

# THE Arthritis Research NEWSLETTER

January 2004

## Research Notes from the Director

Happy New Year 2004! And as always, thanks to all of you who by participating in NDB research advance knowledge of arthritis and arthritis treatment.

2003 was a very busy and very rewarding year for NDB research. Your data contributed to 21 research presentations for the American College of Rheumatology (ACR) Annual Scientific Meeting, and to 17 manuscripts that were published in scientific medical journals throughout the world.

To help you understand what all this means let's take an inside look at the ACR meeting.

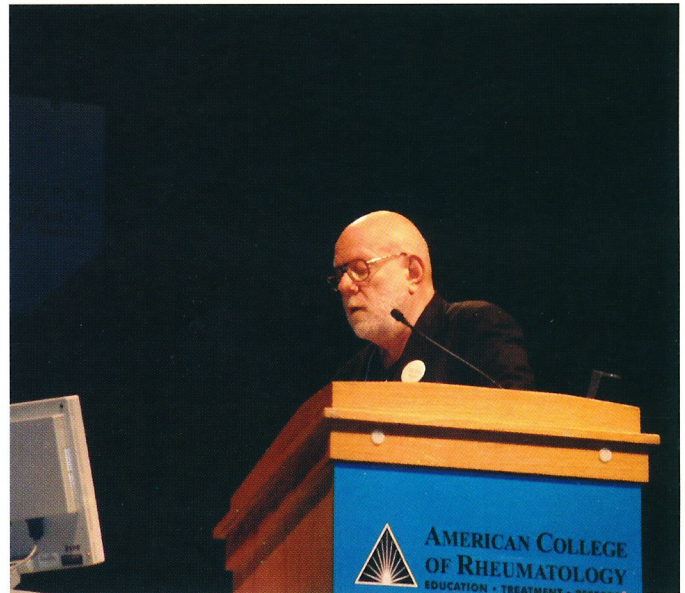
Each fall rheumatologists from all over the world come to the United States for the American College of Rheumatology Research meeting. European and Asian rheumatologists also have research meetings, but the ACR meeting is so big and so important that all serious international researchers make it their business to come to this meeting.

Research that is accepted for presentation at the meeting goes through rigorous evaluation before it is accepted. Researchers who want to present their research at the meeting prepare 'abstracts,' or short summaries, of their work and submit

*This year the NDB had 85% of all abstracts accepted.*

them for review before the end of June. Each abstract is judged by approximately 5 experts who give it a rating based on their estimates of its quality and research importance. Perhaps 50 experts in all participate in the evaluations.

After that, a committee meets and ranks all of the abstracts. The best are selected to be podium presentations; the rest are chosen to be poster presentations. About 50% of the approximately 5,000 abstracts submitted are rejected and are not presented at the meeting. Only about 10% of accepted abstracts



*Dr. Wolfe presenting research findings during a podium presentation at the 2003 ACR meeting.*

become podium presentations. A podium presentation is an oral presentation before a large audience in which the research results are displayed as slides on a large screen.

Perhaps 20 of the very best podium abstracts are presented at 'plenary sessions' – times at the ACR meeting when all other activities are closed down and physicians are asked to come and hear the best abstracts. This year the NDB had 85% of all abstracts accepted, and had five podium presentations, one of which was a plenary presentation. Dr. Victoria Cartwright, a CHORD fellow, presented two podium presentations for the NDB, Kaleb Michaud gave one podium presentation and Dr. Wolfe presented two.

Some people think that poster presentations are a better way to present research. The rheumatologist presenting at a poster session prepares a 3 foot by 5 foot poster which is then mounted to a board. The researcher stands in front of the board for several hours and discusses the study results and answers questions from all of the meeting attendees who come to see the presentation.

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## *Research Notes from the Director* —continued from page 1

The photo to the right shows Dr. Diane Kamen answering questions during her poster presentation. Dr. Kamen was a Chord fellow who did research with the NDB as part of the NDB's role in training young rheumatology research specialists.

After the meeting is complete the next step is to write up our research findings for publications. This is the most difficult part, for the manuscripts we write are rigorously reviewed by highly trained experts, and much care is taken to ensure our results are accurate. All manuscripts pass through this review process, which sometimes can take over a year, before they can be published in scientific and medical journals.

Included in this newsletter is a list of the names of all NDB manuscripts written and published during 2002-2003.



*Dr. Diane Kamen presenting a poster at the 2003 ACR meeting.*

## *Research Highlights from the 2003 ACR Meeting* —

### *Methotrexate laboratory testing and risk of Serious Illness:*

Good news about methotrexate. The NDB presented data on the short-term and long-term safety of methotrexate. Significant laboratory abnormalities were rare. The number of and frequency of tests recommended by the American College of Rheumatology to doctors may be more than needed according to NDB research. Reducing the amount of testing based on scientific research would help save your time and reduce your costs. The other good news about methotrexate is that the rate of cirrhosis (always a worry) was very low. In fact, it was lower in persons taking methotrexate than in those not taking it.



*Kaleb Michaud MS, Diane Kamen MD, and Esi Dewitt MD discussing research at the 2003 ACR Meeting.*

### *Low rates of Visual Loss in Hydroxychloroquine (Plaquenil) Treated Patients*

Some of you may take the drug Plaquenil, known also by its generic name, Hydroxychloroquine. One of the potential worries about this drug is its possible harmful effect on the eye. We evaluated doctors who prescribed Hydroxychloroquine, and people with RA who took the medication. We found that half of the people who took Hydroxychloroquine had eye examinations every 6 months and the other half had examinations every 12 months. We also found that the rate of visual loss directly related to hydroxychloroquine treatment was very, very, very low. Based on this research, the NDB recommended to the American College of Rheumatology that the current recommendations for frequent examinations be changed for most people.

### **Three \$1,000 Awards to Arthritis Research Participants:**

*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 mailed 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 winners from the last questionnaire were Evelyn Byrom of Cameron, MO; Robert Knoebber of Shawnee, KS; Delfina Daugherty of Norwalk, CA.*

*Congratulations to all !*

# WebQuest: More Improvements and a New Look

Over two years ago, at the request of many of you, we launched an Internet version of the NDB research questionnaire. We call it "WebQuest." Most people who have used it were quite pleased and have helped us make several improvements.

For 2004 the WebQuest will have a new look! Below are some actual pictures of WebQuest from the Internet to show you what's changed. The WebQuest will still be as easy as ever to use.

## Why you should use WebQuest rather than the paper surveys...

It's easier and faster. WebQuest remembers who you are and doesn't ask you to complete questions for which we already have an answer. It remembers your medications, as well. And it branches! If a section of the questionnaire doesn't apply to you, WebQuest skips it. Give WebQuest a try.

If you are not now using WebQuest there are two ways to start: 1) go to "Request NDB Questionnaire on the Web" at our home page: [www.arthritis-research.org](http://www.arthritis-research.org) and complete the form or 2) send us an email at [webquest@arthritis-research.org](mailto:webquest@arthritis-research.org).

We will email you everything you need to get started. If you completed the WebQuest last time you will be automatically emailed a new invitation.

We have also launched an Internet version of the NDB Enrollment Questionnaire for people who want to join the NDB research and are not currently participating. It is available on our website at: [www.arthritis-research.org/ndb\\_enroll.htm](http://www.arthritis-research.org/ndb_enroll.htm). So, if you

know anyone with arthritis or other arthritis-related diseases tell them about us. Web Enrollment is quick and easy and it's a great way to forward arthritis research.

If you have any questions about the WebQuest, want more information on the Web enrollment questionnaire, or if your email address has changed, please let us know at [webquest@arthritis-research.org](mailto:webquest@arthritis-research.org) or call us at 1-800-323-5871 x143.

# Growing On the Internet — The NDB Website gets a Facelift, New Features

We have upgraded our Web site to make it friendly and more functional for both patients and physicians. The image (right) shows our new home page. New features include the navigation section on the right with physician and patient specific pages, and then general research pages. We have posted a variety of new information so we invite you to take some time and browse through the website.

Another new website feature we are very excited about is the NDB Forum. The Forum is available for NDB participants to post comments, ask questions, or find out new information. It will be mediated by a NDB Staff member, and allows all NDB participants a place to connect with others in the research project.

The three forum topics are:

**Questionnaires:** In the many years that we have been doing NDB research we have had many questions and comments about our questionnaires — gripes, sighs, and some kudos. This forum is one place you can ask these questions and get a reply from NDB staff.

The screenshot shows the homepage of the National Data Bank for Rheumatic Diseases. The page is organized into several sections: 'Current Activities...', 'Our Mission...', 'About the NDB...', and 'Our Commitment to...'. On the right side, there are three vertical navigation menus: 'Physician Resources', 'Research Resources', and 'Patient Resources'. The 'Physician Resources' menu includes links for 'NDB Research', 'Physician Participation in the NDB', 'NDB Staff and Committee', 'Physician Research for Patients', 'Physician Research for Patients', 'Physician Research for Patients', 'Physician Research for Patients', 'Physician Research for Patients', and 'Physician Research for Patients'. The 'Research Resources' menu includes links for 'Discussions/Questionnaires of Interest', 'Publications of the NDB', 'Physician Participation in the NDB', 'Site Information of the NDB', and 'NDB Staff and Committee'. The 'Patient Resources' menu includes links for 'Physician Research for Patients', 'Physician Research for Patients', 'Physician Research for Patients', 'Physician Research for Patients', and 'Physician Research for Patients'. The main content area contains text about the NDB's mission, its commitment to research, and its role in providing data collection tools and individualized database support.

The screenshot shows the NDB Forum page. The forum is titled 'Forum' and has a table with columns for 'Topic', 'Posts', and 'Last Post'. The table lists several topics, including 'NDB Research', 'NDB Questionnaires', and 'Arthritis-Rheumatology'. Below the table, there are 'Forum Statistics' and a 'Help' section. The 'Forum Statistics' section shows that there are 3 topics in 3 forums, with 11 posts in 1 forum. The 'Help' section includes links for 'Open Forum', 'Read Only', and 'Assisted Required'. The page also includes a 'Cookies and JavaScript' notice and a footer with the NDB logo and contact information.

**Research:** We keep telling you about the research we do, but you don't usually get all of the details. This forum is a place you can ask about specific research we have done. You can also give us suggestions for research that you think is important.

**Arthritis-Rheumatology:** This forum is where you can post questions that are not related to the NDB and is a great place to get information from others participating in the study. In this particular forum the NDB staff will observe rather than comment. But occasionally we'll jump in.

This is your chance to make suggestions to us. We listen carefully to what you say.

You can find the NDB Forum at the following address:  
[www.arthritis-research.org/bbs.htm](http://www.arthritis-research.org/bbs.htm).

## News from the NDB Staff:

Happy New Year 2004! As always we are trying hard to make the questionnaire simple and straightforward without losing any critical information we need to continue research. Below are a few changes you can expect in the January 2004 questionnaire:

- 1). The "For Women Only" section on page 3 has been replaced with questions that deal with neck arthritis. This section is for everyone to answer.
- 2). We have expanded the infection section on page 6 to include flu, colds and chronic bronchitis. And we are now asking if you were treated with intravenous (IV) anti-biotics for some of the infections listed. Please make sure to check over this section carefully so everything gets recorded.
- 3). We have eliminated several questions that deal with depression and anxiety. Since these questions are no longer being used please make sure you fill out the SF-36 section completely which is near the back of the questionnaire (pages 25 and 26).

If you have any questions or need some help completing the questionnaire please email us at: [info@arthritis-research.org](mailto:info@arthritis-research.org) or call us at 800-323-5871 x133 or x140.

**FOR MORE INFORMATION  
OR TO PARTICIPATE**

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## ***CHORD Health Outcomes in Rheumatic Diseases Fellowship Program Update***

The 2003 Annual Scientific Meeting of the American College of Rheumatology marked the completion of the first CHORD fellowship program. Many of the fellows we introduced to you in the last two editions of the newsletter presented research results from your data. Following is a list of the research presented by 2002 CHORD Fellows along with a brief explanation of results (*in parentheses*).

### ***2002 CHORD Fellow Abstracts using NDB data:***

- Methotrexate, Laboratory Testing and Risk of Serious Illness: Analyses in 20,000 Patients — Victoria Cartwright MD (*Methotrexate is quite safe.*)
- Low Rate of Visual Loss in Hydroxychloroquine Treated Patients: Evidence to Revise Monitoring Guidelines — Victoria Cartwright MD (*Toxicity to plaquenil is rare.*)
- Infliximab Dose and Clinical Status in 1,248 RA Patients Seen in Rheumatology Clinical Practice — Richard Stern MD (*Remicade doses are increasing.*)
- Therapy with Biologic Agents is not Associated with an Increased Risk of Cancer Recurrence in Patient with Rheumatoid Arthritis — Melissa Hawkins-Holt MD (*No evidence that Remicade or Enrel causes cancer to recur.*)
- Dose Escalation of Infliximab in Clinical Practice: Data from two large Rheumatology Clinics in Dallas, Texas — Richard Stern MD (*More data on the increased dosing of Remicade.*)
- The Changing Face of Ulcer Disease in Rheumatoid Arthritis and Osteoarthritis — Elizabeth Bentio-Garcia MD (*Who gets ulcers? Which medications prevent ulcers?*)
- Utilization of Anti-Lipemic Agents and Gender Differences Among Subjects with Rheumatoid Arthritis — Abha Gupta MD (*There is a gender gap. Men are treated with drugs to lower cholesterol more often than women.*)
- Workplace Productivity Among Working Persons with RA: Reliability and Validity of the Work Limitations Questionnaire (WLQ) in 836 Patients — Nancy Walker MD (*What it really costs to have RA — Dollars and cents.*)
- Conventional and Disease-Specific Risk Factors for Congestive Heart Failure in Rheumatoid Arthritis — David Wu MD, Eric Lieberman MD, Paola De Pablo MD (*More on the safety of Remicade, and Enbrel. They do not cause heart failure.*)
- The Effects of Biologic DMARDS on Sleep in Patients with RA. — Shahin Bagheri MD (*Do biologic drugs improve sleep?*)

\*CHORD is a program sponsored by Centocor, Inc. and directed by NDB director, Frederick Wolfe, Theodore Pincus of Vanderbilt University, and Hyon K. Choi of Harvard. Physicians who were named as fellows in this program are training to be rheumatologists. During the yearlong fellowship training, CHORD fellows will study with Drs. Wolfe, Pincus and Choi using the research data from the National Data Bank.

## 2002-2003 Publications

- Direct medical costs and their predictors in persons with rheumatoid arthritis; a 3 Year Study of 7,527 Patients. *Arthritis Rheum.* (In Press)
- Lymphoma in rheumatoid arthritis; the effect of methotrexate and anti-TNF therapy in 18,572 patients. Accepted for publication *Arthritis Rheum.*
- Tuberculosis infection in patients with rheumatoid arthritis and the effect of infliximab therapy. Accepted for publication *Arthritis Rheum.*
- Congestive heart failure in rheumatoid arthritis: Rates, predictors and the effect of anti-TNF therapy. Under review 2003.
- Increase in cardiovascular and cerebrovascular disease prevalence in rheumatoid arthritis. *J.Rheumatol.* 30(1):36-40,2003.
- Pain extent and diagnosis: development and validation of the regional pain scale in 12,799 patients with rheumatic disease. *J.Rheumatol.* 30(2):269-278,2003.
- Predicting mortality in patients with rheumatoid arthritis. *Arthritis Rheum.* 48(6):1530-1542, 2003.
- Toward a definition and method of assessment of treatment failure and treatment effectiveness: The case of leflunomide versus methotrexate. *J.Rheumatol.* 30(8):1725-1732, 2003.
- Methotrexate therapy and mortality in patients with rheumatoid arthritis: a prospective study. *Lancet* 359:1173-1177, 2002.
- The effect of health related quality of life on reported use of health care resources in patients with osteoarthritis and rheumatoid arthritis: a longitudinal analysis. *J.Rheumatol.* 29(6):1147-1155, 2002.
- Gastro-protective therapy and risk of gastrointestinal ulcers: risk reduction by COX-2 therapy. *J.Rheumatol.* 29 (3): 467-473, 2002.
- The long-term outcome of osteoarthritis: rates and predictors of joint space narrowing in symptomatic patients with knee osteoarthritis. *J.Rheumatol.* 29 (1): 139-146, 2002.
- The psychometrics of functional status questionnaires: room for improvement. *J.Rheumatol.* 29 (5): 865-868, 2002.
- Increase in lifetime adverse drug reactions, service utilization, and disease severity among patients who will start COX-2 specific inhibitors: quantitative assessment of channeling bias and confounding by indication in 6689 patients with rheumatoid arthritis and osteoarthritis. *J.Rheumatol.* 29 (5); 1015-1022,2002.
- Radiographic methods in knee osteoarthritis: A further comparison of semi-flexed (MTP), schuss-tunnel, and weight-bearing antero-posterior view for joint space narrowing and osteophytes. *J.Rheumatol.* 29 (12) 2597-2601, 2002.
- Neural network based automated algorithm to identify joint locations on hand/wrists radiographs for arthritis assessments. *Med.Phys.* 29 (3): 403-411, 2002.
- A functional promoter polymorphism in the macrophage migration inhibitory factor (MIF) gene associated with disease severity in rheumatoid arthritis. *Genes Immun.* 3 (3):170-176, 2002.