

# THE NDB Research NEWSLETTER

News for Participants in the National Data Bank for Rheumatic Diseases

Jan 2012

## Notes from the Director *Frederick Wolfe, MD*

I promised you in July that I would tell you about research results that we would be presenting in November 2011 at the American College of Rheumatology annual meeting. These results suggested that some arthritis-related treatments might reduce the risk of heart attacks. Physicians call heart attacks “Myocardial Infarctions” or MIs.

Last spring we got a call from researchers at the University of North Carolina and Duke University. They had been studying treatments for osteoporosis called bisphosphonates. You may know bisphosphonates by their brand names, which include Actonel, Aredia, Boniva, Didronel, Fosamax, Reclast, Skelid, and Zometa. During 2010, about 17% of people in the NDB reported using bisphosphonates.

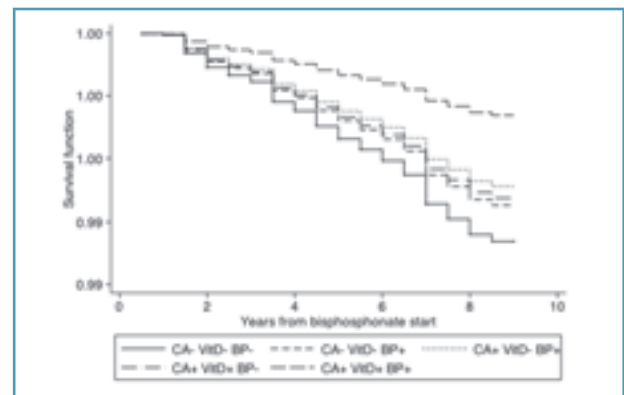
We all lose some calcium from the bones as we get older. But people who lose significant amounts of calcium have the disease called osteoporosis. For such people, bisphosphonates are prescribed. Osteoporosis is pretty much an illness that doesn't cause symptoms, but it is a major cause of fractures as we get older. Bisphosphonates are prescribed, and they can be very helpful in preventing or reducing fractures.

Drug companies compete with each other to develop better and more effective treatments, and many bisphosphonate drugs have been developed by different companies, as you may have guessed by the many different drugs names above. In analyzing the result of the clinical trials of bisphosphonates, researchers discovered, around 2007, that people who had received such treatment had reduced mortality; that is, they lived longer. The reduction in mortality couldn't be explained just by having fewer fractures. Studies suggested that people who received bisphosphonates might be having fewer deaths from heart disease. In particular, perhaps people who took bisphosphonates had fewer heart attacks (MIs).

The NDB was able to help UNC and Duke because we have been collecting information on bisphosphonate use and MIs for a very long time. We set out to understand whether we could show that MIs were reduced in bisphosphonate users. The first thing we did was to review hospital records to be certain that what we were calling MIs were really MIs.

Here are some of the problems we encountered: First, people who had MIs were usually older men, but women were more likely to get osteoporosis. Second, people who weighed more were less likely to have osteoporosis, but they were more likely to have heart attacks and diabetes. So if we compared people taking bisphosphonates directly with those not taking them, the difference in the risk of heart attacks might not be related to bisphosphonates. It could be related to something else: age, sex, weight, other medications, and so on.

In the research we did, we adjusted the analyses so that we compared people at the same age and weight, women with women and men with men. That way everything was the same except the use of bisphosphonates. Here is what we found—Bisphosphonates reduced the risk of MI by about 30% to 50%. This confirmed the results of the previous studies, possibly identifying an extra benefit to taking bisphosphonates.



*In the graph, the top line shows how many people who took bisphosphonates had heart attacks during 9 years of follow-up (about 1%), while the bottom line shows the rate in those who did not take bisphosphonates (about 2%), a difference of about 1% at 9 years of follow-up.*

Proven? Well, maybe. But suppose those who took bisphosphonates were healthier in other ways, say by exercising more. Could it be that exercise, and not bisphosphonates, was the cause of what we observed? It's possible. So we can't be really sure, but it does seem likely the bisphosphonates reduce MIs. We'll submit this research for publication soon. If other studies confirm our results, then we can be sure.

To all of you who allowed us to use your data, thanks. I think we are on to something here.

## LATEST RESEARCH

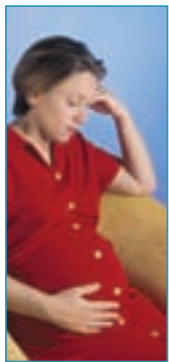
### *How is your Health Literacy?*

Health Literacy (HL) is defined as the ability to understand health information and to use that information to make good decisions about your health and medical care. And it turns out to have a strong association with how well people with arthritis function.

You may remember these questions from the last NDB questionnaire: How confident are you filling out medical forms by yourself? And, How often do you need to have someone help you when you read instructions, pamphlets or other written material from your doctor or pharmacy?

With your answers to these questions we were able to compare HL with other indicators of functionality. HL is more strongly associated with function than prednisone use, smoking history and biologic use. Our report suggests that doctors may be able to quickly identify patients who are at risk for lower treatment success and then help them by increasing HL.

The good news is that health literacy is very high among the 5,300 people in the study group.



### *Study suggests extra attention for women of reproductive age with RA*

Many RA medications are teratogenic, which means they disturb the development of a human embryo or fetus. Pregnancies conceived during the use of these medications have a higher rate of miscarriage. Women then face the difficult decision of whether to continue the pregnancy.

In a study of birth control methods use by premenopausal women with RA, 29% reported using ineffective birth control methods. The results of this small study emphasize the important role rheumatologists can play in making sure that patients taking teratogenic medications do not become pregnant.

## *Support rheumatic disease research with a financial donation*

As a non-profit project conducting ongoing research to improve conditions for people with arthritis, fibromyalgia, lupus and other conditions, the NDB is an organization with ongoing financial needs.

If you would like to make a tax-deductible monetary donation to the NDB to help support this research, we would be very appreciative of your support.

If you would like to make your donation in memory of or in honor of someone please let us know. We will send a letter to the person of your choice to acknowledge your gift.

Donations should be payable to:

The Arthritis Research Center Foundation Inc.  
and sent to:

The Arthritis Research Center Foundation Inc.  
1035 N. Emporia, Suite 288  
Wichita, KS 67214

For more information please contact Rebecca Schumacher at 1-800-323-5871, ext. 119.

Thank you very much for considering a donation to support this important research.

## *Our website for rheumatology questions, RheumMD.org*



On RheumMD.org we've brought together more than 20 volunteer experts to answer your questions about any rheumatic condition. You can also search existing questions and engage the doctors in discussions about the answers.

Here are some questions we've had on the site lately:

- *How safe is prednisone if you have a history of glaucoma and cataracts?*
- *How does a TENS unit help fibromyalgia?*
- *What effects do RA medications have on healing fractures?*

There are many more questions, and we invite you to ask your own at <http://RheumMD.org>.

## *Helping the NDB in other ways*

Achieving the NDB's goals of telling the rheumatology community about patient experience depends on a large group of participants. Here are a couple of ways you can help.

Now available for your support group or arthritis, fibromyalgia or lupus meetings: Our pamphlets explain what we do and how you and can help. Each one has a postage-paid postcard to request more information or an enrollment form to join the project. The pamphlets and a small table-top stand are available free from the NDB. Just contact us at [info@arthritis-research.org](mailto:info@arthritis-research.org) or 800-323-5871 ext. 133. Thank you!

## Welcome New Participants!

Everyone who works for the NDB and all of the doctors and researchers who benefit from our research are extremely grateful for the dedication of you, the participants, for helping with this project. Many of you have been with us for several years or more, but every 6 months we are also glad to see many new people join us. Here is a quick primer on the NDB for the new and a refresher for the old-timers.

The NDB is a non-profit organization that performs research in rheumatoid arthritis, osteoarthritis, fibromyalgia, lupus and other rheumatic diseases. The research is designed to improve the treatment and outcomes of these conditions. The NDB is an independent organization that conducts its own research without influence from pharmaceutical,

insurance, financial or other outside interests. Our research is so well respected that we are often hired to provide independent drug safety verification to the government.

Your personal information will always remain private. We do not sell or share any identifying information about NDB participants. Before we work with researchers or collaborate with other research groups we remove any of your answers that could be used to identify you.

Nearly all of our research is available for you to read on our website. We are glad to answer your general questions about rheumatic diseases and treatments, but we are not able to give personal medical advice.

NDB research is different in an important way—participants report on themselves; data is not collected by doctors or medical staff. With patient-reported data, researchers get a



perspective that short, small clinical trials cannot provide. Our long-term study offers a much broader view of treatment and results. Clinical trials are good at identifying common side effects, but rare or subtle problems, or problems that take longer to develop, are better detected by studies like the NDB. The same is true of long-term effectiveness of a treatment.

So, welcome to the NDB, or thanks again for your continuing participation! If you ever have any questions or need help with your questionnaire, feel free to contact us.

## View your NDB results online

Many of the questions we ask every six months give researchers and doctors scores that show how you're doing. We have heard from many of you that you want to see your results. You can now get these scores any time you need them on our website. If you don't already have an account on our website, start on this page: [www.arthritis-research.org/user/register](http://www.arthritis-research.org/user/register). Having an account helps protect your privacy and lets you access your scores.

You will be able to see scores for every questionnaire you've ever completed for the NDB, and print them for your own information or to show to your doctor. Please email us at [webquest@arthritis-research.org](mailto:webquest@arthritis-research.org) if you have any questions about the website or your scores.



**FOR MORE  
INFORMATION  
OR TO PARTICIPATE**

**Arthritis Research  
Center Foundation, Inc.**

**1035 N. Emporia  
Suite 288  
Wichita, KS 67214**

**Director:  
Frederick Wolfe, MD**

**Executive Director:  
Rebecca Schumacher**

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



## WebQuest

WebQuest is the online version of our questionnaire. The questions are the same as what you get on the paper questionnaire. People who are comfortable using computers should find it easier than the paper version. If you would like to try it, follow the links from our home page, [www.arthritis-research.org](http://www.arthritis-research.org) and make the request, or send us an email at [webquest@arthritis-research.org](mailto:webquest@arthritis-research.org).



### Join Us On Facebook

You can find us on Facebook as "National Data Bank for Rheumatic Diseases." We will try to keep you up to date with any news items that occur between questionnaires.

You can also connect with other participants and NDB staff who have joined our group.

## Refer a Friend

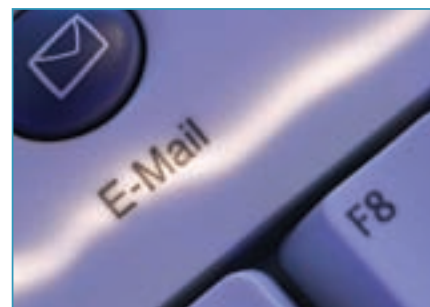
Here's a really easy way to let a friend know about the NDB. Just give us your friend's email address and we'll send out an email invitation to join the study. Go to <http://www.arthritis-research.org/participate/tell-friend>.



## Reminders

While working on your questionnaire, if you have ANY questions about the questionnaire, please contact us right away by email or phone. These might be about technical difficulties or how to interpret a question. If you put your immediate questions in the comments section we probably won't see it in time to answer.

Please use the comments section for any information you think we should have that isn't covered in the questionnaire. This could be about a change in medication that needs explanation or information about other considerations of your condition that you think we need to know. You may also ask general questions that don't require an immediate answer.



## Important Information about 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.

We cannot emphasize enough how important it is for you to let us know whenever you change your email address. To update your email address go to our website and look in the participant's links, or call us.

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. You will need to do this every time you change your email address. Thank you!

## Lottery Winners!

The research data bank can best contribute to research when the questionnaires are completed and returned as soon as possible. We conduct the lottery as a token of our gratitude in help with rheumatology research.

The \$1,000 winners from the last questionnaire were Linda Paine, Toms River, NJ and Priscilla Fitzherbert, Presque Isle, ME. Winning smaller amounts were Leora Brock, Lacygne, KS; Tina Schroeder, Sedalia, MO; Larry Lambe, Asheboro NC; Lillian Kookan, Barnegat, NJ; Jeanette McDaugale, Leadville, CO; Judy VanOrder, Zeeland, MI. Congratulations to all!