



ARAD NEWSLETTER

Australian Rheumatology Association Database

July 2009

Once again the ARAD project team would like to thank ALL participants for their contribution to ARAD. There are over **3,400** participants under the care of **210** rheumatologists across Australia. In particular, we would like to thank all the people who have been contributing to ARAD 'long term'. Thank you for all your patience and support. You are helping us determine the long term benefits and safety of new biologic drugs for all Australian patients with inflammatory arthritis.

It is our duty to remind you that participation in ARAD is voluntary which means that you are free to withdraw from the project at any time (but we hope you don't because the information you give us is very important for following the effects of the treatments on your arthritis). If you no longer complete questionnaires for ARAD, thank you for your participation so far. Should you wish to recommence, please contact your state co-ordinator (details overleaf) so we can update your details and get you active in ARAD again!

Early Results - Update

Thanks to all of you who have been completing the questionnaires. We now have up to 5 years of follow-up data for people taking biologic therapies. We have been able to look at how these drugs affect health-related quality of life. Responses to the Health Assessment Questionnaire (HAQ), the SF-36 Health Survey, Assessment of Quality of Life (AQoL) and EUROQOL were analysed to look at how they changed once patients started on biologics. We found that there were rapid improvements in physical, emotional and mental health measures within the first 6 months. After 6 months most measures continued to improve but the rates of improvement were smaller. These drugs appear to provide long term quality of life improvements that offer patients a chance to engage more fully in their daily activities.

The Pharmaceutical Benefits Advisory Committee (PBAC) is currently undertaking a review of biologic agents listed on the Pharmaceutical Benefits Scheme (PBS). We have been able to provide summary data for the benefits in quality of life as well as the side-effects you tell us about and the reasons you stop taking these drugs or switch to new ones. This has been very valuable information as it is the only place where patients' real-life experience with arthritis and medications is collected over such a time frame. It will help the PBAC develop a robust and realistic model for the cost-effectiveness of biologics. So thank you again - all those pages are being put to good use to put forward a "voice" to government for patients with arthritis.

So when you are completing the questionnaires.....

Biologic DMARDS / Medications

The collection of start and stop dates for medications are very important. If a participant does not remember these dates, ARAD must then try to get them from the rheumatologists. It would be very helpful if participants start to record these dates for their own record and to assist ARAD with collecting this information.

Cancer History

We would like to thank all the participants, Doctors and secretaries that have helped us acquire the histology reports. When a participant informs us of a malignant cancer or skin cancer, we must verify the cancer through histology reports. We obtain these reports from the participant, or their GP or surgeon. In the future it would be very helpful to ARAD if participants remembered to keep their histology reports.

Recent developments in ARAD

Online Web-based questionnaire

We are pleased to announce that the ARAD questionnaire is now available to complete online via a link sent to your e-mail address. As with the current paper version, all information provided to us via the online system will be confidential and the data will be securely stored and managed. In order to complete the questionnaire online, you will need Internet Explorer (Version 6 or higher), Firefox (version 2 or higher), or Safari. Participants who do not want to complete their questionnaires online will continue to have the option to complete the current paper version.

About 50 patients have completed the questionnaire online. Here is some feedback that we have received from participants:

- The online survey is better than trying to hold a pen and sit at a table.
- It is easy to complete - better than the paper version.
- The new online questionnaire is excellent and very easy to use.
- Thank you for providing an online option.
- Found this questionnaire quick and easy to use
- The online questionnaire was very good, easy to follow, thank you.

If you wish to use the web-based questionnaire and we do not have your email address please contact your state co-ordinator or email through to arad@med.monash.edu.au with your preferred email.

Funding and resources

We are very grateful to our funders. ARAD currently receives funding from the Australian Government National Health and Medical Research Council (NHMRC), Monash University, Cabrini Health as well as educational grants from Abbott, Wyeth, and Roche pharmaceutical companies.

Our Staff

We would like to welcome Joan McPhee to the ARAD Team. She is the new ARAD State Co-ordinator for VIC & SA. Joan has worked as a researcher/interviewer in the area of Cancer Epidemiology and Dietetics for the past 18 years. She is a volunteer warm water exercise leader for Arthritis Victoria, practices Tai Chi for Arthritis, and is an active participant of ARAD.

Please contact us through your relevant State Co-ordinator if you have any questions:

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