

THE NDB Research

NEWSLETTER

News for Participants in the National Data Bank for Rheumatic Diseases January 2017

NDB Participant Spotlight

Greetings from a fellow member of the arthritis community! My name is Kate Grafel, and I am a public health graduate student at the University of Nebraska Medical Center. As I write this, I realize that I'm approaching a big milestone: 25 years ago this March, I was diagnosed with juvenile idiopathic arthritis. I was in 6th grade. Back then, I was experiencing excruciating pain in both wrists, my ankles were so swollen that I could barely walk, and—worst of all—I was struggling with the social implications of being an adolescent with a debilitating disease.

Since then, the severity of my disease has fluctuated—I might feel well enough one summer to play sand volleyball every week with my friends, then the next season feel miserable more days than not. Last summer was a tough one as my longtime disease, coupled with childhood hip dysplasia, ate painfully away at my left hip...but tonight, 6 weeks post-hip replacement, I'll take my dog for what has become our usual mile-long walk. I'm rejuvenated and inspired and can hardly force myself to take time off my feet—the upswing of a cycle with which many of us are familiar.

Those ups and downs have huge impacts on our health and quality of life. That's why the NDB collects our survey answers not just once, but every 6 months. The researchers at the NDB compare our answers over time to see how disease activity relates to pain level, energy, mood, functional status, and so on. They look for trends that occur by season or with age or as medications are changed. They check for connections between arthritis and other conditions with which we're diagnosed over time.

I filled out my first NDB survey around 2010. I was enthusiastic at first, but it wasn't long before I started neglecting the e-mails announcing new surveys. I told myself I'd get to it later, but then time would go by and I would assume it was too late for my answers to count. Or I'd start a survey, but I'd wonder what answering the same questions every time could tell anyone. When I got to the questions about how I felt last week or last month, I worried that I might do more harm than good if my memory of that time wasn't perfect. And when I missed one survey, I wasn't sure my answers to the next one would be relevant.

But then I reconnected with the NDB. I looked up articles by the program's directors in medical journals, and I discovered the important research to which my survey responses had contributed. Next, I met with co-director Kaleb Michaud, and I told him all the reasons for my participation tapering off over the years...and he put every one of my concerns to rest. He explained how useful my answers to those same questions survey after survey really were. He assured me that it's okay if my memory is a little fuzzy when it comes to how I felt last week and last month, that whatever I can recall is useful. And he told me that it's never too late for me to participate, that my answers will always be meaningful to the NDB's research.

When I completed that first NDB survey, I had just set out on an educational path that would lead eventually—and unpredictably—to public health. Back then, I couldn't have begun to tell you what public health was, let alone comprehend how the NDB fit into it. It turns out that public health has a lot of different definitions, but my favorite is this one from the Institute of Medicine:

“Fulfilling society's interest in assuring conditions in which people can be healthy.”

Short, sweet, and...incredibly vague. But that's OK, because public health is so many different things. It's annual flu shots. It's campaigns urging farmers to wear ear plugs. It's programs that combat childhood obesity. And it's organizations like the NDB collecting information from people like you and me. That information can lead to improved treatment recommendations, to insurance coverage for costly arthritis medications, and to useful insights into how people live with arthritis—in short, it can help assure conditions in which people with arthritis can be healthy.

My work with the NDB is part of my service learning and capstone requirement for my master's degree. Over the next 12 months, I'll work with the NDB on ways to include even more wonderful contributors like you in its research. I'm thrilled to be working with an organization that has such a big impact on public health and with whose mission I can so closely identify, and I can't think of a better way to celebrate this milestone.

Kate Grafel
MPH student, University of Nebraska Medical Center

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

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.

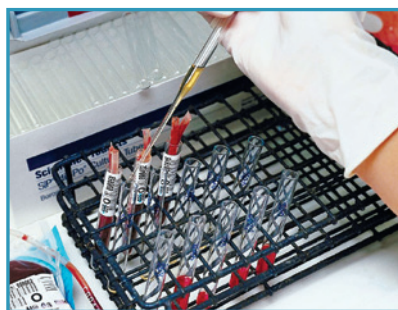
NDB research is different in an important way: Participants report on themselves; data is not collected by doctors or medical staff. With patient-reported data, researchers get a perspective that short, small clinical trials cannot provide. Our long-term study offers a much broader view of treatment 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.



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!



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.

Notes from the Directors

Frederick Wolfe, MD and Kaleb Michaud, PhD

The NDB honored Dr. Wolfe with an award at the ACR Meeting in Washington, DC during the NDB Reception. This event was held to honor Dr. Wolfe, Dr. Michaud, our volunteers and supporters that continue to keep NDB one of the biggest and highly respected non-profit arthritis research organizations in the United States and the world. The NDB would not be here if it was not for Dr. Wolfe

creating it back in 1998 and working each year to support not only the NDB, but the researchers that are helping find better treatments and care for all rheumatic diseases. We thank Dr. Wolfe for his dedicated years of outstanding service and commitment to rheumatology research, his patients, and his staff. He truly makes a difference and is an inspiration!



Dr. Wolfe being presented the NDB award from Dr. Michaud.



A couple of pictures from the NDB Reception honoring our supporters and volunteers!



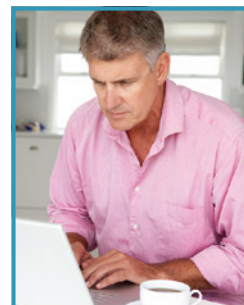
Join Us on Facebook & Twitter



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.



WebQuest

WebQuest is the online version of our questionnaire. The questions are the same as what you get on the paper questionnaire. People who are comfortable using computers should find it easier than the paper version. If you would

like to try it, follow the links from our home page, www.ndb.org and make the request, or send us an email at webquest@ndb.org.

LATEST RESEARCH

NDB was proud to have a booth and over 10 abstracts accepted and presented either orally or by poster at the annual American College of Rheumatology (ACR) meeting held November 2016 in Washington, DC. Over half of the abstracts were completed by researchers working with the NDB data and could not have happened without your help in volunteering your time and completing the questionnaires. **Thank you for adding your voice to the research!**

We are very proud of Kaleb Michaud, PhD, our NDB Co-Director, as he received the Distinguished Scholar Award from the Association of Rheumatology Health Professionals (ARHP). This award is presented to an ARHP member who

demonstrates exceptional achievements in scholarly activities pertinent to arthritis and rheumatic diseases. Dr. Michaud not only is the Co-Director of the NDB, but he is also an Associate Professor at the University of Nebraska Medical Center (UNMC) and works with graduate students and the fellows training to become a rheumatologist. We are grateful for all of Dr. Michaud's support and hard work!



Dr. Michaud receiving the Distinguished Scholar Award at the ACR meeting.

Self-Reported Breathlessness on Exertion Is Associated with Poor Outcomes Among Women with Systemic Lupus Erythematosus (SLE)

Breathlessness is often considered as a predictor of functional outcomes in pulmonary disease, but had not been examined in SLE. Dr. Patti Katz and other NDB researchers examined only women with SLE who completed at least one of the NDB questionnaires. Breathlessness was found to be associated with worse patient-reported outcomes (including health status, lupus activity, pain, fatigue and sleep problems) among this group of women with SLE, even after taking

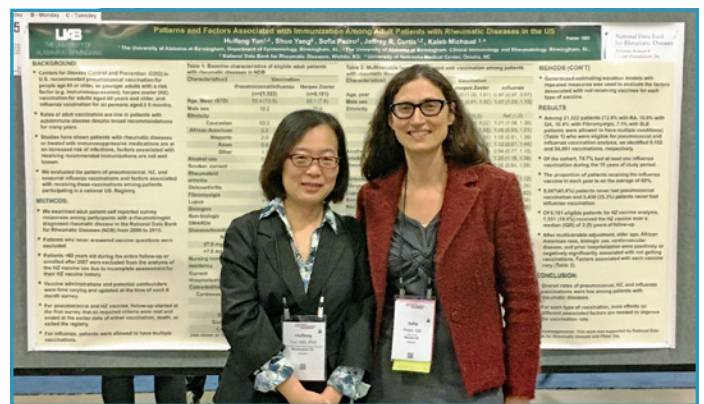
out those patients who noted they were a current or former smoker and had COPD or asthma.



Dr. Katz presenting the Breathlessness poster at the ACR Meeting.

Patterns and Factors Associated with Immunization Among Adult Patients with Rheumatic Diseases in the US

Rates of adult vaccinations are low in patients with autoimmune disease despite broad recommendations for many years. Dr. Huifeng Yun from the University of Alabama at Birmingham (UAB), along with the NDB, examined 21,522 NDB patients who were eligible for pneumonia and influenza vaccinations analysis. Of this group of patients, 74.7% had at least 1 influenza vaccination during the 10 years of study period and an average of 60% received it each year. Regarding pneumonia vaccination, 45.8% never had the vaccination. Patients who were older, African Americans, used a biologic, have cardiovascular disease, and prior hospitalization tended to receive the vaccinations.



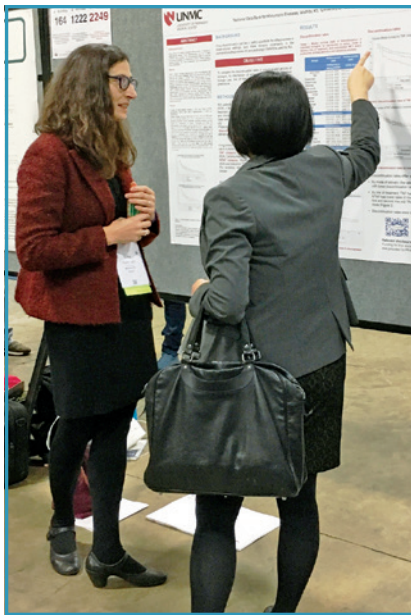
Dr. Yun of UAB and Sofia Pedro of NDB at the Immunization poster.

Comparison of Discontinuation Rates Among Patients with Rheumatoid Arthritis (RA) Initiating Biologics

Using the NDB data and looking at a total of 2,458 patients, we looked at discontinuation, defined as either stopping the drug or adding another Disease-Modifying Antirheumatic Drug (DMARD), of the biologics. As more medication op-

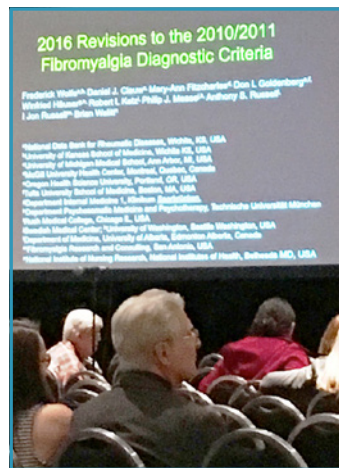
tions became available over the past decade, discontinuation rates of biologics for patients with RA have increased and have become more similar among the drugs. We also found rate to decrease when biologics were taken without methotrexate, but further research needs to be done on this.

NDB statistician and researcher, Sofia Pedro, presenting at the ACR.



2016 Revisions to the 2010/2011 Fibromyalgia Diagnostic Criteria

Dr. Fred Wolfe of the NDB and many other Fibromyalgia Experts worked together and updated the Fibromyalgia Diagnostic Criteria. Previous criteria are valid, reliable, and widely used for fibromyalgia diagnosis and this updated the criteria to address problems and provide further guidelines for use by rheumatologists and other physicians. The physician-based criteria are valid for individual patient diagnosis. The patient self report version of the criteria are not valid for clinical diagnosis in individual patients, but are valid for research studies.



Dr. Wolfe presenting the Fibromyalgia Diagnostic Criteria Revisions at the ACR.



Trends and Determinants of Osteoporosis (OP) Prevention and Management in Patients with Rheumatoid Arthritis Compared to Osteoarthritis

Dr. Gulsen Ozen and other researchers from other universities and the NDB reviewed data from RA and OA patients that had more than 1 year of participation in the NDB. They found that OP management care is slightly higher in RA patients compared to OA. Despite the availability of advanced treatments, the care for OP has not been improving, which may be due to both patient (unwillingness to take more drugs, cost) and physician barriers (lack of time, and focusing more on disease activity and other health conditions).

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 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 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.

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 some revisions to the 6-month questionnaire again with the help of Dr. Katz to help in testing different questions to find the best sets of items for researchers and health professionals to use in treating 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 1,700 enrollees. Participants originate from 25 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.

Plans are underway for the other half of this study: finding a blood test for Dupuytren disease—a biomarker. The most promising tests are not done by standard laboratories. Some are very expensive. To keep costs down, this part of the study will be rolled out in stages as biomarkers are evaluated and the list narrowed down. More details will be released as the launch of the first stage nears.

This is all very exciting: a new era for Dupuytren research with the promise of new ways to evaluate Dupuytren disease and to speed up the process of developing preventative treatments.

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



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.

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.

Participants are always asking us on where to find brochures or information about their arthritis diagnosis. Disease Specific non-profits and organizations are always the best to go to, but here are a couple of organizations and links to their sites that provide information about all arthritis diagnoses:

- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS): https://www.niams.nih.gov/Health_Info/default.asp
- American College of Rheumatology (ACR): <http://www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions>
- Mayo Clinic: <http://www.mayoclinic.org/diseases-conditions>

Arthritis Internet Registry (AIR) News



AIR is a ground-breaking internet-based patient registry and biospecimen collection using the

combination of the patient-study infrastructure of the NDB 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 6,563 participants join and we have collected 1,389 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

Starting in 2017, there will be an online enrollment form for Viral Arthritis patients. 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 patient to help aid in the research.

If you know anyone that may have been diagnoses 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.

Prize Drawing Winners!

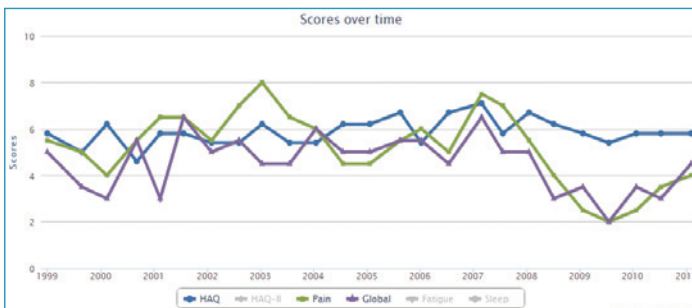
The research data bank can best contribute to research when the questionnaires are completed and returned as soon as possible. We conduct the random drawings as a token of our gratitude in help with rheumatology research. Our random drawings consist of:

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.

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!



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.

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>

FOR MORE INFORMATION OR TO PARTICIPATE

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