

GRAPPA Patient Research Partner Network: Update to the GRAPPA 2020 Annual Meeting

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ABSTRACT. Eleven patient research partners (PRPs) attended the virtual Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) 2020 Annual Meeting. PRPs fully participated in the panel discussion at the 2020 GRAPPA Annual Meeting on the topic of the coronavirus disease 2019 (COVID-19; caused by SARS-CoV-2). The members of the PRP group have been involved in many GRAPPA projects over the last year, including work on the GRAPPA–Outcome Measures in Rheumatology (OMERACT) Core Set, GRAPPA's 2020 Treatment Guidelines update project, and GRAPPA's Collaborative Research Network project.

Key Indexing Terms: GRAPPA, psoriasis, psoriatic arthritis

PRP Network Membership

Eleven patient research partners (PRPs) attended the virtual Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) 2020 Annual Meeting. Two PRPs were unable to attend and 1 PRP retired from the network before the annual meeting occurred.

The current PRP network comprises 13 members (54% female, 46% male), aged 20–80 years, from the following countries: USA (37%), the Netherlands (15%), Brazil (8%), Canada (8%), Hong Kong (8%), Ireland (8%), Israel (8%), and Norway (8%). With regard to the recruitment of new PRP members, we normally use the opportunity of having the PRP group physically together at an annual meeting to welcome new members. This was not possible this year due to the meeting being held virtually. We will resume searching for new members next year. Our goal is to make our network more representative of the global psoriatic disease population (i.e., a better balance by sex, age, race, ethnicity, how recently diagnosed, socioeconomic circumstances, and geographical distribution). We continue to develop and formalize our interviewing process and if necessary, will develop a virtual technique to welcome new members as well.

PRP Involvement in GRAPPA Projects

PRPs fully participated in the panel discussion at this year's annual meeting on the topic of COVID-19. The PRPs involved

also put significant effort into developing material for this discussion.

The members of the PRP group have been involved in many GRAPPA projects over the last year. Within the GRAPPA–Outcome Measures in Rheumatology (OMERACT) Core Set group, 3 PRPs worked on the steering committee, as well as additional PRPs were involved in the working subgroups; particularly in the Physical Function Working Subgroup. PRPs have also volunteered to work on all subgroup areas of GRAPPA's 2020 Treatment Guidelines update project.

GRAPPA was awarded a grant to develop patient self-management pamphlets. Healthcare professionals and PRPs have formed a team to develop these patient-friendly pamphlets. The aim is that the presented primary material will be evidence-based and coupled with professional input to ensure that the messaging is communicated as effectively as possible. PRPs have also been active in contributing to GRAPPA's Education, Research, and Ultrasound Committees.

The Collaborative Research Network (CRN) has involved PRPs in all its areas. Many of the CRN PRPs have also been active in the CRN's submission to the Innovative Medicines Initiative of the European Union for major funding of a joint academia-pharmaceutical industry project. Working closely with GRAPPA's doctors, PRPs also produced patient-friendly COVID-19 guidance for patients with psoriatic disease.

Conclusion

The patient volunteers who work as partners to the GRAPPA members are enthusiastic in providing assistance to those who work toward improving the lives of those living with global psoriatic disease. Our network members look forward to continuing our contributions in the coming year.

As part of the supplement series GRAPPA 2020, this report was reviewed internally and approved by the Guest Editors for integrity, accuracy, and consistency with scientific and ethical standards.

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