IGA INTERNATIONAL GAUCHER ALLIANCE
Driven by passion for patients
International advocacy for Gaucher patients since 1994

2026 So Far: Delivering Global Impact Together



Patient in Mozambique celebrating a life-changing milestone through receiving treatment through Sanofi's charitable access Programme.

International Gaucher Alliance July 2026 Newsletter

WELCOME

As we reach the halfway point of 2026, it is a great opportunity to reflect on what we have achieved together. The International Gaucher Alliance (IGA) may be a small organisation, but our impact is made possible by an extraordinary global network of people. Our Board of Trustees, Working Groups, Gaucher community leaders, patient advocates, clinicians, researchers and many other volunteers generously give their time, expertise and passion to help deliver our ambitious work programme. Together with our member organisations and partners, they enable us to improve the lives of people affected by Gaucher disease around the world.The first six months of 2026 have been incredibly busy, with progress across humanitarian support, research, education, international collaboration and organisational development.



The IGA team with international colleagues at the IWGGD meeting in Trieste.

Programme of Work Impact So Far

Humanitarian Support & Global Gaucher Connect

Every patient deserves the opportunity to receive a diagnosis, access treatment and live the healthiest life possible—regardless of where they are born. During the first half of 2026, we have supported patients, families and healthcare professionals in Afghanistan, Syria, Zimbabwe, Mali, Morocco, Ukraine, Pakistan, Jordan, Yemen and Uganda, helping them navigate what is becoming one of the greatest challenges in rare disease care: obtaining a confirmed diagnosis. In many parts of the world, specialist expertise and diagnostic testing are simply not available. Without a confirmed diagnosis, patients cannot apply for charitable access programmes or receive treatment. Increasingly, our role has become one of diagnostic navigation—connecting local doctors with international experts, arranging enzyme and genetic testing, identifying laboratory partners, supporting sample shipment and building clinical knowledge so diagnoses can be made with confidence.



Marking a 100th infusion milestone through the Sanofi's charitable access Programme, bringing life-changing treatment to Laiza in Mozambique.

This year alone, we have coordinated international diagnostic support for children in Afghanistan and Syria, worked with clinicians in Zimbabwe to build local knowledge and capacity for enzyme replacement therapy, supported charitable access pathways in Morocco and Ukraine, and connected families in Pakistan, Jordan, Mali, Yemen and Uganda with specialist expertise.

In Afghanistan, we have also begun bringing families affected by Gaucher disease together, creating opportunities for peer support while building relationships with local clinicians and laying the foundations for a more coordinated approach to diagnosis, care and future access to treatment.

Behind every treatment is a family whose life has been transformed.



Through collaboration with Sanofi, the IGA is helping to bring hope to children like Nitisha by providing access to treatment through Sanofi's charitable access programme

Global Leadership & Collaboration

The IGA continues to play an active leadership role within the Global LSD Collaborative, working alongside nine (9) international patient organisations to improve outcomes across the lysosomal storage disease community. This year we have contributed to mapping global patient organisations and activities, explored the development of a collaborative Access to Medicines project, and helped identify opportunities for organisations to work more effectively together, reducing duplication and strengthening the collective patient voice.

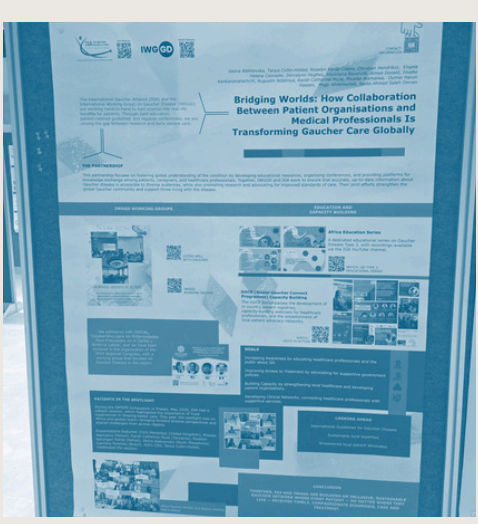
Networking, Growing, Strengthening

This has been the most conference-intensive quarter, with the IGA present at three major international events — the European Conference on Rare Diseases (ECRD) in Prague, the IWGGD Conference in Trieste, and the Rare Diseases International Membership Meeting in Nairobi. Each was a chance to strengthen partnerships face to face.
These connections are already translating into real growth: seven countries, including Ghana, Rwanda and Kenya in Africa and Vietnam in Asia, are now in active development, with four new member organisations expected to join the IGA family in the coming months.



Vesna Aleksovska presenting the IGA's work at the European Conference on Rare Diseases (ECRD) in Prague, strengthening collaboration across the rare disease community.

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Our collaborative poster with the IWGGD showcasing global partnerships that are transforming Gaucher care.

Influencing Clinical Practice

At the International Working Group on Gaucher Disease (IWGGD) meeting in Trieste, the IGA represented the patient voice across several important scientific initiatives. We co-led a session on the challenges and opportunities for Gaucher disease care across Africa, contributed to the development of the new GD3 Supportive Care Guidelines, Clinical Care Guidelines and Comorbidities, and were delighted that our International Gaucher Day poster received a Best Poster Award. The meeting also strengthened our volunteer base, with new lecturers recruited to support the IGA's educational webinar programme. These activities ensure the experiences of patients and families continue to shape international standards of care.



Representing the patient voice at the International Working Group on Gaucher Disease (IWGGD) meeting in Trieste through scientific collaboration, advocacy and education.

Thirty-Two Voices, One Mission

Thirty-two powerful women with Gaucher or caregivers joined Gaucher Community Alliance for a day at Capitol Hill in Washington DC. We spent the day advocating with legislators for newborn screening funding, insurance reform, and Medicare home infusion. Stories were told and friendships created. Looking forward to reuniting at our national conference in October.

By Aviva Rosenberg, Chairperson



Thirty-two women living with Gaucher disease or caring for someone affected gathered on Capitol Hill to advocate for improved access to care and support.

Patient Voice Driving Change

Our Global GD3 Patient and Caregiver Advisory Boards continue to ensure that lived experience is at the heart of everything we do. This year's discussions have explored behavioural and neuropsychiatric symptoms, education, employment and wider unmet needs. The outputs are already leading to tangible results, including a global GD3 unmet needs survey, an international Unmet Needs White Paper, new information sheets highlighting the educational and employment challenges faced by people
living with GD3, and a behavioural webinar that will support healthcare professionals and families worldwide.



Presented at the IWGGD meeting, this poster highlights the achievements and future priorities of the Global GD3 Community Advisory Board.

Education & Awareness

Education remains central to our mission. Building on the success of our African education programme, we are launching a new GD3 webinar series for Central and Latin America and continuing to develop practical educational resources for patients, families and healthcare professionals to improve earlier diagnosis and standards of care worldwide. We are also working on developing webinars for Zimbabwe and South Africa strengthening our collaboration on diagnosis, management and treatment.



Educational webinars continue to connect healthcare professionals, researchers and patient advocates, fostering learning and collaboration across the global Gaucher community.

Breaking Language Barriers in Gaucher Education

Thanks to the support of our community, we successfully delivered the first-ever Portuguese-language webinar on Gaucher disease, bringing together expert speakers from Mozambique, Portugal and Brazil.



Expert speakers from Mozambique, Portugal and Brazil came together for the first Portuguese-language webinar dedicated to Gaucher disease.

The event marked an important milestone in expanding education, collaboration and support across Portuguese-speaking communities, helping to connect patients, healthcare professionals and advocates through shared knowledge and experience.

Collaborative Strength in Antigua Guatemala: Highlights from the 3rd Latin American and Caribbean Congress of Rare Diseases, CEPCAL 2026.

By Patricia Lucki

Antigua Guatemala—with its historic charm and cobblestone streets—recently served as the vibrant backdrop for the 3rd Latin American and the Caribbean Congress of Rare Diseases, CEPCAL 2026. It was an incredible gathering of minds, hearts, and advocates, all focused on a singular goal: improving the lives of those living with rare diseases across the region. The International Gaucher Alliance (IGA) was proud to participate actively, standing side-by-side with our regional partners to make this event a resounding success.



Delegates gathered at CEPCAL 2026 in Antigua Guatemala, united in their commitment to advancing rare disease care through collaboration, knowledge sharing and regional partnerships.

A Powerful Partnership: IGA and ANGEL

The synergy between international and local advocacy was on full display. The collaborative efforts of the IGA and the local Guatemalan association, ANGEL, were absolutely crucial to the success of the event. Together, we bridging the gap between global resources and local realities, ensuring that the voices of patients in Guatemala and the wider region were heard loud and clear.

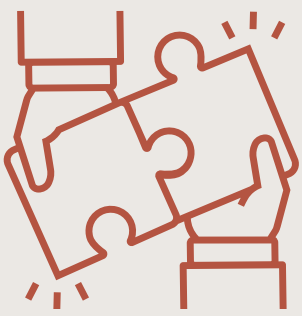
Spotlight on Advocacy: The IGA Poster Presentation

One of our proudest moments at the congress was presenting the IGA poster (crafted in English). The poster acted as a fantastic conversation starter, drawing significant interest from attendees, medical professionals, and fellow advocates. **Public Engagement-** The poster was warmly received, sparking insightful reviews, questions, and comments from the public. **Global Insights** Presenting in English allowed us to share international advocacy frameworks and data, which local stakeholders found highly valuable for comparative learning.



Patricia Lucki represented the IGA at CEPCAL 2026, strengthening partnerships and advancing collaboration across the rare disease community.

The Core Message: Collaboration is Key



If there was one overriding theme of our participation, it was this: we cannot do this alone."To truly address the complex challenges faced by people living with rare diseases, we must foster deep regional and international collaborative networks. This teamwork must cover every angle—from early diagnosis and access to treatment, to emotional support and policy advocacy."

By uniting the local expertise of associations like ANGEL with the global reach of the IGA, we proved that collaboration isn't just a buzzword—it is the lifeline of our community. We return from Antigua Guatemala energized, inspired, and more committed than ever to working hand-in-hand across borders for the Gaucher and rare disease community.

Building the Future of the IGA

Significant progress has been made on our new website, which will launch on International Gaucher Day and provide an accessible, multilingual hub for patients, families, healthcare professionals and member organisations. Alongside this, we continue strengthening our governance, preparing for Board renewal and ensuring the IGA remains a sustainable, trusted and influential organisation for the future.

International Gaucher Day (IGD)



International Gaucher Day on 1 October, is an opportunity to recognise and celebrate the global Gaucher disease community. It brings together people living with Gaucher disease, families, healthcare professionals, researchers, advocates and patient organisations to raise awareness, share experiences and strengthen our collective commitment to improving the lives of those affected. Together, we continue to work towards better care, greater understanding and a stronger future for everyone impacted by Gaucher disease.

Looking Ahead

The momentum we've built during the first half of 2026 will continue into an exciting second half of the year. We look forward to launching our new website, expanding our international education programmes, publishing the outputs from our Patient Advisory Boards, progressing the GD3 Delphi Consensus Project, advancing our voice biomarker and patient-reported outcome research, strengthening humanitarian support for families facing barriers to diagnosis and treatment, and continuing to work with partners across the Gaucher and lysosomal storage disease communities to improve access to diagnosis, care and life-changing therapies.

None of this would be possible without the commitment of our member organisations, volunteers, clinicians, researchers, industry partners and sponsors. Most importantly, thank you to every patient and family who continues to share their experiences and inspire our work.

CONTACT US

Admin@gaucheralliance.org

Phone Number

Website

86-90 Paul Street
London
EC2A 4NE |UK

CHARITY

Charity Number
1192011

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YouTube