

THE Arthritis Research NEWSLETTER

January 2006

Notes from the Director: About Fibromyalgia and All of Us

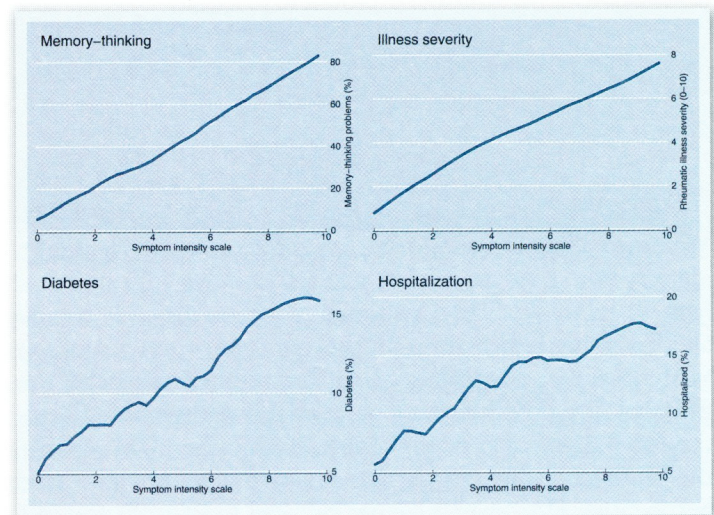
About 9 percent of persons completing NDB questionnaires have indicated that they have fibromyalgia. From time to time you may see articles in the press or on TV about fibromyalgia. However, not everyone knows what it is. We've been interested in fibromyalgia for a long time because all of us have some fibromyalgia symptoms. This year the NDB presented some of our analyses at the annual meeting of the American College of Rheumatology (ACR). I thought you might be interested in some of the data.

Strictly speaking, doctors consider that people who have severe fatigue and generalized aching have fibromyalgia. They almost always have tenderness in their muscles and around their joints. People with fibromyalgia sleep poorly and sometimes have symptoms of depression. But if you think about it, almost all of us have some of these symptoms from time to time. Maybe fibromyalgia symptoms are just a general affliction of humankind? Maybe the question is not whether you have fibromyalgia, but how much fibromyalgia you have.

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We took two questions from the NDB questionnaire: one about fatigue and another about where you are having pain. We made this into a fatigue-pain scale which we called the Symptom Intensity Scale (SIS). People with a score of 0 on the SIS had no pain or fatigue. A score of 10 indicated maximum pain and fatigue. On average, people with scores greater than 6 would usually be diagnosed by a physician as having fibromyalgia. You can think of this scale as indicating the degree of fibromyalgia people have.

About 26,000 people contributed to the graphs shown here. A memory or thinking problem is a common fibromyalgia symptom, but as can be seen in the upper left hand figure, the more fibromyalgia symptoms we have, the more we



report memory or thinking problems. The worse our illness is (upper right), the more severe are our fibromyalgia symptoms. Notice that it isn't just arthritis-related symptoms that are associated with fibromyalgia symptoms. Diabetes and hospitalization are also associated with more fibromyalgia symptoms.

So what does it all mean? Perhaps, that all of us have some degree of fibromyalgia symptoms, and that these symptoms can be brought on by the severity of our medical problems and how we deal with them. So when you think of fibromyalgia in the future, consider that fibromyalgia means severe symptoms, but that those same symptoms are part of us all.

The questionnaire changes a little

There is a famous French saying, "the more things change, the more they remain the same" (Le plus ca change le plus ca le meme chose). The NDB questionnaire has a common base of questions that we have to ask each time. It helps us to get continuity and to understand how treatment and other factors effect the outcome of rheumatic illnesses. One change we are making this year is to eliminate the detailed employment questions. They were part of a 5-year study the NDB was doing with Boston University. That study is now over. The results of it will be reported soon.

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The elimination of the employment questions will save three pages. We are going to take one of those pages back to ask you some questions regarding your experience with the hassles of having a chronic illness. Also we would like to know what you think of your current medications and what factors might make you want to change treatments. Take a look at these questions. Some of them came from suggestions we received from you.

At the end of the questionnaire there is a place for comments and suggestions. If you think there are areas that are important to you that we are missing, please write them there and let us know your suggestions.

Privacy and what happens to the information you give us

We never allow anyone to see any information that might identify you. Everything that you tell us stays with us. In fact, when we analyze questionnaire information we remove all identifying information. In this questionnaire we are asking you for some information that might seem to be personal. It would help us a great deal if you would tell us the last 4 digits of your social security number. This enables the NDB to distinguish participants with similar names and home cities. However, it cannot be used to identify you in any way. So when you see that question, we hope you will complete it.

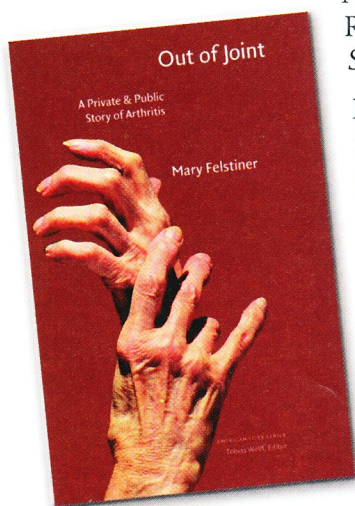
As long as we're at it, I thought you might want to know who sees NDB data. The purpose of collecting information is, of course, sharing the results with others. We report individual serious side effects to the FDA through medication manufacturers. But your identifying information is never reported. We allow medical researchers to study NDB data, but first we remove all identifying information. Even when I analyze NDB information, I don't have access to your name. You might like to know also that we do not allow commercial sources to have NDB data.

Arthritis or rheumatic disease?

Participants have such conditions as rheumatoid arthritis, lupus, osteoarthritis, fibromyalgia, and many others. We have a hard time describing these conditions in a way that applies to everyone. If we speak of "arthritis" then people with non-arthritis conditions such as lupus or vasculitis might think we don't mean them, but we really want their replies, too. Occasionally, we use the term "rheumatic disorder" or "rheumatic disease" to be all inclusive. But those words are a little awkward and take up too much space. However, if you see them, we hope you will understand why we used those words, and if you see the word "arthritis" we hope you might understand that we really mean everyone who is filling out the questionnaire.

Thank you again for all of your effort. We truly appreciate it.

Put this on your reading list



NDB participant and author Mary Felstiner has a new book out about her struggle with Rheumatoid Arthritis. She was diagnosed at age 28. It's called *Out Of Joint: A Private & Public Story Of Arthritis*.

Part memoir, part medical and social history, *Out of Joint* folds Mary's private experience into far-reaching investigations of a socially hidden ailment and of any chronic condition—how to handle love, work, sexuality, fatigue, betrayal, pain, time, mortality, rights, myths, and memory.

Publishers Weekly has this to say about the book:

"Mary Felstiner brings a feminist's eye and a historian's tool kit to this narrative of her decades-long struggle with rheumatoid arthritis (RA)... Felstiner, a professor of history at San Francisco State University, traces the growing scientific understanding of RA, from the earliest accounts in medical antiquity to the latest theories of how pregnancy might trigger the disorder. She touches on treatments, from antimalarial drugs through cortisone and the now-blackballed painkiller Vioxx.... the book's total effect is powerful, and her major chords strike true: RA is a devastatingly disabling condition with steep private and public costs; its disproportionate effects on women have not been adequately addressed; its social, political and interpersonal implications are significant."

The book is 218 pages, published by the University of Nebraska Press (August 8, 2005). List price is \$25. Dr. Felstiner is donating her future proceeds from the book to the Arthritis Foundation. You can read more about the book at the University of Nebraska Press web site: www.nebraskapress.unl.edu.

New Research

Below are selected summaries of research we have presented to the medical community. You can always find all of the NDB's latest and past research on our website, www.arthritis-research.org. Click on the "Latest Research" link. The website has the research in Powerpoint or Adobe Acrobat files. If you see a title that interests you but you can't open the file, let us know and we'll send you a plain text version.

Nearly half of people with RA have difficulty affording care



Rheumatoid arthritis (RA) not only causes bodily pain, it also takes a nasty bite out of peoples' pocketbooks, especially with new and expensive treatments. In a recent NDB study, 32.3 percent of participants reported having moderate difficulty paying for medical care, and 8.2 percent reported great difficulty. The remaining people said they were able to pay the bills without much problem.

Of persons reporting moderate or great difficulty, 37.3 percent did not buy drugs and 7.1 percent skipped surgery because of costs.

The people reporting difficulty earned less money, had less household income, and had high rates of work disability compared to those who paid their medical costs without much problem. They also had more other illnesses (such as heart or lung problems), and decreased functional ability.

The research suggests that the more severe a person's RA is, the more likely he or she will have a reduced ability to pay for medical care. It is important for policy makers, doctors and insurance companies to know that getting required medications and treatment can be an important problem.

The study, authored by Dr. Roxabella Torres, Dr. Fred Wolfe and Kaleb Michaud, studied 8,062 people with RA from the NDB.

Anemia and RA

Even though persons with RA get frequent blood tests, there have been only a handful of small studies that have looked at anemia in those people. These studies showed that between 30 and 60 percent of persons with RA have mild anemia.

Anemia is a lower than normal number of red blood cells in the blood, measured by a decrease in the amount of hemoglobin. Hemoglobin is the red pigment in red blood cells that transports oxygen. Severe anemia can cause problems for people.

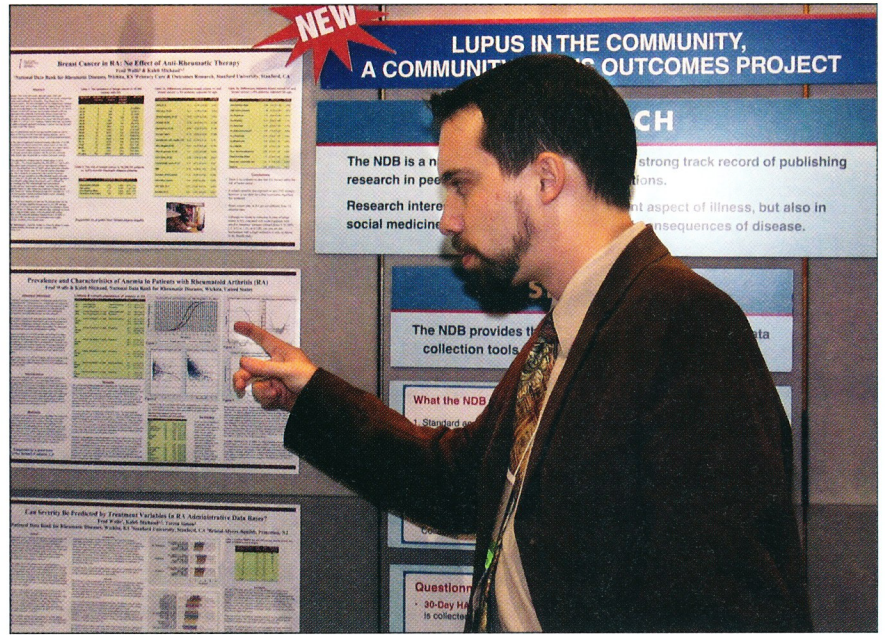
We looked at about 2,000 NDB participants with RA who were also patients in Dr. Wolfe's clinic and compared them to people without RA or other inflammatory rheumatic diseases. We found that anemia occurs in 31.5 percent of those with RA, which is three times the rate of anemia in the general population. Anemia is the result of RA inflammation, and it can contribute to fatigue and not feeling well. In most instances, however, the degree of anemia was slight.



Are people sticking with the new RA medications?

The length of time a person stays on a medication is one way of judging how effective that medication is in treating a chronic disease. People stay on a treatment when it seems to be as good as or better than other available treatments. But other factors, such as cost, insurance and the severity of the disease can also play a part. With this in mind, the NDB looked at participants taking any of three newer treatments, Enbrel (etanercept), Remicade (infliximab) and Arava (leflunomide). Half of patients taking Enbrel or Remicade continue taking those medications beyond 3.5 to 4 years. For Arava, half continue past 2 years. Generally, people with more severe symptoms when they started taking the medications and those with more severe symptoms while they were taking them were more likely to switch to another treatment.

NDB analyst Kaleb Michaud discusses research in the NDB booth at the 69th Annual Scientific Meeting of the ACR (American College of Rheumatology) in San Diego. The NDB launched a new project, "Lupus in the Community."



New Questions

We're introducing some new questions with the January questionnaire. Having a chronic disease makes you very familiar with the medical system. Doctors' offices, hospitals, pharmacies and insurance can help you get through the system, or sometimes they seem to slow you down when all you want to do is feel better. To learn about your experiences, we're asking if you have problems using the system, and if so, how important the problems are to you.

Other new questions ask about what you would need from a new medication. Switching medications can sometimes be a risk. There may be new side effects and the hassle of tests you'll have to take before you can switch. You might get better results or you might not. By looking at your answers to these questions and the severity of your condition, we hope to understand what motivates people to try new medications.

Improved Questions

Last time we asked new questions about how much people pay out of pocket for medications and doctor visits. Many of you commented that the way we allowed you to answer didn't really let you explain how your insurance works. To make answering a bit easier we now ask about your out of pocket expenses for generic and brand name medications separately. What we hope to learn is the average expense for your medications. Some of you pay different amounts for different drugs. In that case, please tell us the average expense to the best of your abilities, either as a dollar figure or as a percentage. Please contact us if you have questions when you get to that section.

Staying on top of the world wide web

There is a world of information about rheumatic diseases available to you on the web, and it changes every day. You could easily drive yourself nuts trying to wade through all of the articles in newspapers, medical journals and medical websites just to see what's new in treatments or research.

Fortunately, you don't have to do all the work yourself. The NDB maintains a blog, or web log, of the latest NDB news and rheumatic disease news from the all over the world. It's called NDB Connection, and it's a great place to start when you're looking for the latest news. We pick out a few of the most interesting news articles each week and refer back to the original article.

Read the blog online at ndb.blogspot.com. There's also an RSS feed so you can be automatically notified whenever the blog is updated. Read about how to use that on the blog.

FOR MORE INFORMATION OR TO PARTICIPATE

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Please call 1-800-323-5871 ext. 140
or email info@arthritis-research.org

Meet the Participants:

Charlotte Stokes

From time to time we hear from NDB participants about their activities. Charlotte Stokes sent us a copy of a newspaper article about her. Mrs. Stokes is a 90-year-old woman from Philadelphia with RA. She creates bronze sculptures that are displayed across the United States, from the assisted living home where she resides, to prominent locations in Philadelphia, to the Montana Governor's office.

Her local newspaper, the Chestnut Hill Local, gave us permission to reprint the article. Thanks to Charlotte and the Chestnut Hill Local. Here are some highlights:

"Charlotte's story is one that reaches foreign lands and spans decades, chasing all sorts of pursuits and interests.... And it is all recorded in her artwork, the walls crowded with canvases or the books stacked on the floor, and the sculptures everywhere that occasionally jump out from the woodwork. Behind each piece of her art there is a romantic tale, a small chapter of a colorful past relegated to some corner of the room.

"Her most recent sculpture, and perhaps the most storied, is a life-size bust of Chief New Chest, a Piegan (Blackfeet) Indian.... She was advised that it would be accepted by the Montana Historical Society, and so the chief's bust was trekked across state lines to a museum display out west. When new Montana governors are voted in, they walk the floor of the museum to pick out artwork to decorate the new office. Brian Schweitzer, the present governor, chose the bust immediately, and it now sits across from his desk.

"Although the inspiration for the bust was a photograph, the great majority of her art is based on experience and encounters, places she has seen and people she's met. Her more common muse is the passerby, the street people who will never know they've been shaped in clay, hardened and



Charlotte Stokes at work on her bust of Chief New Chest.

preserved for all time. She works from a sharp photographic memory and remarkable mental notes about the way an arm is positioned, the way a certain smile bends or the way someone's hair falls just so. The results are sculptures that are not completely true to their subjects, but more accurate to the ways she sees them, or remembers them, which means there is a lot of her in the outcome.

"Charlotte Stokes is the youngest 90-year-old I've ever seen. The giddiness is still in her voice; she's interested in everything (including her massive collection of rare fans); she has this ability to see beauty in unnoticed places, and she occasionally acts shy; there is still this youthful energy that enables her to make such a big splash in the world despite her age."

The complete article is online here:

<http://chestnuthilllocal.com/archives/051905/locallife1.html>

Lottery Winners!

Return your research questionnaire within two weeks of receiving it and be eligible for one of three \$1,000 awards. The research databank 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 arthritis research. The \$1,000 winners from the last questionnaire were Jackie Williams, Fort Riley, KS; Ernestine Watts, Medicine Lodge KS; Mary Hall, Petoskey, MI. Winning smaller amounts were Neal James, South Euclid, OH; Carol Tucker, Dallas TX; Judy Smith, Kansas City, MO; Grace Mauler, Ferndale, WA.

Congratulations to all!

RA self-management at RAHelp.org

The Missouri Arthritis Rehabilitation Research and Training Center at the University of Missouri-Columbia is offering an online self-management program for people with RA. Pain and stress reduction, interpersonal relationships, and fatigue are just a few of the important issues covered. Visit rahelp.org for more information.

How YOU can help the NDB



Helping the NDB in other ways

The success of the NDB depends on a large group of participants. Here are a couple of ways you can help.

Now available for your support group or arthritis 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!

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>

