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The Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) Celebrates Its 20th Anniversary

Dafna D. Gladman[1], Philip S. Helliwell[2], and Philip J. Mease[3]

ABSTRACT. The Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) started in August 2003 with 40 initial participants and celebrated its 20th anniversary with 1036 members, many of whom attended the annual meeting in Dublin, Ireland, on July 15 to 17, 2023. GRAPPA arose from a need experienced by psoriatic arthritis (PsA) and psoriasis (PsO) investigators to meet to address questions related to psoriatic disease (PsD). Though other groups were meeting at the time to classify and discuss PsA, GRAPPA arose from a desire to include international clinical and investigational researchers of both dermatology and rheumatology. The organization has built awareness of PsO and PsA, developed and validated research assessment tools to measure clinical status and disease outcomes, published multiple treatment recommendations, supported basic and clinical research on PsD pathophysiology, fostered interactions across research fields, and educated the future generation of PsO and PsA researchers. The group continues to focus on major priorities affecting patients with PsD and will continue evolving in the next decades.

Key Indexing Terms: education, GRAPPA, psoriasis, psoriatic arthritis, research

The Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) was developed following the establishment of the Classification of Psoriatic Arthritis (CASPAR) Study Group.[1] Prior to the development of GRAPPA, Dr. Philip Helliwell (Leeds, UK) initiated a study with a group of European investigators who worked together to develop classification criteria for psoriatic arthritis (PsA).[1] Dr. Dafna Gladman (Toronto, Canada) requested that Dr. Helliwell include additional members from Europe as well as some from North America. This larger group of investigators, the CASPAR Study Group, had financial support from the European Alliance of Associations for Rheumatology (EULAR). In June 2001, the CASPAR Study Group met during the International League of Associations of Rheumatology (ILAR) in Edmonton, Canada. There, it was decided to broaden the scope of the group from just developing classification criteria to encompass other issues related to PsA.

Also in 2001, Dr. Philip Mease (Seattle, USA) heard Dr. Desiree van der Heijde describe the origins and purpose of the Assessment of Spondyloarthritis international Society (ASAS), which was focused primarily on spondyloarthritis. Drs. Mease and Helliwell met with Dr. van der Heijde at the Ghent Spondyloarthritis Congress meeting in 2002 to consider if there should be a chapter of ASAS devoted to PsA and psoriasis (PsO). Because the vision for the PsA and PsO group was to have equal participation of rheumatologists and dermatologists, it was concluded that it would be better for such an association to be its own entity so that it could accommodate both specialties.

Throughout 2003, numerous thought leaders involved in PsO and PsA research and education around the world, including rheumatologists, dermatologists, representatives of patient service leagues, and the pharmaceutical industry, teleconferenced and emailed about establishing a society that could meet, exchange knowledge and ideas, and conduct collaborative research. Dr. Mease sought a multipharma sponsorship for an international meeting of rheumatology and dermatology researchers, as well as patient service league participation, and organized a first meeting in New York City on August 14, 2003.

As invited participants arrived at the Marriott Hotel for the meeting, New York City went dark. A blackout on the eastern seaboard (Figure 1) forced participants to climb multiple flights of stairs to get to their rooms (Figure 2). Robin Shapiro, who administered the meeting, discovered lights on at the Westbury Hotel as she walked up Manhattan

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As part of the supplement series GRAPPA 2023, this report was reviewed internally and approved by the Guest Editors for integrity, accuracy, and consistency with scientific and ethical standards.

[1]*D.D. Gladman, MD, Division of Rheumatology, Department of Medicine, University of Toronto, Schroeder Arthritis Institute, Krembil Research Institute, Toronto Western Hospital, Toronto, Ontario, Canada;*
[2]*P.S. Helliwell, MD, Leeds Institute of Rheumatic and Musculoskeletal Medicine, University of Leeds, Leeds, UK;* [3]*P.J. Mease, MD, Swedish Medical Center/Providence St. Joseph Health, and University of Washington School of Medicine, Seattle, Washington, USA.*

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Address correspondence to Dr. D.D. Gladman, Toronto Western Hospital, 399 Bathurst Street, 1E-410B, Toronto, ON M5T 2S8, Canada. Email: dafna.gladman@utoronto.ca.

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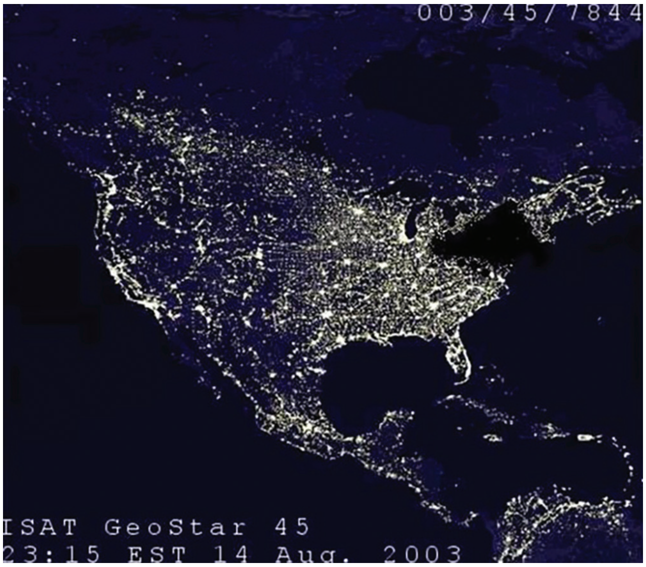

Figure 1. Blackout on the date the first meeting was to take place.

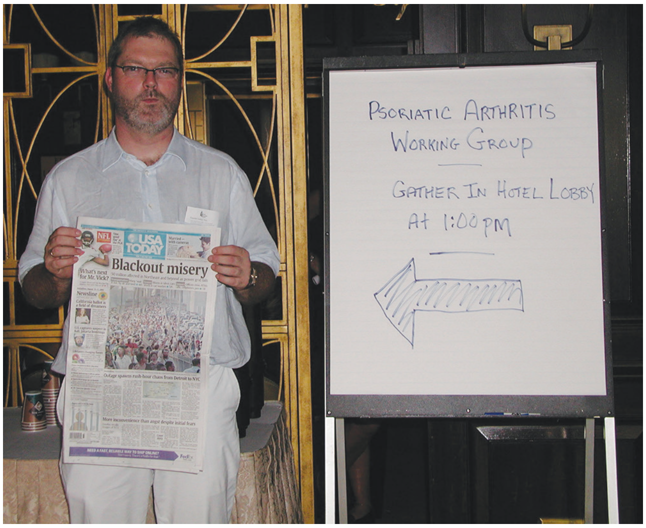

Figure 2. First meeting participant exhibits newspaper article on blackout misery.

Figure 3. Attendees of the first meeting of what would become GRAPPA. GRAPPA: Group for Research and Assessment of Psoriasis and Psoriatic Arthritis.

the next day, and immediately arranged for the meeting to be moved to the Westbury.

In total, 40 people attended (of whom 75% were rheumatologists, 20% were dermatologists, and 5% were patients) and participated in the meeting proceedings (Figure 3).[2] Following presentations on PsA,[1] the group concentrated on identifying outcome measures to be used in clinical trials and observational cohorts.[3] A name for this new group was proposed by Dr. Helliwell, which was accepted, and GRAPPA was born. GRAPPA has held annual meetings since 2006.

GRAPPA's first mission statements were developed, which included the following:

- Increasing awareness and early diagnosis of PsO and PsA
- Development and validation of research assessment tools to measure clinical status and disease outcomes
- Evaluation of treatment modalities and treatment recommendations
- Supporting and conducting basic research on PsO and PsA disease pathophysiology
- Fostering communication between rheumatologists, dermatologists, representatives of patient advocacy organizations, patient research partners (PRPs), biopharmaceutical companies, regulatory agencies, and others who are interested in the advancement of care of PsO and PsA.

Several major projects have been accomplished by GRAPPA members in the past 20 years, including the following:

- Publication of the CASPAR criteria, which are now accepted as the inclusion criteria for clinical trials and observational cohorts[1]
- Projects on outcome measures in PsA through GRAPPA's Outcome Measures in Rheumatology (OMERACT) community[4,5]
- Development of the Psoriatic Arthritis Disease Activity Index (PASDAS) and the GRAPPA Composite Exercise (GRACE) instrument through the GRACE project[6]
- Publication of the first treatment recommendations for PsA in 2009,[7] with updates in 2015[8] and 2022.[9]

Education projects have included the following:

- Educational symposia held virtually and in person for rheumatologists and dermatologists around the world.
- Educational symposia in collaboration with the Spondyloarthritis Research and Treatment Network (SPARTAN), ASAS, the National Psoriasis Foundation (NPF), the Spondylitis Association of America (SAA), and the International Federation of Psoriasis Associations (IFPA).
- Educational initiatives in collaboration with pharmaceutical companies and continuing medical education companies.
- Development of a slide collection that has been updated in collaboration with Young-GRAPPiAns. The slide collection is housed on the GRAPPA website and the slides are available for download.
- Development and activation of an application for screening questionnaires to calculate disease activity (skin and joints).

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- Development of training videos for the assessment of peripheral joints, enthesitis, dactylitis, axial disease, and PsO that are housed on the GRAPPA website (www.grappanetwork.org).

Several collaborative research initiatives have included

- GRAPPA-industry projects assessing drug response and biomarkers for response
- Establishment of the Collaborative Research Network (CRN), which has now been incorporated into the research committee of GRAPPA with several projects underway
- Establishment of the Innovative Medicines Initiative (IMI) consortium, Health Initiatives in Psoriasis and Psoriatic Arthritis Consortium European States (HIPPOCRATES), in Europe in collaboration with GRAPPA
- Establishment of the Accelerating Medicines Partnership (AMP) autoimmune and immune-mediated diseases program: the Elucidating the Landscape of Immunoendotypes in Psoriatic Skin and Synovium (ELLIPSS) consortium in the US, in collaboration with the HIPPOCRATES network
- Initiation of a study aimed at defining axial disease in PsA (Axial Involvement in Psoriatic Arthritis [AXIS]) in collaboration with ASAS.

GRAPPA has grown substantially since 2003. The membership is now up to 1036 and includes rheumatologists, dermatologists, PRPs, representatives of patient service leagues and biopharmaceutical companies, and others who are all stakeholders in the care of patients with PsA and PsO. Including PRPs in all GRAPPA educational and research activities has been an important way to give patients a voice in the organization. Forming Young-GRAPPA is helping nurture the future of research and education in PsA and PsO by giving a greater voice to early career researchers and clinicians. The organization is now truly global, both in education and in membership, with members representing 63 countries, including many under-resourced parts of the world.

Most recently, further update of the governance rules and a reorganization of the leadership structure led to the development of a board of directors, a steering committee, and several subcommittees with representation and leadership by steering committee members. Young leaders are being promoted to take over from the founders of GRAPPA. These individuals are expected to develop strategic aims for the next decade.

It has been a great pleasure to be part of the organization for the past 20 years, to see it mature, and to review its accomplishments. We wish GRAPPA a happy anniversary and hope to follow further successes in the next decade.

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