

NDB Participant Spotlight

Contributed by Deb Elliott

Rheumatoid arthritis was not on my radar when I was diagnosed with it in 2008 at age 54. I'd never known anyone personally who had it and had never thought I was at risk. But once I began researching I was amazed it hadn't surfaced earlier—I was not a healthy eater—sugar, breads, and red meat were my staples, I was working in a high stress job and not handling the stress well, and I eventually discovered that my grandfather, who died before I really knew him, suffered from RA, along with his brothers who were crippled from it. My body was a ticking time bomb for RA. My RA started with intense pain in my shoulder that couldn't be dulled with even the strongest pain relievers. A steroid shot would provide my only relief. I was lucky in that my general practitioner diagnosed me almost immediately. I understand that is not always the case.

“I remember wondering if there would ever be a day I woke up when my first thought wasn't about RA and how it would affect me that day. I can now say that I rarely “worry” about my RA anymore.”

My doctor referred me to a rheumatologist and I was anxious to learn all I could from him regarding RA. What I learned after that first visit was that with medication I could hope to control the progression of the disease but it would never be cured. I asked if there were any foods that I should eat or abstain from to help and he informed me that research shows food has no effect on RA. And even though I asked numerous questions, that was the extent of what I learned about RA from him.

Thus began my journey of learning all I could about RA. And the first thing I learned was that I did not want to be on RA drugs any longer than I had to. The long-term side effects didn't appeal to me. After spending literally hundreds of hours researching on the computer, ordering books, talking with others, etc. I was convinced that even though the research is not plentiful and most sample sizes are very

small, there is enough reputable research to suggest that food does in fact impact RA. In addition, after reading personal stories and numerous blogs from people who were using diet and supplements to control their RA, I didn't feel I had anything to lose by trying.

I educated myself on “healthy” foods, anti-inflammatory foods, and supplements that might be helpful. I began a strict diet, rich in fish, nuts, beans, quinoa (prior to this I had no clue what quinoa was), fresh fruits and vegetables. And I eliminated sugar, processed foods, and eventually gluten. When I began my diet, I remained on my methotrexate and Plaquenil®. After a few years, I stopped the methotrexate and continued with the Plaquenil®. Then I stopped all meds and did great for nearly two years. However, when I “slacked off” of my strict diet, I had to get back on Plaquenil®, which I am currently on today. Prior to the start of my diet I had a few more flares that resulted in steroid shots. Since the diet, which is going on five years now, I've not had a flare.

Two years ago I finally got the courage to try a new rheumatologist. I also have a homeopathic doctor, as well as my general practitioner. We are a team—each knows what the other is doing and we're working together on my health. My rheumatologist is open to the idea that food does have an effect on RA. My homeopathic doctor has worked on “healing my gut” which has made a huge step forward in my wellness. I am currently on 200 mg of Plaquenil® a day with the hope of discontinuing it this fall when I visit with my rheumatologist again.

When I was first diagnosed with RA I was concerned about my future—I'm a very active person. My hobbies include gardening, riding motorcycles, quilting, boating and skiing, running around with grandkids, traveling, and walking. I didn't want my RA to restrict any of these activities. I remember wondering if there would ever be a day I woke up when my first thought wasn't about RA and how it would affect me that day. I can now say that I rarely “worry” about my RA anymore. I am far more energetic and healthy today than I was in my 30's. If it

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Welcome New Participants! Thank You Volunteers for Your Time and Voice!



Everyone who works for the NDB and all the doctors and researchers who benefit from our research are extremely grateful for the dedication of

you, the participant, in helping with 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.

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weren't for a few swollen joints on my fingers, which is due to osteoarthritis as much or more than RA, I wouldn't even realize I had it.

My frustration with the medical world is that research for RA seems to focus more on what drugs are more beneficial than what the cause is, how it can be prevented, and what can be done to cure it. I understand why this occurs—drug companies are making a lot of money off those of us who have RA. If you don't believe this, start paying attention to the commercials on television. And there isn't a real incentive for them to find a cure. That leaves us as consumers to travel our own path toward finding out what works for us.

The alternative path has its disadvantages. The insurance world is not set up for curing the disease, it is designed to manage the pain and progression. Whereas my insurance will pay for doctor/rheumatologist visits and medication, it will not pay for my homeopathic doctor or any supplements, the very things that are most helping my RA. Another disadvantage is that eating healthy is neither cheap nor easy. We are on the go a lot and fast food is not my friend. So I end up packing meals wherever I go, including motorcycle trips. We have a special place attached to my husband's Harley for this. But the benefit far outweighs the negatives. I feel better now than at any other time in my adult life.

As someone who has benefited from alternative treatment, I feel it is my obligation to share my story with others so they understand there are options available for managing/curing this disease. My hope is my story can reach the medical world—teaching hospitals, rheumatologists, general practitioners, researchers, as it's time another course of action is pursued.

I understand there are those whose RA requires drugs to control it. But in my situation, and I'm suspecting others like me, diet and supplements are definitely an option to investigate. Best advice—find medical personnel who share your vision, educate yourself as much as possible, become in charge of your own health, and let your positive attitude guide you to wellness.

The NDB would like to thank Deb for volunteering her time and sharing her journey with you! Over the many years of research done by the NDB, we have learned that each participant has a different journey through life with their disease. The NDB does not condone or promote any one treatment or life choice due to each participant's journey being different, but we want to share them with others to show how different each one is.

Spotlight on Non-Profits and Organizations

There are times a participant may need to find a doctor to help with their disease: they have moved, changed to a different health insurance plan, their current doctor retired or moved, or they may need to find a specialized doctor to help with their disease. Here are a couple of organizations and links to searches to help find a specialized doctor:

American College of Rheumatology (ACR)

<https://www.rheumatology.org/I-Am-A/Patient-Caregiver/Health-Care-Team/What-is-a-Rheumatologist>

<https://www.rheumatology.org/Directories/Find-a-Rheumatologist>

American Academy of Dermatology (AAD)

<https://www.aad.org/public/diseases/why-see-a-dermatologist>

<https://www.aad.org/find-a-derm>

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.

Reminders



While working on your questionnaire, if you have ANY questions about the questionnaire, please contact us right away by email (webquest@ndb.org) or phone (1-800-323-5871). 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.

The Medical Information Release form is completely optional and does not need to be signed to be able to participate in the research. We use the medical records to help validate medical events that may be related to rheumatic diseases or the safety of medical treatments. The value of the research and the time people put into helping us is increased when we can confirm the details of such events—we thank those of you that have signed the form to add your medical record information to the data bank. Your information is always confidential, and your participations is extremely valuable to the research with or without the signed medical information release form.

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.



You can find us on Twitter 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.

LATEST RESEARCH

NDB was proud to have Kaleb Michaud, PhD, Co-Director, and Sofia Pedro, MS, Statistician, represent the NDB via meetings and a poster at the annual European Congress of Rheumatology (EULAR) meeting held mid-June 2017 in Madrid, Spain.

The poster/abstract being presented covered the research from the NDB and the RAlly study regarding serious adverse events in RA patients taking abatacept and other biologics and DMARDs. It showed there was no increased risk in cancer or infections with abatacept when compared to starting other biologics or DMARDs.

This research could not be done without the sites, physicians, and patients that recruit and participate in the NDB and RAlly study.

Thank you for adding your voice to the research!



Dr. Kaleb Michaud and other members of the American College of Rheumatology (ACR) met with senators in Washington, DC in May to promote arthritis research.



Dr. Kaleb Michaud (with Ted Mikuls, MD) received the University of Nebraska Medical Center Distinguished Scientist Award for 2017 and Department of Medicine Clinical Research Award.

Future Projects

We have a couple of new projects that we will be starting soon outside of our usual questionnaires. The first project is about collecting waist measurements. We always ask about height and weight, but understanding waist size helps researchers to better understand the impact of arthritis medications and on physical activity. We'll be mailing out tape measures to help collect this.

We'll also be starting to collect some in-person interviews with some of you, starting first with patients in the Tennessee/Georgia/Florida area this summer. Researchers will be asking questions about patient's disease(s) and how it affects their lives. The information from this project will be added to the regular questionnaire data and we are looking to see if adding on this other information helps to see how the burden of the disease affects patients, their families, and the community around them.

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 random drawings as a token of our gratitude in help with rheumatology research. Our random 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.

Ongoing Projects

University of California San Francisco (UCSF) RA and Lupus Cohorts

Ongoing collaboration efforts with Dr. Patricia Katz and UCSF have been successful in producing ongoing research with the help of the UCSF study patients continuing to participate in the NDB.

We have made revisions to the 6-month questionnaire again with the help of Dr. Katz to help with several projects in viewing specific questions and groups of questions that may help in improving treatments and care for patients across all diseases including lupus.



International Dupuytren Data Bank (IDDB) Progress on the International Dupuytren Data Bank

The International Dupuytren Data Bank launched in November 2015 as a collaboration between the Arthritis Research

Foundation and the Dupuytren Foundation. The IDDB currently has over 2,200 enrollees. Participants originate from 31 countries. The majority are from the United States, Canada, the United Kingdom and Australia.

It's important for the Dupuytren community (you!) to spread the word about this study and to encourage others with Dupuytren disease to enroll. The online shortcut link is easy: **DupStudy.com**. The first follow-up survey is about to go online to dig even deeper into the nature of Dupuytren disease.

As a study enrollee, your privacy is essential. Your contact information isn't shared with anyone, not even for the Dupuytren Foundation email newsletter. If you haven't received emails directly from the Dupuytren Foundation, you may be missing out on other Dupuytren related updates. Sign up now at Dupuytren.org/Newsletter.

Thanks for taking part of this important work. Because of your participation, there is hope to cure Dupuytren disease and related conditions.

Charles Eaton, MD

Executive Director, Dupuytren Foundation



WebQuest

WebQuest is the online version of our questionnaire. The questions are the same as what you see on the paper questionnaire. People who are comfortable using computers should find it easier than the paper version. If you would like to try the web version, follow the links from our home page, www.ndb.org and make the request, or send us an email to webquest@ndb.org.

NDB Questionnaires & Primary Diagnosis

As you may see on the cover of the paper questionnaires that are mailed out, it states a diagnosis on the cover, i.e. Rheumatic Diseases, OA, Lupus and Gout. 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. We wish we could have a questionnaire for each and every diagnosis, and are adding more in the future (next up Psoriatic Arthritis and Spondyloarthropathies), but currently we have the following questionnaires:

- **OA** is sent to people with osteoarthritis and asks the majority of the questions

in the Rheumatic Diseases questionnaire and an extra set of questions that are used by rheumatologists to help with OA patient care.

- **Lupus** is sent to people with lupus and includes some of the questions in the Rheumatic Diseases questionnaire, but also has many questions specifically about Lupus.

- **Gout** is sent to people with gout. 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.

- **Rheumatic Diseases** is sent to all RA, fibromyalgia and other diagnoses not

listed above (i.e. psoriatic arthritis, ankylosing spondylitis, lower back pain, polyarthralgia, etc.). This questionnaire asks the questions that will help aid the researchers to see the entire view of how these diseases affect peoples' lives.

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.

Notes from the NDB Staff

Every 6 months we send our questionnaires to you, our great participants who volunteer your time to add your voice and information to the NDB. The NDB is not only driven by the staff, but also by our participants that help with the research: from completing the questionnaires to add data to the data bank, working directly with projects within the NDB, serving on our advisory board, and also by the comments/suggestions/questions from the comment section on the forms, emails, phone calls, and letters. Each and every one we receive is read and from these comments can become changes to the questionnaire or may provide an idea for a research project. Over the years we have some comments/suggestions/questions that are asked every 6 months and we would like to share these with all of you to provide more information about the NDB and why your participation is very important and greatly appreciated.

“Why do you want my medical records for any hospital stays or outpatient procedures if they don’t have anything to do with my disease?”

First, it is always optional for you to sign the consent in the questionnaire to allow us to send for medical records and we will still use the data you provided within the questionnaire. We use medical records to help show how accurate the data is that you provide and makes the data collected even more powerful to support the research being published and provided to the healthcare community and public. Part of the research we do is the safety of medications and even

though you may not have had a hospitalization or procedure done because of your disease, it may be attributed to a medication. We can only find this out if we collect this data over time to show if there are an increase in any type of reason for a hospitalization or procedure. We have also seen within the research that having other illnesses may also impact your primary rheumatic disease. The only way it was possible to see this is with the data provided from medical records in addition to the questionnaires.

“My disease is in remission-why do you want me to continue filling out the questionnaires?”

We are always happy to hear when participants note their disease is in remission, as it helps in knowing we are all making a difference to hopefully find a cure for our diseases one day. Everyone’s journey is different with their disease and we want to continue capturing data from participants that are in remission to help to see if there is anything different from that participant compared to others. This data also helps to see if certain treatments and/or lifestyles help to stay in remission.

“Why do you ask the same questions over and over?”

The NDB is called a longitudinal data bank, which means it collects the same data over different points in time and provides long-term data. If we did not collect the same data over different points in time, we would not be able to compare how participants are doing now to 5-15 years ago. This long-term

data also helps with treatments to see if any side effects may show up after many years of drug use.

“You are only working to benefit insurance companies or the government or help pharmaceutical companies.”

The NDB is an independent research non-profit organization and we do not work to benefit insurance or pharmaceutical companies or the government, rather we are working to help get better treatments and costs down for all rheumatic disease patients. Using your answers and those of thousands of other participants, we are able to advise doctors, lawmakers and industries about drug safety, the likelihood of side effects, and the costs and burden of the diseases. We also want to stimulate new research by making data available to health professionals, i.e. doctors, students at universities, epidemiologists, nurses, physician assistants, and with other organizations and our participants. This research is more focused on looking for similarities and differences among people with rheumatic diseases. With the help of the participants who complete the questionnaire, we are able to make suggestions to doctors and patients about how best to care for a condition. And, we’re able to help governments, employers, and policy makers understand how much these conditions affect people’s lives, the community, and the economy. NDB research does shape the treatment and medications used in rheumatic diseases, and we could not do it without the help of each participant in the study.

**WAIT! WE WANT
YOUR VOICE
TO BE HEARD!**

**DO NOT
THROW THIS
SURVEY AWAY!**

The only way we can do this is with your help in filling out our questionnaires. We understand they may be overly long or repetitive for some, and so we want to hear from you on what we can do to improve your participation with us. We are a non-profit research organization with a staff of 16 that combines the experiences of thousands of patients over time for use by rheumatologists, nurses, immunologists, epidemiologists, and even health economists. We are the ONLY longitudinal research study that asks the level of detailed questions we have with so many people with rheumatic diseases, and we do this with a relatively small amount of grant funding. So before you decide to not participate, please let us know what we can do either by phone (1-800-323-5871), email (info@ndb.org), or mail. We want to hear from you, as we are passionate about helping fight these diseases and truly make a difference!

Arthritis Internet Registry (AIR) News



AIR is an internet-based patient registry and biospecimen collection using the combination of the patient-study infrastructure of the NDB and the nation-wide availability of Quest Diagnostics blood collection sites. 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 6,623 participants join and we have collected 1,430 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

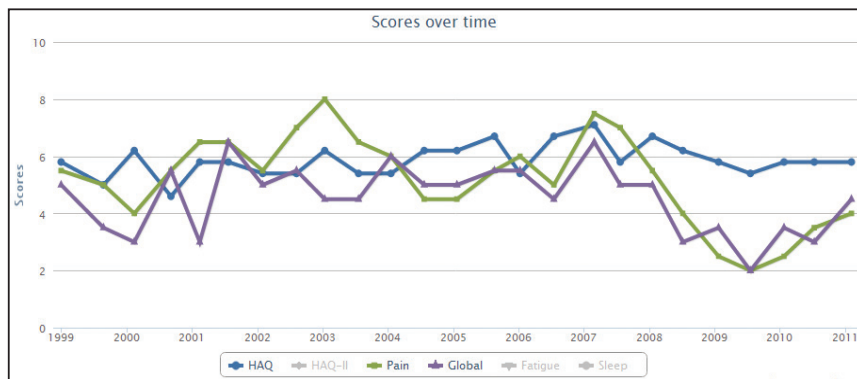
Our new online enrollment form for Viral Arthritis patients is now available. With the Zika and Chikungunya viruses and various others, they can cause severe and painful joint symptoms that can last from months to several years and data needs to be collected on these patients to help aid in the research.

If you know anyone that may have been diagnosed with Zika, Chikungunya, or another viral illness that caused severe and painful joint symptoms, please invite them to join to help with the research.

AIR is a partnership between leading academic researchers 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. Naides, MD, Quest Diagnostics Nichols Institute.

— 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 keeps your information private 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.

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!

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.

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, and ends up in your Inbox and not your Spam or Junk folder. You will need to do this every time you change your email address.

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 email or call us. Thank you!



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>

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 in 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 made 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.

FOR MORE INFORMATION OR TO PARTICIPATE

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