

# THE NDB Research NEWSLETTER

News for Participants in the National Data Bank for Rheumatic Diseases January 2014

## Notes from the Directors

Kaleb Michaud, PhD

*In the last newsletter I wrote about my personal reasons for answering "Why do arthritis research?" I received a surprising amount of positive feedback for bringing my personal story out. Thanks for your encouragement, and I will add more personal notes in the future.*

### Five-Step Update

By Kaleb Michaud, PhD

Last November I had the honor of being the 1 and only researcher from the US invited to speak at a meeting in Prague on rheumatology patient registries. See, the NDB is the largest registry of its kind in the US with over 10,000 active patients and over 35,000 patients participating since 1998. The most impressive aspect is that all of the NDB is powered by the patients who want to do their part to make a difference. European registries have it a bit easier since many of the countries require their patients and doctors to fill out similar questionnaires in order to receive their treatment.

The 2 talks I gave covered the changing scene of US healthcare and future issues of arthritis research. I mentioned how some everyday tools could make it easier to measure how we are feeling. For example, I have a pedometer that shows when and how much exercise I do (most of the time it reminds me that I need to take a break from my computer screen). Some of you have been trying out our new smartphone app research project that tries to see if there is a measurable connection between our social and phone behavior and our arthritis pain.

We are also starting another exciting new project that may be a first direct step at preventing rheumatoid arthritis (RA). In 2014 we will start out by asking a few of you to provide some additional information about your direct biological family members. For example, I have 3 relatives that would qualify; my parents and my sister. I would then ask them to

fill out a short survey about their health, and, if they are especially interested in helping out, to each donate some blood. Our goal with this study is to see if we can understand the hereditary aspects of RA, and find ways to test treatments for preventing RA in those who are at higher risk.

Participating in research can be a family experience. Some of you have relatives or spouses that also fill out our surveys. Some of you may have identical twins. When scientists analyze our data, they don't know about these relationships. We hope this new study will help make all the questions you answer even more valuable as we create the familial connection with others. Many scientists believe that RA and other rheumatic diseases come about with a combination of 4 factors: genetic susceptibility (what we inherit from our parents), environmental exposures (smoking, pollution, etc.), hormone changes, and an abnormal immune response (trauma, infection). Stay tuned for more details.

*"We hope this new study will help make all the questions you answer even more valuable..."*

This past October Dr. Wolfe, myself, and other NDB researchers were honored to have 5 of our scientific abstracts chosen as top submissions at the American College of Rheumatology annual meeting. Some of these are listed later in this newsletter. It was a sign of the importance costs can have on patients when my abstract on comparing cost-effectiveness

of a few treatment strategies was chosen as a plenary presentation at a meeting with over 14,000 in attendance.

Also in attendance were several patients who participate in the NDB/AIR. It was great to meet some of you in person at our booth! It makes such a difference seeing patients support our work and the research impact it is making worldwide. Likewise, it was good for the patients at our booth to be reminded that there are many dedicated individuals at the NDB who make it all possible. With our questionnaires and emails, I imagine it can be difficult to remember that there are so many real people involved. Thank you again for your participation!

# LATEST RESEARCH

In October 2013 at the Annual American College of Rheumatology Meeting, the NDB was involved in over 10 research abstracts and talks on various subjects that used the data that you have provided to us over the years. The majority of these will end up as papers published in medical journals and this would not have been possible without your participation.



The NDB had a booth at the conference to be able to visit with other researchers, participants and other non-profit groups that we currently work with and hope to do future work with. We were pleased to be visited by CreakyJoints ([creakyjoints.org](http://creakyjoints.org)), OTIS/MotherToBaby ([mothertobaby.org](http://mothertobaby.org)) and Arthritis Introspective ([arthritisintrospective.org](http://arthritisintrospective.org))—all great organizations that we are pleased to work with and/or have participants in our research.

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

Here are some overviews of the research from the meeting:

## ***Discontinuation Rates in Patients with RA of Triple DMARD Therapy***

Using the NDB data, we were able to have one of the first studies ever able

to provide discontinuation rates of triple therapy (methotrexate, sulfasalazine and hydroxychloroquine taken at the same time) using patient supplied data.

Overall discontinuation rates were high and patients tended to switch between several combinations of methotrexate, sulfasalazine and hydroxychloroquine rather than biologics.

## ***The Use of Medical Marijuana for Pain Treatment***

One of the main sessions at the meeting covered medical marijuana as a treatment for chronic arthritis pain. Since medical marijuana is currently approved for use in certain states, this subject is now being covered more due to the side effects and safety for patients. Currently, there are studies being done on an injectable form of medical marijuana that would be injected in the affected joint to help take away the inflammation and associated pain with minimal side effects. Researchers are working to take out the part of the plant that causes the “high” side effect. Information was also given about certain studies done outside of rheumatic diseases that showed the “high” side effect lasted about 5 hours after taking it with impaired mental and physical response time. If rheumatologists are prescribing in the states or countries where it is legal, they should make sure they are informing the patients about this so they do not try to drive or do tasks that may be hindered. The data also showed that taking an oral pill was the best form to take, but the side effects are still currently there. This session also showed that as of the time of the meeting, there were no studies completed in rheumatic diseases to aide doctors and patients on understanding

if medical marijuana should be used. In the current NDB 6-month questionnaires you will see that we have added a couple of questions about medical marijuana that will help the NDB, along with other researchers, find out basic information on how prevalent the usage is and how helpful it is for patients.

## ***Performance of a Computer Based Method to Measure Erosions in RA Hand X-rays***

Researchers at Brigham and Women’s Hospital in Boston, MA used data from 112 patients in the NDB that had hand x-rays from their first visit and one follow-up visit. This study compared a computer based method to the Sharp method (the main way rheumatologists use to read x-rays). The computer based method was able to read the x-ray a little faster and can almost as accurately assess the progression of the disease in patients with RA, which suggests that it could also be used to read the x-rays.

## ***Somatic Symptoms and Mental Illness—Getting the Appropriate Diagnosis***

Due to how rheumatic diseases have symptoms that can also be considered a mental illness, NDB and other researchers are currently trying to determine which questions to ask patients to make sure they are being properly diagnosed.

In the current 6-month questionnaire you will see 2 new sets of questions being asked about certain symptoms of the body, depression and anxiety. These questions will allow the researchers to compare to other data to see if they can effectively help in making the correct diagnosis.

## *The Impact of Menopause on RA Activity*

Participating female RA patients in the NDB that answered the health assessment questionnaire (HAQ) section on daily functions allowed us to show that menopause appears to worsen disability as measured by the HAQ. This finding is similar to other studies showing a modest negative influence of menopause on RA severity.

## *Sleep Disorders and Rheumatic Diseases*

A session on sleep disorders was presented at the meeting to help rheumatologists understand the different types of sleep disorders. Since fatigue is a common symptom of rheumatic diseases it is important for rheumatologists to understand the different types of sleep disorders to be able to help their patients. Sleep apnea is one of these disorders, but there are others and proper tests can help to figure out if their patients have a sleep disorder that may also be affecting their lives and adding to their rheumatic disease. The presenter also noted that everyone should get 7-8 hrs of sleep each night. Too little sleep can cause mental and physical problems and too much sleep might mean there is something else happening causing the patient to be sleeping more than normal.

## *NDB Questionnaires and Primary Diagnosis*

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

**-RA/Fib** is sent to all RA, Fibromyalgia and all other diagnoses (i.e. psoriatic arthritis, ankylosing spondylitis, lower back pain, polyarthralgia, etc.). This questionnaire asks all the questions that will help aid the researchers to

get the entire view of how a patient’s disease affects their lives.

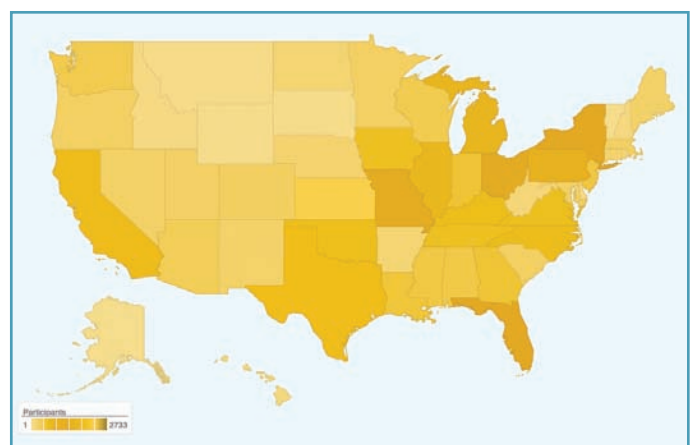
- OA** is sent to all osteoarthritis patients and asks the majority of the questions in the RA/Fib questionnaire and a certain set of questions that are used by rheumatologists to help with OA patient care.
- Lupus** is sent to all lupus patients and has majority of the questions in the RA/Fib questionnaire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

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

## *NDB Participants on the Map*

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

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

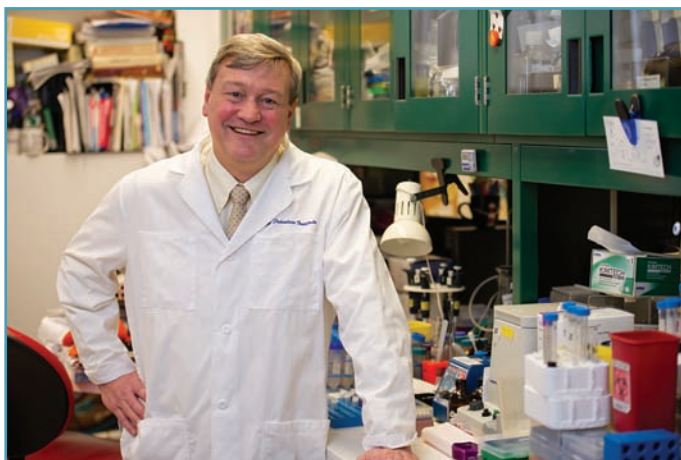




# Arthritis Internet Registry (AIR) Update

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 4,600 participants join and we have collected over 850 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 is pleased to announce the addition of academic researcher, Peter Gregersen, MD from the Feinstein Institute for Medical Research. Dr. Gregersen is Director, Center for Genomics & Human Genetics, The Feinstein Institute for Medical Research and Professor, Molecular Medicine, Hofstra North Shore-LIJ School of Medicine. Originally trained as a rheumatologist, Dr. Gregersen, has been working in the area of genetics for more than two decades and has led several major international consortia to study the genetics of rheumatoid arthritis, systemic lupus, myasthenia gravis, myositis and



other autoimmune disorders. He has spearheaded the development of robotic biorepository and informatics resources to support his studies.

The Royal Swedish Academy of Sciences selected Dr. Gregersen to receive the prestigious Crafoord prize for his genetic research in rheumatoid arthritis. The prize was presented in Stockholm by the king of Sweden on May 2, 2013.

## Latest Research from AIR

Genetic analysis, that we reported on in the last newsletter, done by Robert Plenge and the BROAD group at Harvard Medical is the basis for a soon to be launched SAGE Networks/DREAM project: Rheumatoid Arthritis Responder Challenge. This project brings together investigators from all over the world who have contributed genetic data on many thousands of samples from patients with RA, with the goal of identifying genetic predictors of response to therapy with a class of drugs known as TNF inhibitors. This project will challenge data analysts all over the world to come up with the best method of prediction, and this can then be tested and refined in additional studies. We hope to use the AIR project in these follow up studies.

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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*

John Hardin, MD  
*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.

## 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](mailto:kim@ndb.org) or by phone at 1-800-323-5871 ext. 143.

## 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](mailto:info@ndb.org) or 800-323-5871 ext. 133. Thank you!





## Meet the Staff: Patricia Katz, Ph.D.

Patricia Katz, PhD, Professor of Medicine at the University of California, San Francisco (UCSF), will join the NDB in January 2014 as an expert Lupus Research Consultant.

Dr. Katz has been involved in rheumatology research for over two decades. She currently oversees two studies at UCSF that follow the health and well-being of individuals with rheumatoid arthritis (RA) and lupus, primarily through annual telephone interviews. The RA study has been in existence for 30 years, and the lupus study for 12 years, so Dr. Katz is quite experienced in creating surveys that are relevant to individuals with rheumatic diseases. Dr. Katz's own research has long focused on the development of disability in RA and lupus. In particular, she has tried to shift the measurement of disability from considering only very basic activities of daily living (such as personal hygiene or preparing meals) to including a broader view of the activities that people want to do in their daily lives. More recently, she has also shifted her research to examining the role that body composition (fat and muscle) plays in the development of disability and disease status in rheumatic diseases. Dr. Katz is excited about the opportunity to help expand the contributions of the NDB to lupus research to improve the lives of people with that condition.



Staff members Kathy, Betty and Deb and the "Winter Village" they put up every year in the NDB office for the entire office building workers and visitors to enjoy through the Holiday Season.

## 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 Dorothy Wade, Watkinsville GA and Ludwik Bysiek, Clopton AL. Winning smaller amounts were a participant from Spencer, NE; Bill Morse, Crete IL; Nichole Cepero, Titusville FL; Melanie Bee, Logan UT; Phyllis McKinney, Las Vegas NV; a participant from Clearwater, FL. Congratulations to all!

## Join Us On Facebook & Twitter

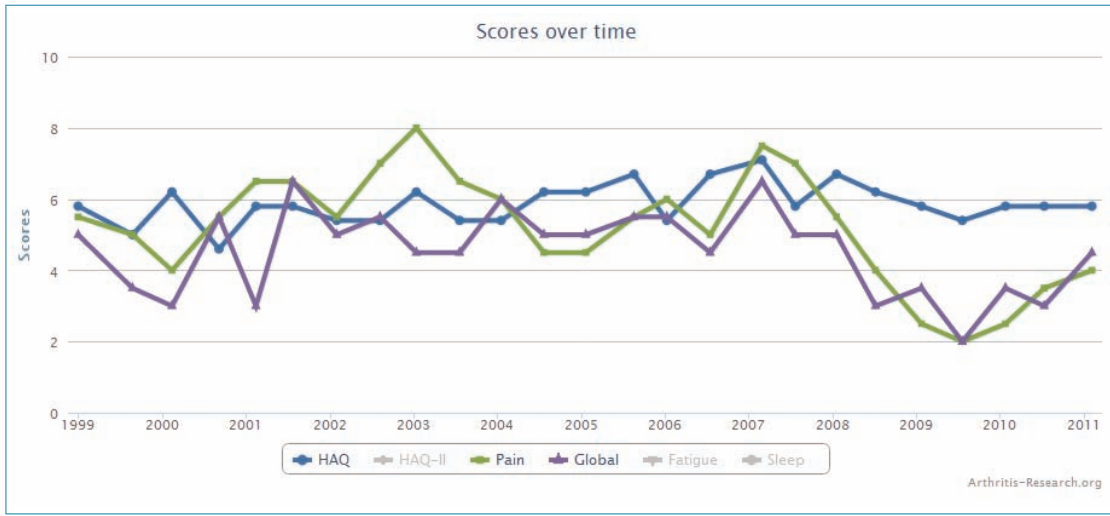


You can find us on Facebook as "National Data Bank for Rheumatic Diseases." We will try to keep you up to date with any news items that occur between questionnaires. You can also connect with other participants and NDB staff who have joined our group.



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

## 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](mailto:webquest@ndb.org) if you have any questions about the website or your scores.

## 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?*
- *Is there a relationship between RA and pericardial effusion?*

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](http://www.ndb.org) and make the request, or send us an email at [webquest@ndb.org](mailto:webquest@ndb.org).



## Refer a Friend

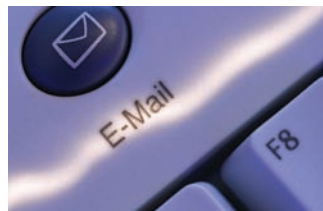
Here's a really easy way to let a friend know about the NDB. Just give us your friend's email address and we'll send out an email invitation to join the study. Go to <http://www.ndb.org/participate/tell-friend>.

## 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.

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](mailto: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.

## 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](http://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](mailto:Rebecca@ndb.org).

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

## 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](mailto:info@ndb.org)**

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