

President's Report

It is now a full 5 years since GPAC's first official meeting at ICPP in Milan, in 2019. Sue Burrell is still in position as the current President. We would like to thank Sean Hegarty (Past Vice-President) and Joaquin Montoto (Past-Secretary) for their time and commitment to being part of the inaugural GPAC Executive Team. Both Sean and Joaquin are remaining in Stewardship roles until 2025 as we officially welcomed Kika Shabot into the role of Acting Vice-President and Acting Derry Wilcox as GPAC's new Treasurer at our delayed AGM in February 2024. Once officially in role, the Charity Commission will be updated to reflect the new Trustee Board (the Executive Board), and Derry will be transitioned in to be a Bank Signatory too.

Our last AGM (February 2024 – Delayed from Sept 2023) took place via Zoom, and was well represented with engagement from 13 different countries/PAGs. We also a new face join our meeting, Nadežda Pejović from the new porphyria PAG in Serbia – we welcome Nadezda who is engaged and keen to get involved.

Since February, GPAC Executives and Members have been meeting regularly to accomplish shared goals and initiatives for and with the global porphyria community. GPAC also spent significant time, considering a matter within our community. After consultation with the Charities Commission, and with external guidance on how to proceed, we spoke with all parties and have identified a position that ensures GPAC activities are unhindered – whilst remaining engaged and focused to work with all groups/organisations working to serve the porphyria community.

Looking forward: We are excited to be holding our next AGM at the International Congress of Porphyrins and Porphyria (F2F) in Pamplona on Saturday 21st September 2024, and via Zoom for those unable to travel to the Congress. The GPAC meeting will be structured to hold a 5 hour meeting which will include our AGM, an interactive workshop focusing on GPAC priorities and goal setting for 2025 and beyond. The meeting will then conclude with presentations from various pharmaceutical companies, including: Alnylam Pharmaceuticals, Disc Medicine, Portal Therapeutics, Mitsubishi Tanabe as well as an update from Dr Oscar Millet on current developments and research into CEP. The hope is that this style of programming will foster great opportunities for engagement with other PAGs, as well as other stakeholders, researchers and clinicians that we may be able to partner with for the benefit of the porphyria families across the world.

Progress to date

Meetings, connections and fostering global relationships: The GPAC Executive Board have met on many occasions since February, 2024, to work on GPAC priorities and working tasks (including the domestic matter aforementioned), ICPP planning (for the Spanish Patient Day, the Patient and Doctor Workshop [formerly the Patient Day], Poster displays and GPAC's Meeting), as well as the general management of GPAC. The President and Vice-President have been meeting weekly or biweekly to engage and support initiatives on a global level. The Executive has also been working with pharma/industry representatives and clinical leaders, on numerous occasions, about sponsorship, disease awareness events/communications and to foster partnering relationships to help share information about trials, trial data, new medicines, research and awareness.

We are excited to build further upon this work with our community at ICPP in Pamplona, in September, with many meetings and social engagements planned where we hope to build relations further to align on plans to benefit the porphyria patient community.

Sue Burrell was involved in a paid social media collaboration with Katri Parri (from the Spanish Patient Association, Katri is a social media influencer/content creator and now works for the United Porphyria Association). This project was funded by Alnylam Pharmaceuticals, it aimed to raise awareness and reach and was released on Global Porphyria Day (18-May-2023). Sue Burrell received honorariums for this engagement via her paid role with the BPA.

PAGs becoming Members of GPAC: Following the AGM in February 2024, GPAC made plans for PAGs to complete their Joining Form, over the months leading up to the next AGM in Pamplona, where it was planned that all those ready to be voted on as Members would be voted on at the AGM in Pamplona.

GPAC's Working Groups (WG): Across 2023 and to date, most of GPAC's WGs have not been meeting regularly and it as decided at the Member meeting in July that the Working Groups would be reviewed to reflect more of the work that GPAC are actually doing. Work in all areas will continue, on an ad-hoc basis as needed/proposed by the community of PAGs that GPAC represent. As reported at our last AGM, much work is still ongoing via our Members (namely, between groups in America [APF and UPA], Brazil, Canada, Chile, Italy, Mexico, Serbia, Spain – to name a few)! There have been specific collaborations between a number of organisations to deliver education events/conferences (face-to-face, hybrid and virtually) to educate, connect and empower patients and physicians. The success of which demonstrates the benefits that can be achieved from working together.

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's *Global Porphyria Day project* for GPD on 18 May 2024. Anna Mann again took a significant and active role in the deployment of this project which achieved the successful delivery of disease specific awareness videos on EPP, AIP, VP and HCP and a final video on CEP which will be shared at ICPP in Pamplona. The #MyPorphyria awareness campaign was deployed across social media and encouraged the sharing of further #MyPorphyria content. We are very grateful to the patients that bravely and openly shared their stories of the lived realities of living with porphyria, in their own words and in their own language, #MyPorphyria! We are very grateful that our sponsors agreed that GPAC could retain the 2023 sponsorship funds to fulfil the project aims in 2024. Thank you to the Awareness Team (Anna, Kristen, Nicole, Kelly) for your work on this successful GPD/#MyPorphyria videos and 'Light up for porphyria' – steered predominantly by Kelly Burns (part of the Awareness WG, from the Canadian association).

Website and Office 365: For the last few years GPAC have been planning on setting up a new website and transferring our emailing/file structures to Office 365. GPAC would like to specifically thank Anna Mann for her initial work on the new website –

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which has a look and feel that represents our organisation better and which was timed to be ready to launch the new GPD videos. This is just the first stage of the website and we look forward to developing this further. We'd also like to thank Antony Fearn for his voluntary work in transferring GPAC's email platform from Mijndomein to Office 365, a free platform to GPAC, as we are a registered charity in the UK.

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.

Challenges and resolutions: GPAC has been working find ways to work in a collaborative and inclusive manner and all New Members will be encourage to abide by this approach to working together, in a respectful and committed professional manner. *GPAC's Bylaws and information pack, GPAC's Membership guidelines and joining form* as well as *GPAC's Executive and trustee declaration form* were all agreed at our last AGM and are being implemented to support all of GPAC's work.

Internal GPAC resource became a significant problem in 2023, when the President was off sick injured for a number of months! Since February 2024, this workload is being spread more between the Executives and we have also noted a shift as a number of key individuals are coming forward to help steer and share the workload. This model appears to be working better and at the meeting in July, it was decided to 'refocus' our Working Groups to be more focused on tangible outputs.

As Kika Shabot and Derry Wilcox move into their Executive roles, there has been a positive shift and new fuel within the Trustee Board to prioritise and accomplish clear and tangible action points. With this shift, Sue Burrell is currently happy to remain in the post of President and suggests looking to step back in around 12 or 24 months.

Strategic aims identified for 2024-2025

In addition to healing divisions within GPAC, which will be imperative for success. GPAC has many aims for the next 12 months.

- **Executives will develop GPAC's infrastructure** to enable the succeeding Executive Board to continue to move GPAC forward. Transition of Derry into the Treasurer role and as a bank signatory, as well as development of the necessary *policies and procedures* to protect GPAC and our Members.
- **GPAC resilience: Identify candidates** interested in Working Groups and succession planning for GPAC to ensure the Executive Team is sustainable and resilient.
- **Members: Elections of Members:** the Joining Forms will be finalised and all PAGs wishing to become Members will be voted as such at the AGM in Pamplona, September 2024.
- **Finances: Evolve workload plans and resources to fund projects:** funding will be secured to enable GPAC to work professionally and recruit appropriate resources to manage projects identified by the Working Groups. In Pamplona, they set tangible and clear aims, objectives and action/endpoints that can be reviewed at each meeting, we have received nearly £18000 as of November 2024
- **Awareness WG** will identify end points around RDD/GPD/PAW.
- **Mental health WG** will focus on how specific points on protecting and supporting the minds of the porphyria community.
- **Information sharing WG** will identify specific aims to include 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.
- **New groups WG** 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.
- **Humanitarian WG** will work alongside physicians and patient groups to guidepost patients and potential patients to diagnostics, care and treatments.

GPAC also hopes to work in 2025 to establish more formalised collaboration routes with physicians, scientists, rare disease networks and other stakeholders, including pharmaceutical networks in order 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.

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Global Porphyria Advocacy Coalition Income Statement

November 11 2023 to November 10, 2024

Income	
Grants	£0.00
Donation	£24,290.00
Sponsorship	£0.00
Membership Donations	£562.60
Other Income	£0.00
Total Income	£24,852.60
Expenses	
Awareness	£4,000.00
Communications	£143.88
Website	£168.78
Meetings/ Gatherings	£0.00
Administration	£0.00
Travel	£0.00
Conferences	£0.00
Dues/ Membership fee	£0.00
Tax	£0.00
Total Expenses	£4,312.66
Net Income (Loss)	£20,539.94
Current Balance	£28,660.73

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