

THE NDB Research

NEWSLETTER

News for Participants in the National Data Bank for Rheumatic Diseases

July 2015

Notes from the Directors

Kaleb Michaud, PhD

“Truly exceptional!”

These are the words often spoken by doctors and scientists when they start to work with the information that you, the patient, provide through our questionnaires.

Similar to a year ago, I've been busy traveling to meetings and conferences presenting our latest findings and inviting other researchers to work with us. One thing remains, that we collect more information from you and other patients than any other major study out there, and we've been doing it for a lot longer. So when Congress wanted to know whether Medicare should pay for injectable biologic medications, they came to us!^{*} When patient advocacy groups wanted to know the economic, physical, and mental burden of having arthritis and related rheumatic diseases, they cited work using your answers. When doctors want to know what questions are the most important to ask in their clinics, they rely on us!

Why toot our own horn? Because no one else will! Since you only hear from us twice a year, it's important that you know that the questionnaires you complete are so valuable to the medical research community and ultimately will impact the quality of care you and others receive in the future. If this wasn't true, we wouldn't be doing it. It's also a reason we're a non-profit corporation—we aren't selling your data to the highest bidder—rather, we make sure your data is being used by the top researchers to make a difference. We will never discourage you from participating in other studies, but we do want to remind you why you completing our questionnaires are still so very valuable.

Questionnaire Changes

We've taken away a few items from last year and replaced them with a few new questions. We're working with Dr. Joshua Baker at the University of Pennsylvania about weight gain and loss impact on arthritis, hence the question about your maximum weight. We're also working with the Arthritis Foundation in testing a new 29-item questionnaire about your overall health—some of the questions will look like repeats, but, again, we're not allowed to change them.

If you have lupus or SLE, you may notice that we've made dramatic changes to your questionnaire. We're working with Dr. Patricia Katz from the University of California, San Francisco in updating these questions to be even more specific to the impact of your disease. This is more important than ever as there are several new drugs

being developed for lupus that will come out within the next couple years. There is a greater-than-ever demand for understanding how lupus affects you and how the current drugs help or don't help. Please contact us if you have doctor-confirmed lupus and are not getting our lupus questionnaire.

“...we make sure your data is being used by the top researchers to make a difference.”

Personal Connections

I had the distinct pleasure to meet a few of you in person this past year. Before being introduced, one of you congratulated me on getting married and thanked me for the work we are doing (proof that these words are read!). We talked about our life before and after joint replacement, and I truly enjoyed the personal connection. I know that I can't do that with each of you, but do know that all of your questions and comments are read by real people here at the NDB.

And to add a personal note, there is something I'm struggling with these days. I am struggling to decide what to do with my wrist. I had both of them replaced in grad school 15+ years ago and apparently the “warranty” is up on my left wrist—lots of pain and I'm needing a brace for support. The surgeons I asked don't want to replace it again and would rather fuse it solid. This has me unusually nervous as I depend so much upon my limited yet functional wrist motion. I'm taking some solace from others with fused joints—so many of you have had something like this done already—but it's never easy no matter how many times it's done. I've had my toes fused and have never walked the same, BUT at least I am able to walk!

So when I fill out the questionnaires in my doctor's office, my “HAQ Score” has increased because of my wrist, and we talk about it and I continue to postpone a final decision. I know I'll have to do it, but it's more a matter of when. Thank you again for letting me share. Even though we publish research on data given from many patients at once, we know that each of us has a personal story of how our conditions affect us.

Thanks for reading and thank you again for your participation!

^{*}Our research showed that injectables were similar in effectiveness as intravenous biologics and recommended that they should be covered under Medicare.

LATEST RESEARCH

In June 2015, at the Annual European League Against Rheumatism (EULAR) Meeting, the NDB data collected from all projects, was used for multiple research presentations.

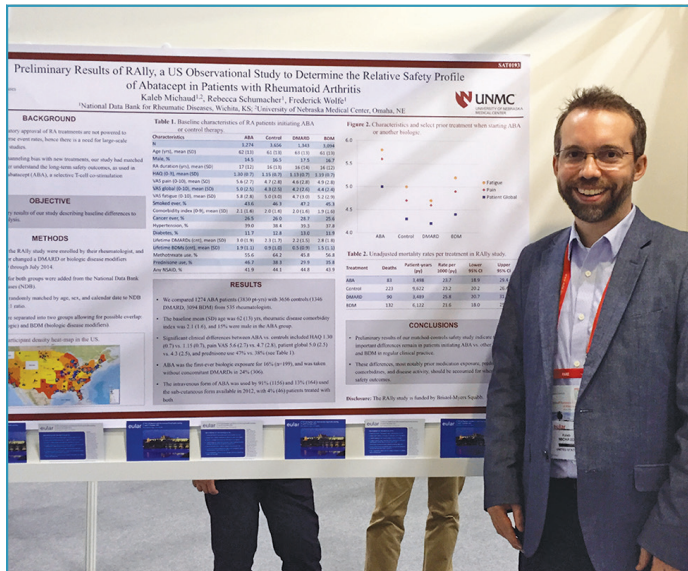


Kaleb Michaud, PhD with Dr. Humeira Badsha from Dubai at the EULAR conference near Rome, Italy.

risk of depression onset for obese and non-obese women with SLE or RA. Obesity does appear to be a risk factor for development of depression among women with SLE or RA. This is an important finding, since you can modify obesity and reducing obesity is likely to lead to additional health benefits such as reduced cardiovascular disease.

Preliminary Results of Rally—An Observational Study to Determine the Relative Safety Profile of Abatacept in Patients with Rheumatoid Arthritis (RA)

Patients enrolled into the NDB and Rally that responded to the 6-month questionnaires from 2009 through 2014 allowed us to present preliminary results of our study describing baseline differences to help guide future analysis. Patients taking abatacept (Orencia) were matched to a control group, which included 2 groups of patients that were on a DMARD or biologic disease modifier (BDM)—all groups either started or changed their medication to be included. Preliminary results indicate that important differences remain in patients starting abatacept versus other DMARDs and BDM. The most notable differences, with abatacept being higher than the control group, were: medication exposure, prednisone use, disease activity, and comorbidities (diseases or conditions that coexist with a primary disease, but they also stand on their own as a specific disease—i.e. high blood pressure, congestive heart failure, emphysema, liver problems). These should be accounted for when analyzing safety outcomes.



Dr. Michaud at the research abstract presentation.

Here are some overviews of the research from the meeting:

Obesity Is a Risk Factor for Depression in Women with Systemic Lupus Erythematosus (SLE) and Women with Rheumatoid Arthritis (RA)

Obesity as a risk factor for the onset of depression had been studied in general populations, but had not been studied in SLE and RA. Data from the NDB was used to examine the

Smart Phones and Rheumatic Disease Patient Outcomes

Last year we started a new project using a smartphone app to collect daily and weekly surveys. The results have shown to be very useful along with the combined NDB questionnaires and we have found some items that may become very useful for patients and doctors. This is being used in a new clinical study to start later this year at Harvard University from Dr. Yvonne Lee.

By September 1st, the current smartphone app from Ginger.io will no longer be active. All data collected until then will still be used in research projects. We are currently working on obtaining support from another smartphone app to replace it and improve it to be even more useful to you and your doctors. If you have any questions, please email Rebecca Schumacher at rebecca@ndb.org

We thank all of you that have been able to help with the smartphone study & hope you will try out the new one when it is available!

Spotlight on Non-Profits and Organizations

We are always being asked “Where can I get help or find out information about my disease?” and we are now pleased to include in every newsletter 2 or more Non-Profits or Organizations that may be of help to you.



The Arthritis Foundation exists to conquer arthritis. Known as the Champion of Yes, the organization leads the fight for the arthritis

community and helps conquer everyday battles through life-changing information and resources, access to optimal care, advancements in science and community connections.

Founded in 1948, the Arthritis Foundation's work today focuses on four major areas:

- Helping people ease their arthritis pain through personalized information, innovative tools and other forms of support.
- Making sure that everyone with arthritis has access to game-changing medicine and essential health care through advocacy efforts.
- Pouring energy and optimism into scientific discovery that will improve quality of life and pave the way to a cure.
- Leading the fight against juvenile arthritis and childhood rheumatic diseases while addressing the unique needs and challenges families face.

In May 2015, the Arthritis Foundation held its first Arthritis Registry Workshop, convening registry experts from around the world to find common ground and work together to accelerate improving health outcomes for people with arthritis & related diseases. The Arthritis Internet Registry representatives were among workshop participants who shared knowledge and experience to strengthen data collection and analysis.

Learn more at www.arthritis.org.

CreakyJoints®

Offers News & Support to Patients

CreakyJoints® is a free community of support and resources for people with all forms of arthritis. As a member, you'll get info about co-pay cards and assistance, news about the latest evidence-based arthritis treatments, connections to fellow patients and caregivers on the Message Board, and opportunities to participate in arthritis research and advocacy. Established in 1999 by arthritis patient and advocate Seth Ginsberg, CreakyJoints is a community of more than 70,000 arthritis patients and caregivers from all 50 U.S. states. We will never ask you to donate money. Watch a short video of patients talking about CreakyJoints at www.creakyjoints.org/why-join-creakyjoints and join today!

Family Research Project

There is great interest from patients, doctors and researchers to try to find and understand the effect of genetics and other measures in aiding in the diagnosis, treatment, and eventual cure of RA and other diagnoses.

We have created a Family Medical History questionnaire where you can answer questions about your close biological relatives (father, mother, brothers, sisters, and children) and build a family tree. For adult relatives (18 and older) who are alive and willing, you can then invite them to enroll in the NDB to answer a few questions about themselves.

To complete your family medical history form online, please see our enrollment page at: www.familyhistory.ndb.org

Health Diary for Future Questionnaire

Our six month Questionnaires are always covering the previous six months and we see many comments of “How am I supposed to remember everything that happened from January-June or July-December?” We are currently working on setting up an online Health Diary for those that create a login on the NDB website (www.ndb.org) and a paper format for those who may not be able to create a login on our website.

Here is a snapshot of what we have created to capture medication changes and health events during this six months to help complete the next questionnaire:

Health diary for July - December 2015

Please feel free to use this optional form to help keep track of when you add/stop medications or have an important health event. We hope this will make it easier to fill out your next regular questionnaire in 2016. This form is for your personal use only, you do not need to mail it to us.

Please enter ALL medications that you have started or stopped between July 1, 2015 and December 31, 2015, with or without a prescription. Please include aspirin, birth control pills, pain pills, alternative therapy, health supplements and any pills sold in health food stores.

Name of drug, medicine or alternative therapy	Dose (if known)	Date Started in 2015	Date Stopped in 2015
1) _____	_____	_____	_____
2) _____	_____	_____	_____
3) _____	_____	_____	_____
4) _____	_____	_____	_____
5) _____	_____	_____	_____
6) _____	_____	_____	_____
7) _____	_____	_____	_____
8) _____	_____	_____	_____
9) _____	_____	_____	_____
10) _____	_____	_____	_____
11) _____	_____	_____	_____
12) _____	_____	_____	_____
13) _____	_____	_____	_____
14) _____	_____	_____	_____
15) _____	_____	_____	_____

Please list any health events you had between July 1, 2015 and December 31, 2015. Please include hospitalizations, heart conditions, lung conditions, strokes, infections (cold and flu included), endoscopies, x-rays, urine analysis, etc.

Health Event	Date	What hospital or clinic
1) _____	_____	_____
2) _____	_____	_____
3) _____	_____	_____
4) _____	_____	_____
5) _____	_____	_____
6) _____	_____	_____

NATIONAL DATA BANK
for RHEUMATIC DISEASES
800.323.5871 | ndb.org

We need your help in making sure this will be helpful and useful for you. Please email us at: webquest@ndb.org OR call us at: 1-800-323-5871 and let us know your thoughts and comments.

Arthritis Internet Registry (AIR) News



AIR is a ground-breaking 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 5,800 participants join and we have collected over 1,000 biospecimens on a variety of rheumatic diseases.

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.

Latest Research from AIR

We are pleased to have Dr. Stanley Nades, from Quest Diagnostics, give an update on research that used AIR data for the biomarker, 14-3-3 η (eta) and future research regarding the mosquito virus, Chikungunya. AIR is interested in following patients that were diagnosed with Chikungunya, since they have now shown that this virus can cause severe joint pain, including arthritis, that can last for months. If you, or anyone you know, have been diagnosed with Chikungunya, please have them visit www.ndb.org to sign up to help in collecting data on how the Chikungunya virus affects patients which will help with setting up guidelines for proper diagnosis and treatment of this new type of viral arthritis.

AIR Investigators Report on Ability of 14-3-3 η Assay to Identify Inflammatory Arthritis in Patients with Osteoarthritis

An Arthritis Internet Registry (AIR) study on osteoarthritis (OA) was presented at the 2015 European League against Rheumatism (EULAR). In collaboration with Quest Diagnostics, National Data Bank for Rheumatic Diseases investigators studied the use of a new biomarker for rheumatoid arthritis (RA) and psoriatic arthritis (PsA) to identify inflammatory arthritis in osteoarthritis patients. The biomarker, 14-3-3 η (eta), is found in joint-lining tissue, synovium, and brain tissue. Synovium releases 14-3-3 η into synovial fluid and serum in RA patients and, to a lesser extent, PsA patients. 14-3-3 η itself promotes joint inflammation. Differentiating RA or PsA from OA, or identifying inflammatory arthritis in the presence of co-existing OA, can be difficult. Examination and traditional biomarkers such as C-reactive protein (CRP), rheumatoid factor (RF), and cyclic citrullinated peptide antibody (CCP) may be insufficient, especially for physicians without specialized training and experience.

The purpose of this AIR study was to estimate the specificity of 14-3-3 η among a cohort of patients with physician confirmed osteoarthritis. AIR participants were surveyed by questionnaire, and physician and/or medical records were queried. Biosamples from 166 participants with a physician-confirmed diagnosis of OA were tested for CRP, RF, CCP and 14-3-3 η .

In the present study, the low frequency of 14-3-3 η in this group of individuals with OA supports the high specificity of 14-3-3 η observed for RA. Further, 14-3-3 η may be used to help identify RA or PsA patients amongst those being followed for OA. 14-3-3 η may be particularly useful in the primary

care setting to screen OA patients for misclassification of RA or PsA as OA, or for concurrent inflammatory arthritis in the setting of OA.

You can find the full scientific article from Stanley J. Nades, M.D., Medical Director, Immunology, Quest Diagnostics Nichols Institute, San Juan Capistrano, CA on our website: <https://www.ndb.org/participate/newsletter/ndb-newsletter-july-2015>

Chikungunya – A Mosquito Borne Viral Arthritis Emerging in the United States

Chikungunya virus infection causes a febrile (fever) illness with severe and painful joint symptoms. The name chikungunya comes from the African Kimakonde language and means “that which bends up” or “to become contorted,” describing the stooped appearance of the infected person. Well known in Africa, India, and Asia, where it causes both large-scale outbreaks and sporadic cases between epidemics, chikungunya virus is transmitted by mosquitoes, principally *Aedes* species. The illness has spread to Europe and the Western hemisphere in recent years as the virus adapted to additional mosquito species and the mosquito range spread with climate change. During outbreaks, humans are the major reservoir, but in Africa they have also found that monkeys, baboons and some bat species are animal reservoirs.

After a bite by an infected mosquito, the time between exposure to an infection and the appearance of the first symptoms is 1-12 days. Chikungunya has an explosive onset with a high fever and severe joint pain, commonly accompanied by chills, headache, red eyes, sensitivity to light, pain behind the eyes, sore throat, nausea, vomiting, abdominal pain, swollen lymph nodes, and muscle pain. A rash often appears on the trunk and extremities, and occasionally on the face,

palms, and soles, 1 to 10 days after the start of the illness. The joint pain moves around the body and predominantly affects the small joints of the hands, wrists, feet, and ankles, with less involvement of the large joints in the knees and hips. Previously injured joints may be more severely affected. Although the majority of the symptoms of the illness typically last 7 to 10 days, joint symptoms, including arthralgia, arthritis, and tenosynovitis, may persist for months in the majority of patients.

Outbreaks typically develop after heavy rains and can be very quick to spread in cities. Most cases in the U.S. are from people returning from traveling from the Caribbean and Latin America, but in the summer of 2014, several patients in Florida had not traveled to those areas and they think were infected by mosquitoes in Florida.

Because they are seeing patients from previous outbreaks with joint pain and swelling after 3 years, it is important to do research and follow patients to help in making sure they are being diagnosed appropriately with chronic chikungunya arthritis and not rheumatoid arthritis. Especially since both may be treated similarly with Methotrexate and certain biologics. With chikungunya, tests can be ran to look for a certain marker noting if the patient had the virus, which is very useful when diagnosing.

You can find the full scientific article from Stanley J. Nades, M.D., Medical Director, Immunology, Quest Diagnostics Nichols Institute, San Juan Capistrano, CA on our website: <https://www.ndb.org/participate/newsletter/ndb-newsletter-july-2015>

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

Peter Gregersen, MD
The Feinstein Institute for Medical Research

Stanley J. Nades, MD
Quest Diagnostics Nichols Institute



Csaba Siffel, MD, PhD, PMP
Arthritis Foundation



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 <https://www.ndb.org/participate/tell-friend>



NDB Questionnaires and Primary Diagnosis

We are asked a couple times each phase "Why did I get a questionnaire for RA/Fib, but my diagnosis is Psoriatic Arthritis (or many other diagnoses)?" As you may see on the cover of the paper questionnaires that are mailed out, it states a diagnosis on the cover, i.e. RA/Fib, OA, Lupus and Gout. The NDB Questionnaires first started out with only one version to cover all diagnoses, which was called "RA/Fib". But over the years, as the NDB has been able to work with experts in other diagnoses, we have added on other questionnaires geared to ask more specific questions for certain diagnoses. The main one is still called "RA/Fib" to keep the questionnaire naming consistent over all the years of data collection. We wish we could have a questionnaire for each and every diagnosis, and might in the future, but currently we have the following questionnaires:

- **RA/Fib** is sent to all RA, fibromyalgia and all other diagnoses (i.e. psoriatic arthritis, ankylosing spondylitis, lower back pain, polyarthralgia, etc.). This questionnaire asks all the questions that will help aid the researchers to see the entire view of how a patient's disease affects their lives.

- **OA** is sent to all osteoarthritis patients and asks the majority of the questions in the RA/Fib questionnaire and an extra set of questions that are used by rheumatologist's to help with OA patient care.
- **Lupus** is sent to all lupus patients and has majority of the questions in the RA/Fib questionnaire and asks specific questions for understanding how lupus affects patients.
- **Gout** is sent to all gout patients. Dr. Ted Mikuls and other researchers at the University of Nebraska Medical Center have helped to design this shorter and unique questionnaire specifically for patients with gout.

This is the reason we ask on the enrollment forms for your primary diagnosis, so we can make sure that we are sending you the correct questionnaire that will ask you the questions that would best reflect how your disease is affecting your life. Please let us know at any time if your primary disease changes or if you have any questions about this by emailing us at webquest@ndb.org or calling us at 1-800-323-5871.

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.

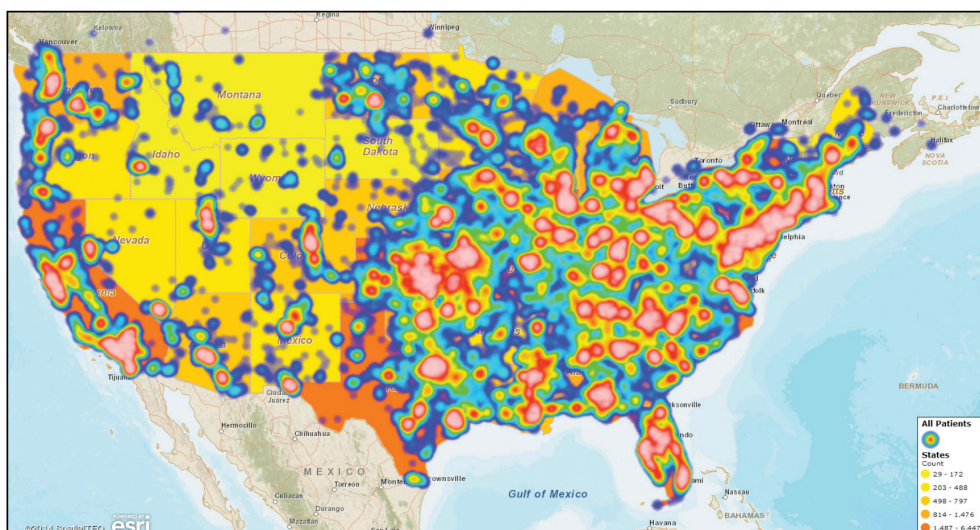
Your personal information will always remain private. We do not sell or share any identifying information about NDB

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.



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: <https://www.ndb.org/user/register>

Prize Drawing Winners!

The research data bank can best contribute to research when the questionnaires are completed and returned as soon as possible. We conduct the prize drawings as a token of our gratitude in help with rheumatology research.

Our prize 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 1/2 months.

4 drawings for \$50 each for those who complete a shorter questionnaire via mail or phone anytime within the 5 1/2 months.

The prize drawing winners from the last questionnaire were: Carie Lamke, Charles Lathem, Elizabeth Loos, Christine Brown, Kelly Baker-Miller, Mary Harrington, Joanna Downe and Wendy Matson. Congratulations to all!

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.

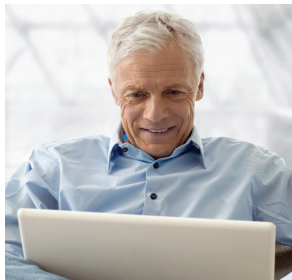


We have just started our new Twitter account and you can find us as “@ndb_org”. We have added this for those that may be on Twitter but not on Facebook and we will be tweeting news items to start with.

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. Available for your support group or arthritis, fibromyalgia or lupus meetings, our pamphlets explain what we do and how you and others 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!



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 at: webquest@ndb.org.

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.

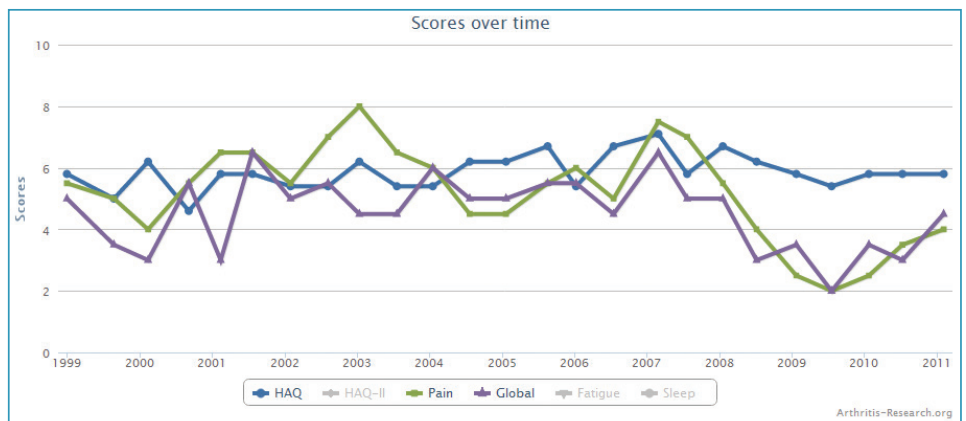
As always, your privacy is protected and there is absolutely no cost to you. Your lab results will be available directly to you through a secured login on our website. You can also print out the lab results and take them with you to your next doctor appointment.

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 Betty Pew by email at betty@ndb.org or by phone at 1-800-323-5871 ext. 143.

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: <https://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.

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.

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.



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!

FOR MORE INFORMATION OR TO PARTICIPATE

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

DIRECTORS: Frederick Wolfe, MD | Kaleb Michaud, PhD
EXECUTIVE DIRECTOR: Rebecca Schumacher

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

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