

GRAPPA

Group for Research and Assessment of Psoriasis and Psoriatic Arthritis

GRAPPA NEWSLETTER JUNE 2015

A Message from Wolf-Henning Boehncke, GRAPPA President

Greetings from Geneva!

My three years as GRAPPA president have gone by so quickly. It is hard to believe that in just a few weeks I will be “passing the hat” to Philip Helliwell when we convene in Stockholm for our 2015 Annual Meeting and Trainees symposium.

As I reflect back on my term, I am struck not only by the growth of our organization and its accomplishments in bringing together rheumatologists and dermatologists under a common goal, but also how diverse and global we are as a group. The truly international and interdisciplinary character of this organization is underlined by the fact that, after two North American rheumatologists, the third president of Grappa was a European dermatologist.

I would like to gratefully acknowledge the role of the Executive Committee that helps run things day to day, and the Steering Committee that guides GRAPPA's objectives, as well as our corporate supporters, all becoming more and more important, as GRAPPA grows.

I hope you will be able to attend the annual meeting and our Tuesday afternoon session where I will update our members on where we stand as an organization and where we see ourselves headed in the future. We will also be introducing our newly-elected GRAPPA officers. *Look for an email soon about how to vote for our future officers.*

To that end we are trying something new this year, a Presidential Round Table. It is our hope that this open forum will provide members with an opportunity to guide the future of the society and to make recommendations for projects, and indeed anything else they would suggest to improve the way things are right now.

Thank you to each of our members for their dedication and contributions to making this organization what it is today.

Wolf-Henning Boehncke
GRAPPA President

NEW This Year at the Annual Meeting – GRAPPA Presidential Round Table!

During the final session of the 2015 GRAPPA Annual Meeting, former, current and future presidents Dafna Gladman, Philip Mease, Wolf-Henning Boehncke and Phillip Helliwell will host a round table discussion on GRAPPA's organizational objectives.

Topics for discussion will include:

- Past and future goals and directions
- Issues we are facing including new areas we might want to explore in the future
- Effectively reaching different parts of the globe

The last 15 to 20 minutes will be an open microphone session from the audience. Don't miss this opportunity to guide the future of GRAPPA and share your opinions and recommendations in an open forum setting!

New PsA Treatment Recommendations Nearing Publication

Based on a body of evidence gleaned from extensive literature reviews, the Treatment Recommendations Committee has completed new recommendations for the treatment of Psoriatic Arthritis.

Last year GRAPPA published a supplement in the *Journal of Rheumatology* comprised of a paper for each of the working PsA groups: peripheral arthritis, axial, enthesitis, dactylitis, skin, nails and comorbidities. Each paper contained a great systematic literature review of the evidence behind different therapies in their area. The individual groups then

developed new treatment recommendations based on the supporting evidence for therapies used to treat their specific symptom. The groups are now synthesizing their evidence-based recommendations into one paper for publication.

Following development of the recommendations, committee co-Chairs Laura Coates, Arthur Kavanaugh, Christopher Ritchlin and Philip Mease sent a survey to GRAPPA membership for feedback on the treatment recommendations. They will present the final draft of the overarching principles for the treatment recommendations at the annual meeting in Stockholm, pending the members' completion of the survey.

The recommendations were supported by over 80 percent of the membership including both healthcare professionals and patient research partners. Final drafts of the treatment schema and the evidence table on which they are based will also be presented. They are being finalized for the paper, with input from all of the individual group leaders and have also been endorsed by the membership via Survey Monkey.

In addition, a full draft of the paper will be circulated to all of the group leaders prior to the annual meeting for their comments before publication. After incorporating these comments, an abstract describing the new treatment recommendations will be submitted to ACR to share them with the rheumatology community.

GRAPPA Educational Initiative Expands Learning Opportunities for European and American Clinicians

GRAPPA is committed to educating clinicians in the latest research, best practices and treatment options. The Educational Initiative Subcommittee continues to develop innovative curricula and host free grant-supported workshops throughout the US and Europe – and in the future, South America.

The SPARTAN-GRAPPA educational symposia conducted across the US has now completed 25 CME accredited programs since 2012. These popular symposia covering axial spondyloarthritis and psoriatic arthritis are offered as full-day, half-day, and quarter-day CME programs. New this year, an evening program was offered in San Antonio and Seattle.

These symposia impart knowledge in various formats: plenary talks, “hands-on” workshops and allowing attendees to answer rheumatology boards examination-style questions using an audience response system. Last year, a full-day symposium was conducted in Chicago, Cleveland, Tampa, and Boston, and in addition, a quarter-day symposium was held in collaboration with the ASAS group at the end of the ACR annual meeting in Boston in November 2014.

GRAPPA also embarked on a partnership with the National Psoriasis Foundation for a series of full and half-day symposia, “Advancing Knowledge and Practice in Psoriasis and PsA: the Rheumatology-Dermatology Collaborative Initiative” in cities around the US.

Last year's European meetings were held in Antwerp in January, Leeds in February, Oslo in March, Frankfurt in April and Seville in May. Meetings are also planned for Athens and Milan in October and November.

The European meetings are not only a valuable education tool, they also bring together dermatologists and rheumatologists for a shared agenda of lectures and workshops. Feedback on the workshops has been overall very positive – for example, 95 percent of the respondents who attended in Antwerp said they would recommend the course to a colleague. GRAPPA will also be expanding its educational offerings to South America at the Brazilian Rheumatology Association annual meeting in Curitiba, Brazil.

Philip Mease and Atul Deodhar will present updates on the SPARTAN-GRAPPA symposia at the annual meeting in Stockholm. Philip Helliwell will present a GRAPPA slide set and Kristina Callis Duffin will share updates to GRAPPA's online training modules.

Publications Committee Update

The past year was a busy one for the GRAPPA Publications Committee. 2014 publications include:

June 2014: “Annual Meeting of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), Toronto, Canada, July 12–13, 2013.” This series of articles, published in the *Journal of Rheumatology*, reflects the content of the Annual GRAPPA meeting in Toronto in July 2013.

November 2014: “Systematic Review of Treatments for Psoriatic Arthritis: 2014 Update for the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA).” This was a series of eight articles published in the Journal of Rheumatology assessing the efficacy of treatment for peripheral arthritis, dactylitis, enthesitis, psoriasis, nail disease, and axial disease as well as comorbidities and extra-articular manifestations.

June 1, 2015: The committee also submitted articles summarizing the annual meeting in New York, July 2014. This was published June 1 and may be accessed online at <http://jrheum.com/grappa/grappa2014.html>.

Lastly, once the final paper of the GRAPPA treatment recommendations is complete, it will be submitted for publication.

Publishing in medical journals is an important component of GRAPPA’s educational objectives, and extend the information shared at GRAPPA meetings to an even broader audience.

Flare Definition Project

The ability to define a psoriatic arthritis flare would benefit both patients and their providers. However, there is no clear definition of a flare. A tool that would help clinicians define and identify a flare would be useful in cases where treatment is withdrawn or tapered, not only for detecting deterioration, but as a guide to changing treatment and allowing patient input.

Philip Helliwell and Anna Caperon are working to establish a flare definition and a tool for use by clinicians. Their current study builds on qualitative interviews by taking a battery of items and surveying both patients and doctors using an internet survey and the Delphi technique.

Under the headings of joint, emotional, participation, fatigue and miscellaneous, they surveyed three different cohort groups, asking them to rate the relevance of the item for distinguishing a flare. The cohorts included two patient and one physician group who were sent an online survey: the Psoriasis and Psoriatic Arthritis Alliance, the Bath PsA support group and members of GRAPPA.

Survey respondents were asked to rate the relevance of each item on a nine-point scale and were also asked to suggest any items they thought were missing. Those items meeting the acceptance criteria, and the suggestions for new items were used for the second round of surveys.

As a result of this exercise, 14 items were agreed upon as important by patients, and 22 items by physicians. Six of these were shared between the two groups. Twelve new items were suggested by respondents to the first survey.

More work will need to be done to develop a flare tool, including testing it with new cohorts. However these are the first steps to its creation. An abstract of the study has been submitted by Anna Caperon and Philip Helliwell for publication and results also will be reported in Stockholm at the GRAPPA annual meeting.

Patient Research Partners Represent Six Countries at this Year’s Annual Meeting

For the third time GRAPPA Patient Research Partners (PRPs) will participate in the annual GRAPPA meeting in Stockholm. This year they will represent six different countries. They come from Canada, Ireland, the Netherlands, United States and the United Kingdom.

Their role will be to represent the perspective of people with psoriasis and psoriatic arthritis in the different plenary and breakout sessions. The patient coordinators, Ina Campbell and Maarten de Wit, with the help of two committed medical doctors, have developed a preconference program for the patients. The aim is to prepare patients for their participation in the meeting.

To help the PRPs better understand the themes and projects that will be presented at the meeting, the Patient Research Partners have created a booklet of lay summaries. The booklets will be distributed before the conference.

Patient participation in GRAPPA is still a challenge but the enthusiasm to promote and support the implementation is steadily growing. During the meeting, the patient research partners will have the opportunity to present their views in

the plenary session on Wednesday. In this session the potential roles of patients and benefits of their participation in scientific research will be emphasized as well as the barriers that patients and professionals have to overcome.

NIH-PROMIS® in Psoriatic Arthritis

Developed by the National Institutes of Health, the Patient Reported Outcomes Measurement Information System (PROMIS) is a collection of generic patient reported outcome measures that use the World Health Organization's International Classification of Functioning framework. PROMIS measures are structured by unidimensional health domains and are generic measures intended for the assessment of chronic medical conditions.

Potential advantages of using NIH-PROMIS® measures over legacy measures in PsA are their ability to be used across chronic medical conditions, improved measurement properties and decreased participant burden through the use of computer-adaptive testing technology.

Selected NIH-PROMIS® measures will be assessed longitudinally in a cohort of patients with psoriatic arthritis concomitantly with traditional measures, disease activity and routine clinical assessments. The study will provide preliminary evidence towards feasibility, reliability and validity of NIH-PROMIS® measures in psoriatic arthritis and will inform future use of NIH-PROMIS® measures in clinical care and research in psoriatic arthritis. Ana-Maria Orbai will report on NIH-PROMIS® at the GRAPPA annual meeting.

7th Annual GRAPPA Trainees Symposium Highlights Research from Around the Globe

GRAPPA continues to take an active role in encouraging young physicians and scientists through the Trainees Symposium. As part of each annual meeting since 2008, the symposium highlights the research of rheumatology and dermatology trainees, residents and fellows from all over the world.

This year, there were 34 submissions from 14 countries. Of these, seven trainees were selected for oral presentations: Shai Brikman, Israel; Anna Caperon, UK; Elena Generali, Italy; Tania Gudu, France; Sian Yik Lim, US; Josefina Marin, Argentina; and Michael Milliken, US. Anna Caperon will be presenting her findings on FLARE with Dr. Philip Helliwell during the Flare Module Plenary Session on Wednesday July 8. The others will give oral presentations based on their abstracts at the trainees' session the morning of Tuesday July 7.

Oral presentations include research on fatigue in PsA, impact of statins on survival in psoriasis and PsA, gender differences in clinical features, methotrexate use and mortality in psoriasis and PsA, investigation into fibromyalgia in PsA and the use of power Doppler ultrasound to predict flare in PsA. In addition, 26 posters will also be presented at the meeting on a variety of scientific and clinical topics related to psoriasis and PsA.

Trainees Symposium Chair Christopher Ritchlin began the symposium as an opportunity for trainees and fellows to develop their research skills through presentation and discussion of their work.

"We want the next generation of scientists and physicians to become engaged in psoriasis and psoriatic arthritis so we can improve quality of life and function for patients with these disorders. We also want to start a dialogue between dermatologists, rheumatologists and scientists at an early stage in their careers to enhance collaborations and increase the chances that advances will take place," says Ritchlin.

The poster session will be during an extended coffee break and "poster walkabout" after the oral presentations on Tuesday morning. Plan to meet these talented young researchers and learn more about their work.

Update on the International Dermatology Outcomes Measurement Initiative (IDEOM)

One of the biggest obstacles to obtaining optimal care for psoriasis patients and their clinicians is the misconception that psoriasis is a cosmetic issue. Treatment options, research support and payor coverage often fail to address important aspects of the disease such as quality of life, nail disease, metabolic syndrome and cost efficacy – as well as psoriatic arthritis and the associated cardiovascular morbidity and mortality. But what if you could establish validated and

standardized outcome measures that satisfy the needs of all stakeholders and can be applied to clinical research and practice?

That is exactly what the International Dermatology Outcomes Measurement (IDEOM) aims to accomplish.

Spearheaded by Alice Gottlieb, IDEOM is a non-profit initiative established to find psoriasis outcome measures that are useful in the clinical setting and satisfy the needs not only of physicians and regulators, but also of payers and patients.

Using OMERACT's (Outcome Measures in Rheumatoid Arthritis Clinical Trial) methodology as a model, IDEOM gathers information from relevant stakeholder groups. The perspective of patients, health economists, payors, physicians and regulatory agencies are included from the onset, because, as Gottlieb explains, access is the major obstacle to optimal psoriasis care. "Too often, psoriasis is viewed by payers and regulators as largely a cosmetic problem and not of equal severity as, for example, the rheumatologic disorders. In part, this is due to outcome measures which do not take into account all aspects of psoriatic disease and may not be helpful in distinguishing which drugs add extra value." As a result, she adds, payers are making decisions on physician and drug quality based upon claims databases in community practice, which do not assess patient severity or disease-specific outcomes.

Like OMERACT, IDEOM is interactive, and its development is data-driven. Stakeholders are given a vote and majority rules. IDEOM accomplishments in the two years since its inception include:

- Obtaining 501C3 status
- Publishing four peer-reviewed publications
- Increasing support and involvement from pharmaceutical companies, including the addition of new members from pharma
- Various presentations of their work including the OMERACT meeting
- Collaborations with AAD, GRAPPA, ADIPSO, NPF, Advancing Innovations in Dermatology and IFPA
- Completion of two Delphi exercise questionnaires and preparation for a third

The initial Delphi questionnaire was generated from the meeting in January 2013, as well as from additional input from the various stakeholders. Results from the first Delphi Exercise were presented in Toronto in 2013 and from the second round in Rome, in 2014. The first round identified 21 items for further evaluation in creating outcome measures from various perspectives including those of patients and health care providers. These 21 items were used in the second Delphi exercise. The highest scoring items were psoriasis morphology, location and area, and psoriatic arthritis. Patients and doctors agreed that PSA assessment was an essential outcome measure that is rarely addressed in psoriasis trials.

Though pleased with the progress, Gottlieb says there is more work to be done.

"Regulatory approval and publications are just the beginning. The true finish line is when the patient gets to the right doctor and the right treatment and their disease has minimal to no impact on their quality of life."

Gottlieb and Kristina Callis Duffin will present an update on IDEOM at the annual meeting in Stockholm.

GRAPPA and OMERACT

Core outcome measurement sets ("core sets") provide useful information to clinicians, patients, decision makers and other stakeholders about the effectiveness of treatments. However patients were not involved in the initial development of the Psoriatic Arthritis core set. The GRAPPA-OMERACT PsA working group engaged the GRAPPA Patient Research Partners (PRPs) to develop a plan for revising the core set that would involve patients at each step.

The GRAPPA OMERACT Project is currently focused on three specific projects: focus groups, a literature review and a domain and instrument assessment. PRPs are involved in each of these.

Focus groups are ongoing at US sites and will include other countries. Preliminary focus group results will be presented to GRAPPA PRPs at the annual meeting for their input.

A literature review of PsA clinical trials conducted in the past five years is in progress. It will summarize outcome measures and domains assessed in recent clinical trials. For outcome measures, information will be extracted on development, patient involvement, validation in PsA, feasibility and responsiveness.

The domain and instrument assessment project uses datasets from clinical trials in PsA to assess the correlation among outcome measures (within domains and among domains) and among change in outcome measures and change in patient global assessment.

Findings from the three ongoing projects will be assembled and presented to PRPs during a virtual meeting. Some preliminary results may be available for the GRAPPA annual meeting. After discussion with the PRPs, results will be made available to the GRAPPA membership and time will be allotted for feedback and discussion from the membership.

Once feedback is collected at the virtual and annual meetings, Delphi surveys will be conducted for patients and physicians separately and draft core domain sets will be created. This may be two separate core domain sets (one from the patient's perspective and one from the physician's perspective). A nominal group technique (NGT) meeting will be organized (including both physicians and PRPs) to reconcile patient and physician rankings of domains and measures.

Once the proposed core domain set is agreed upon, a draft core measurement set will be created.

Update on PsA BioDAM

GRAPPA has long identified the development of biomarkers with the potential to predict joint damage (erosion) as a key project. GRAPPA investigators have designed the biomarker development project and have appointed the Contract Research Organization (CRO) (Toronto; iPART) but to date have been unable to identify sufficient funding support for this important project. It is apparent however that funding opportunities will improve once evidence for candidate biomarkers is available.

In order to move the project forward, two approaches are currently being taken:

- (1) GRAPPA is linking with both current and future Randomized Controlled Trials (RCTs) where appropriate clinical and radiographic measures are being included, to ensure that bio-samples (blood/urine/DNA) are obtained at various time-points.
- (2) Individual GRAPPA investigators (Toronto/Leeds) are conducting Investigator-Initiated Studies (IIS) which are using changes seen on MRI instead of plain X-ray imaging and correlating these changes with levels of known biomarkers. A discovery arm using "omic" technologies is also planned for these studies.

Results from these initiatives should emerge in 2016, providing the GRAPPA community with essential information with which to move forward to a larger scale validation study.

What is the Biomarker Project?

Psoriatic arthritis (PsA) is frequently a co-morbidity of psoriasis that can lead to bone and joint damage. Being able to identify and treat patients who have PsA early in the disease could prevent radiographic progression and improve clinical outcomes. However the diagnosis and therapy of psoriatic arthritis is hampered by the fact that there are no susceptibility markers to determine psoriasis patients who will develop PsA or worsening symptoms such as erosion and new bone formation.

The PsA BioDam project is an observational study of psoriasis patients over a 24-month period with the primary objective of determining biomarkers that predict structural damage in PSA and examining whether clinical and laboratory markers, either alone or in combination, can predict progressive disease. GRAPPA and OMERACT developed the protocol for the study and began recruiting subjects in 2012. Since that time, the study has continued and expanded as investigators identify opportunities for collaboration and funding.

Get Connected!

GRAPPA's Website has links to more than a dozen related organizations including AAD, ACR, ASAS, OMERACT, PANLAR, SPARTAN and various psoriasis and psoriatic arthritis patient groups.

Visit www.grappanetwork.org and click on the RESOURCES button on the left hand side above the sponsor list or go directly to www.grappanetwork.org/resources.php.

You do not need a user name or password to access this part of the site.

Thank You for all Your Support!

We would like to thank our current sponsors and welcome our newest innovation level sponsors, Crescendo Biosciences and Mallinckrodt. The continued support of our corporate members makes GRAPPA's initiatives, programs and research possible.

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GRAPPA EVENTS -- SAVE THE DATES

- **GRAPPA Adjacent to EULAR**, Thursday, JUNE 11th, 8:15 – 10:30 am, Room Verdi, Hall 3, main entrance side, upper floor at the Fiera Roma Convention Center, Rome, Italy
- **GRAPPA 2015 Annual Meeting**, evening of Monday, JULY 6th and all day JULY 7th and 8th, Stockholm Sheraton Hotel, Stockholm, Sweden. Register at <http://www.cvent.com/d/zrql4k>.
- **GRAPPA Psoriasis Forum** at the Annual Meeting of the Pacific Dermatologic Association, Thursday, AUGUST 6th, 2 – 4 pm, Montage, Park City, Utah. Must be registered for the PDA meeting. (2 CME credits)
- **SPARTAN-GRAPPA Symposium**, Saturday, OCTOBER 17th, 7:45 am – 4:30 pm, Philadelphia, PA, location to be determined, register online starting next month at www.123Signup.com/SPA-GRA (7.5 CME credits).
- **GRAPPA Adjacent to ACR**, date and location TBD, November, 2015, San Francisco, CA
- **GRAPPA Adjacent to AAD**, date and location TBD, March 2016, Washington, DC
- **GRAPPA 2016 Annual Meeting** in Miami, FL, Thursday, July 14th (evening reception) and JULY 15th and 16th, 2016

View www.grappanetwork.org for event information updates
