

# THE NDB Research

## NEWSLETTER

News for Participants in the National Data Bank for Rheumatic Diseases

July 2010

## Notes from the Director

Frederick Wolfe, MD

### ***New fibromyalgia criteria, real-world biologic outcomes, and more***

This edition offers something for everyone. If you have lupus or RA, you'll be happy to know that we have just published a paper on the safety of hydroxychloroquine, more commonly known by its trade name "Plaquenil." Plaquenil is widely used in both of these illnesses. It's also used to treat malaria. But there is one problem with Plaquenil. It can cause damage to the retina. In fact, it can cause blindness. But how often do these problems occur? Pretty much, doctors haven't known. In the paper I just published with Dr. Michael Marmor, the Stanford University ophthalmologist, we found that toxicity occurred in only 1/2 of 1 percent of people who used the treatment. The risk of toxicity was low in the first 7 years of exposure, but by 7 years the risk was around 1%. We hope that these findings will aid the rewriting of screening guidelines for eye problems. For now, people being treated with Plaquenil should probably get eye examinations at yearly intervals. It seems likely that by doing that, toxicity, if it occurs, can be detected early. Thanks to everyone with lupus and RA who participated in the study. This study will make a difference to how these illnesses are treated.

The NDB led the development of two sets of new criteria that should be of interest to everyone. First, we led the development of the American College of Rheumatology (ACR) criteria for diagnosing fibromyalgia. And, second, we modified the criteria so they could be used in research in everyone, whether or not you have RA, psoriatic arthritis, osteoarthritis or fibromyalgia. This is an important accomplishment because it allows us to better understand pain problems in all illnesses. Based on this research, we investigated what causes people with RA and OA to develop fibromyalgia type symptoms. We submitted this research to the ACR annual meeting.

By now, everyone who watches television knows about fibromyalgia from all of the ads that pharmaceutical companies air each day. Here is some other information from the NDB that may help put the advertising in perspective. Do you die from fibromyalgia? No. A 35 year study sponsored by the NDB found no evidence of increased mortality. We evaluated more than 8,000 people with fibromyalgia. Joining me in the study were researchers at the University of Michigan, Georgetown University and the University of Nebraska.

We also published a major RA study this year. It had two sets of results that I think were interesting. First, that biologic therapy wasn't as good in real life as in clinical trials. But perhaps that was explained by the second result: Overall, people with RA were doing pretty well. Many were doing well enough so that the biologic therapy couldn't help as dramatically as in the clinical trials.

If you want to see any of the studies, send us an email and we will get them too you. Thanks to everyone for helping make this year's research available and important.

***"A 35-year study found no evidence of increased mortality in fibromyalgia."***

### ***Join Us On Facebook***

We are now on Facebook. Find us at National Databank for Rheumatic Diseases.



Take part in discussions with others who have auto-immune diseases, find articles on latest research and learn more about the NDB.

# LATEST RESEARCH

## Lupus questionnaire may be helpful outside of specialty clinics

If you are a person with lupus in the NDB, you may remember a new set of questions we added about a year ago called the Lupus Damage Index Questionnaire (LDIQ). The LDIQ, we hoped, might be a substitute for the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SDI).

Only lupus specialists administer the SDI, but the LDIQ can be administered in community clinics or

self-administered by patients. Both are designed to gauge the unfortunate fact of permanent organ damage in many people with lupus. For this study, the LDIQ was given to people in physicians' clinics and in the NDB questionnaire.

With your answers, we confirmed that the self-administered questionnaire can be nearly as accurate as the SDI in assessing the progression of lupus. Although the people completing the LDIQ in a clinic had better agreement

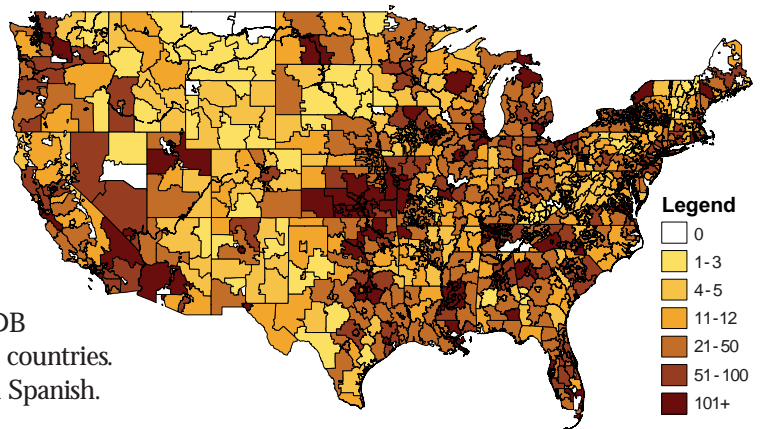
with their doctor's assessment using the SDI, it's not clear whether that means the results are actually more accurate that way. The accuracy may be affected by doctor-patient communication and a doctor's incomplete knowledge of a patient's lupus medical history.

This information about the LDIQ means that it may be possible to expand lupus research to include cases where direct physician assessments of patients may not be possible.

## Where do NDB participants come from?

Shown here is a representation of NDB participants from the US (our apologies, AK and HI, we were unable to have your maps ready for this newsletter). Each area represents a US Zip code, color-coded by the number of participants. You can see we have a concentration around Wichita, KS, which is where Dr. Wolfe's clinic was and where the NDB offices are. Other concentrations center on cities and on doctors who have encouraged their patients to join the NDB.

You can see we are everywhere in the US! Internationally NDB participants tend to come from English and Spanish speaking countries. NDB questionnaires are available in international English and Spanish.



## 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.

**FOR MORE  
INFORMATION OR  
TO PARTICIPATE**

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Wichita, KS • 67214

Director  
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Please call 1-800-323-5871 ext. 140  
or email [info@arthritis-research.org](mailto:info@arthritis-research.org)

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

You may know that the NDB is unable to give personal medical advice to you because of the research we conduct and because real advice often requires a visit to a doctor. But we are now able to connect you with a group of rheumatology experts on our new website, RheumMD.org.

More than 20 experts have volunteered to answer your questions about any rheumatic condition. You can also search existing questions and engage in a dialogue with doctors in the comments.



We hope you visit the site regularly when you have questions, and please share the site with your friends.

## ***New Questions***

New questions this time ask about periodontitis (PD) and infection with *Porphyromonas gingivalis* (*P. gingivalis*) and arthritis. Periodontitis is inflammation and infection of the ligaments and bones that support the teeth.

Some researchers suspect a role for PD and *P. gingivalis* in arthritis risk and progression. Your answers to these new questions will help shed light on a possible relationship between

arthritis and PD, and will also provide some useful context to a separate genetic study looking at the same possibility.



## ***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, to helping 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.

## **Lottery Winners!** **Our Lottery Drawings are changing!**

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. Due to uncontrollable circumstances with mail delays, email delays & phone delays, we want to make it fair to everyone who participates in the 6-month surveys to have a chance at our lottery drawings.

We will change the Lottery drawings to the following:

2 drawings for \$1,000 each for those who complete a large questionnaire via mail, web or phone within the first 4 weeks.

2 drawings for \$500 each for those who complete a large questionnaire via mail, web or phone any time within the 5-½ months\*.

4 drawings for \$50 each those who complete a shorter questionnaire via mail or phone anytime within the 5-½ months\*.

## **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!

## **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 honor of someone please let us know. We will send a card 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 Ste 288  
Wichita, KS 67214

Or donate online via [www.JustGive.org](http://www.JustGive.org)

We wish we could do more, but due to cost constraints we are limited on what we can give for the drawings. We want to thank each of you again for all your help with the research. We definitely could not do it without you!

\*Why 5-½ months? We have to do the drawings before the end of the 6 months in order to get the winners listed in the next newsletter

The \$1,000 winners from the last questionnaire were Robert Baile, Springdale, AR; Charlotte Van Anda, Mission Viejo, CA. Winning smaller amounts were Judith Wilke, Gilbertsville, KY; Ann Utterback, Gaithersburg, MD; Kenneth Fromm, Beloit, KS; Joanne Conduff, Yakima, WA; Geraldine Adkins, Wellington, KS; Barbara Walton, El Dorado, CA. Congratulations to all!

## **WebQuest**

WebQuest is the online version questionnaire. The questions are the same as the ones 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).

## **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/enrollfriend.htm>



## **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 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 or 140. Thank you!