

GRAPPA 2016 Project Report

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ABSTRACT. At the 2016 annual meeting of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), members received updates on several ongoing research and educational efforts. Among them were updates on the FLARE instrument, the Biomarker Project, GRAPPA's logo and Website, continuing progress on the video training project, and numerous educational project efforts in 2016. (J Rheumatol 2017;44:706–10; doi:10.3899/jrheum.170153)

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Members of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) continue to pursue core objectives of their mission, specifically identifying research assessment tools, pursuing research in disease pathophysiology, and providing education. At the 2016 annual meeting, members received updates on the FLARE instrument, an effort to assess disease flare in psoriatic arthritis (PsA); the Biomarker Project, a collaborative research effort to identify and study biomarkers of joint damage; efforts to update GRAPPA's logo and Website; continuing progress on the production and use of video training modules; and numerous educational projects in 2016.

The FLARE Instrument

In PsA, disease activity may not be sufficiently described using only core outcome measures. Indeed, patients often complain of a disease flare, which they describe as something beyond just the physical symptoms of the disease. In a quali-

tative study, patients identified 9 overarching themes pertaining to flare: physical symptoms, social withdrawal, psychological symptoms, fatigue, loss of normal function, triggers, management of pre-flare, management of flare, and timing¹.

No measures have been validated to assess disease flare in PsA. A systematic literature review in 2011 found only 5 articles relating to flare in PsA. Most studies analyzed the inverse or absence of a disease target, such as remission or low disease activity². Similar studies assessing the prevalence of flare after treatment tapering and withdrawal have identified the absence of low disease activity as the definition of flare^{3,4}.

Recently, a GRAPPA-sponsored study advanced the previous qualitative work. Further discussion at the annual meeting of GRAPPA in 2015, followed by Delphi surveys of both physicians and patients⁵, resulted in a putative "flare" instrument (Figure 1).

A prospective, multicenter validation study of this instrument is now planned to be conducted in dermatology and rheumatology units; patients will be recruited consecutively at the outpatient clinics during normal followup. Demographic, clinical, and functional data, as well as quality of life, will be recorded at baseline and at 1 followup visit. An "anchor" question ("Do you think you are having a flare at the moment?") for both patients and physicians will be used. A decision to change or increase disease-modifying drug treatment will be used as a surrogate for active disease. Using data from the GRAPPA composite exercise study, we estimated that about one-third of patients will require treatment change; therefore, to ensure sufficient numbers of patients to allow regression analyses, we will require at least 300 participants.

GRAPPA Biomarker Project

In 2015, GRAPPA established the biomarker subcommittee, with Dr. Paolo Gisondi (Dermatology) and Dr. Oliver FitzGerald (Rheumatology) as co-leads. After preliminary

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As part of the supplement series GRAPPA 2016, 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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Flare questionnaire

These symptoms have been suggested by people having a 'flare up' of their disease. Please answer 'yes' or 'no' to these questions.

	Yes	No
Have you recently experienced:		
A change/increase in itchiness of your skin		
A recent change/increase in the area of skin involved		
A recent change/increase in joint pain		
A recent change/increase in the number of tender and/or sore joints		
A recent change/decrease in inability to perform activities of daily living, such as washing and dressing		
A recent change/decrease in ability to move easily		
A recent change/increase in frustration		
A recent change/increase in depression		
A recent change/increase in feeling of tiredness all the time		
A recent change/increase in the number or combination of symptoms from your disease		

	Yes	No
Do you think you are having a flare of your disease at the moment?		

For how long have you had these changes in symptoms?	Yes	No
Less than a week?		
Between one week and two weeks?		
Between two weeks and four weeks?		
Between a month and three months?		
Over three months		

Figure 1. Flare questionnaire.

discussion, the co-leads identified key areas of research interest, and following a leadership retreat discussion at the GRAPPA 2016 annual meeting, the biomarker subcommittee merged with the GRAPPA research subcommittee.

Four major areas of biomarker research have been identified, including the Psoriatic Arthritis BIOMarkers of radiographic DAMage (PsA-BioDAM) project, which has been discussed previously⁶, but also biomarkers of development of PsA in a population of patients with psoriasis, biomarkers of disease activity, and biomarkers that predict treatment response in both psoriasis and PsA.

GRAPPA has for some time identified biomarkers of joint damage as the priority area of biomarker research in PsA⁶. To date, GRAPPA has been unable to identify sufficient funding support for a definitive biomarker of joint damage

study; however, funding opportunities will likely improve when there is more evidence for candidate biomarkers. Two approaches are currently under way: first, GRAPPA is working with pharmaceutical companies such as Amgen and Pfizer to link with current and future randomized controlled trials, particularly those where appropriate clinical and radiographic measurements have been recorded together with collection of biological samples. Second, individual GRAPPA investigators in Toronto, Ontario, Canada, and in Leeds, UK, are using magnetic resonance imaging changes instead of plain radiographic imaging and correlating these changes with levels of known biomarkers. A discovery arm using some of the "OMIC" technologies is also planned.

Finally, at a GRAPPA 2016 workshop, members discussed the concept of establishing a research collaborative network,

which might help to promote collaborative projects that would prove difficult to do at any single center. With the development of a virtual bio bank, samples might be shared between collaborating units. After considerable discussion, it was agreed initially to circulate a survey to all GRAPPA members seeking their views on the establishment of a research collaborative network and enquiring as to their capacity and willingness to contribute. The results of this survey were presented at the GRAPPA meeting adjacent to the American College of Rheumatology (ACR) meeting in Washington DC, USA, in November 2016.

Logo and Website

At the 2015 annual meeting of GRAPPA, members discussed steps to improve recognition and branding of the group, with updating GRAPPA's logo determined as the first priority. A small committee was formed, a number of potential logos were sought from designers, and once a short list was reached, committee members voted on the best logo and colors. To maintain consistency, the colors remained green and purple, but a cleaner logo design was chosen to brand future GRAPPA work.

Updating the GRAPPA Website was the next priority. After several members reported navigation difficulties in finding content, a Website map was developed that identified key areas that the Website should contain, including specific areas available only to members who log in to the site. Members also researched potential Web designs by looking at several Websites of nonprofit organizations in the United States and Europe. Once an outline was finalized, it was sent to 3 Web designers for their proposals, and after review, the Website committee chose Brian Stoll of Sound Info Services to develop the new Website. Stoll created a draft Website that committee members reviewed before it went "live." The membership database was integrated and the Website was published on April 7, 2016.

Now that the new design has been developed, ongoing work includes providing content on the Website. In parallel to the rebranding of the logo and Website, the GRAPPA slide decks have also been redesigned and are available for download from the Website (www.grappanetwork.org). Additional content will include links to a library of GRAPPA publications and resources for the patient research partners.

Video Training Modules on Physical Examination of Joints, Enteses, Dactylitis, Spine, Skin, and Nails

The GRAPPA video training project, an ongoing educational initiative started in 2010 that provides online standardized training for psoriasis and PsA severity measures used in clinical trials and registries, now includes 18 modules that cover physician-assessed psoriatic involvement and severity of skin, nails, joints, enteses, dactylitis, and spine. The development and evolution of these modules have been previously described^{6,7}.

Of 18 available modules, 12 cover skin and nail assessments, and 6 cover psoriatic musculoskeletal involvement (Table 1)^{6,8}. Each module consists of a narrated video or slide presentation with photographs and diagrams created by GRAPPA experts. The rheumatology modules include demonstration of the measures on volunteer patients. Most dermatology modules include a certification portion to assess proficiency.

To date, the most accessed module covers the Psoriasis Area and Severity Index (PASI)⁹ and body surface area¹⁰. Additionally, there are now two 6-point physician's/investigator global assessment (PGA or IGA) modules and three 5-point PGA/IGA modules, all of which were created in partnership with the industry sponsors to accommodate their protocol training needs. Two studies have examined the inter-rater reliability of the PASI following video training using the GRAPPA dermatology modules⁶.

The rheumatology modules include 2 new modified versions of dactylitis and enthesitis, 1 that covers the Leeds enthesitis instrument only, and 1 of dactylitis without the use of a dactylometer. A second joint count assessment, presented by Dr. Arthur Kavanaugh, MD, has also been added.

GRAPPA is currently partnered with 3 different vendors who have contracted with pharmaceutical industry sponsors to provide video training to their investigators using sponsor-specific customized workspaces tailored to individual study requirements. GRAPPA members can access all modules through the ePharmaSolutions portal. Future directions of the video project include translation of modules to Chinese and other languages, as well as re-recording of some rheumatology videos to provide greater flexibility to sponsors' protocol needs.

Educational Projects

Members of GRAPPA continue to collaborate with other research and education associations as a core part of GRAPPA's mission to educate those involved in the care of and advocacy for patients with psoriasis and PsA and their families. Educational efforts aimed at dermatologists and rheumatologists, generalists, physiatrists, orthopedists, nurse practitioners, physician assistants, nurse specialists, medical students, residents and fellows, members of the pharmaceutical industry, healthcare agencies, and payor groups are global in reach and include continuing medical education (CME) and non-CME in-person lectures and symposia, online education, journal articles, textbooks, and newsletters.

Members of GRAPPA served as content developers and faculty for numerous GRAPPA educational activities in 2016. In full-day symposia, dermatologists and rheumatologists presented paired lectures on epidemiology and classification, clinical features, pathophysiology and genetics, and assessment and management of psoriasis and PsA. Some symposia also included small groups with patients to teach

Table 1. GRAPPA Video Project: module descriptions. Summarized from Mease, *et al.* J Rheumatol 2016;43:979-85; with permission⁶.

Module	Description/notes
PASI and BSA	Photographic examples of erythema, induration, and scale, methods of assessing area score, and BSA instruction.
6-point sPGA, v. 1	Erythema, induration, and scale assessed 0–5, then averaged and rounded to nearest whole numbers (adaptation of National Psoriasis Foundation Psoriasis score).
6-point sPGA v. 2	Erythema, induration, scale each scored 0–5, using slightly different scale descriptions than v1.
6-point sPGA, v. 3	Erythema, induration, scale assessed and a single score of 0–5 assigned (no rounding).
5-point sPGA	Erythema, induration, and scale assessed individually, then averaged and rounded to nearest whole numbers.
5-point IGA2011 “modified” ⁷	Erythema, induration, and scale assessed 0–4. Certification module available (3 examples).
NAPSI	Describes features of matrix and nail bed psoriasis and how to perform this measure.
mNAPSI	Description of the rationale and method.
PSSI	Adaptation of PASI for scalp assessment.
PPPASI	Adaptation of PASI for scoring palmar-plantar pustular or nonpustular psoriasis.
TPSS	Assesses target plaques, scores erythema, induration, and scale.
Dactylitis and enthesitis v. 1	Dactylitis background and use of dactylometer; enthesitis background, evaluation using LEI, MASES Enthesitis Index, the Enthesitis Skeletal exam, SPARCC Enthesitis Index, Major Enthesitis Index, and 4-point Enthesitis Index.
Dactylitis and enthesitis v. 2	Dactylitis background and use of dactylometer; enthesitis background, evaluation using LEI only.
Dactylitis and enthesitis v. 3	Dactylitis background and use of dactylometer; enthesitis background, excludes use of dactylometer.
Synovitis	Includes educational content on joint exam and synovitis introductions, video demonstration of examining joints.
Joint count assessment	Pragmatic approach to the tender and swollen joint count.
Axial disease assessment	Includes background and video demonstration of measuring cervical rotation, chest expansion, occiput-to-wall/tragus-to-wall distance, forward flexion, lateral bending of spine, examination of the hip.
BSA	Describes background and rationale for the handprint method of determining BSA involvement of psoriasis.

Shaded rows indicate new additions in 2016. GRAPPA: Group for Research and Assessment of Psoriasis and Psoriatic Arthritis; PASI: Psoriasis Area and Severity Index; BSA: body surface area; sPGA: static physician’s global assessment; IGA2011: Investigator’s Global Assessment 2011; NAPSI: Nail Psoriasis Area Severity Index; mNAPSI: modified NAPSI; PSSI: Psoriasis of the Scalp Severity Index; PPPASI: Palmar-Plantar Psoriasis Area and Severity Index; TPSS: Total Plaque Severity Score; LEI: Leeds Enthesitis Index; MASES: Maastricht Ankylosing Spondylitis Enthesis Score; SPARCC: Spondyloarthritis Research Consortium of Canada.

use of ultrasound and techniques of physical examination of joints, entheses, dactylitis, spine, skin, and nails.

In Europe, Drs. Philip S. Helliwell, Kurt de Vlam, Luis Puig, and Wolf-Henning Boehncke organized day-long dermatology-rheumatology symposia in Leeds, London, Moscow, Milan, and Stockholm. In Asia, a 2-day symposium was conducted in Seoul, Korea, chaired by Dr. Philip J. Mease. Lectures by GRAPPA members were presented at the Asia-Pacific League Against Rheumatism meeting in Shanghai.

GRAPPA has collaborated with the Spondyloarthritis Assessment and Treatment Network (SPARTAN) since 2012 to provide CME symposia on PsA and non-PsA forms of spondyloarthritis (SpA), including ankylosing spondylitis, nonradiographic axial SpA, and other forms of SpA. These have included full-day standalone symposia, half-day symposia (as part of regional rheumatology society meetings), and evening lectures. In 2016, US CME symposia and lectures occurred in Boise, Dallas, Boston, New York, and Cleveland. The Pan-American League Against Rheumatism hosted a symposium at its annual convention in Panama City. An additional collaboration with the Assessment of Spondyloarthritis international Society (ASAS) was a symposium at the annual ACR meeting in Washington, DC.

In collaboration with the National Psoriasis Foundation,

GRAPPA hosted several dermatology-rheumatology symposia in San Francisco, Dallas, Boston, Seattle, and Cleveland in a format similar to that of the international symposia described above; attendees included dermatologists and rheumatologists, as well as trainees.

GRAPPA’s Education Committee co-chair, Dr. Amit Garg, was acknowledged for his role in promoting education about psoriasis by the American Academy of Dermatology (AAD), which awarded him the Thomas Pearson Memorial Education award. Similarly, Dr. Philip J. Mease, the other Education Committee co-chair, was inducted as a Master of the ACR for his role in education and research in rheumatology, particularly PsA.

At a brainstorming session about future education activities, held prior to GRAPPA’s 2016 annual meeting, members made several suggestions:

- Develop half- to full-day educational modules to present to trainees in academic medical centers.
- Develop Web-based educational modules.
- Develop psoriasis-PsA educational symposium at the AAD meeting analogous to the GRAPPA-SPARTAN-ASAS symposium at ACR.
- Develop educational applications for smartphones or computers.
- Increase and diversify (geographically) the membership of the Education Committee.

These research and educational updates demonstrate the scope of activities that take place under the GRAPPA umbrella. Members remain committed to these collaborations, which will further our understanding and improve our ability to care for patients with psoriasis and PsA.

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