

FORWARD

WINTER
2018

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

Latest Research
and Current Projects

Frequently Asked
Questions

Looking Back & Moving Forward

Forward Questionnaire

Tailored to Your
Primary Diagnosis

Read more on page 10 >

Letter from the Co-Director

Dear Reader,
We hope you enjoyed reading the previous issue of our newsletter. With this issue, we hope you'll gain a greater insight into Forward™—The National Databank for Rheumatic Diseases, the largest patient-powered study of rheumatic diseases.

Patients who enroll in a registry live longer than those who don't—this is a fundamental truth that drives us Forward. It is why we are so relentless in our search for answers that others cannot find. It is why we seek to grow our collective knowledge base by learning from the past to understand the future, drawing unparalleled insight from the tapestry of life's journey. It is why we continue to reach beyond the boundaries of what's comfortable or possible.

In these pages, you'll find frequently asked questions about Forward questionnaires, important reminders about how to get the most from joining the registry, and information about the research studies you've contributed to by participating. In a special feature (p. 7–9), we take time to both reflect upon the history of the NDB and share our new vision for the future, including our new name, **Forward**.

Thank you for your continued participation and support. It's because of you that we are able to provide important data to the researchers and specialists who shape treatments and improve health outcomes for those living with rheumatic diseases. Let's move Forward.

Sincerely,

Kaleb Michaud, PhD
Co-Director, FORWARD



In This Issue

- 3 **Arthritis Internet Registry (AIR) News**
- 4 **New Items in the Questionnaire**
- 6 **Supporting Forward**
- 7 **Feature: Looking Back, Looking Forward**
- 10 **Primary Diagnosis**
- 11 **Frequently Asked Questions**

Join Us on Facebook & Twitter

Currently, 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 Forward staff who have joined our group. For those that may be on Twitter but not on Facebook, we will be tweeting news items on Twitter as **@ndb_org**



**NATIONAL DATA BANK
FOR RHEUMATIC DISEASES**



@ndb_org

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 Forward questionnaires, we hope to discover biological reasons why some treatments work better than others and why some are more toxic than others 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.**

ARTHRITIS Internet Registry

News from AIR

AIR, the Arthritis Internet Registry, is an internet-based patient registry and biospecimen collection that combines the patient-study infrastructure of Forward and the nationwide availability of Quest Diagnostics blood collection sites. Participants in AIR complete the same questionnaires as the participants in the Forward Databank, but are noted as AIR participants due to the way they enrolled. Some AIR participants consent to donate blood samples for the biospecimen collection.

To date, 6,720 participants have joined us, helping us collect 1,486 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. Our purpose is to bring together a community of arthritis patients to enable discovery research and social networking via the internet.

Latest Research from AIR

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

If you know anyone that may have been diagnosed with Zika, Chikungunya, or another viral illness that caused 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, Forward and the University of Nebraska Medical Center
- + Stanley J. Naides, MD, Quest Diagnostics Nichols Institute

WELCOME
NEW
PARTICIPANTS!

Thank You Participants for Your Time and Voice!

EVERYONE WHO WORKS WITH FORWARD, and all the doctors and researchers who benefit from our research, are extremely grateful for your dedication in helping with this project. Many of you have been with us for several years. But every six months, we are also glad to see many new people join us. Here is a quick primer on Forward for the newcomers.

Forward is a nonprofit organization that studies rheumatoid arthritis, osteoarthritis, fibromyalgia, lupus, psoriatic arthritis, gout, and other rheumatic diseases. Our research is designed to improve the treatment and outcomes of these conditions.

We are an independent organization that conducts its own research without influence from pharmaceutical, insurance, or financial companies, or other outside interests. Our research is so well respected that we are often hired to provide independent drug safety verification to the government.

If you participate in our studies, your personal information will always remain private. We do not sell or share any identifying information about Forward 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.

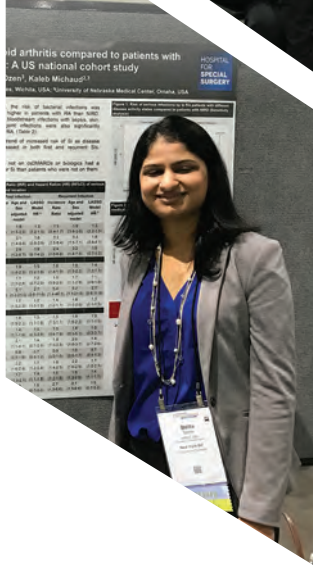
Nearly all of our research is available for you to read on our website. We should note, however, that while we are glad to answer your general questions about rheumatic diseases, we are not able to give personal medical advice.

Forward is different from other rheumatic disease databanks in that 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 ours.

WELCOME TO FORWARD, OR THANKS AGAIN FOR YOUR CONTINUING PARTICIPATION! IF YOU EVER HAVE ANY QUESTIONS OR NEED HELP WITH YOUR QUESTIONNAIRE, PLEASE CONTACT US BY EMAIL AT WEBQUEST@NDB.ORG OR CALL US AT 1-800-323-5871.

news

FORWARD'S CO-DIRECTOR KALEB MICHAUD, PHD, AND STATISTICIAN AND RESEARCHER SOFIA PEDRO, MS, PRESENTING A POSTER AT THE 2017 ACR/ARHP ANNUAL MEETING.



PATRICIA KATZ, PHD, ALEXIS OGDIE, MD, AND KALEB MICHAUD, PHD, AT THE FORWARD BOOTH AT THE 2017 ACR/ARHP ANNUAL MEETING DISCUSSING RESEARCH PROJECTS AND QUESTIONNAIRES.



BELLA MEHTA, MD, RESEARCHER AT HSS (HOSPITAL FOR SPECIAL SURGERY IN NYC), PRESENTING HER POSTER AT THE 2017 ACR/ARHP ANNUAL MEETING.

Recent Research

OUR MOST RECENT RESEARCH RESULTS

Are RA Patients at a Higher Risk for Car Accidents?

In a study with a total of 37,743 patients, we found evidence that suggests loss of independence and reduced hand mobility may be linked with poor driving and vehicle accidents.

Concomitant Hydroxychloroquine Impact on Anti-TNF Persistence in Patients with Rheumatoid Arthritis

In a study of 8611 patients, we found combining hydroxychloroquine (HCQ) with TNFi's such as etanercept, infliximab, and adalimumab increases efficacy of drug treatment.

Medications Associated with Osteoporotic Fracture Risk in Patients with Rheumatoid Arthritis

Some anti-depressant medications (SSRI) and opioids (narcotic pain relievers) were found to be linked with higher osteoporotic fracture risk in people with RA. This may be due to an association between use of

these medications and increased fall risk. When managing pain with opioids, clinicians should be aware of fracture risk.

Real-World Oral Methotrexate Adherence Measured Electronically in Patients with Established Rheumatoid Arthritis

Patients taking methotrexate were monitored using a remote electronic Medication Event Monitoring System. About half had adherence issues with methotrexate. We will need larger and longer follow-ups to improve methotrexate adherence.

Risk of Serious Infection in Patients with Rheumatoid Arthritis Treated with Biologic Vs. Non-Biologic DMARDs

Biologics were associated with increased risk of serious infections compared to conventional non-biologic DMARDs (disease-modifying antirheumatic drugs). Other factors that affect infection risk include old age, comorbidity burden, pulmonary disease, higher disability, disease activity, and cumulative glucocorticoid exposure.

Serious Infection Risk in Patients with Rheumatoid Arthritis Compared to Patients with Non-Inflammatory Rheumatic Diseases: A US National Cohort Study

People living with rheumatoid arthritis are at a higher risk of serious infections compared to people with non-inflammatory rheumatic diseases such as osteoarthritis. In people with RA, serious infections may be caused by the disease itself, comorbid conditions, or medications.

The Lasso Selection Model in Rheumatology Epidemiologic Studies

LASSO represents a powerful but rarely applied method to select models for epidemiologic analysis. Compared to current strategies, LASSO is less variable and still provides interpretable models.

What Does It Mean to Have Rheumatoid Arthritis Now? A Current Burden of Disease Assessment in the United States

Even in this era of effective new treatments, the burden of living with RA is still severe and important.

THANK YOU VERY MUCH TO THE FORWARD PARTICIPANTS & RESEARCHERS—THIS COULD NOT BE DONE WITHOUT YOU!

New Items in the Questionnaire

WE RECENTLY PRESENTED RESEARCH on Rheumatoid Arthritis (RA) and the possible higher risk for car accidents. The data we used for this research was from hospital records and did show that involvement in car accidents was linked to reduced hand mobility, an outcome that is associated with RA disease activity. We want to understand more about this and the importance of driving in your life, so we have added a couple of driving questions in this current questionnaire to help with this research.

In addition, Forward is working on new research with the University of Nebraska Medical Center (UNMC), who have received a grant to test RA and osteoarthritis patients in cars and car simulators—the very first grant of its kind! Together, the data from both research projects will help to get a better understanding on how arthritis may affect vehicle driving and if improving it may reduce accidents.

We have also added and revised some questions about pain. We're trying to understand what most people consider to be an acceptable level of pain. Each person is different, and in this time of extra concern about pain medications, we want to get a better sense of patients' expectations so doctors can respond appropriately.

We appreciate all of your comments and suggestions, as it is not only researchers that are interested in this information, but also many of you, our participants in Forward.

Prize Drawing Winners!

The Forward Databank can best contribute to research when 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 of \$1,000 each for those who complete a large questionnaire via mail, web or phone within the first 4 weeks.
- + 2 drawings of \$500 each for those who complete a large questionnaire via mail, web, or phone any time within the 6 months.
- + 4 drawings of \$50 each for those who complete a shorter questionnaire via mail or phone anytime within the 6 months.

Spondyloarthritis: A New Research Questionnaire

What is spondyloarthritis? Spondyloarthritis is a type of inflammatory rheumatic disease that affects the entheses (the sites where ligaments and tendons attach to bones) and causes arthritis. People with spondyloarthritis often experience inflammation that causes pain and stiffness, often of the spine, though some forms can affect the hands, feet, arms, and legs. Spondyloarthritis can also lead to bone destruction, causing deformities of the spine and poor function of the shoulders and hips.

What diagnoses are part of the spondyloarthritis family? Spondyloarthritis, psoriatic arthritis, ankylosing spondylitis, reactive arthritis (formerly termed Reiter's syndrome), axial spondylitis, spondyloarthropathy, and inflammatory bowel disease-associated arthritis (includes Crohn's and ulcerative colitis).

Participants of Forward that have spondyloarthritis listed as their main diagnosis will be receiving a questionnaire that has "spondyloarthritis" on the cover. This questionnaire was needed to be able to ask the certain questions that only relate to this diagnosis and will be very important in helping with the research for new medications and treatments of spondyloarthritis.

For more information on spondyloarthritis, visit <https://www.spondylitis.org/About-Spondylitis>.



Support Rheumatic Disease Research with a Financial Donation

As a nonprofit project conducting ongoing research to improve conditions for people with arthritis, fibromyalgia, lupus, and other conditions, Forward is an organization with ongoing financial needs.

If you would like to make or bequest a tax-deductible monetary donation to Forward 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 can 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!

KEEP
THIS
IN MIND

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.

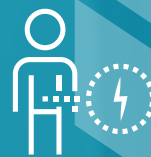
The Medical Information Release form is completely optional and does not need to be signed to be able to participate in the research. We use the medical records to help validate medical events that may be related to rheumatic diseases or the safety of medical treatments. The value of the research and 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 Databank. Your information is always confidential, and your participation is extremely valuable to the research with or without the signed medical information release form.

WAYS
TO HELP
FORWARD



LOOKING BACK MOVING FORWARD

MEET FORWARD—THE NEW FACE AND NAME OF THE NATIONAL DATABANK FOR RHEUMATIC DISEASES (NDB), THE LARGEST ONGOING STUDY OF ITS KIND.



277

CONDITIONS STUDIED



100+

CO-AUTHORS OF STUDIES



43

YEARS SPENT
CONDUCTING STUDY



30+

UNIVERSITY, PARTNER AND
COUNTRY COLLABORATIONS

RESEARCH

LOOKING BACK. MOVING FORWARD

AFTER ALMOST 20 YEARS OF LEADERSHIP serving patients living with rheumatoid arthritis, we took some time to reflect on where we started, where we've been, and where we're going.

Looking Back

We began our journey in 1998, when Dr. Frederick Wolfe had a vision to create a large, comprehensive database that covers both clinical and quality-of-life measurements over a long time. Such a database would benefit patients' lives in the long run and provide insights that are difficult to find using traditional, short-duration studies.

What started as just a vision has grown tremendously. Dr. Wolfe started the National Databank for Rheumatic Diseases (NDB) by writing to 900 rheumatologists, encouraging them to invite their patients to participate. Fast-forward to today, and

more than 10,000 people actively contribute to research in rheumatoid arthritis, lupus, fibromyalgia, Dupuytren's, and more than 60 other rheumatic diseases.

Thanks to the valuable contributions of patients, the NDB has advanced our understanding of rheumatic diseases—researchers have been able to evaluate drug safety, drug effectiveness, and long-term outcomes. Patients who participate in the registry also benefit, as registry participants live longer lives.

Looking Forward

Looking at our accomplishments over the past 20 years, it would be all too easy to pat ourselves on our back. Nevertheless, like all things in life, there's always room for improvement.

This year, we decided to look inward and ask ourselves and our partners some tough questions. Who are we? What do we stand for? What do we want our future to look like? And how do we best serve our patients' needs?

Our answer is **Forward**, the new face of the National Databank for Rheumatic Diseases. Simply put, Forward is our organization's core mission over the last 20 years—to advance research and discovery in Rheumatology and beyond through human connection and deep insight.

Forward takes everything that the NDB stands for and focuses those efforts to bridge the gap between human needs and scientific discovery. As always, our approach to research is rooted in meaningful human connections, enabling groundbreaking treatments and therapies that defy the odds and rejuvenate lives. With this new identity, we aim to inspire the next generation of researchers and specialists and provide hope that one day, we can enjoy a life free of pain.

As we look Forward, we hope to accomplish as much in the next 20 years as we have in the previous 20. We hope you join us as we work together in our strive towards a cure.

A HISTORY OF THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

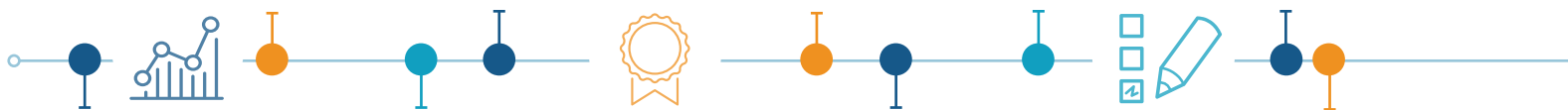
1974: Frederick Wolfe, MD, a rheumatologist in Wichita, KS, establishes the first rheumatology clinic to collect patient data using a computerized database.

1995: Dr. Wolfe receives ACR Distinguished Rheumatologist Award.

1998: The National Data Bank for Rheumatic Diseases (NDB) is established by Dr. Wolfe.

2001: Dr. Wolfe becomes an ACR Master for outstanding contributions to the field of rheumatology.

2002: NDB establishes expanded international databanks with assessments available in English, French, Spanish, Portuguese, and Zulu.



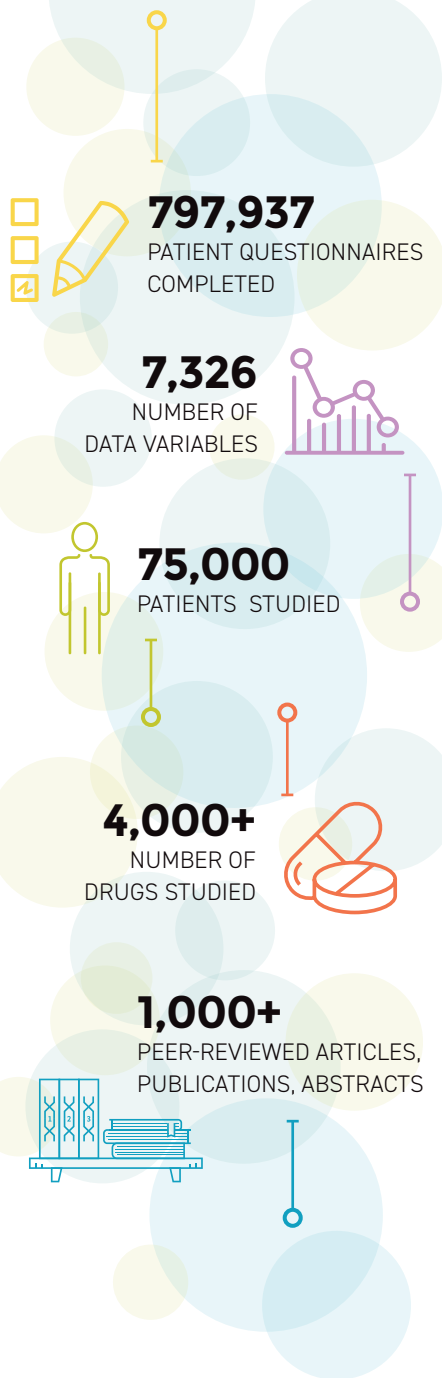
1960s: Donald Mitchell, MD, professor of medicine at the University of Saskatchewan, and Joseph Levinson, MD, professor emeritus of medicine and pediatrics at the University of Cincinnati, begin collecting and storing patient data.

1975: The first large-scale database system for chronic diseases is established by Doctors Wolfe, Fries, Mitchell, Levinson and Medsger, who combined their data to create a fledgling system that evolved into ARAMIS (Arthritis, Rheumatism, and Aging Medical Information System).

2000: ClinHAQ/FAXBack questionnaire systems are introduced to streamline the collection of patient data.

2002: NDB makes comprehensive patient questionnaires available online, making it easier than ever for patients to participate.

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 Forward Databank.

With the help of Dr. Katz, we have made revisions to the six-month questionnaire in order to help with several projects that may improve treatments and care for patients with any rheumatic disease, including lupus.

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

The International Dupuytren Data Bank is steadily growing and currently has over 2,600 enrollees. The first phase of the IDDB is collecting information on Dupuytren disease sufferers, and the second phase is to collect blood samples from enrollees to develop a blood test for Dupuytren disease.

Routine blood tests aren't affected by Dupuytren, so we have to check non-routine tests. This is a difficult challenge, which is why there is not yet a Dupuytren blood test. We're meeting this challenge with two of the newest techniques in biologic research, systems biology and aptamer-based assays.

Systems biology studies the ways that many different factors—genes, proteins, biologic byproducts, and others— influence each other. Aptamer assays, originally developed to do DNA testing, can test hundreds of circulating proteins at the same time for less cost than would be needed for conventional testing.

The combination of systems biology and aptamer assays is a potential breakthrough toward a Dupuytren blood test. There's work to be done sorting out the details, but we're working hard, and prospects are good for the first set of blood testing to begin in 2018. Very exciting!

Charles Eaton, MD
Executive Director, Dupuytren Foundation



2004: HAQ-II—an updated questionnaire that handles more dimensions of health and provides more clinical information—is developed.

2005: PAS (Patient Activity Scale) and PAS-II developed—establishing the foundation for the RAPID3 index.

2007: Dr. Wolfe presents biologic pharmacovigilance results to FDA.

2011: NDB's Arthritis Internet Registry (AIR) starts to recruit patients, collect biosamples.

2016: Dr. Michaud receives Distinguished Scholar Award from ARHP.

2003-2005: CHORD Research Fellowship directed by Doctors Wolfe, Choi, and Pincus with 45 rheumatology fellows conducting research with NDB data.

2004: NDB launches thrice-daily PDA study on biologic efficacy.

2006: NDB asked by the United States Congress to conduct a cost-effectiveness analysis (CEA) for biologics.

2010: Kaleb Michaud, PhD, appointed as co-director of the NDB.

2012: NDB launches smartphone study with Ginger.io



**DR. ALEXIS
OGDIE**

is Assistant Professor of Medicine and Epidemiology at the Perelman School of Medicine, University of Pennsylvania. She is an expert in the care of patients with spondyloarthritis (SpA) and is the founder and Director of the Penn Psoriatic Arthritis and Spondyloarthritis Program. Dr. Ogdie completed a Master of Science in Clinical Epidemiology in order to design observational studies of SpA. The goals of her research are to:

- 1) determine how to best measure response to therapy in spondyloarthritis,
- 2) develop treatment strategies for psoriatic arthritis to improve patient outcomes, and
- 3) understand the triggers that lead to the development of psoriatic arthritis.

Forward Questionnaires & Primary Diagnosis

You may have noticed that the cover of each paper questionnaire that is mailed out states a diagnosis, be it Rheumatic Diseases, OA, Lupus, or Gout. Over the years, as Forward has been able to work with diagnostic experts, we have added to our Rheumatic Diseases questionnaire to ask more specific questions for certain diagnoses. We wish we could have a questionnaire for each and every diagnosis, and are adding more in the future, but we currently offer the following questionnaires:

- + **OA** is sent to people with osteoarthritis and includes the majority of the questions in the Rheumatic Diseases questionnaire, along with 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.
- + **SPONDYLOARTHRITIS** (our newest questionnaire) is sent to people with spondyloarthritis, psoriatic arthritis, and ankylosing spondylitis, and includes additional questions about spondyloarthritis. These questions have been developed with Dr. Alexis Ogdie, Assistant Professor of Medicine and Epidemiology at the Perelman School of Medicine, University of Pennsylvania.
- + **RHEUMATIC DISEASES** is sent to all RA and fibromyalgia patients and those with diagnoses not listed above (e.g., lower back pain, polyarthralgia, etc.). This questionnaire 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**.



View Your Forward Databank 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 your scores any time you need them on our website. If you don't already have an account on our website, register today at 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 Forward Databank, as well as 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.



Frequently Asked Questions

Every six months, we send our questionnaires to you, our great participants who volunteer your time to add your voice and information to the Forward Databank. Forward is not only driven by the staff, but also by our participants that help with the research, whether completing the questionnaires to add data to the Databank, working directly with projects at Forward, serving on our advisory board, or by staying in touch through emails, phone calls, letters, or the comment section on our forms. Each and every message we receive is read, and these comments often lead to changes to the questionnaire or provide an idea for a research project. Over the years, we have gotten some recurring comments/suggestions/questions that are asked every six months or so, and we would like to share these with all of you to provide more information about Forward and why your participation is very important and greatly appreciated.

“How does enrolling in the research study help?”

For example, research from this project helped doctors understand that drugs are now the major cost in RA instead of hospitalization and medical care, how to recognize significant improvement in a patient's condition, and the safety and side effects of numerous drugs. Using your answers and those of thousands of other patients, we are able to advise doctors and lawmakers about drug safety and the likelihood of side effects. Our research does shape the treatment and medications used in arthritis and other rheumatic diseases. This is a slow and ongoing process, and your help is an important part of it.

“How do I know which diagnosis is my primary diagnosis?”

Your primary diagnosis is mostly up to you—whichever you consider the most important. You can decide based on how much trouble each one gives you, or money and time you have to spend on treatment, or any other considerations. However, by looking at the medications you take we may decide to place you in a diagnosis. For example, because RA medications are mostly unique to RA, if you are taking those you will probably stay in the RA group. Also, the questionnaires for all the diseases we cover are very similar.



Helping Forward in Other Ways

Achieving Forward's goals of telling the rheumatology community about patient experience depends on a large group of participants. Available for your arthritis, fibromyalgia, or lupus support group or 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 Forward. Just contact us at info@ndb.org or **800-323-5871** ext. 133. Thank you!

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 18 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!

For More Information or to Participate

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Please call 1-800-323-5871 or email info@ndb.org

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