

THE NDB Research

NEWSLETTER

News for Participants in the National Data Bank for Rheumatic Diseases January 2013

Notes from the Directors

Frederick Wolfe, MD — Kaleb Michaud, PhD

There is growing recognition of the importance of the research we do here at the NDB, specifically patient-centered and patient-reported research. What our founder, Dr. Wolfe, and other rheumatologists have known for decades, is that so much can be learned directly from the patient's experience. What this increased interest means is that the NDB will be working closely with even more world experts on rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), osteoarthritis (OA), fibromyalgia (FMS) and other rheumatic diseases.

The next rheumatic disease to receive its own custom questionnaire is gout. Gout has become much more common in the past 20 years as diets and exercise habits have changed. And unlike most of our diseases we follow, a patient with gout can go months to years without being affected, but then with no notice can flare with dramatic inflammation and pain.

Because of this unusual flare cycle, we are working on introducing a special questionnaire just for when you are having a flare – starting with gout patients and then being added for RA, SLE, and others. We hope that during the time when you are having a flare that you can answer some questions about it. We also still need to know about the experience of patients with other rheumatic diseases that we didn't mention above. Every bit helps even if the disease is very uncommon, it's just impractical for us to make a disease-specific survey for all 100+ diseases we follow.

There are many positive changes coming to the NDB, many of which we reported to those of you who have given us your email address. The first is that we have made our website address much easier to remember and type. It's [ndb.org](http://www.ndb.org). So you

may notice that our email addresses have changed to this new name, too. Fortunately both the old address (www.arthritis-research.org) and new one (www.ndb.org) will work and take you to the same place.

“Gout has become much more common in the past 20 years as diets and exercise habits have changed.”

The second change has to do with our internet surveys. We have teamed up with DatStat, a world-leader for online medical research surveys, to help us provide you an easier to use experience when you answer our online questionnaires. This does mean that we're changing the medications page again, but we think you will like the results. It's much easier to see and print out a report of the medications all together. As always, these changes come from your feedback which we always read and appreciate.

Lastly, we are creating a patient advisory board which is made up of a select volunteer group of our patient participants who will provide us feedback on new research projects and other changes to the NDB. Be sure to let us know if you are interested in being involved on this board by emailing us at webquest@ndb.org. We believe this will help us conduct better research that is important to you and improve your experiences while answering our surveys.

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.ndb.org/participate/tell-friend>.



LATEST RESEARCH

This past November at the Annual American College of Rheumatology Meeting, the NDB was involved in over 10 research abstracts and talks on various subjects that used the data that you have provided to us over the years. The majority of these will end up as papers published in medical journals and this would not have been possible without your participation.

We thank each and every one of you—it could not be done without you!

Here are some of the findings from the meeting that you made possible:

Predictors and Discontinuation Rates of Biologics in RA Patients since 1998

Using the NDB data from 1998 to 2011, we showed that RA patients tend to remain on their initial and second biologic (ie. Enbrel, Remicade, Humira, Orencia, Cimzia, Simponi, Actemra) for long periods suggesting the drugs are effective. The most common reason for stopping a biologic was due to side effects.

Worse overall health strongly predicted discontinuation. If patients noted higher amounts of health problems (ie. heart, liver, or kidney problems, etc.) and they smoked, they were more likely to discontinue their medication. Co-medication with methotrexate helped to lower discontinuation.

The research also showed that with more biologics to choose from, the impact of overall health on discontinuations lessened but discontinuation rates in patients who started their biologics since 2004 are higher due to having more options.

Pneumonia Vaccination in RA, OA and SLE patients

Our data showed that despite recommendations from various medical groups throughout the world for all patients with autoimmune diseases like RA and SLE, nearly 1 out of 3 of these patients <65 years of age did not report receiving a pneumonia vaccination. Those most likely to get the vaccinations are >65 years of age, for all diagnoses including OA, and have a presence of lung disease, for RA and SLE patients. SLE patients who used prednisone were also more likely to get the pneumonia vaccination.

Increased Incidence of Herpes Zoster (Shingles) in SLE Patients

Herpes Zoster (Shingles) is the painful reactivation of latent chicken pox (varicella zoster) virus infection. In comparing doctor diagnosed systemic lupus erythematosus (SLE) patients to those with non-inflammatory musculoskeletal conditions (ie. osteoarthritis, back pain, etc.), it showed that SLE patients at all ages had an increased incident of herpes

zoster and also that SLE patients had the lowest herpes zoster vaccination rate for those who were eligible to get a vaccination.

Patient Reported Outcomes—Home Reports versus Clinic Reports

Registries are a common tool for collecting patient outcome measures (pain, fatigue, overall health and everyday activities). In comparing



data from a patient entered registry versus a registry collected at the clinic visit, we showed that patients reported a higher level of disease severity in the clinic than at home. This was also true of patients who respond in the clinic and are seen more often, which may be due to patients going in when their disease is affecting them the most or have more severe health care needs. Patients responding via the web do not differ in severity from patients who respond via paper, but patients who respond by telephone report worse outcomes (pain, fatigue and everyday experiences) except for overall health assessments, i.e. overall how does your disease affect you.

Join Us on Facebook & Twitter



You can find us on Facebook as “National Data Bank for Rheumatic Diseases.” We will try to keep you up to date with any news items that occur between questionnaires. You can also connect with other participants and NDB staff who have joined our group.

We have just started our new Twitter account and you can find us as “@ndb_org”.

We have added this for those that may be on Twitter but not on Facebook and we will be tweeting news items to start with.

Meet the Staff *Kaleb Michaud, PhD*

Last newsletter you may have noticed an addition to the “Notes from the Director” section from Dr. Kaleb Michaud. Kaleb has been working with the NDB since 2001 helping with statistical analysis and research projects and is currently our



Co-Director along with Dr. Wolfe. He has a long history with Dr. Wolfe and the NDB starting when he was first diagnosed with juvenile rheumatoid arthritis at the age of 3 by Dr. Wolfe back in the 70's. Having the need of a wheelchair as a kid, several joint surgeries, and many medication failures and successes has provided him with a unique insight into arthritis research and has been part of his motivation in advancing the field for patients of all ages.

Along with his role in the NDB, Dr. Michaud is an assistant professor in the Division of Rheumatology & Immunology at the University of Nebraska Medical Center (UNMC) in Omaha. He is also the principal investigator for the Rheumatoid Arthritis Investigator Network (RAIN) rheumatology database, an investigator with the Veterans Affairs RA (VARA) registry, and is the director of the UNMC rheumatology fellowship research program.

When Kaleb needs some down time from his busy work schedule, he enjoys hosting his friends over for a movie in his self-built theater or for various games. He enjoys board games so much that he has created a very large (~2,000) library of games to share with the community.

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.

Now available for your support group or arthritis, fibromyalgia or lupus meetings...our pamphlets that 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@ndb.org or 800-323-5871 ext. 133. Thank you!

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 participant, in 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.

Our website for rheumatology questions, RheumMD.org

On RheumMD.org we've brought together more than 20 volunteer experts to answer your questions about any rheumatic condition. You can also search existing questions and engage the doctors in discussions about the answers.

Here are some questions we've had on the site lately:

- *How safe is prednisone if you have a history of glaucoma and cataracts?*
- *How does a TENS unit help fibromyalgia?*
- *What effects do RA medications have on healing fractures?*

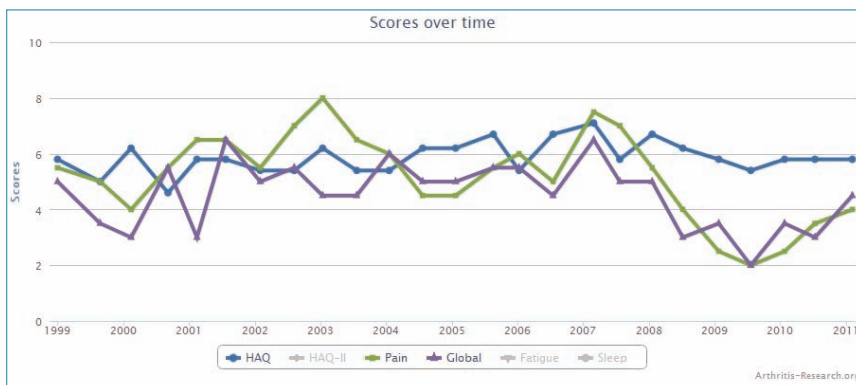
There are many more questions, and we invite you to ask your own at RheumMD.org.



View your NDB results online

Many of the questions we ask every six months give researchers and doctors scores that show how you're doing. We have heard from many of you that you want to see your results. You can now get these scores any time you need them on our website. If you don't already have an account on our website, start on this page: <http://www.ndb.org/user/register> Having an account protects your privacy and lets you access your scores.

You will be able to see scores for every questionnaire you've ever completed for the NDB, and print them for your own information or to show to your doctor. Please email us at webquest@ndb.org if you have any questions about the website or your scores.



Donate Blood for Research!

You can help advance arthritis research by donating a blood sample. By analyzing your blood in combination with your answers to the NDB questionnaires, we hope to discover biological reasons why some treatments work better and why some are more toxic to an individual.

As always, your privacy is protected and there is absolutely no cost to you. Your lab results will be available directly to you through a secured login on our website. You can also print out the lab results and take them with you to your next doctor appointment.

Blood collection takes place only at Quest Diagnostics laboratory sites, which are located in many cities across the US.

To donate blood, you must first sign a consent form, which we will mail to you. If you are interested in donating a blood sample, please contact Kimberly Harp by email at kim@ndb.org or by phone at 1-800-323-5871 ext. 143.

**FOR MORE
INFORMATION
OR TO PARTICIPATE**

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Kaleb Michaud, PhD**

**Executive Director:
Rebecca Schumacher**

**Please call: 1-800-323-5871
or email:
info@ndb.org**

Arthritis Internet Registry (AIR) Update

The Arthritis Internet Registry (AIR) is going strong after two years! AIR is an internet-based patient registry and biospecimen collection using the combination of the patient-study infrastructure of the NDB, the nation-wide availability of Quest Diagnostics blood collection sites and the patient outreach of the Arthritis Foundation. Participants in AIR complete the same questionnaires as the participants in the NDB, but are noted as AIR participants due to the way they enrolled into the data bank. Some AIR participants consent to donate blood samples for the biospecimen collection. We currently have had over 3,000 participants join and we have collected over 500 biospecimens on a variety of rheumatic diseases.



For those of you who may not know, AIR is a groundbreaking study using the internet to create a community of arthritis patients for discovery research. AIR recognizes

the importance of research to improve the lives of arthritis patients and the needs of patients to discuss their disease with other patients. The purpose of AIR is to bring together a community of arthritis patients to enable discovery research and social networking via the internet. AIR has been focused on enrolling patients, collecting relevant clinical data, and collecting blood biospecimens for discovery research. Such research includes understanding genetic predictors of RA risk, cardiovascular complications and response to RA therapies. As AIR grows, we will add social networking capabilities to allow arthritis patients to communicate with other arthritis patients about their disease.

First study approved to use AIR!

Dr. Robert Plenge at the Harvard Medical School received a grant from the BROAD Institute and the Arthritis Foundation for his project: Genomic Analysis in the AIR Cohort. His project will use some of the biospecimen collected along with the data from the questionnaires as an opportunity to show a new way for comparing the genetic data to laboratory data results from Quest Diagnostics and clinical data results from the questionnaires. One goal is to show that this may be one of the new ways to collect patient samples for discovery genomics research and next-generation patient registries.

AIR is a partnership between leading academic researchers, the Arthritis Foundation and Quest Diagnostics. The main researchers and advisors working on and supporting AIR are the following:

Kaleb Michaud, PhD - *NDB and the University of Nebraska Medical Center*

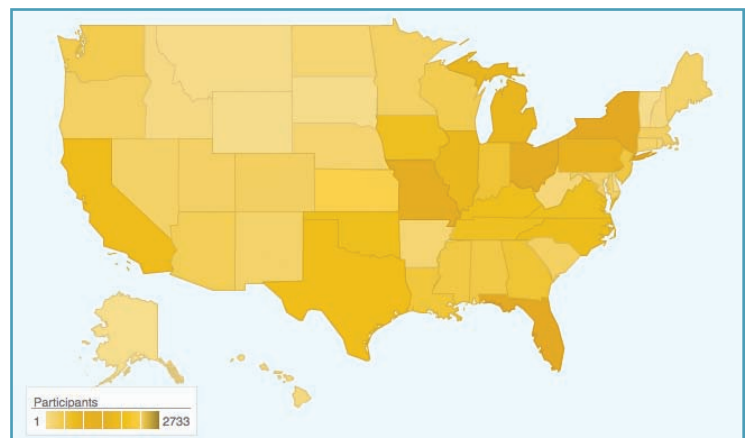
Robert Plenge, MD, PhD - *Harvard Medical School*

Stanley J. Naides, MD - *Quest Diagnostics Nichols Institute*

John Hardin, MD - *Arthritis Foundation*

NDB Participants on the Map

Participants who have set up an account on our website will be able to see maps that show where participants are from and overall pain scores for each US state and also per specific diagnosis groups. The maps are set up for the following diagnosis groups: rheumatoid arthritis (RA), fibromyalgia, lupus, other inflammatory rheumatic diseases (which include psoriatic arthritis, ankylosing spondylitis, etc.) and non-inflammatory rheumatic diseases (which include osteoarthritis, osteoporosis, etc.).



You can view this map by logging into your account on our website or if you don't already have an account on our website, you can set one up by going to this page on the web: <http://www.ndb.org/user/register>

Lottery Winners!

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.

Our lottery drawings consist of:

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 for those who complete a shorter questionnaire via mail or phone anytime within the 5 ½ months.

The \$1,000 winners from the last questionnaire were Margaret Eudaly, Winfield KS and a participant from Kimball, MI. Winning smaller amounts were Nancy Morse, Crete IL; Carol Koehler, Spokane WA; Lillian Bebee, Milwaukie OR; Roberta Montgomery, Seymour IN; Douglas Irwin, Prairie Village KS; Elda Dautreuil, St Martinville LA. Congratulations to all!

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.

WebQuest

WebQuest is the online version of our 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.ndb.org and make the request, or send us an email to webquest@ndb.org.

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:

Arthritis Research Center Foundation Inc.

and sent to:

Arthritis Research Center Foundation Inc.
1035 N. Emporia, Suite 288
Wichita, KS 67214

Or you can donate online by visiting www.JustGive.org and type in Arthritis Research Center Foundation.

For more information please contact Rebecca Schumacher at 1-800-323-5871, ext. 119 or Rebecca@ndb.org.

Thank you very much for considering a donation to support this important research.

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@ndb.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!