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Patients become full partners in inflammatory arthritis and psoriasis research

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EXPERT ANALYSIS FROM THE 2014 GRAPPA AND SPARTAN ANNUAL MEETINGS

NEW YORK – Improvements in clinical trial design for psoriasis, psoriatic arthritis, and other inflammatory diseases are being credited to a decision to enlist patients as full partners, not just advisors or consultants, in research initiatives.

"Rheumatologists, I think, have been leaders is recognizing that patients can bring an expertise to clinical research that is unique and ensure that study endpoints are relevant to outcomes important to them," reported Dr. William Tillett, a research fellow in the department of rheumatology at the Royal National Hospital for Rheumatic Diseases in Bath, England.

Dr. Philip Mease

The value of patient research partners (PRP) was a recurring theme at the joint meetings of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) and the Spondyloarthritis Research & Treatment Network. GRAPPA, in particular, has been fostering research collaborations with patients since 2006.

"It has been an evolution. Patients were initially enlisted to sit in when trial designs were being discussed. Now, we are talking about full partnership so that they are involved at the inception with

equal partnership that includes veto power and author credit," Dr. Tillett explained.

At the GRAPPA meeting, an afternoon symposium was devoted to optimal strategies for fostering collaboration with PRPs, which builds on work already initiated with a group called Patient Involvement for Outcome Measures in PsA (PIOMPsA). In turn, PIOMPsA, formed 2 years ago, was largely modeled on PRP initiatives led by OMERACT <http://www.omeract.org/> (Outcomes Measurement in Rheumatology).

"OMERACT has been involving patients in clinical research design for about 10 years," reported Dr. Philip J. Mease, director of rheumatology research at Swedish Medical Center, Seattle. "The idea of making patients full-blown partners is more recent, but I think there is increasing appreciation for what the right patients can contribute to improve study design."

The initiatives are spreading through rheumatology and other inflammatory diseases. At the GRAPPA meeting, updates on patient initiatives to influence clinical research were presented not only from the work of PIOMPsA and OMERACT but also from the International Dermatology Outcomes Measures (IDEOM <http://www.dermoutcomes.org/>) consortium. Created in collaboration with the National Psoriasis Foundation (NPF), IDEOM is bringing clinicians and patients together to define standard outcome measures.

"There are no really good measures to evaluate relative severity of psoriasis from the patient's perspective," reported Dr. Alice Gottlieb, professor of dermatology at Tufts Medical Center, Boston. Tools traditionally used in clinical trials, such as the Psoriasis Area Severity Index (PASI) "are not practical in the clinic" and do not necessarily reflect the impact of psoriasis on quality of life when used as a study endpoint, she said.

PIOMPsA has now conducted several meetings, including one held in conjunction with OMERACT in Budapest, Hungary, in early May 2014. Like IDEOM, PIOMPsA has been focused on developing consensus on core symptoms of its target inflammatory disease. This is critical because the ability of clinical trials to generate relevant data is dependent on first defining meaningful endpoints, according to Dr. Tillett, who presented the PIOMPsA deliberations at the GRAPPA meeting.

In Budapest, for example, a vote was taken on whether to add fatigue to a list of core symptoms for PsA that includes impaired physical function, skin lesions, and joint pain. Fatigue was added to the list by a vote in which 70% supported it as a core PsA symptom, said Dr. Tillett, who recently published on the goals and underlying concepts of PIOMPsA (Curr. Rheumatol. Rep. 2014;16:418 <http://www.ncbi.nlm.nih.gov/pubmed/24623563>).

According to Dr. Tillett and Dr. Mease, PRPs are an answer to the repeatedly reported disconnect between physicians and patients in rating disease severity. By involving patients with interest in clinical research and collaborative skills, treatment trials have the potential to generate data more useful to practical patient management.

"It will be very difficult to show objectively that patient-aided trial design leads to better studies, but this is a reasonable expectation. I think that the contributions we have already seen from these collaborations bear this out," said Dr. Tillett, who expects the concept to spread to other fields of medicine.

Dr. Tillett reported financial relationships with AbbVie and Amgen. Dr. Mease reported financial relationships with AbbVie, Amgen, Biogen Idec, Bristol-Myers Squibb, Celgene, Crescendo Bioscience, Genentech, Janssen Pharmaceuticals, Lilly, Merck & Co, Novartis, Pfizer, UCB Pharma, and Vertex. Dr. Gottlieb reported financial relationships with Abbott, Actelion, Amgen, Bristol-Myers Squibb, Celgene, Centocor, Novo Nordisk, Teva, and UCB.

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