

GRAPPA 2023 Patient Research Partner (PRP) Network Update: Enhancing PRP Involvement Within GRAPPA

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ABSTRACT. Nine patient research partners (PRPs) attended the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) 2023 annual meeting in person in Dublin, Ireland. The importance of close relations between researchers, clinicians, and PRPs was highlighted at the PRP premeeting, with discussion regarding PRP engagement within GRAPPA with the GRAPPA leadership team. A presentation was given by PRPs at the plenary session, and there was continued active engagement of PRPs in breakout sessions, workshops, and plenary sessions compared to previous annual meetings. The GRAPPA PRP Network is committed to supporting the GRAPPA mission and contributing the unique perspectives of dedicated, knowledgeable individuals with the lived experience of psoriatic disease. This report provides a summary of the GRAPPA PRP Network meetings at the GRAPPA 2023 annual meeting and the continued commitment of the GRAPPA PRP Network to enhance PRP involvement within GRAPPA activities.

Key Indexing Terms: GRAPPA, patient participation, psoriasis, psoriatic arthritis, researcher-patient relations

Patient Research Partner Network: Governance

The Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) Patient Research Partner (PRP) Network comprises 12 PRPs from 7 countries with varied backgrounds, psoriatic disease (PsD) history, and careers who support the researchers, physicians, and other GRAPPA members in GRAPPA's research and educational efforts. GRAPPA began a consistent collaboration with PRPs at its 2013 annual meeting, with increasing PRP representation at subsequent meetings and within GRAPPA projects.¹⁻⁵ The GRAPPA PRP Network policies and procedures were endorsed with consensus of all PRPs and the GRAPPA Executive Committee in December 2017.² Soon after, the PRP handbook was completed,⁴ which includes resources for PRP members such as a glossary, an overview of often-used disease assessment tools, and recommended literature. Discussion this year involved the need to refresh and update the documents to reflect changes within GRAPPA, specifically the increased PRP Network involvement in GRAPPA activities. This will be a key priority for the coming year.

PRPs at the GRAPPA 2023 annual meeting

Nine PRPs attended the in-person GRAPPA 2023 annual

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meeting in Dublin, Ireland, actively participating in workshops, breakout sessions, and additional working group meetings. An essential and successful part of the PRP premeeting was open dialogue with the expanded GRAPPA leadership team, in which fundamental principles of engagement and inclusion were discussed. The meeting included topics such as PRP involvement in working groups and new projects; setting guidelines for collaboration between researchers, clinicians, and PRPs; and providing administrative support to the PRP Network. Recruitment of additional PRPs was also discussed to address the growing number of GRAPPA projects and to diversify the PRP Network in terms of PsD manifestations, age, race and ethnicity, and global representation.

Increasing the presently small number of PRPs in a data-driven manner will ensure sufficient PRP input in all current GRAPPA-related projects and programs, to avoid overburdening the current PRPs. A plan of action was established and will be the subject of future communications.

The annual meeting allows for networking with members and individual clinicians and researchers. This was especially true with respect to engagement of the PRP Network and the Young-GRAPPA (Y-GRAPPA). Y-GRAPPA approached the PRP leadership with requests for additional engagement, which led directly to participation in educational webinars in the last quarter of 2023, in which the patient perspective was included in the Q&A sessions.

The annual meeting format enabled expanded exchange of ideas, allowing PRPs to continue to provide the added value of their unique perspectives as individuals with the lived experience of PsD, consistent with contributions in previous meetings.¹⁻⁵ PRPs also helped engage attendees in workshops. Several sessions dealt directly with issues in which the patient perspective, presented by PRPs, was vital in imparting a better understanding of the diagnostic, management, and/or treatment goals

of PsD.⁶ These included a session on depression in PsD, a session from the Difficult-to-Treat Psoriatic Arthritis (PsA) working group, and a session specifically about involving PRPs in GRAPPA activities. In those sessions, the PRP was not just part of a panel or Q&A session, but a speaker, sharing their perspectives with the presenter.

The PRPs continue to appreciate the ongoing collaboration and inclusion in the annual meeting, initiated by past PRP leadership in concert with GRAPPA leadership. The PRPs believe this offers a valuable, effective strategy for ensuring the lived experience of PsD is heard.

Enhancing PRP involvement within GRAPPA activities

Within the last few years, the involvement of PRPs in GRAPPA research and education has increased noticeably. There is a rising demand for PRP involvement in various activities. One of the plenary sessions, presented by PRPs Suzanne Grieb and Maarten de Wit,⁷ focused on ways to further involve PRPs in GRAPPA research and other activities.

In order to assess recruitment and current engagement, the PRP premeeting included an assessment of how the network is engaged in activities related and unrelated to GRAPPA, as shown in the Table.^{8,9} The PRP Network believes that GRAPPA contributions are strengthened due to knowledge gained from many PsA-related activities, within and outside of GRAPPA.

The PRP Network is also building specific content on the new GRAPPA website to represent the network and its activities, as well as providing resources for researchers, clinicians, and the

PRP Network. The content should be available in early 2024 and will enable GRAPPA members to review, expand, and strengthen projects of mutual interest with the PRP Network.

Future plans

The PRP Network has expanded their presence significantly over the years thanks to strong past leadership and member contributions, ensuring the lived experience of PsD is included in GRAPPA. The PRPs will continue to enhance support and knowledge-sharing within GRAPPA and expand collaboration with researchers and clinicians in research, education, advocating for care, and healthcare innovation. At present, the PRPs have initiated an internal working group to build a gap analysis of current PRP Network membership, set criteria and guidelines, and determine a screening process for recruiting PRPs. This will allow for data-driven recommendations for expansion and diversification of the network. PRPs will continue working to develop a PRP section of the GRAPPA website.

Conclusion

The GRAPPA PRP Network is expanding its involvement within GRAPPA through active participation in various committees and working groups, thanks to past clinician and PRP leaders who championed the inclusion of the patient voice. PRPs are looking forward to intensifying their collaboration with researchers, clinicians, and Y-GRAPPA, and believe that by strengthening and diversifying the PRP Network, the added value of their collective contributions will continue to increase.

Table. GRAPPA PRP involvement in internal and external GRAPPA activities and partnerships.

| GRAPPA PRP Activities | Non-GRAPPA–Related PRP Activities |
|--|---|
| GRAPPA 2024 Annual Meeting Planning Committee | APLAR |
| GRAPPA Difficult-to-Treat WG | ELLIPSS (AMP project in PsD) |
| GRAPPA Education Committee | EULAR PARE |
| GRAPPA Guidelines Committee ⁷ | HIPPOCRATES consortium (GRAPPA-EU) ⁸ |
| GRAPPA Membership Engagement Committee | IDEOM |
| GRAPPA/OMERACT working group | IFPA |
| GRAPPA-ASAS (AXIS study) | NPF |
| GRAPPA Publications Committee | SAGE-PsA study |
| GRAPPA Research Committee | |
| GRAPPA Steering Committee | |
| GRAPPA Treatment Guidelines Committee | |
| GRAPPA website development | |
| Scoring of posters for the GRAPPA annual meeting and trainee symposium | |
| Slide library project | |
| Y-GRAPPA | |

AMP: Accelerating Medicine Partnership; APLAR: Asia Pacific League of Associations for Rheumatology; ASAS: Assessment of SpondyloArthritis international Society; AXIS: Axial Involvement in Psoriatic Arthritis cohort; ELLIPSS: Elucidating the Landscape of Immunoendotypes in Psoriatic Skin and Synovium; EULAR: European Alliance of Associations for Rheumatology; GRAPPA: Group for Research and Assessment of Psoriasis and Psoriatic Arthritis; HIPPOCRATES: Health Initiatives in Psoriasis and Psoriatic Arthritis Consortium European States; IDEOM: International Dermatology Outcome Measures; IFPA: International Federation of Psoriasis Associations; NPF: National Psoriasis Foundation; OMERACT: Outcome Measures in Rheumatology; PARE: People With Arthritis/Rheumatism Across Europe; PRP: patient research partner; PsA: psoriatic arthritis; PsD: psoriatic disease; SAGE-PsA: Sex- and gender-based analysis of the effectiveness of advanced therapies in PsA; WG: working group; Y-GRAPPA: Young GRAPPiAns.

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