

FORWARD

FALL
2018

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

**The Latest
FORWARD
Research**

**Battling
Brain Fog?**

Learn more
on page 4 >

CELEBRATING
20 YEARS
OF FORWARD

**INSIGHTS
into Your
Chronic Illness**



welcome

Letter from the Co-Director

Dear Reader,

Hello, and thanks for picking up this latest edition of FORWARD magazine. I'm thrilled to share with you that we, and all of the participating patients, researchers, and physicians that make up the FORWARD family, are currently celebrating the 20th anniversary of The National Databank for Rheumatic Diseases (FORWARD).

Since its founding in 1998, FORWARD has been representing the patient voice in rheumatic disease research, thanks to the efforts of our founder Dr. Frederick Wolfe. Dr. Wolfe saw the need to see what was happening to patients outside of the clinic, and FORWARD has been following that mission for the past 20 years. In this issue, you'll find an exploration of FORWARD's history with both patients and researchers and hear from some of the FORWARD team members who spend their days making this study possible.

We hope that this issue will inspire you, the individuals who make everything we do possible. Without people like you who are willing to give their time, effort, and energy into answering the FORWARD questionnaires, we would not have the pleasure of adding to and supporting the research and understanding of the diagnosis, treatment, and prevention of rheumatic diseases. To all of our participants: thank you for your support! We can't wait to have another 20 years with you.

Sincerely,

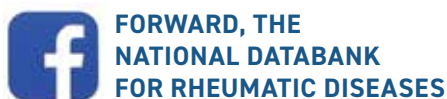
Kaleb Michaud, PhD
Co-Director, FORWARD

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Join Us on Facebook & Twitter

Currently, you can find us on Facebook as "**FORWARD, the National Databank 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](https://twitter.com/ndb_org).



New Study for FORWARD Participants

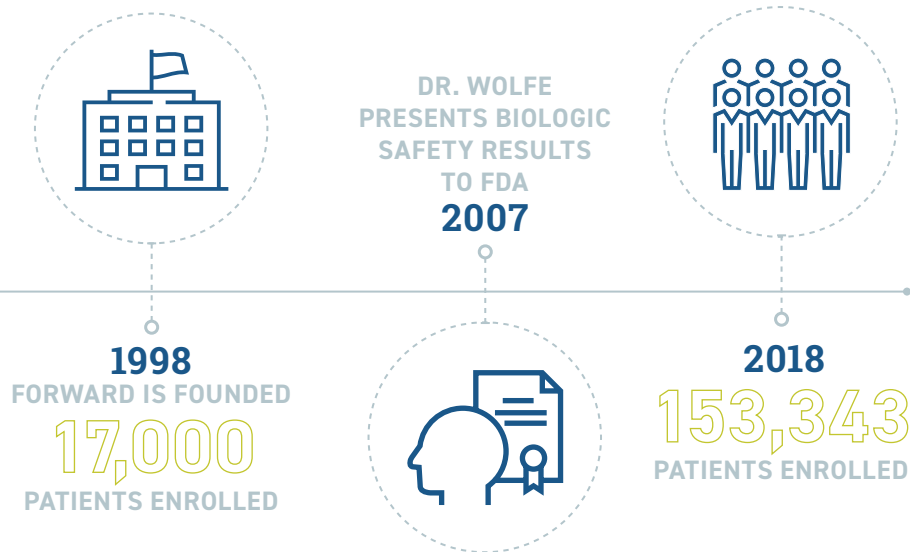
Are you starting or have you recently started one of the following medications?

- + **XELJANZ (TOFACITINIB)**
- + **ENBREL (ETANERCEPT)**
- + **HUMIRA (ADALIMUMAB)**
- + **SIMPONI (GOLIMUMAB)**

We have started a new study using a remote electronic Medication Event Monitoring System (MEMS) device to measure medication adherence (taking your medication as directed). The MEMS device is a cap on a medicine bottle that notes the day and time when the cap has been removed and put back on the bottle.

If you would like to know more, please contact us by email at info@ndb.org or by calling **1-800-323-5871, ext. 143**.





Thank You 20-Year Participants

FORWARD is excited to extend a special thank you to all of the National Databank for Rheumatic Diseases participants. This year, we've officially been contributing to and impacting research into the diagnosis, treatment, and prevention of rheumatic diseases for 20 years. None of this would be possible without the incredible participants who so graciously share their experiences with us by filling out the FORWARD questionnaire every six months.

For newcomers, here is a quick primer on FORWARD. FORWARD is a nonprofit organization, independent from pharmaceutical, insurance, or financial companies, dedicated to studying 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.**

You can also benefit rheumatic disease research by participating. Every 6 months, FORWARD provides participants with a questionnaire where you'll be asked to reflect on your condition and symptoms over the past six months. You can fill out a paper copy of the questionnaire, or do it online, in your own time. **By participating, you'll be helping to improve the treatment and outcome of rheumatic diseases.**

Don't worry—your personal information will always remain private, because FORWARD doesn't share identifying information about its participants. Before we work with researchers, we make sure to remove any information that could be used to identify you in your questionnaire.

FORWARD is different than other rheumatic disease databanks because all of FORWARD's data is patient-reported—meaning that it comes directly from you, rather than a doctor or clinical staff. This gives researchers a perspective that short, small clinical trials cannot provide. Our long-term study offers a **patient-focused** approach to research, providing a much broader view of treatment and results and the way that they effect patient's lives.

Research depends on patients like you sharing their experiences to improve the treatments and outcomes of rheumatic diseases. **Welcome to FORWARD, and to all of our current, past, and future participants: thank you. Your dedication and support are making a difference.**

ARTHRITIS Internet Registry

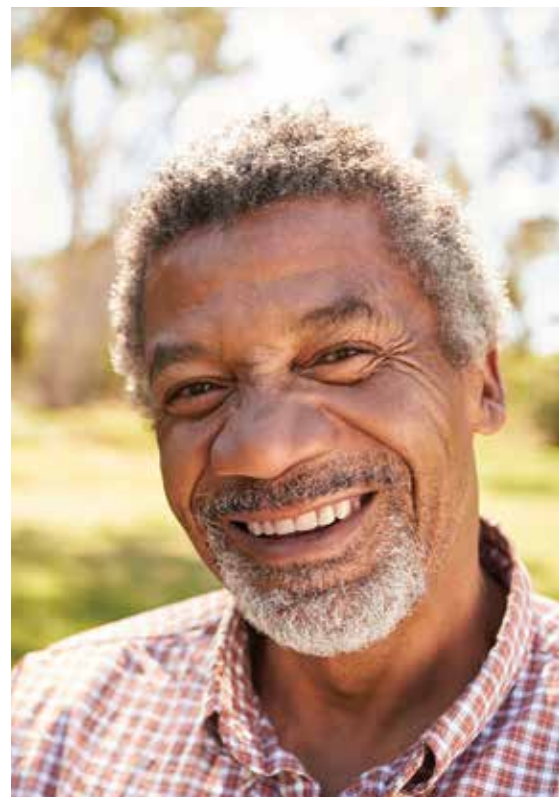
Give Blood for Research

Participants in Arthritis Internet Registry (AIR) complete the same questionnaires as the participants in FORWARD, but many also donate biospecimens, including blood samples, at one of several Quest Diagnostics laboratory sites across the US.

By analyzing participants' blood in combination with their answers to the FORWARD questionnaires, we hope to discover biological reasons why some treatments work better than others. To date, we have had 6,777 participants join, and we have collected 1,532 biospecimens on a variety of rheumatic diseases.

If you wish to join AIR, as always, your privacy will be protected, and there is absolutely no cost to you. Your lab results will be available directly to you—you can even print out the lab results and take them with you to your next doctor's appointment.

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.



insights



“Just a Suggestion...”

Ever get tired of people who don't have a chronic illness offering you unsolicited suggestions for ways to improve your illness? Here are three common comments and how you can respond to and reframe them.

HAVE YOU TRIED...?

Often, people who aren't sick underestimate the amount of time people with chronic illnesses spend researching their illness. Trying to be helpful, they'll often suggest an “herbal remedy” that “worked for my cousin's wife” so you can “ask your doctor!” You can reply to these comments with “Thanks, good to know.”

YOU DON'T LOOK SICK TO ME!

This comment can be especially draining to hear, but often it is meant as a compliment. Sometimes people are trying to understand your chronic illness, but don't know how to ask about it. When faced with this comment, a simple “Thanks” can help with changing the subject. Letting others know about your journey with your chronic illness can also help them to understand more about it.

JUST THINK POSITIVE

The “just think positive” tends to be a response from others who don't want to hear about your problems—or they've heard you and they're really trying to encourage you to go in a different direction. Remember that you are entitled to feel however you feel about your illness.

Ultimately, the choice is yours whether to deflect comments or address them. Remember, the people in your life who are supportive make all the difference.



BRAIN FOG Getting You Down?

Have you ever walked into a room and thought, “Wait, why did I come in here?” This common situation may feel especially familiar to individuals with rheumatic diseases. If you have RA or another rheumatic disease, you've likely found yourself feeling extra forgetful, having trouble concentrating, or struggling to think through problems as clearly as you once did.

Many researchers agree—these symptoms are related to the impact of inflammation on the brain. In fact, a recent study from Michigan Medicine's Chronic Pain and Fatigue Research Center highlighted specific areas of the brain that can be studied further to gain more information about and potentially develop treatments for these symptoms. Sometimes, feeling forgetful is just normal—it can be related to stress, medications, and various other factors, too.

WHAT YOU CAN DO ABOUT BRAIN FOG

Talk to your doctor: Certain RA treatments have been shown to help with brain fog. Your doctor can help you decide if one of these is right for you and can potentially suggest other treatment options.

Get some sleep: Feeling disoriented after a night of little to no sleep can make regular brain fog even worse. Taking this step to limit additional brain fog can help you stay on your toes during a busy day.

Make a plan: Use the tools available to you to take remembering out of the equation—create well organized files for documents that are clearly labeled and set reminders on your phone calendar.

Exercise: Getting some exercise can help you clear your head. Take a break and go for a walk around the house or outside to relax.

Participating in FORWARD gives researchers the information they need to advance research about rheumatic diseases. Ready to make your voice heard? Contact us at **1-800-323-5871** today.

CELEBRATING 20 YEARS

of Patient-Focused Research



Without your voice and every other FORWARD participant's voice, we wouldn't be able to celebrate 20 years of contributing to the diagnosis, treatment, and prevention of rheumatic diseases.



LET'S KEEP RHEUMATIC DISEASE RESEARCH MOVING FORWARD— TOGETHER

TO DATE, FORWARD participants have contributed to research for the following rheumatic diseases:

- + Rheumatoid Arthritis
- + Osteoarthritis
- + Fibromyalgia
- + Lupus
- + Dupuytren's Disease
- + Psoriatic Arthritis
- + Juvenile Idiopathic Arthritis (JIA)
- + Gout
- + Ankylosing Spondylitis and many more!

Are you ready to add your voice to rheumatic disease research? Join FORWARD in improving the diagnosis, treatment, and prevention of rheumatic diseases by visiting www.forwardndb.org or calling 1-800-323-5871.

SINCE DAY 1, patients have been the focus of the National Databank for Rheumatic Diseases (FORWARD). Even before the official founding of FORWARD, Frederick Wolfe, MD, knew that the patient's experience outside of the clinic was vital to the understanding of rheumatic diseases. That's why, in 1974 (44 years ago!), Dr. Wolfe stood at the head of patient-focused data collection by establishing the first rheumatology clinic to collect patient data using a computerized database. Only a year later, he joined forces with Drs. Fries, Mitchell, Levinson, and Medsger, who together combined their patient-focused data and created the fledgling databank, ARAMIS, that preceded FORWARD.

Even in these early days, Dr. Wolfe was focused on the patient experience—he found that ARAMIS had too few centers involved, that some of the data was incomplete or even out of date, and that the questionnaire focused too much on

in-clinic questions. Dr. Wolfe wanted to focus more on the patient's experience outside of the clinic—how their day-to-day lives were affected by their rheumatic disease and various treatments.

1998: FORWARD IS FOUNDED.

In 1998, Dr. Wolfe officially founded the National Databank for Rheumatic Diseases, now called FORWARD. After writing to over 900 other rheumatologists, Dr. Wolfe began collecting information from over 17,000 patients about their day-to-day experience with their rheumatic diseases, medications, pain levels, and various forms of therapy they've experienced.

Over the years, those 17,000 patients have grown to 153,343 patients, and each and every one of those patients is making an important contribution to the study of rheumatic diseases. As the founder of FORWARD, Dr. Wolfe has invested his life in connecting with patients and understanding their experience



**FORWARD'S ARTHRITIS
INTERNET REGISTRY (AIR)
STARTS TO RECRUIT PATIENTS
AND COLLECT BIOSAMPLES**

2011



**FORWARD
IS FOUNDED**

1998



outside of the clinic: "Rheumatologists develop lifelong relationships with their rheumatoid arthritis patients," says Dr. Wolfe. "We take a long look at the outcomes of these illnesses. This allows us to conduct observational studies that tell us, for example, how well a drug works under real-life circumstances, unlike clinical trials, which tell you only how well a drug can work under idealized circumstances."

2010: KALEB MICHAUD, PHD, IS APPOINTED AS CO-DIRECTOR.

In 2010, FORWARD took a big step and began looking forward and preparing for the future. Dr. Kaleb Michaud, who you may have read about in previous issues of FORWARD magazine, was appointed as co-director, alongside Dr. Wolfe, and began handling many aspects of the NDB. Dr. Wolfe, Dr. Michaud, and the FORWARD team have guided the NDB for the past eight years. The FORWARD team has, throughout the years, had the chance to get to

know the incredible group of people who are sharing their experiences with researchers to improve rheumatic disease research.

All FORWARD participants are providing a great service, and we've experienced incredible conversations with participants who call with questions about the questionnaire or who have trouble filling it out on their own. Many of these participants will ask to speak with certain FORWARD team members by name, year after year. We consider ourselves very lucky to have the chance to interact one-on-one with these incredible individuals who are willing to give their time and energy to add their voice to rheumatic disease research.

Rheumatic disease research has come far in the past 20 years, and so has FORWARD. We're grateful for the past 20 years of patient-focused research and data collection—and we can't wait to experience the next 20.

The Voices of FORWARD

"I send a card to every patient I speak with, as a compassionate gesture of support."

"Our participants are the best! They call to say thank you; send us pictures, letters, and comments to update us on how they are doing; and volunteer their time to help with the research. We wouldn't be here without them and their support."

"We are great at just being there for the patients and caring about what they go through."

"The work we do here is for a worthy cause and is very important. Also, the data that we collect from our participants all over the country is invaluable to helping us strive for a cure and treatment options for autoimmune diseases. We appreciate the dedication and efforts of all our participants in our ongoing study."

"The key to the longevity of our research is not only the accuracy and detail of the data collected, but to make sure each of our participants know that their input is valued."

"PATIENTS ARE THE LIFEBLOOD OF FORWARD."






"The data is a gift from the patient and we must treat it with great dignity and integrity."

"We would not be here without the ongoing support of the rheumatology community—the patients, doctors, nurses, clinic staff, researchers, universities, organizations, and industries. Their support is what makes us strive to be the best and to continue FORWARD on our journey to help rheumatic disease patients throughout the world."

research

- + There are **OVER 120** rheumatic/musculoskeletal disorders
- + There are approximately **4,000 BOARD-CERTIFIED RHEUMATOLOGISTS** in the US (and declining)
- + Over **54 MILLION** patients have rheumatic disorders
- + **ABOUT 1 OUT OF EVERY 5-10** visits to a primary care provider is for a rheumatic disorder
- + Arthritis/back pain is the **SECOND LEADING CAUSE** of a disability
- + There are **300,000 KIDS UNDER 16** with juvenile arthritis in the US
- + **APPROXIMATELY 30%** of working-age adults with arthritis are unable to work due to their disease
- + The number of patients diagnosed with a rheumatic disorder is projected to grow to **78 MILLION ADULTS** by 2040

IN THE PAST 20 YEARS, FORWARD PARTICIPANTS HAVE CONTRIBUTED TO

-  **277** CONDITIONS STUDIED
-  **75,000** PATIENTS STUDIED
-  **4,000** DRUGS STUDIED
-  **7,326** DATA VARIABLES
-  **1000+** PEER-REVIEWED ARTICLES, PUBLICATIONS, AND ABSTRACTS
-  **43** YEARS OF PATIENT-FOCUSED RESEARCH
-  **30+** UNIVERSITY, PARTNER, AND COUNTRY COLLABORATIONS
-  **797,937** PATIENT QUESTIONNAIRES COMPLETED



FORWARD Participants Making a Difference

Here are just a few of the important areas of research to which you contribute every time you fill out a FORWARD questionnaire:

Risk of Obstructive Sleep Apnea in Rheumatoid

Arthritis. Obstructive Sleep Apnea (OSA) is a relatively common disorder, but did you know that it's more common in individuals with RA than the rest of the population? Even accounting for common predictors of both RA and OSA, like age and weight, rheumatic disease activity is also associated with OSA. Why? OSA is linked to increased inflammation, so it can make RA symptoms worse.

Defining Pain That Does Not Interfere with Activities Among Rheumatoid Arthritis (RA)

Patients. How much does your RA pain affect your everyday activities and functioning? For every patient, it's different. Understanding the different ways that patients rate their pain and its impact on their life is necessary to improve function and RA treatment. Further research is needed to determine options to decrease the functional impact of pain.

Taking Care

Assisting someone with a rheumatic illness can be tough, given how unpredictable rheumatic illnesses can be and how much they affect day-to-day life. Whenever you assist a friend or family member with a rheumatic disease with day-to-day chores or projects, keep these tips in mind:

TAKE TIME FOR YOURSELF. As a caretaker, it's easy to get overwhelmed. Find ways to take time for yourself, whether that be going for a walk, taking a long bath, or scheduling an hour a day or a day or two each week to have someone else help out around the house. Use this time to focus on the things that you enjoy and recharge your energy levels.

DON'T DO IT ALL. Don't try to take on the burden of every emotional and physical need. Instead, establish resources that you and the person you help care for can turn to when you need

to. This may be a friend or neighbor to help with the cleaning when you're especially busy, or a therapist or support group for either of you to talk to.

CELEBRATE THE GOOD DAYS.

When someone has a rheumatic disease, tasks and activities that used to be simple can sometimes feel impossible. When you're spending time with your friend, partner, or family member with a rheumatic disease, help them celebrate and enjoy the "good days" when their pain and fatigue may be more manageable. This can be an exciting, relaxing, and enjoyable time for the both of you.

EDUCATE YOURSELF. If you're spending a significant amount of time with or caring for an individual with a rheumatic disease, understanding more about what's happening in their body can help you better understand their experience and how you can help them.



GET EDUCATED

Take a look below for some resources you can use to learn more about rheumatic disease.

1. **Rheumatologist**—If your spouse, family member, or close friend has a rheumatic disease, they may want you to go along with them to see their doctor, especially if you're assisting with medication or other treatments. Use those appointments to ask questions about how the disease may be affecting the patient's daily life and any questions or concerns you have about treatment options.
2. **Support groups**—You're supporting someone important to you. Why shouldn't you also receive some support as you play that role? There are support groups available for caretakers—you can find them on social media, or through non-profit organizations like The Arthritis Foundation.
3. **Online Resources**—The internet has plenty of information that you can use to educate yourself. While you can't trust everything you read online, here are some reliable options:
 - + American College of Rheumatology at rheumatology.org
 - + The Arthritis Foundation at arthritis.org
 - + Medical News Today at medicalnewstoday.com

WHAT
YOU NEED
TO KNOW

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 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, and 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.

I'm feeling better.

Do you still want my answers?

We're glad that your rheumatic disease isn't active at the moment! Ironically, it's when you're feeling good that we really need your participation so we can figure out what worked for you and whether it might apply to others, as well as compare any secondary conditions you might have with those of people who are not as healthy as you. If we only studied people who were feeling bad, it would be impossible to know what treatments work.

Conversely, people who come out of remission also provide a lot of valuable information. Of course, we hope your remission is very lengthy.

What does normal mean anyway?

Great question! You'll find that many of the questions are subjective. We want you to answer them from your perspective. For example, we're interested in whether something is heavy to you, not to Arnold Schwarzenegger. Likewise, unless the question says otherwise, we're interested in your current abilities, not those when you were younger or healthier. Normal is based completely on you and what you think is normal.

What happens to the information I provide?

The information you provide will be entered into a computer databank for use by medical researchers. Researchers describe their findings in articles that are published in medical journals and in presentations at national and international meetings. That way, all doctors who treat arthritis are able to receive the benefits of the research. What they learn will help them to provide better medical care to people with rheumatic diseases and similar medical conditions.

Some questions don't apply to me. How do I answer?

If you come across a question you don't understand or don't see how it applies to you, we'd suggest that you try to choose the choice that best fits how it might apply to you. We're always available to talk through the questions and your responses if you find that helpful. Otherwise, just know that we try to make sure the questions make sense for everyone and that all appropriate answers are listed. If not, simply select the best choice, even though it may not be completely correct for you.

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 forwardndb.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.

GO ONLINE
TO SEE
YOUR
RESULTS



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.

KEEP
THIS
IN MIND

Prize Drawing Winners!

FORWARD can best contribute to research when the questionnaires are completed and returned as soon as possible. We conduct 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 four weeks.
- + 2 drawings for **\$500 each** for those who complete a large questionnaire via mail, web, or phone any time within the first six months.
- + 4 drawings for **\$50 each** for those who complete a shorter questionnaire via mail or phone any-time within the first six months.

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 an 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 click **"Update Contact Info"** under the **"Participants"** tab. Of course, you can always email or call us, and we will change it for you. Thank you!

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 patient support groups/meetings, health fairs, offices, churches, or clinic waiting rooms—our pamphlets that explain what we do and how you and others can help. Each one has a postage-paid postcard to register and become a participant of FORWARD.



The pamphlets and a small tabletop stand are available free from FORWARD. Just contact us at info@ndb.org or **800-323-5871, ext. 133**. Thank you!

Refer a Friend

Here's a really easy way to let a friend know about the Databank. Just give us your friend's email address and we'll send out an email invitation to join the study. Go to forwardndb.org/participate/tell-friend.

About WebQuest

WebQuest is the online version of our questionnaire. The questions are the same as what you see on the paper questionnaire. People who are comfortable using computers may find it easier than the paper version. If you would like to try it, follow the links from our home page, forwardndb.org, and make the request, or send us an email at webquest@ndb.org.

Wait! We Want Your Voice To Be Heard!

We need your help in filling out our questionnaires. We are a nonprofit 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 fighting these diseases!

For More Information or to Participate

Arthritis Research Center Foundation, Inc.
1035 N Emporia | Suite 288 | Wichita, KS 67214
Please call 1-800-323-5871 or email info@ndb.org

Directors

Frederick Wolfe, MD
Kaleb Michaud, PhD

Executive Director

Rebecca Schumacher

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