# THE NDB Research NEWSLETTER

News for Participants in the National Data Bank for Rheumatic Diseases January 2016

## Notes from the Directors Kaleb Michaud, PhD

## A Story About Being Heard

The last day of the biggest conference of the year was here and I was busy as ever. I had 2 presentations and 5 meetings scheduled before leaving, and now I was getting a text from United Airlines that my flight was canceled. I scrambled to find a new flight that left 3 hours earlier, and had to reschedule all my events to the morning.

I checked out of the Marriott skyscraper and climbed into an Uber SUV carpool headed for the airport. Relief and exhaustion hit me—this was day 7 in downtown San Francisco of the American College of Rheumatology (ACR) annual scientific meeting and each day was filled with meetings and activities from 7am until 10pm. As I gave an audible sigh, I noticed the rider in the front seat. He had medium-length dark hair and stubble, was similar in age to me, and had healthy skin indicating a climate with more sun than Omaha, where I live. I made polite conversation and asked where he was headed—Tucson. Then I noticed his hand. His finger joints had signs of swelling and showed deformation even worse than mine.

Having rheumatoid arthritis, or more concisely, being an adult with juvenile idiopathic arthritis, this is one of our curses. I look in the mirror or pictures of myself and notice everything that doesn't look "normal". In non-summer months when clothes conceal all my limbs, the main part of me that would give me away is my hands—I was fortunate to be living most of my career with an invisible disease. So after years of being trained to notice and judge my own body changes and sources of burden, I am similarly quick to notice the same on others. And I'm not alone.

*"…this is always just one patient's voice. With the NDB, I get the voices of THOUSANDS of patients."* 

A few years earlier at an ACR meeting an attendee in a wheelchair came up to my poster while I was discussing the research with another doctor and he asked me, straight up, "How long have you had arthritis?" My first reaction was annoyance—I was caught! (This was before I had "outed" myself to you or any of the medical research community.) Then I became self-conscious and asked, "What gave it away?" He pointed out my hands and face and that he was an expert at noticing such signs; I was not alone in my perceptive abilities.

Back in the SUV, apparently this was Kevin Purcell, the man who founded Arthritis Introspective, a non-profit dedicated to improving the lives of young and middle-age adults with arthritis and rheumatic diseases (we'll highlight them in our next newsletter). We got along quickly, and learned that we had many friends in common who also have arthritis. We told stories of how the friendship of others who had and were going through similar health issues made a big difference in our own lives.

Kevin asked why I didn't take on a more active patient advocate role on various boards and committees, and that my voice would make a big difference for patients. A slight smile appeared as I sat back and replied, "That's a tough one. I am ecstatic that more groups are including a patient representative, but this is always just one patient's voice. With the NDB, I get the voices of THOUSANDS of patients."

And that's it, that's the point of all this. YOU, the only one who can speak for you, give us your voice each time you complete one of our questionnaires. From this we learn so much! We learn how difficult (or for some, how easy) it is to get your expensive medications. How specific pain in a couple joints really impacts your overall well-being compared to others. How your blood pressure medications sometimes interact with your stomach or allergy medications. How you really want to be independent and don't want to be reliant on others. How going off of medications that are working can really make things worse. How you had to change jobs or how you lost your job after you got arthritis because you couldn't do things the same way as before. How the pain and fatigue during a flare makes it hard to be friendly with your friends and loved ones, and much more...

When you complete these questionnaires, you make your voice heard by the medical science community and it changes clinical care. From you and patients like you we wrote the primary paper showing the actual (rare) risk of vision issues with hydroxychloroquine (plaquenil)—and this is the basis of all current guidelines recommending vision testing at specific years after taking this medication. From you, we learned that many of the anti-TNF biologics are similar in how well they work, so that Medicare would then pay for all of them. From you we learned which questions are best in helping create the new criteria for

# LATEST RESEARCH

This year at the annual American College of Rheumatology (ACR) meeting held in San Francisco with over 16,000 attending, the NDB and fellow researchers were pleased to present multiple research abstracts selected as oral presentations, along with multiple poster presentations. The NDB had many great moments that we would like to share with you along with some of the research presented at the meeting.

First, we are very proud of Patricia Katz, PhD, our lead researcher on lupus, as she received the prestigious "Lifetime Achievement Award" for the Association of Rheumatology Health Professionals (ARHP). This is the highest honor that the ARHP gives out and is presented for demonstrating a sustained and lasting contribution to the field of rheumatology and rheumatology health professionals.

One of the main reasons for Dr. Katz receiving the award is all of her great work with rheumatology research and patients. She had multiple research abstracts, posters, & oral presentations accepted not only for her research at the University of California San Francisco (UCSF), but also for her new research with the NDB. The NDB is very thankful for Dr. Katz's time, generosity, and hard work!



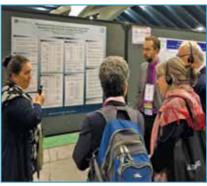


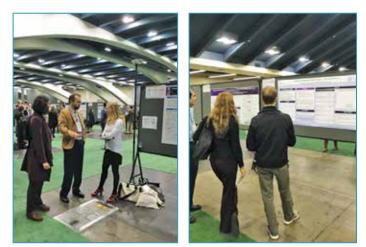
Our fellow statistician, Sofia Pedro, MS, presented research on "Does the Risk of Serious Infection Among Elderly RA Patients Differ By Age of Disease Onset?" at one of the main sessions.



Our Co-Directors, Frederick Wolfe, MD and Kaleb Michaud, PhD, were also very busy at the meeting with oral presentations, poster presentations, poster session tour guide, and session moderating.







Poster presentations at the ACR meeting.

Here are some overviews of the research from the meeting:

#### Does the Risk of Serious Infection Among Elderly Rheumatoid Arthritis (RA) Patients Differ By Age of Disease Onset?

RA patients who have onset of RA after they are 60 years old are less likely to be treated with biologics, even when accounting for disease activity compared to RA patients at the same age who had onset of RA before they were 60. The data showed no increased risk of serious infections when comparing the groups and supported providing similar treatment for both groups.

#### A Comparison of Physician-Based and Patient-Based Criteria for the Diagnosis of Fibromyalgia

The ACR has criteria to help in diagnosing fibromyalgia. There is one criteria using only physician-reported data and another criteria using only patient self-reported data. Data from both groups were compared to determine the degree of agreement between the 2 different methods. Overall the comparison showed good agreement between the two methods and if patient questionnaires were used to obtain clinical data for patient diagnosis, they should be used along with the physician data to help with confirming the diagnosis.

#### Impact of Smoking on Patient-Reported Disease Status and Symptoms Among Women in Lupus

Smoking appears to be associated with an increased risk of RA and with more severe symptoms, so we looked at the impact of smoking on patient-reported disease status and symptoms in lupus. Current smokers had significantly worse self-assessments of lupus disease status and worse symptoms. This shows the importance of assessing smoking and supporting stopping smoking efforts among women with lupus.

#### Comparison of Juvenile Idiopathic Arthritis (JIA) and RA Patients in the National Data Bank for Rheumatic Diseases

Researchers at the University of Alabama at Birmingham (UAB) used the NDB data to do a comparison of adult JIA and RA patients with similar ages and lengths of disease duration. They found that JIA patients tended to have higher pain scores, longer morning stiffness, and more rheumatologist visits.

#### Mortality Among Systemic Lupus Erythematous (SLE) in the National Data Bank for Rheumatic Diseases/Does the Risk of Mortality in Patients with RA Change over Time or Disease Duration?

These two research projects compared mortality in SLE and RA patients to mortality in non-inflammatory rheumatic disease (NIRD) patients. Both show that SLE and RA have a higher risk of mortality when compared to NIRD and the general population. In SLE, mortality was particularly increased for male and younger patients, similar to what other studies have shown. Important factors for an increased risk for mortality included: worse disease activity, more comorbidities (i.e. high blood pressure, ulcers, neurological problems, etc.), & smoking. There was a slight trend over time for decreasing mortality in RA hinting the possible impact of improved treatments.

# Initiating Statin Medication and Risk of Fatigue in Rheumatoid Arthritis

Researchers at the University of California San Francisco and the University of Nebraska Medical Center used the NDB data to see if starting a statin (medications to help with cardiovascular disease) increased fatigue in RA patients, since this has been reported as a common side effect in general users of statins. The study was able to show very strongly that new use of a statin is not associated with significant risk of increased fatigue. Findings are important because statins are commonly used in RA and fatigue can have a major impact on quality of life.

#### Notes from the Directors, continued from Page 1

diagnosing fibromyalgia. From you we continue to learn what are the most important side effects, if any, on the important medications you take—many of these may end up on the commercials on TV (and there are a lot of these!).

These are but a few examples of many where your answers to our questionnaires are used to help doctors and patients receive better care and results from around the world! Your voice is important. I am happy to speak for myself as a patient as needed, but it's never the same as speaking on behalf of you and so many others. I know my personal example is somewhat unique to younger adults with arthritis, and that there's an entirely different issue with being older with arthritis as it becomes somewhat expected and others can more easily dismiss its burden. This isn't something that I've personally experienced, but I can see it from some of your answers, your "voice".

So thank you again for reading and for making your voice heard. We are constantly getting new and talented researchers from around the world to use the combination of your voices to learn more about arthritis and rheumatic diseases. We are also always making changes to the questionnaire (and trying to shorten it whenever possible) in our paper and online forms. Thank you again! I sincerely hope that you make your voice heard through the next questionnaire.



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**.

# Arthritis Internet Registry (AIR) News

# ARITRES INTERNET

AIR is a ground-breaking internetbased 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 over 6,400 participants, and we have collected over 1,250 biospecimens from people with a variety of rheumatic diseases.

AIR recognizes the importance of research to improve the lives of people with rheumatic disease 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

At the ACR Meeting this past November, a research abstract was presented by the AIR researchers using some of the biospecimens that have been collected. Here is an overview of the research that was presented:

#### Serum 14-3-3eta Protein Elevation in Osteoarthritis (OA) Suggests Misclassification or Concurrent Inflammatory Arthritis

14-3-3eta is found in synovial fluid and serum of RA patients and to a lesser extent, erosive psoriatic arthritis (PsA) patients. Differentiating RA or PsA from OA can be difficult and the purpose of this research was to see if using



14-3-3eta biomarker would be able to help with this. The research showed that 14-3-3eta may be useful to help identify RA or PsA patients amongst those being followed for inflammatory arthritis and to screen OA patients for misclassification of RA or PsA as OA, or for concurrent inflammatory arthritis, in primary care.

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. Naides, MD** *Quest Diagnostics Nichols Institute* 

Amanda Niskar, DrPH, MPH, BSN Arthritis Foundation

# 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.

# New Projects and Participants

#### University of California San Francisco (UCSF) RA and Lupus Cohorts join the NDB!

Dr. Patricia Katz has been working with the NDB for the past couple of years to help with not only new research, but to also find a home for the participants that were a part of the UCSF RA Panel and Lupus Outcomes Study. Over the past year, the UCSF RA Panel and Lupus Outcomes Study participants have been contacted by UCSF and the NDB to help in the transition. This great collaboration will help with being able to do comparisons between diseases and to be able to continue the great work that UCSF was doing.

We welcome all of the UCSF study patients and thank you for continuing your contribution to this important research!

#### International Dupuytren Data Bank (IDDB)

We are proud to announce that we have officially started enrollment in the International Dupuytren Data Bank (IDDB)! This research project is to help find a cure and treatments for Dupuytren Disease and related diseases and is sponsored by the Dupuytren Foundation (see more about this great organization in the next section "Spotlight on Non-Profits and Organizations").

*What is Dupuytren disease?* Dupuytren disease is the most common crippling hand condition that people have never heard of. It affects at least ten million Americans, making their fingers permanently bent, sometimes severely. Why isn't it more commonly known? Dupuytren contracture makes the

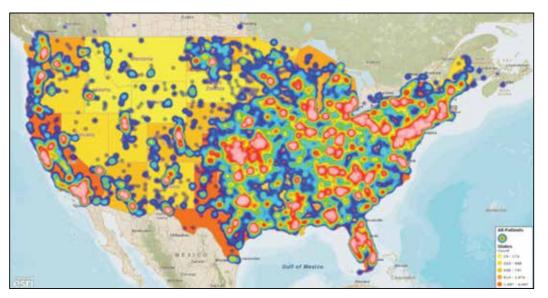
fingers look bent and relaxed, not obvious unless the person tries to open their hand. It progresses slowly, usually doesn't hurt, and mostly affects seniors. It is often confused with arthritis or tendinitis.

Why is it important? Bent fingers are only part of the picture. Dupuytren disease is a systemic problem. It can affect the hands (Dupuytren contracture), the feet (Ledderhose Disease). the penis (Peyronie Disease), or the shoulder (Frozen Shoulder). Developing one of these increases risk of developing others. It is a serious health issue. People with Dupuytren contracture have greater risk for cardiovascular disease, several types of cancer, and early death—for reasons unknown. There is no prevention and no cure. Why? The only available treatments are by surgeons, and so most research has been on procedures, not the core biology. Current treatments are inadequate. Surgeons perform procedures for contractures, but improvement is often partial, temporary for most, and complications of retreatment are common. Despite recent progress in reducing complications of treatment, rates of progression and recurrence have not improved in the last fifty years. Understanding Dupuytren biology may lead to better treatment for other serious medical conditions. Dupuytren biology overlaps that of other fibrotic conditions, including cardiovascular disease, cirrhosis of the liver, pulmonary fibrosis, scleroderma and others. It's no coincidence that all of these conditions also lack effective medicines - they share parallel biologic pathways. Of all these, Dupuytren disease is the most accessible to study.

You can find out more about the IDDB at: http://dupuytrens.org/enroll-in-the-iddb/

## 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.arthritis-research.org/user/register

# 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 Non-Profits or Organizations that may be of help to you.

### **DDUPUYTREN FOUNDATION**

The Dupuytren Foundation works to develop a cure for the most common inherited disabling hand condition: Dupuytren disease.

#### http://dupuytrens.org/

*Our mission is to find a cure for Dupuytren Disease as rapidly and efficiently as possible.* All our board members are intensely focused on this goal because we are either hand surgeons who have seen too many problems from Dupuytren Disease, have Dupuytren Disease ourselves, or both. Our membership represents all 50 states and spans 70 countries. We provide free patient support, host academic conferences, and author academic publications.

Our flagship effort is the *International Dupuytren Data Bank* (IDDB). The IDDB is a research project with a target of finding the cause and cure for Dupuytren Disease and related conditions. The IDDB has been developed by the Dupuytren Foundation in collaboration with the UCLA Department of Human Genetics, the NDB, the Mayo Clinic Biobank, and other academic groups.



IFAA is the only global nonprofit created entirely by patients who have executive

business & higher education backgrounds. We understand the community needs like no other. So what does IFAA do?

We Identify & Resolve Community Gaps. Our core purpose is to use our personal patient knowledge, along with professional business and education backgrounds, to watch for community gaps then work towards implementing change and providing solutions. We take on issues that matter to the patient today and establish change to better the lives of patients tomorrow.

*We Work Hard to Construct a Global Network.* Working with other community leaders plays a fundamental role in our project development and solution implementation. The more ideas and expertise, the better potential for success.

*We Strive for Awareness Differentiation.* IFAA will encourage patients, supporters, and the public to verbally differentiate types of arthritis so the umbrella term "arthritis" does not continue to breed misunderstanding and confusion about the scope of these diseases.

#### http://www.IFAutoimmuneArthritis.org

Also, *World Autoimmune Arthritis Day* was established by the International Foundation for Autoimmune Arthritis in 2012, officially falling on May 20th. It is currently listed on over 2 dozen health calendars internationally. The event unites dozens of nonprofits, advocates, and experts from around the world to provide educational and awareness information to patients, their supporters, and the general public.

Until 2015, WAAD was run in the form of an online convention, with virtual booths, live presentations, and various activities for both patients and supporters. However, the new platform is that of an interactive 'raceway', headquartered on this website, http://www.WorldAutoimmuneArthritisDay.org and the WAAD Facebook and Twitter pages, but sends participants to links and pages to learn more about valuable resources. It also boasts awareness posters to share, live Call to Action Crowd Rally activities, and live webinars. The event has also been extended to take place over a 6-day period to help encourage participation in all time zones around the globe and increase both the fun and competition factor.



## 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.arthritis-research.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.

#### http://dupuytrens.org/enroll-in-the-iddb/

# NDB Questionnaires & 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 created other questionnaires with specific questions for specific 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:

- OA is sent to people with osteoarthritis 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 people with lupus and includes some of the questions in the RA/Fib 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.
- RA/Fib is sent to all people with RA, fibromyalgia and other diagnoses not listed above (e.g., 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 a person's disease affects their 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.

# **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  $\frac{1}{2}$  months.

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

The prize drawing winners from the last questionnaire were: Susan S., Helen L., Gareth W., Sophie P., Benny C., Cordelia M., and Amy M. Congratulations to all!

# 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.



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.

## 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.

## 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!

#### 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

# 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.arthritis-research.org/participate/tell-friend

# 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 <u>VERY IMPORTANT</u> 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 call us. 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.

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