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The Psoriatic Arthropathy Alliance is a registered national charity dedicated to raising awareness and helping people with psoriatic arthritis and its associated skin disorder known as psoriasis.

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EDITORIAL

The recent problems in a trial with healthy volunteers (see page 13) of the drug called TGN1412 made by German pharmaceutical company TeGenero makes us probably all wonder about the safety of the drugs we are taking.

The issues of rofecoxib (VIOXX) and subsequent law suits in the USA (also see page 13) add to the concerns that we may have, despite a treatment being licensed and available.

The role of drug trials and the monitoring of licensed products is regulated and well controlled. In the last issue of Skin 'n' Bones Connection (issue 22) we reported the improved systems for people to report suspected side effects in a pilot scheme where Yellow Cards will be available via pharmacies, GP surgeries and other NHS outlets.

In this issue we have reproduced an article on clinical trials in psoriasis (see page 3) which will give you a view of the complexities of a trial and the various stages that have to be passed before a drug reaches the market place and can be prescribed.

With the various 'hoops and hurdles' that have to be negotiated, and the level of scares and information surrounding treatments it has to be considered as to why any researcher would want to conduct a clinical trial at all. Well I think that apart from any commercial consideration or monetary gain, there is an overwhelming view to understand disease and make outcomes for patients much better. The location cover photo of this issue is where 250 such individual researchers and patients met. It was the venue for OMERACT 8.

OMERACT stands for Outcome Measures in Rheumatology.

The acronym OMERACT was coined at the first conference held in Maastricht, the Netherlands in 1992, limited to Outcome Measures in Rheumatoid Arthritis Clinical Trials.

Since then, the OMERACT initiative has turned into an international informal network, working groups and gatherings interested in outcome measurement across the spectrum of rheumatology intervention studies.

OMERACT strives to improve outcome measurement through a data driven, iterative consensus process. OMERACT has a 5 member Organising Committee with members from 3 continents; it has a 15 member Scientific Advisory Committee composed of international opinion leaders from 9 countries.

What does it do? To improve outcome measurement, OMERACT organises conferences that take place every two years and rotate around the globe.

For these conferences, topics of interest are prepared by self-appointed groups of experts. These topics are then prepared for the conference by literature review and specification of the points for discussion. Most topics are

discussed in workshop format, where the aim is to make explicit the areas of agreement and disagreement, and to prioritise the research agenda. In several areas, the group has taken the lead in actually performing the necessary research to bring back to the conference. Recently, small group workshops have emerged alongside OMERACT conferences to speed up the work. When enough data is available, a full module is organised with the intention to come to consensus on guidelines.

At OMERACT 8 there was for the first time a psoriatic arthritis module with the objective of defining clear assessment tools for research outcome measures.

A measure is applicable when it passes the OMERACT Filter in its intended setting. The OMERACT Filter can easily be summarised in only three words: Truth, Discrimination, and Feasibility.

Each word represents a question to be answered of the measure, in each of its intended settings:

- **1. Truth:** is the measure truthful, does it measure what it intends to measure? Is the result unbiased and relevant? The word captures the issues of face, content, construct and criterion validity.
- **2. Discrimination:** does the measure discriminate between situations that are of interest? The situations can be states at one time (for classification or prognosis) or states at different times (to measure change). The word captures the issues of reliability and sensitivity to change.
- **3. Feasibility:** can the measure be applied easily, given constraints of time, money, and interpretability? The word captures an essential element in the selection of measures, one that in the end may be decisive in determining a measure's success.

The inclusion of patients at OMERACT 6 held in Australia in 2002 saw a change in the mind set of the organisers, further patient involvement at OMERACT 7 2004 and the inclusion of psoriatic patients this year has led to the OMERACT Executive Committee agreeing that patient participation in an appropriate way and is seen as a necessary aspect of the development of international consensus.



Some of the 250 OMERACT 8 delegates