Connect patient families for networking, learning, and mutual encouragement.
- Increase awareness of Gaucher Disease (GD) among doctors in the region.
- Educate families on diagnosis, treatment, and management of GD.
- Foster leadership within national GD advocacy.
- Identify and understand country-specific challenges.
- Prof. Dr Derralynn Hughes gave a lecture on Gaucher Disease, Dr Phoebe Wamalwaand and Dr Nicholas Wanjohi shared case studies and talked about the challenges they face in diagnosis, management and treatment. The IGA CEO, Tanya Colin-Histed talked about the Charitable Access to Medicines Programme.

Supporting Ethiopia

- The IGA is focused on raising GD awareness and building healthcare capacity through partnerships with local experts, promoting early diagnosis with Dried Blood Spot (DBS) cards, providing education via webinars/workshops, advocating for access to medications, and offering compassionate enzyme replacement therapy.

- On 30 May the IGA, in collaboration with A Rare Cause, supported the organisation of an online seminar by the Ethiopian Endocrine and Metabolism Society, titled Gaucher and Other Inherited Metabolic Diseases - Global and Ethiopian Perspectives. This event was marked by the presence of 148 dedicated participants, who showed remarkable engagement throughout the sessions. The discussions fostered a deeper understanding of the challenges and the need for cooperation in the diagnosis and treatment of rare metabolic disorders in Ethiopia and wider Africa.

Supporting Sri Lanka

The IGA collaborates with partners to establish a national rare disease registry, including GD, to: understand prevalence, identify treatment and management needs, improve care through education and awareness and advocate for policy changes using registry data.

In October 2024, the Rare Disease Forum of the Sri Lanka College of Paediatricians and the International Gaucher Alliance (IGA) hosted a hybrid session on Lysosomal Storage Disorders (LSD), focusing on Gaucher Disease (GD) (Overcoming barriers: Bridging the gap between global and local needs in Lysosomal Storage Diseases with focus on Gaucher Disease). The goal was to raise awareness about diagnosing and managing LSD in children and provide charitable access to enzyme replacement therapy. Held at Lady Ridgeway Hospital, Sri Lanka's top children's hospital, the webinar had over 100 in-person attendees and around 50 online participants. Dr Aimee Donald from Royal Manchester Hospitals, UK, and Prof. Derralynn Hughes from University College London provided insightful presentations on recognising, diagnosing and managing Gaucher disease. These talks were particularly useful in updating the audience's knowledge of the latest advancements in Gaucher disease treatment.

Central Latin America Symposium

On October 17, 2024, the Latin American Symposium on Gaucher Disease was held within the 2nd Congress on rare and uncommon diseases in Latin America and the Caribbean. This important event was attended by patients, treating physicians and geneticists from Latin America, especially Central America, a region that was normally forgotten by this type of event. Medical geneticists from Costa Rica, El Salvador, Honduras, Guatemala, Nicaragua and the Dominican Republic had the opportunity to share knowledge with their peers from Argentina, Brazil, Chile, Uruguay and Mexico, and to participate in workshops with biologists, biostatisticians, bioengineers and other high-level professionals. Gaucher patients from Guatemala and Mexico also participated.

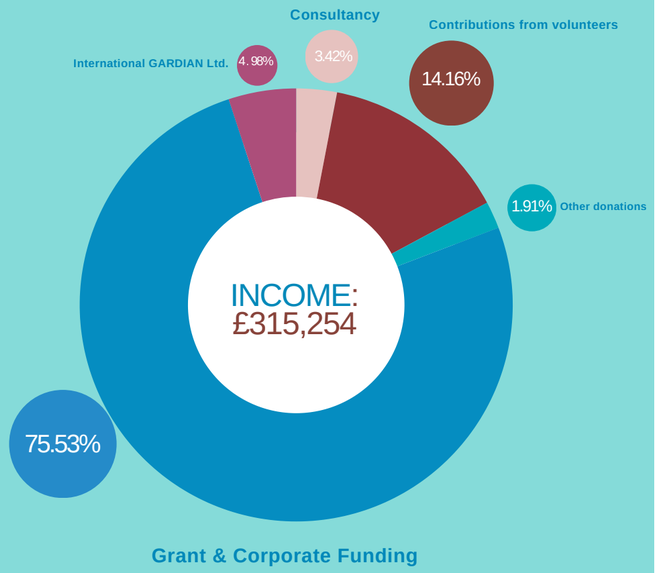
The IGA's Vesna Aleksovska speaks with Chris Hendriksz about the work we are doing with A Rare Cause in Africa and Sri Lanka.

African educational webinar

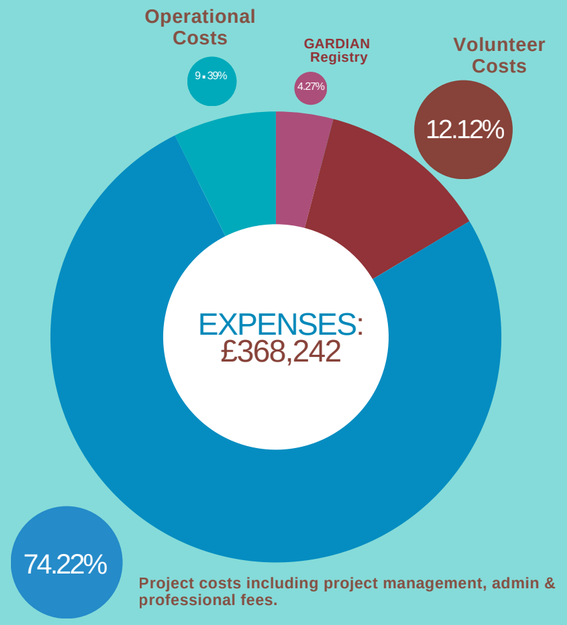
in partnership with IWGGD and A Rare Cause

Prof. Dr. Patrick Deegan, consultant physician in General Medicine and Metabolic Diseases, Cambridge University Hospitals NHS Foundation Trust (CUH), covered the latest approaches to managing Gaucher disease, including enzyme replacement therapy, substrate reduction therapy and gene therapy, and he focused on bone problems in Gaucher disease.

Financial report



Grant & Corporate Funding



Project costs including project management, admin & professional fees.

Our board of Directors, CEO, volunteers and doctors have donated over 1785 hours of their voluntary time to our activities.

THIS IS EQUAL TO £44,637.

We are extremely grateful for this dedicated support.

The work of the IGA Board of Directors was supported by very dedicated and passionate staff: Chief Executive Officer, Operations Officer, Communications and Campaigns Officer and Developmental Officer.

The IGA is funded through grants and sponsorship from several companies and organisations, and through our CEO and Board members undertaking consultancy work.

To ensure its independence, the IGA will only accept funds up to an amount not exceeding 35% of its annual budget from any one pharmaceutical company.

As a responsible organisation, the IGA has a reserves policy to enable us, in the event of receiving no further funding, to continue to serve our global community and implement a strategy to address how to take the IGA forward.

A HUGE THANK YOU TO OUR SUPPORTERS...

… for believing in us and sponsoring our extensive work programme activities, various projects and events throughout the year. Without your generous support, we could not make a better world for Gaucher patients!

The IGA Impact Report gives an overview of the IGA's finances for 2024 on a cash basis. This differs from our statutory accounts which are done on an accrual basis. Please keep this in mind if comparing the documents. Many of our projects are long-term and any unspent funding will be rolled into the following year.

In 2025 we commit to Advancing Patient Support & Research Globally

IGA Board and Staff

IGA Strategic Plan 2024 - 2029

- Following the successful launch of our podcast **'Gaucher Voices'** we will focus on what it is like to live with Gaucher disease in different parts of the world.
- Continue to expand the **Global Gaucher Connect Programme** to include more countries and activities
- Build an **Information Repository for Patients and Caregivers on nGD:** Provide a hub for all information on nGD, including links to clinical trials, published papers, guidelines, patient stories, patient support avenues
- Create a **global collaborative research network for nGD**
- Develop a **nGD community advisory board**
- Bring **stakeholders** together for two days annually, one for satellite meetings and one for everyone
- Develop a **5-year patient-prioritised research strategy**, with quarterly online meetings for updates and progress
- Work in **collaboration** with A Rare Cause (ARC), the International Working Group on Gaucher Disease (IWGGD) and other stakeholders including Industry partners to tackle the challenges of access to diagnostics for patients and families in Africa
- Continue to ensure access to information and our services by providing **translation** and interpretation in as many languages as possible
- Expand our **WhatsApp services** and look at new ways to bring information to more people
- Grow our **Youth Council** to ensure that young people continue to have a strong voice
- Continue our efforts to understand the community's stance on **Newborn Screening**, developing a position paper that serves as a valuable resource for patients and advocates to address the issue within their respective countries

Connect With Us

Website www.gaucheralliance.org

E-mail info@gaucheralliance.org

Phone +44 (0)1453 796402

Address 86-90 Paul Street, London, EC2A 4NE UK

Registered Charity Number: 1192011