

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 or 800-323-5871 ext. 133 or 140. Thank you!



WebQuest

WebQuest is the online version of the questionnaire. The questions are the same as what you get on the paper questionnaire, and people who are comfortable using computers for things like paying bills and shopping 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 and make the request, or send us an email at 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>



FOR MORE INFORMATION OR TO PARTICIPATE

National Data Bank for Rheumatic Diseases
Arthritis Research Center Foundation, Inc.
1035 North Emporia • Suite 288 • Wichita, KS • 67214
Frederick Wolfe, MD, Director Rebecca Schumacher, Executive Director
Please call 1-800-323-5871 ext. 140 or visit www.arthritis-research.org

THE NDB Research NEWSLETTER

News for Participants in the National Data Bank for Rheumatic Diseases January 2007

Notes from the Director

The January 2007 questionnaire

As you start in on your new questionnaire, I hope you will notice that we have streamlined some of the formatting. It should be easier and faster to complete. And it is shorter. If you haven't completed a questionnaire on the web yet, we invite you to try one; WebQuest goes much faster because you can skip questions that don't apply to you. If you're comfortable using a computer you'll find WebQuest to be easy to use.

A new name

The NDB is taking on a new name: RALLY. RALLY will not replace the NDB, but it will be an additional name. RALLY represents a new project that the NDB has undertaken assessing the safety and effectiveness of a new biologic treatment for rheumatoid arthritis (RA) called Orenzia (generic name: abatacept).

"You can now get a graphic printout of your questionnaire results over time."

RALLY has a web site, www.ndbrally.org, that you might take a look at. One feature of the website that I think will really interest those of you who have been participants in the NDB is this: You can get a graphic print-out of your questionnaire results over time.

Also, people who are not NDB participants can see how they are doing on the RALLY site by completing a quick questionnaire. Please feel free to show the site to your family and friends so they can see what your participation in the NDB is all about.

Research results

Last year we asked you many questions about your medications, including what it would take to make you change and what you liked and didn't like about medical treatments. We thought the results were interesting. By the way, we have sent these results to

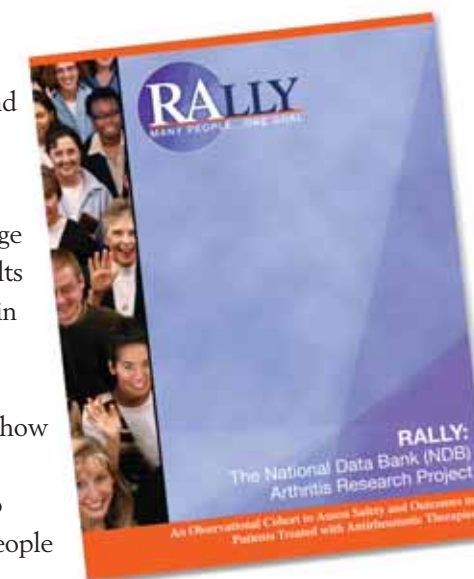
a medical journal, and it has been accepted for publication.

On the following page are some of the results that you won't find in the paper but we thought might be of interest to you. We show the questions and answers according to diagnosis. Overall, people with RA were most satisfied with their medications, and those with fibromyalgia were least satisfied (Q1 and Q2). Side effects were a great concern to everyone (Q3). People with RA and 'other' (for example, lupus) were less concerned about medications that required IVs (Q7). Insurance company hassles were a concern with about half of you.

When we further analyzed the results, we found this: The most important factors that explained why people would or would not want to change medications were "satisfaction with control over arthritis (Q2)" and risk of side effects (Q3). There is much, much more in this report than what we are showing here. If you want a copy, send us an email.

By the way, if you are wondering about medical costs (Q8), the graph of costs on page 2 can give you some idea of total yearly medicals costs for the various diagnoses in the table.

Finally, here are a couple of additional items that might be of interest. To be published soon in the medical journal Arthritis and Rheumatism is our report on the effect of biologic treatments, such as Remicade, Enbrel and Humira, on the risk of developing lymphoma. We found no increased risk. Soon we will submit our paper on the risk of cancer and drug treatment. We presented the paper at the American College of Rheumatology annual meeting in November. You can find a copy of the slides on our web site, and also look at earlier research presentations on a variety of topics of interest to people with rheumatic diseases.

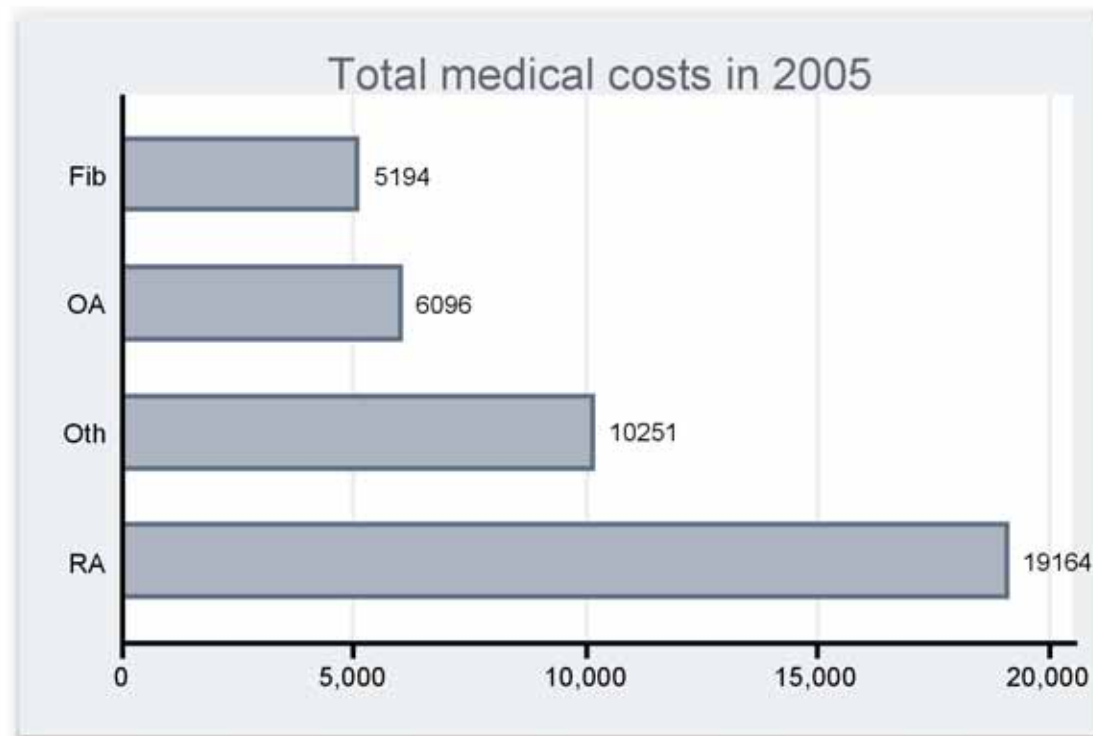


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Research Results (continued)

Questions and answers about medications.

Question	RA	OA	Fibromyalgia	Other
Q1. As long as I don't get worse I wouldn't want to change my arthritis medications	63%	54%	41%	54%
Q2. I don't need new medications because I am satisfied with the control I have over my arthritis.	53%	40%	24%	44%
Q3. I don't want the risk of side effects that might come from taking new medications.	72%	68%	62%	67%
Q4. I want to follow my doctor's suggestions, and my doctor thinks I don't need to change medications.	71%	66%	47%	64%
Q5. I am concerned that new treatments might not work as well and that I might lose control of my arthritis.	68%	48%	47%	57%
Q6. I don't think there are medications currently available that are better than the medications I am using now.	66%	64%	50%	60%
Q7. I don't want to take treatments that require injections or IVs.	35%	62%	50%	41%
Q8. I can't afford the cost of new medications.	42%	39%	41%	37%
Q9. Getting approval from my insurance company and the hassle of tests and medical visits for new drugs are important problems for me.	54%	48%	49%	50%



Numbers are in dollars. Fib: Fibromyalgia, OA: Osteoarthritis, Oth: Other rheumatic diseases, RA: Rheumatoid Arthritis



Happy New Year! from the folks at NDB!

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 at 1-800-323-5871.

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. 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!

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 Patsy Campbell, Harrah, OK; Bonita McKoon, Osawatomie, KS; Ann Kute, Louisville, KY. Winning smaller amounts were Dora Schibonski, Sauk Rapids, MN; Linda Richards, Wichita, KS; Margaret Jolliff, Cape Vincent, NY; Claudia Towers, Tiverton, RI; Suzanne Lovett, Toledo, OH; Phyllis Moore, Johnstown, OH.

Congratulations to all!

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.

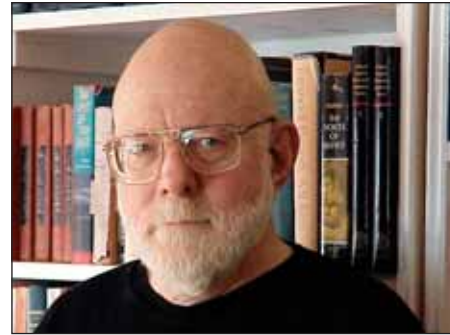
Your personal information will always remain private. We do not sell or share any identifying information about NDB participants. Before we work with researchers or collaborate with other research groups we remove any answers that can be used to identify you.

Nearly all of our research is available for you to read on our website.

The NDB grew out of the rheumatology practice of Dr. Frederick Wolfe, the director of the NDB. Dr. Wolfe stopped seeing patients in 2004 to focus on research. More than 1,000 rheumatologists have helped the NDB. About 10,000 people with rheumatic diseases participate in the NDB every six months.

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



NDB Director Dr. Frederick Wolfe

themselves; data is not collected by doctors or medical staff. With patient-reported data, researchers get a perspective that short, small clinical trials can not 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.

Questionnaire changes



While the questionnaire is mostly the same this time, we have reorganized the paper version to make it easier to read and complete. It's also a bit shorter. When you get to a page with a new format, please take a good look before starting to answer.

Here's a question that frequently comes up: "What time period are you asking about?" Nearly all the questions refer to the past 6 months, which means July through December on the current questionnaire. When we ask about that period of time, even if you are answering the questionnaire in April, we want you to remember back to July through December.

Other questions ask about shorter time periods, such as the last four weeks, the last week, or simply "now." In those cases we are asking about the time just prior to when you fill out the questionnaire, whenever that may be. If you are not sure what time period we're asking about, please get in touch. We hope that our format changes make things a bit clearer.

Latest Research

Fibromyalgia and Quality of Life

People with fibromyalgia experience a profoundly reduced quality of life, according to new research. Reduced physical and social function, general health and vitality, and increased pain are among the problems we confirmed by looking at your answers to our questionnaire.

The research looked at people who have osteoarthritis and Survey Fibromyalgia (SF) and compared them to people with osteoarthritis only. SF is a classification of fibromyalgia symptom severity for research purposes. People in the SF group are judged to have fibromyalgia by their answers to standard rheumatic disease questionnaires, but may or may not have a fibromyalgia diagnosis from a doctor. In the study, 507 people met the SF criteria, and 2,910 had osteoarthritis only.

People in the SF group were more than twice as likely to live at or below

the poverty level, with household income reduced by \$10,632. They were three-to-four times more likely to have stopped work for medical reasons and to have received US Social Security Disability payments. In general, the quality of life measurements showed the equivalent loss of more than two healthy years of life for each decade lived.

While the study illustrates the difficulties experienced by people with fibromyalgia it does not attempt to indicate a causal relationship between the difficulties and the disease.



According to the National Fibromyalgia Association, fibromyalgia is a "chronic pain illness characterized by widespread musculoskeletal aches, pain and stiffness, soft tissue tenderness, general fatigue, and sleep disturbances." Osteoarthritis is a common disease marked by damage to and loss of cartilage in the joints.

Former Vioxx Users are Mostly the Same



By now, nearly everyone has heard about the trouble with Vioxx, the now-controversial pain killer that was taken off the market in 2004. We wanted to see how former Vioxx users are doing now.

We found that people with arthritis who stopped taking Vioxx (rofecoxib) after the painkiller was withdrawn from the market in September 2004, had no measurable worsening of their health.

Pain, general health, quality of life, ulcer rate and gastrointestinal symptoms were analyzed. In 18 months of study no

statistically significant changes in these measures were identified.

We studied 863 people taking Vioxx in the first half of 2004. Half of the study participants had stopped taking Vioxx at the time of market withdrawal in September 2004. One year later fewer than one percent were still taking Vioxx. Most switched to NSAIDs (non-steroidal anti-inflammatory drugs, which include aspirin and ibuprofen, among many others). About 20 percent switched to Celebrex (celecoxib).