

President's Report

It is now 5 years since the Global Porphyria Advocacy Coalition's (GPAC's) first official meeting in 2019 in Milan. The Executives of Sue Burrell (President), Sean Hegarty (Vice President) and Joaquin Montoto (Secretary) are still in position, but are looking to take on Stewardship roles in 2024, in readiness for a new set of Executives taking up positions, by our next AGM in September 2024.

Our last AGM (Sept 2023) took place at the International Congress on Porphyrins and Porphyrias (ICPP) in Sofia, Bulgaria. It was wonderful to see so many PAG leaders from around the world back together in a face-to-face setting after the Covid pandemic! A further 5 country Members joined our meeting via Zoom. In advance of the AGM, Marco Mo resigned from the role of GPAC Treasurer, a post which still remains unfilled. Over the last 12 months, GPAC have not managed to meet regularly, due to various life-changing personal/family matters and a period of complete inactivity due to illness/injury effecting the voluntary contributions of the President and Vice President. This has had a direct and significant impact on GPAC's activities and achievements. GPAC has also been drawn into a problem within the community which has taken time away from pushing GPAC initiatives at the pace seen in previous years. Collectively, this has resulted in the halting of many GPAC initiatives and progress.

We are excited to be holding our Delayed-2023 AGM, via Zoom, on Saturday 3rd February 2024. On completion of the AGM, the Executives will encourage collaboration, professionalism and working together, as this is in the best interests of GPAC and will help to foster an engaged and stronger global porphyria patient community - a voice for patients that needs to be heard!

Progress to date

Meetings, connections and fostering global relationships: The GPAC Executive Board have only met on a couple of occasions to move actions forward for GPAC, since September 2022. The President has individually spent many additional hours working to resolve conflict in a way that all parties can share their voice. The President and Vice-President have met to discuss aims, strategic direction and other tasks. The Executive also worked 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.

GPAC had a very successful AGM and Global Gathering in Sofia, Bulgaria, 2022 with excellent presentations/talks/updates from Modern Inc., Disc Medicine and Alnylam Pharmaceuticals. After the meeting, there was an opportunity to network for all attendees, this was enabled with (gratefully received) sponsorship from Alnylam Pharmaceuticals and Disc Medicine. These networking opportunities are invaluable, they foster relationships which help enable deeper connections and understanding around the patient and their needs for trials and end-points, as well as research and change needed within the porphyria sphere, that may not otherwise have occurred.

Sue Burrell (GPAC's President) attended and presented (as a PAG Leader for GPAC and the British Porphyria Association, BPA) at two leadership meetings organised by Alnylam Pharmaceuticals. The first in Berlin, in February, alongside Ipnnet physicians on 'The importance of leveraging the power of patient voices' to a group of European clinicians interested in the acute porphyrias. The second, was alongside two other patient leaders from other rare disease areas at a series of 'Patient advocate consulting sessions' in Boston, USA, to discuss the challenges affecting patients in rare disease areas. Sue Burrell received honorariums for these engagements via her paid role with the BPA.

GPAC's Executives: Following the AGM in 2022, GPAC finalised a number of pivotal documents which are now able to support the running and day-to-day management of GPAC, including: *GPAC Bylaws and information pack; Charter for working together; GPAC Membership guidelines and joining form; GPAC Executive and trustee declaration form.*

GPAC's Working Groups (WG) despite GPAC having a number of working groups, including: *Cross Border Support WG; Media WG; Treatments and Research WG and GPAC and Research.* Most have not met 'officially' over the course of 2023. Nonetheless, work has still been ongoing via our Members (namely, between groups in America [APF and UPA], Brazil, Canada, Chile, Italy, Mexico, 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* secured just over £10,000 GBP sponsorship from Alnylam, Disc Medicine and a donation via the UPA from Mitsubishi Tanabe for 2023's *Global Porphyria Day project* (April 19th 2023) which fit with the APF's Porphyria Awareness Week. In 2024, the decision is to move this to have GPD on 18 May, to fit with the Spanish International Porphyria Day, it was suggested that the 11-18 May 2024 could be Porphyria Awareness Week which will be confirmed in due course. The Global Porphyria Day project aimed to record and release a number of disease specific awareness videos as part of the #MyPorphyria awareness campaign. The goals were to raise awareness of porphyria to help with diagnosis, testing and understanding of the lived realities of porphyria by engaging the global porphyria community to share their real-life stories, in their own words and in their own language, #MyPorphyria! The project paused when the President had an injury and was off work for several months. All sponsors have agreed that the sponsorship funds received in 2023 can be retained by GPAC in order to fulfil the project aims in 2024. We are very grateful for the funding and look forward to continuing the project. The first video was greatly received and much of the work on the pre-recorded content can be continued in time for 2024 awareness efforts. The EPP video will be the next footage circulated.

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.

Annual Report 2023

Delayed to
03-Feb-2024



Challenges faced: GPAC is still finding ways to work in a collaborative and inclusive manner and our *Charter for Working Together* asks all GPAC Members to respect and commit to working together professionally. *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 will be 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! Upon returning to fitness and work, the President needed to prioritise paid work, rather than voluntary endeavours which has stunted GPAC's progress across 2023. This highlighted very clearly that the current President has been doing the bulk of the work and this is an unsustainable format – which needs to be addressed.

The existing Executives would like to step down from their roles (ASAP). The current Trustees are looking for a new and enthusiastic leadership team to steer GPAC forward in an engaged, professional and inclusive manner. The process for the Election of Officers was agreed at the last AGM in Sofia and was planned for early 2023, this will now occur in 2024 ready for a formal transition as soon as possible.

The conflict noted within the GPAC community has taken time away from other porphyria work and has had an emotional impact too. This will be addressed at the Delayed- 2023 AGM to find a way of drawing a line under it and moving GPAC forward.

Strategic aims for 2024

In addition to healing divisions within GPAC, which will be imperative for success. GPAC has many aims for the next 8 months.

- **Develop its infrastructure** to enable the succeeding Executive Board to continue to move GPAC forward, including tasks around the *website, Office 365* and a series of necessary *policies and procedures* to protect GPAC and our Members.
- **Identify candidates** interested in Executive positions
- **Elections:** hold an EGM (Extraordinary General Meeting), if possible. Or work towards election of new officials (with a supported transfer via Stewardship) – by the latest date of 2024 AGM in Pamplona, September 2024.
- **Evolve workload plans** to ensure that the Executives are not overstretched and that the entity remains sustainable now and in the future. A plan will be agreed at the AGM to determine how this will work.
- The **Awareness** group will fulfil the GPD/PAW plans measured by the delivery of a successful awareness campaign.
- The Working Groups will continue to evolve by setting tangible and clear aims, objectives and action/endpoints that can be reviewed at each meeting.
- Explore the suggested **Buddy System** to support New Groups to assess whether it is achievable
- Assess whether it is achievable to source full **translation services** - which are costly, but would significantly increase accessibility for the whole porphyria community.
- Be involved in **future research** with other industry representatives so the burden of porphyria is more widely understood and to further validate to the existing patients that they are not alone in the impact their porphyria has on them and their families. Patient Leadership Council's may form some of this work. We'd also like to acknowledge thanks to the patient advocacy researchers who keep contributing/pushing research to improve things for porphyria patients.
- GPAC still has desires for a **Research and Information** WG which will develop an online resource that will store papers such as these, to increase access for the whole GPAC community.

Huge THANKS: GPAC would like to thank Desiree Lyon for her dedication and service to the global porphyria community over 40+ years, she has been a force and inspiration to patients around the world for many years... we wish her the very best in her retirement!

Treasurer's Report

All funds were very gratefully received by GPAC.

GPAC's accounting period runs from 11 November to 10 November – and is reported to the Charity Commission Annually. Detailed income/expenditure for 11-Nov-2021 to 10-Nov-2022 and 11-Nov-2022 to 10-Nov-2023 will be circulated with this Annual Report for 2023.

Summary: Since GPAC began, we have received an overall income and expenditure as follows and currently have £7,976.91 in GPAC's Bank Account (around £6,000 is already allocated to GPD/PAW 2024).

Summary of GPAC Accounts to date: as of 3-February 2024		All figures noted in GBP	
GPAC Total Income received to 3-February 2024		GBP	
	Income		GBP
Total Income			£15,752.11
GPAC Total Expenditure to 3-February 2024			
	Expenditure		
Total expenditure			-7,775.20
Total funds available for GPAC (as of 3-February-2024)		£7,976.91	

Income and Expenditure Account for the period 11 November 2022 - 10 November 2023
Global Porphyria Advocacy Coalition
CIO Reg No: 1189694

	GBP £	GBP £
Income	8884.8	8884.8
 Less Expenditure		
Software subscriptions (Zoom)	143.88	
Website and telephone	153.73	
GPAC events - room hire/catering	1819.72	
Financial fees	50.04	
Video editing	4750	
	<u>6917.37</u>	6917.37
 Income/expenditure		<u>1967.43</u>