

THE NDB Research

NEWSLETTER

News for Participants in the National Data Bank for Rheumatic Diseases

July 2013

Notes from the Directors

Frederick Wolfe, MD — Kaleb Michaud, PhD

Why do arthritis research?

By Kaleb Michaud, PhD

I get this question surprisingly often when others learn of my science background, interests, and what I currently do. I rarely have the time to give them my full answer, and as you may be seeing more and more of my name, I feel it's important to explain. So please pardon me this one time as I replace this usually scientific space with something a bit more personal.

In fact it is very personal. Most people have a friend or family member who is affected by arthritis in some way. In my case, I have several close friends who developed lupus, rheumatoid arthritis, and even Wegener's granulomatosis in their 20s and early 30s (3 cases occurred after having their first child). In my family, one grandmother had fibromyalgia, another grandmother has osteoarthritis, which required both of her shoulders to be replaced, and my mother has recently developed a unique inflammatory osteoarthritis of her fingers.

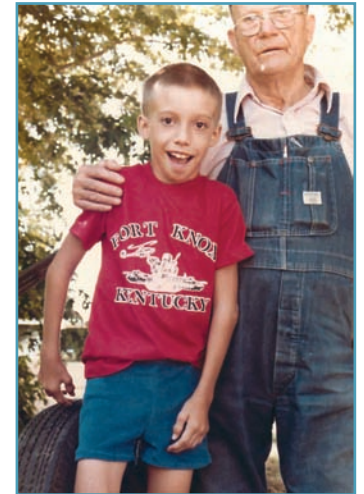
“As a child I didn't understand why I was being punished by this disease...”

Though in my case, and as mentioned in our last newsletter, my experience is a bit unusual as I was diagnosed with juvenile rheumatoid arthritis (JRA) when I was three years old. In what seems like medical ancient history, I had my knee drained and biopsied and was put in the hospital for a month for observation and recovery—a very dramatic experience for a 3-year old! Over the years I went in and out of using wheelchairs,

canes, and braces and took a lot of pain pills—up to 16 aspirin a day. My parents drove me to experts across the country where they were told that I likely wouldn't live very long and would be wheelchair bound. When I was around 6, I was rushed to the hospital for an infection that nearly took my life. When I was 8, I was given gold shots; they were so painful that my father had to carry me out of the clinic the first few times.

I cannot imagine what my parents had to go through for me, but out of necessity I grew up faster than most. As a child I didn't understand why I was being punished by this disease, but I was determined to make the most of the brief time given to me. My curiosity thrived and I wanted to know why and how everything worked often to the chagrin of my ministers, teachers, and doctors. As a teenager, I was back in the hospital for various reasons and surgeries, and I was always asking the doctors questions about what was happening. As I reached adulthood I was put on new drugs that seemed to help enough so that I made it through college in NY on my own two feet.

If you're one of the “lucky ones” to be affected directly, you know how difficult it can be for others to understand just what you are going through. In graduate school in CA I joined a small group of young adults that had various forms of juvenile idiopathic arthritis (the new name for JRA). It was so refreshing to be able to talk about and compare scars from various surgeries and treatments with peers who had been through the same thing. Each individual story was different as was the progress and effect of each disease. Tragically, one of the



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LATEST RESEARCH

Rheumatoid Arthritis Patients & Abatacept Use NDB News

Last June at the annual European League Against Rheumatism (EULAR) scientific meeting in Madrid, the NDB presented some of the results from the RALLY study (the abatacept safety registry) and data from other rheumatoid arthritis (RA) patients in the data bank.

The research showed the characteristics of RA patients receiving abatacept without any prior biologic medication were older had more years of smoking, diabetes, cancer, high blood pressure and other medical problems. These patients also showed that they used less prednisone and methotrexate. When looking at RA patients who received abatacept as their 2nd biologic medication ever taken, the biologic they predominantly took first was infliximab. And then, when looking at RA patients who received abatacept as their 3rd biologic medication, their previous biologics tended to be etanercept, infliximab and adalimumab.

These characteristics will be important to take into consideration when future analysis comparing effectiveness of newer biologics is done.



Social Networks and Research

NDB Co-Director Dr. Kaleb Michaud was invited to speak at the 2013 EULAR meeting on his findings on social media research in arthritis. He went over how patients have access to helpful medical advice and community forums, but also access to medical misinformation and how recruitment of patients for research via some social networks, ie. Facebook, Twitter, has increased a lot over the past few years. He also showed prior and existing research using social networks and how new issues have now developed from it and discussed ways to work on the issues. He ended his talk discussing NDB's new research using smartphones.

At the end of last year, NDB emailed a mini-questionnaire asking for participant input on changes to questionnaires, additional mini-questionnaires for medications and major health events, overall contact from NDB and volunteering for a newsletter profile or patient advisory board. We would like to thank all of you that completed this mini-quest and because of your input we are able to move forward with certain projects.

We had over 500 participants note that they were interested in volunteering for a newsletter profile, the patient advisory board or to help with other items.

You will see in this newsletter a profile from one volunteer and some volunteers have been invited to be on the AIR advisory board. Other volunteers that either completed the WebQuest or provided an email address also helped us in testing out a different version of our online questionnaire. After their feedback, we found that it was not going to work for many of our participants and so we will be revisiting and revising our original version instead. Volunteers have most recently helped us in future planning for our Medications section in the WebQuest—to make it simpler to complete and to get it set up to be able to update medications in between 6-month questionnaires.

If at any time you're having difficulty in either answering or finding time to complete the questionnaire, online or in paper form, please let us know and we can work with you to help find a way to keep you involved in a way that works best for you. It's very important for research that we get at least a minimum update from you and so we want to do what we can to not lose your participation. We are modifying our forms exactly for this purpose and we have research assistants who are happy to speak with you on the phone.

All of this is only possible because of your participation in the NDB.

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

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. Here are a couple of ways you can help.

Now available for your support group or arthritis, fibromyalgia or lupus meetings...

our pamphlets explain what we do and how you and 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 research@ndb.org or 800-323-5871 ext. 117. 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, to 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.

Notes from the Directors, cont. from Page 1

most jubilant members of our group, Jessica, died of kidney failure in her late 20s; this was a stark reminder of the kind of unfair disease we were facing.

After getting both of my wrists replaced, I found myself dissatisfied with my graduate school environment and decided to take a break. Dr. Wolfe invited me to return to KS to be his statistician at the NDB. Needless to say, I loved it and thrived!

My frustration with the lack of progress in treatments in the 1980s was funneled into understanding the many new treatments available, what side effects they may have, and what we can do to get more in the pipeline. The



financial hardships my parents and grandparents went through with my care and their care have led to wanting to understand the financial impact these diseases have on our society. Finding it difficult to share exactly what I was feeling has driven me to try and develop better quantitative questions that can help describe exactly what is happening to others. And the appearance of a random affliction to a 3-yr old has led to collaborations with bench scientists at examining markers in our blood that may assist us in finding and preventing these diseases from ever occurring.

All of my personal experiences contribute to answer the “why research arthritis” question. Our chronic diseases, unlike most others, require long-term study. The pain may be more tolerable for a few months or years and then return without notice. And this research is best done by having the people with “arthritis” share their experiences with the scientists and researchers so that they can fully understand what impact these diseases have and what they can do to help make it better for us and future generations. I am proud to do what I can to help further this research and bring new findings and data to top scientists from around the world, yet, as we so often tell you, I could not do it without your help and participation. So, thank you, yet again, and I look forward to many more years of discoveries and progress.

Dr. Wolfe is taking a much-deserved break from this newsletter as he works on a new book and spends a few weeks away visiting his lovely grandchildren.

Meet the Participants

Contributed by Fara Hentsch, a NDB Participant

Managing Rheumatoid Arthritis — Do Not Let it Manage you

Don't kid yourself. It's a war. It's you trying to have a normal life battling against this weird disease where your body is actually attacking your joints, that to me sounds like war.

I was twenty years old. I woke up and I couldn't move my fingers. They were hot and swollen and fat like sausages. My new husband had to help me button my shirt and zip my jeans. I was so scared and kept wondering what was happening to me.

I started by going to the local GP's. (Rheumatologists weren't very prevalent in rural areas in the late 70's). Their answer was to load me up with high doses of aspirin. It did cause my fingers to feel better, but only because they turned me into an ear-ringing zombie.

"I firmly believe there is a direct correlation between exercising and managing arthritis."

I finally found an internal medicine doctor that took on my case. Over the next two years he tried just about everything he could think of and the Rheumatoid Arthritis (R.A.) still wasn't under control. He had interned at the Mayo Clinic in Rochester, MN so referred me there. They recommended a combination of drugs and I went into remission for four years.

Through the next thirty years or so I tried drugs that didn't work and drugs that did work. Eventually the successful drugs quit working and the search was on for the next one that would work. Through this search I had one constant. I have always exercised. When I was young I found I loved to run. As I got older I found aerobics, racquetball, hiking, dancing, and golf. When I was having flares it affected my feet, knees, neck, shoulders, and especially my hands. The first doctors I went to said I had to stop exercising and just take it easy. Guess what? I felt worse. I decided I knew my body better than anyone and disregarded their advice. I cautiously started to exercise again.

Now doctors encourage you to stay active and try to keep your muscles strong. I firmly believe there is a direct

correlation between exercising and managing arthritis. I believe those little endorphins your body releases do more than make you feel good. I believe they stop the disease from progressing. After 33 years of the disease, it is still mainly in my hands (most of the damage was done in the early years when we were struggling to get the disease under control). Now you're probably thinking "I can't exercise. I hurt all over. I barely have enough energy to get out of bed." But what if it could change your life? What if you started getting more active and you felt so much better? What if it changed your quality of life and you could do things by yourself instead of asking for help? What if you could play with your kids or grandkids instead of just watching?

If you're serious about giving exercise a try, here's what you have to do to start:

1. *Run it by your doctor and get his/her permission. On that same note, don't settle for the first doctor you try. If they aren't trying to get you the same quality of life you want, look for someone else.*
2. *Start by walking and gradually build up your distance. Many people make the mistake of doing too much the first few times and get discouraged when they're stiff and sore.*
3. *Schedule your fitness just like you schedule going to lunch. If you vaguely say "I would like to get a work out in today", it won't happen. Instead say "I'm going to do a Jillian DVD tonight as soon as I get home from work."*
4. *Know your exercise weaknesses. I know if I come home from work and sit down or eat, I'll never get a workout in. I change from my work clothes to work out clothes and hit it.*
5. *Try to work out every day, but vary your routine so you don't get bored. If you can walk, vary your path. As you get stronger incorporate trails or hills and more distance. They say if you do something every day for 3 weeks it becomes a habit. I challenge you to give this a chance and see how you feel after 3 weeks.*
6. *If you are weak in one body area, exercise another. There are some great exercise DVD's for people to do from a chair, or even a bed.*
7. *Be creative and sneaky to get your work out in. You might be doing errands or taking a short car trip with someone, so have them drop you off before you get home. Of course this takes some planning and you'll need to have your shoes*

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Arthritis Internet Registry (AIR) Update

AIR is a groundbreaking 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 4,000 participants join and we have collected over 700 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. 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.

AIR would also like to thank the patients, scientists and doctors that have agreed to be on our advisory boards. They will help guide the research that will use the AIR data and make sure that the participants, data and samples are protected. These volunteers were chosen from the over 500 participants that noted they were interested in the patient advisory board and the



scientists and doctors are those that also contacted the NDB, AF or Quest and noted they were interested. The volunteers will be on the boards for 3 years and will

be meeting at least 2 times a year. If you were not chosen this time, we will keep you on our list and may also ask for your help in other ways.

Latest Research from 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 used 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. The project was able to show that this is one of the new ways to collect patient samples for discovery genomics research and next-generation patient registries.

Quest Diagnostics is currently working with Dr. Kaleb Michaud and the NDB on another study using the blood samples to look at a specific biomarker that may be used to spot RA before symptoms arise. By combining the data collected in the 6-month questionnaires, they are also testing to see if this new biomarker can identify if medication is actually working to treat rheumatoid arthritis.

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 Vernachio, PhD
Arthritis Foundation

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.



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.

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 if you donated blood, you will be able to see your lab results, 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.

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 and published research 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 and updates.

Meet the Participants, cont. from Page 4

along. However, I always find walking is so much more rewarding if you have a specific destination (like home).

I also walk sometimes to breakfast instead of taking the car to town.

8. Say it's windy or cold—Don't skip your workout. Walk with the wind and have someone pick you up. Hint—take a cell phone in case they forget to get you (happened to me). Also, look for a sheltered area to walk that will take away the wind or cold. (Think woods or river bank path.)

9. Exercise will also help you lose weight, which of course will also help manage your arthritis. As you exercise, it seems to also make you more aware of what you're putting in your mouth.

10. Exercise is also a great stress reliever and coping tool. Who couldn't use a little more of that in their life?

So what do you think? Are you ready to give getting active a try to improve your life?

Remember, this is war and you can't win unless you play. This has worked for me and it may not work for everyone, but hope that what I have shared may be of use to others.

NDB would like to thank Fara for volunteering her time and contributing to the newsletter!

If you would like to be profiled in a future newsletter, please contact NDB staff member, Amy Yearout via email: amy@ndb.org or phone: 1-800-323-5871 ext. 126.

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 Virginia Riley, Franklinton LA and Margaret Calogero, Bridgeport PA. Winning smaller amounts were Brigitte Rutenberg, Philadelphia PA; Michael Bernhardt, Belleville IL; Lori Stuehmeyer, Arcadia MO; and participants from Locust Grove LA, Oskaloosa KS and Harleysville PA. Congratulations to all!

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.

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!



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.



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>.

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 research@ndb.org

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