



ARAD NEWSLETTER

Australian Rheumatology Association Database

January 2010

A BIG thank you to all ARAD participants for their contribution from the ARAD project team. 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. With over 3,800 participants under the care of 222 rheumatologists across Australia you are helping us determine the long term benefits and safety of new biologic drugs for all Australian patients with inflammatory arthritis.

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

Quality of Life questions

Please answer these questions as best as you can. We understand that sometimes you may be not be quite sure what is being asked and so the answers may not fit your situation but we ask that you do the best you can e.g. taking a bath - if you wanted to would you be able to? When we use these answers we really only do so by comparing them with your previous answers or any answers that you make in the future. So if you have any problem with interpreting the question just try and interpret the question the same way each time. That way the answers will be consistent.

Pain, stress or illness questions

We are interested in all pain, stress, or illness that you have at the time that you are answering the questionnaire. It is not important whether the symptom is caused by your disease or not. So please feel free to fill the questionnaires in with all your complaints!

Cancer History

In section 8 of the 6 monthly questionnaires we ask for any NEW cancers. We are really interested in this information but we would like to ask that you fill in only cancers that have been diagnosed *since the last questionnaire* that you filled in. New cancers can include new occurrence of the same cancer such as in skin cancers or a different type of cancer to one that you have had previously. We do need to confirm any cancers that have been specified in the questionnaires so by only filling in new cancers you save us work and yourself the phone call!

If you have any problems with answering questions please call or email one of the state coordinators. They will be more than happy to help you.

Early Results - Update

A special thanks for all those who have been completing questionnaires for over 5 years. This has enabled us to come up with some results on the length of time between starting a biologic drug and diagnosis. A comparison was made between two time periods with the results showing a significant difference. The mean number of years between diagnosis and starting biologic drugs was just over 14 years for 2003 to 2005 and around 12 years and 3 months for the time period 2006 to 2009.

Also as part of our analysis of health-related quality of life we have found that people who started their biologic therapies (Enbrel, Humira, Remicade, MabThera, Orencia) when these drugs first became available in the early 2000s had poorer health-related quality of life than people who have started more recently. This is probably because those early patients who had failed the traditional therapies did not have any other options for treatment. Patients who fail traditional therapies nowadays can move straight on to biologics.

Other Interesting Results

Recently a systematic review was published on the effects of biologics on Rheumatoid Arthritis. Check out the plain language statement on the Cochrane Collaboration website by typing the link below into your web browser. <http://www.cochrane.org/reviews/en/ab007848.html>

Recent developments in ARAD

Online Web-based questionnaire

Don't forget that the follow-up ARAD questionnaires can be completed online. The online questionnaire provides more information to help you answer the questions than the paper questionnaires. Access is via a link to the questionnaire sent to your e-mail address. To register to use the online questionnaire please contact your state co-ordinator or email to arad@med.monash.edu.au with your preferred email 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 7 or higher), Firefox (version 2 or higher), or Safari. Of course participants who do not want to complete their questionnaires online will be able continue to complete the current paper version.

Funding and resources

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. So thank you to all.

Participation in ARAD

ARAD will shortly be sending new consent forms to all participants. If you receive a paper questionnaire it will arrive with your next questionnaire, sooner if you do the questionnaire online. This is necessary as Medicare had previously specified that the consent should have a limited time period. The consent in the new form will be indefinite.

Participation in ARAD is voluntary which means that you are free to withdraw from the project at any time. However if you wish to withdraw ARAD would still like to continue to use your information to monitor for any changes in health statistics such as prescription medications, hospitalisations, cancers and deaths but this is done without contacting you. If you wish to discontinue the ARAD access to this information, please write, fax or email to notify us of this on **ONE** of the following:-

Write to CCRE at: ARAD DMC, DEPM Monash University, Reply Paid 83087, Melbourne VIC 3004
OR Fax: 1800 022 730 OR email: arad@med.monash.edu.au

If you no longer complete questionnaires for ARAD, ARAD thanks you for your participation so far. Should you wish to recommence, please contact your state coordinator (details below) so ARAD can update your details and get you active in ARAD again!

Our Staff

We would like to welcome Maree Williams (ARAD Project Manager) and Mandy Burns (NSW State Co-ordinator) to the project team. So please say a big hello to them if you speak to them! Also thanks to Joy Rappo who has been helping out in the interim.

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

ARAD State Co-ordinators

Joan McPhee

State Co-ordinator: VIC, SA
Tel. (03) 9508 1137

joan.mcph@med.monash.edu.au

Mandy Burns

State Co-ordinator: NSW, ACT
Tel. (02) 9113 2982

Lyndall Henderson

State Co-ordinator: WA, QLD, TAS, NT
Tel. (02) 9926 8579

lyndallh@med.usyd.edu.au

