

# THE Arthritis Research NEWSLETTER

July 2004

## *Research Notes from the Director: The NDB Goes International*

Hello and Welcome! First and foremost thanks to all of you who by participating in NDB research advance knowledge of arthritis and arthritis treatment.

Like 2003, this year is proving to be a very busy and exciting time for NDB research as we take our first steps into the international arthritis community. Our questionnaires have been translated into Spanish, French and Portuguese. In addition, we currently have active projects in Portugal with others starting in Brazil, Argentina, and Germany within the next year, and we've collaborated with other arthritis researchers from Canada, England, Norway, Belgium and France.

We are also becoming more active in presenting NDB results internationally. Last fall your data contributed to several research presentations for the 2003 American College of Rheumatology (ACR) Annual Scientific Meeting where 23 different countries were represented. In June, you contributed to 8 research presentations for the 2004 European League Against Rheumatism (EULAR) annual meeting held in Berlin Germany. Researchers and doctors from around the world attended this meeting.

*This month the NDB will be expanding our Internet questionnaires to include people with arthritis all over the world.*

EULAR and the ACR annual meetings are the two largest venues for arthritis research worldwide, and most researchers attend both. In recent years EULAR has grown rapidly as Europe unified into a common European Union (EU). In some respects European arthritis research has been outpacing the research in the US. Paul Emory's research group in Leeds, England pioneered new methods of arthritis

evaluation using ultrasound and magnetic resonance imaging (MRI), and then went on to test new treatments plans in rheumatoid arthritis. Ravinder Maini, in England, was the developer of Remicade (infliximab). In the Netherlands Ferdinand Breedveld (Leiden) and Maarten Boers (Amsterdam) tested new and aggressive treatments for RA. This research has resulted in changes to the way rheumatologists all over the world now treat rheumatoid arthritis. Now US and European researchers work in parallel on the development of new drugs and other arthritis treatments.



The kind of research work that we do here at the NDB is also being done in Europe. Databases from groups of patients working with Dr. Alan Silman and Dr. Anthony Woolf in the United Kingdom, Dr. Angela Zink in Germany, Dr. Tore Kvien in Norway, Dr. Lars Klareskog in Sweden and Dr. Piet van Riel in the Netherlands

parallels the work we do here. Unlike the US, European researchers have a large advantage: generally their governments support database research and allow linking of databases which allows researches to have more detailed information available to them. Current regulations in the US do not support this level of data sharing, and at this time the National Institutes of Health (NIH) has not shown much interest in supporting this type of research.

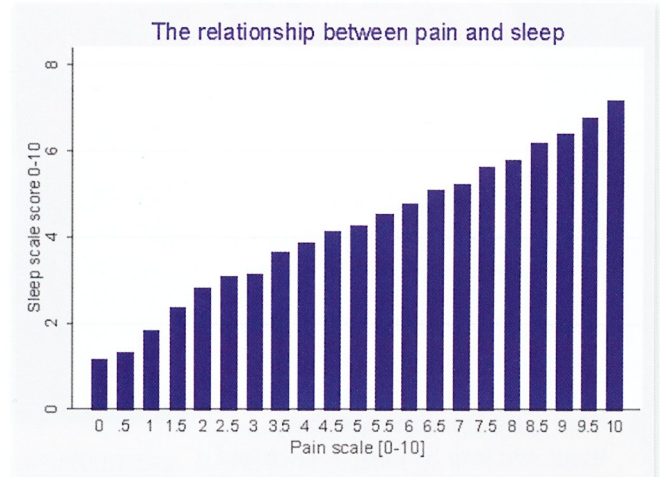
The world has been made a lot smaller by the Internet and allows us to collaborate with other researchers regardless of where we live. We are excited about our collaborations with researchers in Europe and South America. This month the NDB will be expanding our Internet questionnaires to include people with arthritis all over the world. So it is a small world after all.

P.S., Our Web pages will have copies of the NDB EULAR presentations for those of you who are interested. If you want more information about the EULAR meeting go to [www.eular.org](http://www.eular.org). For abstracts of the research that was presented try [www.eular.org/eular2004/index.cfm](http://www.eular.org/eular2004/index.cfm)

# Research Highlights from

## Trouble Sleeping?

Difficulty sleeping is a common problem. Between having pain, children crying, cats and dogs going in and out, worries and the call of nature, it's not surprising that many of us have disturbed sleep. It has been said the new biologic drugs (Enbrel, Humira, Remicade) improve fatigue because they specially improve sleep. We wondered whether this was true, so we studied whether people taking biologics had better sleep and less fatigue than persons not taking biologics. Remember those sleep and pain scales you fill out with each questionnaire? What we found—you may have guessed it—is that taking biologics did not have a special effect on sleep. The graph (to the right) explains this all pretty well. The more pain you have the less well you sleep. You may think this is a “no brainer,” but many doctors don't think about troubles with sleep. They should. It is not the specific drug you are taking; it is how well the drug works.



## Current RA Therapies and Heart Problems



One potential worry associated with arthritis treatment is the effect some of the medications may have on your heart. Current cardiovascular research suggests that inflammation is an important risk factor for heart disease in the general population. Data indicate that rheumatoid arthritis patients have an increased risk of heart problems.

We evaluated people with RA who took biologic medications (such as Enbrel, Remicade, Humira) and/or DMARD therapy (Disease-modifying, anti-rheumatic drugs, such as Arava, Penicillamine, and Plaquenil). We found that arthritis therapy had no effect on heart problems.

In addition to inflammation, it is reported that diabetes may also increase the risk of heart disease. Diabetes development can be independent of arthritis, but it may be enhanced by the use of corticosteroids (drugs like prednisone), a commonly used RA treatment.

In a second study we evaluated people with RA who took biologic medications and other DMARD therapies and found these therapies did not have an effect on the development of diabetes. Prednisone, but not RA, appeared to increase the risk of diabetes. As diabetes is associated with increased risk for heart problems, use of prednisone among RA patients may be an independent risk factor for cardiovascular disease.

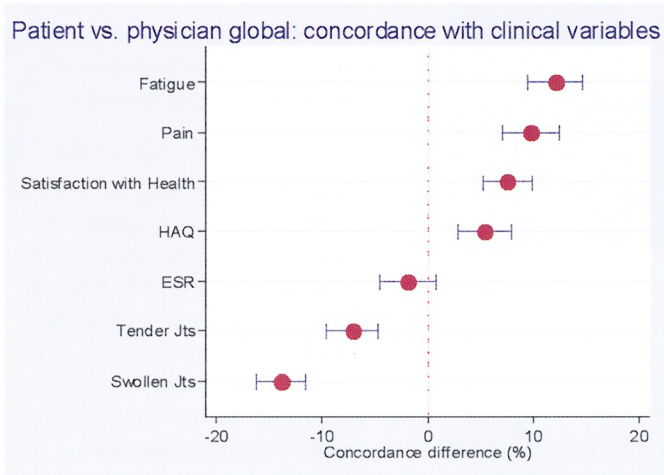
### Refer a Friend

Here's a really easy way to let a friend with arthritis know about the NDB. Just give us your friend's email address and we'll send out an email invitation to join the study. Go to <http://www.arthritis-research.org/enrollfriend.htm>.

# the 2004 EULAR Meeting

## How and Why Patients and Physicians Disagree

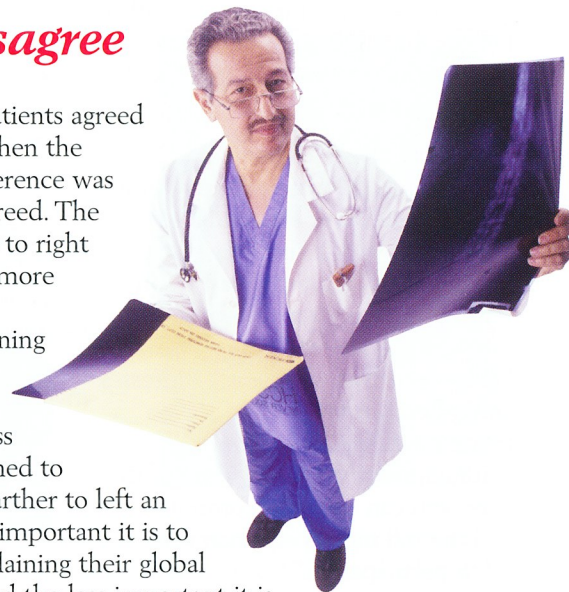
In another presentation at the EULAR meeting, the NDB presented information on how patients and physicians disagree on what is most important. In a study of more than 700 persons with rheumatoid arthritis who were examined by Canadian and US rheumatologists, doctors and patients



carried out separate evaluations. We asked the doctors to rate how well the patients were doing ('physician's global rating') and then asked the patients the same thing ('patient's global rating'). Using those ratings we were able to compare how patients and doctors rated other factors. In the graph above we present what we call the 'concordance difference' or how

physicians and patients agreed and disagreed. When the concordance difference was 0 both groups agreed. The farther an item is to the right (e.g. fatigue) the more important it is to patients in explaining their overall global severity rating, and the less important it seemed to physicians. The farther to the left an item is the more important it is to physicians in explaining their global severity rating, and the less important it is to persons with arthritis.

The graph shows important differences. Physicians didn't rate fatigue, pain and function as importantly as patients, and patients didn't think joint swelling and tenderness was so important. In our report to the EULAR meeting we suggested, based on this study, that doctors should use questionnaires to understand how patients feel. It would make them better doctors, we think, and it would certainly put them more in tune with their patients. We are interested in your opinion about this, too. You might go to the 'forum' on [www.arthritis-research.org](http://www.arthritis-research.org) and let us know your thoughts.



## No Increase in Liver Problems or Hospitalizations Among RA Patients Using Biologics

Good news about biologic therapies. Recent reports from a number of sources indicate that the rate of serious liver problems (those requiring hospitalization) was *higher* for persons receiving biologic therapies than for those receiving arava and methotrexate.

We found that biologic therapies are actually associated with a *lower* rate of liver problems (about 10% lower) compared with arava and methotrexate. Also, the rates of liver hospitalization are similar among the four biologic treatments (Enbrel, Remicade, Humira, and Kineret) and the rates do not differ statistically from those patients not receiving biologic therapy.

**FOR MORE INFORMATION  
OR TO PARTICIPATE**

**Arthritis Research  
Center Foundation, Inc.**

1035 North Emporia • Suite 288,  
Wichita, KS • 67214

Director  
Frederick Wolfe, MD

Executive Director  
Kathleen Urbansky

please call 1-800-323-5871 ext. 133  
or email [info@arthritis-research.org](mailto:info@arthritis-research.org)

# The Internet, the NDB, and You

Everyone uses computers and the internet more and more to do business and communicate with family and friends. We here at the NDB are no exception. As a non-profit organization we're always looking for ways to do our work more efficiently.

Right now about 25 percent of patients in the NDB use WebQuest to fill out their surveys, and every six months we see more signing up. This means a significant savings in printing and mailing costs. But the Internet also lets us do more with less. Please note that your email addresses and other information are always treated with the highest level of confidentiality. Here are some of the ways you can use your computer and the internet to enhance your NDB participation.

## WebQuest

WebQuest is our online questionnaire. The questions are the same as what you get on the paper questionnaire, but computers make it all easier for you. WebQuest remembers who you are and doesn't ask you to complete questions for which we already have an answer. And it saves you time by remembering your medications and skipping questions that don't apply to you.

If you are not now using it, go to "Request NDB Questionnaire on the Web" (<http://www.arthritis-research.org/webquest.htm>) at our home page [www.arthritis-research.org/patients.htm](http://www.arthritis-research.org/patients.htm) and make the request or 2) send us an email at [webquest@arthritis-research.org](mailto:webquest@arthritis-research.org).

## Email

For patients using WebQuest, email is our primary method of getting in touch with you. Even if you're not using WebQuest, we'd like to be able to send you important information by email. It's important that we have your current email address. To update your email address go to <http://www.arthritis-research.org/UpdateEmail.htm>.

Here's a VERY IMPORTANT step you can take to make sure our email gets to you: Add us to your email address book. Our address is [webquest@arthritis-research.org](mailto:webquest@arthritis-research.org). This will ensure that our mail makes it through the spam blockers.

Later this year we hope to begin issuing an e-mail newsletter. If you have email, please make sure we have your email address even if you're not using WebQuest.

## Website

The website continues to be the main internet resource for NDB patients, researchers and physicians. Find it at [www.arthritis-research.org](http://www.arthritis-research.org). Please browse the site to learn

what we do and how we do it. You'll meet the people who work here and see the important research that you make possible.

The website is a great resource for past newsletters, lists of research publications and links to helpful NDB web pages and websites of arthritis-related organizations.

## Forums

The Forum is an exciting new feature available for NDB participants to post comments, ask questions, or find out new information. It will be mediated by an NDB Staff member, and allows all NDB participants a place to connect with others in the research project.

The three forums topics are:

**QUESTIONNAIRES:** In the many years that we have been doing NDB research we have had many questions and comments about our questionnaires – gripes, sighs, and some kudos. Past posts have covered technical difficulties with WebQuest and the appropriateness of certain questions we ask.

**RESEARCH:** This forum is a place you can ask about specific research we have done. You can also give us suggestions for research that you think is important.

**ARTHRITIS-RHEUMATOLOGY:** This forum is where you can post questions that are not related to the NDB and is a great place to get information from others participating in the study. Popular questions here cover arthritis drugs and treatments.

You can find the NDB Forum at the following address <http://www.arthritis-research.org/bbs.htm>.

## Blog

The NDB Connection is our new Blog (or Web log) where we'll let you know about important, interesting or fun news related to arthritis, research and/or the NDB. We update the blog every couple of days. It's a great way to check in with the NDB and the world of arthritis research. It's at [ndb.blogspot.com](http://ndb.blogspot.com)



## More Information

If you have any questions about the WebQuest or anything else related to the NDB, please let us know at [webquest@arthritis-research.org](mailto:webquest@arthritis-research.org) or call us at 1-800-323-5871 x133.