# Annual Report: YE November 10, 2025*

*GPAC's accounting period runs from 11 November to 10 November – and is reported to the Charity Commission Annually.

## President's Report

In the last year, GPAC has continued to grow! Sue Burrell remains as the current President. Kika Shabot was officially welcomed into the role of Vice-President and Derry Wilcox into the role of Treasurer. The Charity Commission was updated to reflect the new Trustee Board (which is also the Executive Board).

At our last AGM and Member meeting, which took place in-person in Pamplona, Spain (September 21, 2025) prior to the opening of the ICPP Congress and Patient Day (commencing September, 22), we had engagement from … countries physically at the meeting, with additional attendees joining via Zoom from …. Our work in engaging and building a well-connect porphyria community has continued, with new groups engaging and joining GPAC from Norway, Colombia, - Kika Shabot is working to build a GPAC that is able to collaborate and support our Spanish speaking porphyria friends across Latin America. We are excited to see this develop further over the coming months.

GPAC attended a meeting with Ipnet before the main ICPP began, in Pamplona. We met with the current (as of 2025) and the past (ending end-2024) Ipnet Board to discuss collaborative efforts moving forwards. GPAC and Ipnet signed a Memorandum of Understanding (MoU) to formalise our commitment to work together and explore aligned projects to best service the global porphyria community. Efforts are continuing to develop in different areas, including: 1) the organisation of ICPP in Istanbul, Turkey (26-30 September, 2026). GPAC are working with the organising committee to ensure the Patient Day will be a huge success; 2) working with Ipnet's International Porphyria Support Group – a humanitarian group of clinicians and scientists from around the world who are committed to supporting clinicians on the ground in locations where there are no Expert Centres or good porphyria knowledge – helping to bridge the gap for patients across the world.

GPAC has established an Advisory Council to fully support the work that GPAC is embarking upon, this includes the current Executives/Trustees (Sue Burrell, Kika Shabot, Derry Wilcox), past Executives (Joaquin Montoto and Sean Hegarty), the current and past Patient Representative on Ipnet (Nadia Petrovic and Liz Gill) as well as our first Clinical Advisor, Professor Sverre Sandberg. The Council will meet twice a year and will support decision-making at the Executive level.

GPAC Executives and Members have been meeting regularly to accomplish shared goals and initiatives for and with the global porphyria community.

**Looking forward:** We are excited to be holding our next AGM at the International Congress of Porphyrins and Porphyria (F2F) in Istanbul, Turkey on Saturday 26 September 2026, and via Zoom for those unable to travel to the Congress. The GPAC meeting will last 6 hours and will include our AGM, updates from our working groups, to identify activities for 2027 and beyond, as we as PAGL development sessions. The meeting will conclude with presentations from various industry partners, including: Alnylam Pharmaceuticals, Disc Medicine, Portal Therapeutics, Mitsubishi Tanabe as well as other updates on new developments/research that may evolve over the coming year. The hope is that this style of program will provide some pivotal learnings for the PAG leaders, whilst also fostering great opportunities for engagement with other PAGs, stakeholders, researchers and clinicians that we may be able to partner with, for the benefit of porphyria families across the world.

**Progress to date**

**Community engagement: Meetings, connections and fostering global relationships:** The GPAC Executive Board are meeting regularly to best support our GPAC Member organisations, clinician networks and industry, including: ICPP planning (for Istanbul's scientific and patient sessions). They are working with pharma/industry representatives and clinical leaders to support the global porphyria community in the following ways: discussions and sponsorship/grant discussions/applications, disease awareness events/communications and to foster partnering relationships to help share information about trials, trial data, new medicines, research and awareness. GPAC's President and Vice-President meet weekly to engage and support initiatives on a global level.

We are excited to build further upon this work with our community over the coming months as we plan ICPP 2026 and engage in other meetings and social engagements (including International Porphyrias Symposium IPS, October 2024) where we will be focused on continuing the build relations with other partners and stakeholders who align on projects that we feel could benefit the global porphyria patient community.

The Executives have been involved in a PLC (Patient Leadership Council) with Alnylam (alongside other PAG leaders from the USA. This PLC has meeting's scheduled in 2025 (online and F2F) – all involved in this PLC (from GPAC and beyond) will be compensated for their time and input as Experts in AHP.

In March 2025, GPAC took on Freya Jackson – as GPAC's Administration and Communication's Assistant (in a self-employed capacity), for a few hours a week. Freya is having a significant and positive impact on GPAC initiatives. She supported the delivery of a successful Global Porphyria Day (GPD)/awareness campaign which had excellent impact. In addition to supporting administrative and policy development (including Charity Commission compliance actions, website management, content creation, social media/comms channels), Freya developed and distributed GPAC's first Newsletter in August 2025 – the analytics of which show increased porphyria engagement across all of our social media platforms.

**PAGs becoming Members of GPAC:** At the AGM in September 2024, GPAC voted on the following PAG's as Members:

At the virtual meeting on 20-Sep-2025, GPAC will re-vote on the existing Members and any new ones that have completed the Joining Form.

**GPAC's Working Groups (WG):** In Pamplona, GPAC Members re-focused our priorities for the Working Groups, focusing on 1) Awareness (incl. GPD); Mental Health; Humanitarian efforts (supporting Ipnet); Communications (newsletter and general comms); Education (incl. porphyria related conference and direct PAG leader/expert patient talks – SB attended and shared her experienced at F2F meetings and virtually too.

The *Awareness WG* has remained active and successfully deployed the remaining sponsorship/funding of the £10,000 GBP sponsorship from Alnylam, Disc Medicine and a donation via the UPA from Mitsubishi Tanabe for 2023/2024 *Global Porphyria Day project* for GPD on 18 May 2024/2025. Freya Jackson support these efforts which resulted in significant engagement and community building around this time. In 2023-2024, the #MyPorphyria awareness campaign was shared with new content in the form of the CEP content, which encouraged the sharing of further #MyPorphyria content. In 2025, GPAC also created some content from the PAG leaders from around the world. It was powerful hearing the drive that motivates these amazing individuals to keep pushing for improvements for porphyria patients worldwide!

Plans for 2026 GPD and general awareness are developing at the minute. We look forward to developing these campaigns so that we can share global porphyria voices. Again, we'd like to thank the patients who are so inspiring as they bravely and openly shared their stories of the lived realities of living with porphyria! #MyPorphyria! Thank you to the Awareness Team for your work on this successful GPD/#MyPorphyria campaign and 'Light up for porphyria' – steered by Kelly Burns (from the Canadian association).

**Website and Office 365:** GPAC has been working hard on full integration to Office 365. The website and email system were transferred from Mijndomein to Office 365 and SquareSpace.

**Research and GPAC:** Over the last year or so, various global patient representative from the GPAC community have been involved in publications relevant to porphyria, the rare disease community, trials and regulatory processes/bodies responsible for providing access of medicines to patients. Thank you to all for your commitment to these areas.

**Strategy/Plans for 2025-2026 and beyond:** 1) Information Sharing WG: Communication and outreach – consistent, regular and professional communications to expand GPAC's reach into the global community; 2) Translation to include all GPAC meetings with LIVE translator translations and investigations into AI translations for the website and written communications; 3) Awareness campaigns: RDD, GPD, general awareness in accessible content in Asia, and Africa as starting points; 4) Education: Development program for PAG leaders, 3-5 sessions per year, excellent resource for PAGs; 5) Mental Health Team – conducted research to identify the level of MH support that is available in the countries around the world. The results will be presented at IPS, with further stage to the project planned to develop a host of MH resources that can be made available to all, these will be reviewed and analyzed in a second part of the research which should be delivered at ICPP in 2026; 6) ICPP Scientific and Patient Day program design – underway; 7) Research – support industry to conduct research/trials that should ultimately support the global porphyria community.

**Shift to GPAC operations:** The GPAC Executives have revisited the idea of having someone work for GPAC in a paid capacity as a way of moving GPAC activities and engagement to the next level. The Executives and Advisory Council reviewed this concept further and agreed to following: 1) Formulate a budget to enable this change in working; 2) Sue Burrell to step back as a Trustee for GPAC, but remain as GPAC President (leading the Executives – Kika and Derry/Trustees; supported by GPAC's Advisory Council); 3) Sue to take on a temporary paid role (for 12 months) to take GPAC forward over the coming year (during this time, SB will source budget for GPAC for 2026 and beyond); a review of this set-up will begin in the Spring 2026, ensuring that a more permanent position can be established before the AGM GPAC/Meeting, 2026, Istanbul.

**Strategy/Plans for 2025-2026 and beyond (identification of relevant WG name, if possible) – developing from last AGM:**

1+2) *Information Sharing WG*: Communication and outreach – consistent, regular and professional communications to expand GPAC's reach into the global community; *Translation* to include all GPAC meetings with LIVE translator translations and investigations into AI translations for the website and written communications; finalising the website, management of social media, newsletter which will be fully translatable, via our website, in order to increase accessibility for the whole porphyria community.

3) Awareness campaigns: RDD, GPD, general awareness in accessible content in Asia, and Africa as starting points;

4) Education: Development program for PAG leaders, 3-5 sessions per year, excellent resource for PAGs; Education of GPAC Executives (at medical conferences) to ensure they can report back and share/distribute important updates to all countries; Work alongside Ipnet.

5) Mental Health Team – focus on how specific points on protecting and supporting the minds of the porphyria community. Research was conducted to identify the level of MH support that is available in the countries around the world. The results will be presented at IPS, with further stage to the project planned to develop a host of MH resources that can be made available to all, these will be reviewed and analyzed in a second part of the research which should be delivered at ICPP in 2026;

6) ICPP Scientific and Patient Day program design – underway;

7) *Research* – support industry to conduct research/trials that should ultimately support the global porphyria community.

8a) *Community building/new groups WG*: Identify candidates interested in Working Groups and succession planning for GPAC to ensure the Executive Team is sustainable and resilient – ongoing. Members: all Members will be re-voted on at AGM and 'new Members' can join at this stage, if requirements are met. GPAC will be welcoming and supportive of individuals and rare disease groups who are committed to working together, professionally and in-line with our Charter for Working Together.

8b) Formalise collaborative routes with physicians, scientists, rare disease networks and other stakeholders, including Ipnet and industry networks to establish meaningful alignment with shared goals/purpose for

priorities and goals. We'd also like to acknowledge thanks to the patient advocacy researchers who keep contributing/pushing research to improve things for porphyria patients.

9) Succession planning/developing GPAC infrastructure: still need to address Derry as a Signatory on the bank account. Freya has generated the required *policies and procedures* that GPAC needs.

10) Finances: Secure funding to enable GPAC to work professionally and recruit appropriate resources to manage projects identified by the Working Groups.

11) *Humanitarian WG* will work alongside physicians and patient groups to signpost patients and potential patients to diagnostics, care and treatments.

# Treasurer's Report

## Financial Statement — 11 November 2024 to 10 November 2025

Receipts and Payments basis. Figures below are drawn from GPAC's Financial Tracking System, reconciled against Barclays, Wise and PayPal records.

| | Restricted (GBP) | Unrestricted (GBP) | Total (GBP) |
|---|---|---|---|
| **RECEIPTS** | | | |
| Voluntary income (donations and grants) | 15,714.67 | 81.53 | 15,796.20 |
| Other income | 0.00 | 0.01 | 0.01 |
| **Total receipts** | **15,714.67** | **81.54** | **15,796.21** |
| **PAYMENTS** | | | |
| Charitable activities | 987.96 | 18,271.70 | 19,259.66 |
| **Total payments** | **987.96** | **18,271.70** | **19,259.66** |
| **Net movement in funds** | **14,726.71** | **(18,190.16)** | **(3,463.45)** |
| **Funds brought forward (11 Nov 2024)** | **0.00** | **28,660.73** | **28,660.73** |
| **Funds carried forward (10 Nov 2025)** | **14,726.71** | **10,470.57** | **25,197.28** |

*"Restricted" funds are receipts a donor has designated for a specific purpose; "Unrestricted" funds can be used for GPAC's general charitable purposes. No Designated funds were held during the year.*

## Restricted Funds

| Fund | Purpose | Received (GBP) | Carried forward (GBP) |
|---|---|---|---|
| Mitsubishi Tanabe Pharma America, Inc. | Corporate Sponsorship — 2025 Strategic aims / ICPP PAG displays | 10,000.00 | 10,000.00 |
| Disc Medicine, Inc. | Vignette Study Recruitment grant | 1,860.86 | 1,860.86 |
| Amgen Inc | Website development & translation (#RAREis Global Advocate Grant) | 3,853.81 | 2,865.85 |
| **Total restricted funds** | | **15,714.67** | **14,726.71** |

*The Mitsubishi Tanabe and Disc Medicine funds had not been spent as at 10 November 2025 and carry forward in full. £987.96 of the Amgen fund was spent on website-creation work (Anna Mann, 15 April 2025), leaving £2,865.85 carried forward. Any unspent portion of the Mitsubishi Tanabe sponsorship must be returned to the funder per the sponsorship agreement.*

## Charitable Spending by Programme

| Programme | Spend (GBP) | % of total |
|---|---|---|
| ICPP Conference | 5,556.65 | 28.9% |

| | | |
|---|---|---|
| Unclassified (NA) | 5,441.08 | 28.3% |
| Conferences — Other than ICPP (IPS) | 3,431.80 | 17.8% |
| Website & Communications | 3,408.68 | 17.7% |
| Admin (Governance & Core Administration) | 698.99 | 3.6% |
| Global Porphyria Day / Awareness | 661.61 | 3.4% |
| Translation | 60.85 | 0.3% |
| **Total charitable spending** | **19,259.66** | **100.0%** |

*"Unclassified (NA)" covers payments not yet tied to one specific programme above, including core operating costs. "Admin" covers governance and core administrative staff time (meetings, executive support).*

## Suggested Budget for 2026

Secured budget from Alnylam Pharmaceuticals, Disc Medicine, Mitsubishi Tanabe Pharma America, Portal. Still to connect with Clinuvel LTD and Recordati Rare Disease.

| Budget line | GBP |
|---|---|
| Communication and outreach | 11,635.00 |
| Translation costs | 15,000.00 |
| GPD/awareness campaign and materials, including contingency | 15,000.00 |
| Education program and initiatives | 15,500.00 |
| Mental Health project 2025-2026 | 15,000.00 |
| ICPP GPAC Meeting — 26 September 2026 | 12,500.00 |
| GPAC patient community display at ICPP — Istanbul, 2026 | 4,000.00 |
| International Community Engagement | 39,000.00 |
| **Total suggested budget 2026** | **127,635.00** |

*All funds gratefully received by GPAC. GPAC's accounting period runs from 11 November to 10 November – and is reported to the Charity Commission annually.*

## Bank Balances at AGM (presented 20 September 2025)

This is a snapshot presented to Members at the AGM ahead of the financial year end, not the audited closing position. The verified financial-yearend closing balance on 10 November 2025 is £25,197.28, shown in the Financial Statement above.

| Account | GBP |
|---|---|
| PayPal Balance | 628.78 |
| Barclays Balance | 29,906.66 |
| **Total Assets (20-Sep-2025 snapshot)** | **30,535.44** |

10 Ruskin Road | New Costessey | Norwich | Norfolk | NR5 0LL
Charity No: 1189694 | gpac-porphyria.org