

# THE NDB Research

## NEWSLETTER

News for Participants in the National Data Bank for Rheumatic Diseases January 2010

## Notes from the Director

Frederick Wolfe, MD

### It's a Complex World – What Should We Do?

In November 2009, a US government commission made new recommendations for screening for breast cancer. You'll remember that the recommendations caused a firestorm. Some people thought they were a good idea, but a great many people, including the press and politicians, thought that the recommendations were a very bad idea. You'll remember the main part of the recommendations: Women should have mammograms beginning at age 50, not at age 40 as had been the previous recommendation and practice.

At the same time the US Congress was working on health care legislation. Among the many concerns surrounding the legislation is the problem of controlling costs. Even though American health care is the costliest health care system in the world, it does not deliver the best medical care. One way to control costs is to limit services and another way is to limit payments to providers.

#### Does limiting services mean less care?

Sure it does. Is it a good idea? Maybe yes, maybe no. Every year the cost of medical insurances rises, in part because it is paying for more care that keeps getting more expensive.

Insurance makes up for the increased cost of the care in several ways: first by increasing premiums (your regular insurance payment), second by increasing copayments (your out-of-pocket expenses), and third by restricting services. Restricting services might mean that your arthritis must meet some severity test to be covered for certain treatments, or that you need to have received certain other treatments before you can get more expensive treatments. If you want physical therapy or psychiatric care, the types and duration of treatments may be limited. And your insurance company might not want to sell you insurance if you have a pre-existing condition — or they might increase your premiums so much that you can't afford to buy insurance.

One complaint that comes up in the debate about health care reform is that care will be rationed by the government. But even private insurers are rationing right now by increasing premiums and out-of-pocket costs, which will prevent some people from buying insurance or force them into plans with less coverage.



For a moment let's forget about the insurance companies, drug companies, hospitals, doctors and patients who are lobbying Congress to get their share. Instead let's just take a look at the breast cancer-mammogram problem. It provides a good way to look at some of the underlying issues. Patients who have had breast cancer that was found in their forties by annual mammograms are upset. They say that if the new recommendations were in place their cancers would not have been detected. But, if we want to detect all cancers, maybe we

should do the screening every six months, maybe even every three months. And maybe we shouldn't just screen for breast cancer. There is

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colon cancer and thyroid cancer and dozens of other cancers and diseases that can be detected by testing. Not only would most of us not want to spend so much time getting screened, but health care costs would go up further, as would our personal, out-of-pocket costs.

So, we need to decide just how much testing and treating we want. It's an easy choice if the benefits are great and the costs or potential side effects are slight. But what if the benefits are slight? If you have fibromyalgia or fibromyalgia symptoms,

— Continued on page 2

## Notes from the Director (continued)

should you use Lyrica® or Cymbalta®, expensive treatments that may not be better than other inexpensive generic treatments? And what about biologic treatments for rheumatoid arthritis? Should their use be linked in some way to their costs and effectiveness?

Other countries have required not only drug effectiveness, but also reasonable, competitive costs. A number of studies have shown that biologic treatments for rheumatoid arthritis are about equally effective, but that some drugs are much more expensive than others. Should they be restricted?

Many of the controversial issues come down to the difference between looking at medical care as an individual compared with looking at it from a group perspective. People ask themselves, "What should I do if it doesn't, on average, work for all of us, but works for me?" If we only think about

ourselves, then costs will go up and up because there is always someone who gets some benefit from some treatment or test.

And there is another important issue in the mammography controversy: How to balance the harms that would be done by restricting mammography with the benefits that would come by having fewer false positives, less worry, less testing and lower costs. Who is to decide what's good and what isn't? One of the reasons the recommendations provoked such controversy was that there was no obvious benefit. That is, many people could see a benefit, but many thought it made things worse.

We need cost-effectiveness studies to help us make decisions. Sometime the answers we get are clear and unequivocal. But having more information is always better than having no information.

### The NDB and cost-effectiveness.



NDB studies are deeply involved with cost-effectiveness. Last November we submitted a paper for publication about the safety of hydroxychloroquine (Plaquinel®). This is a widely used treatment for Lupus and RA. However, in some instances it can lead to loss of vision and even blindness. NDB data could lead to better recommendations on how often to monitor hydroxychloroquine.

NDB data built from your answers to the questionnaires featured in the fall issue of the *Annals of Internal Medicine*. A study using the data found that generally, treatment using disease-modifying antirheumatic drugs (DMARDs), such as methotrexate, may offer a long-term economic benefit if it allows people whose RA would have worsened dramatically to

keep working. The cost-effectiveness of very early intervention with biologics remains uncertain. The article is titled "Treatment of Very Early Rheumatoid Arthritis With Symptomatic Therapy, Disease-Modifying Antirheumatic Drugs, or Biologic Agents: A Cost-Effectiveness Analysis." You can find the article in Nov. 3, 2009 issue of the *Annals of Internal Medicine*, Volume 151.

The NDB has also been collecting information on Lyrica® and Cymbalta®, and how effective they may be for fibromyalgia. This information is scheduled for analysis early this year. Stand by.

Biologic therapy has been available for rheumatoid arthritis for more than 10 years. The NDB has taken a look at its effectiveness based on thousands of reports from you over this time. By the time I write to you again in our July newsletter, we will have the study results available and on the way to being published. So, once again, stand by.

### 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**

**Arthritis Research  
Center Foundation, Inc.**

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Executive Director: Rebecca Schumacher

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

# LATEST RESEARCH

## New Questions

There are a few new questions in this current NDB questionnaire about an important topic: health literacy. Health literacy is the wide range of skills that people develop over their lifetimes to seek out, understand and use health information. The 2003 National Adult Literacy Survey (NALS) suggests that our health care system requires a level of health literacy above that of many adults in the U.S.

While the amount of health literacy research has increased in the past decade, very little is known about health literacy and arthritis. We are working with doctors at the University of Colorado Denver (J. Hirsh and L. Caplan) to study the relationship between health literacy and rheumatoid arthritis. The current study will attempt to clarify the factors that are important in this relationship. If we can understand this relationship better, it may eventually improve the ability of doctors to communicate with their patients and improve patient education.

There are many ways to determine a person's health literacy. While older methods required long, in-person interviews, newer research shows that a single question may be able to accurately identify a person's health literacy. The current NDB questionnaire takes advantage of this newer research for improved efficiency. There are also questions about important related topics, such as the percentage of time survey respondents take their medications.

Both Drs. Hirsh and Caplan are Assistant Professors of Medicine, Division of Rheumatology, University of Colorado Denver School of Medicine.

Dr. Hirsh is an Attending Physician at Denver Health Medical Center.

Dr. Caplan is an Attending Physician at the Denver Veterans Affairs Medical Center, and participated in the NDB's CHORD program for rheumatologists in training.

## 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.

## 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 six 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.

## ***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

### ***Lottery Winners!***

Return your research questionnaire within two weeks of receiving it and be eligible for one of three \$1,000 awards. The research data bank can best contribute to research when the questionnaires are completed and returned as soon as possible. Anyone who completes the questionnaire within two weeks of receiving it will be eligible for the award — given as a token of our gratitude in help with rheumatology research. The \$1,000 winners from the last questionnaire were Donna Lister, Sparta MI; Connie Scharff, Winfield KS; Sarah Boss, Cape Vincent NY. Winning smaller amounts were Helen Hugunin, Janesville WI; Mildred Moore, San Francisco CA; James Williams, Rochester Hills MI; Michelle Man, Fremont CA. Congratulations to all!

### ***WebQuest***

WebQuest is the online version 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).

### ***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!

