How to Make Your Voice Heard
Learn more on page 7

Rheumatic Research
Insights into Your Chronic Illness

Forward March Self-Care
with Kaleb Michaud, PhD
Co-Director of FORWARD
Dear Reader,

I’m thrilled to share with you the latest edition of FORWARD magazine. Inside, you’ll meet two of our members, learn tips that can make your day-to-day life simpler, and get updates on the latest rheumatology research conducted through the FORWARD Databank. Of course, this research would be impossible without your help. Dr. Frederick Wolfe founded the Databank in 1998 because he saw a need to understand what was happening to patients beyond the clinic. Patients may leave clinics for any number of reasons (for example, moving, changing insurance, or switching doctors), but clinical studies can’t track what happens afterward. FORWARD is different—it’s an ongoing, collective Databank to which anyone with a rheumatic disease can contribute for as long as they choose. Everyone has a different experience, and we’ll never know whether treatments and lifestyle adjustments work unless we hear from you. Thank you for your continued participation in our study, and as you look through this magazine, I hope you find the knowledge and inspiration needed to take care of yourself and your illness.

Sincerely,

Kaleb Michaud, PhD
Co-Director, FORWARD

Join Us on Facebook & Twitter

Currently, you can find us on Facebook as “National Data Bank for Rheumatic Diseases.” We will 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

Spotlight on Nonprofits & Organizations

AMERICAN COLLEGE OF RHEUMATOLOGY (ACR)

The American College of Rheumatology (ACR) is a nonprofit organization with the divisions of the Association of Rheumatology Health Professional (ARHP) and the Rheumatology Research Foundation (RRF) that works to improve the care of patients with rheumatic diseases and advance rheumatology through doctors, health professionals, and scientists worldwide. The ACR has great information for patients and caregivers regarding various rheumatic diseases and treatments:

+ [rheumatology.org/I-Am-A/Patient-Caregiver](http://rheumatology.org/I-Am-A/Patient-Caregiver)

There are times a participant may need to find a doctor to help with their disease, whether they have moved or changed to a different health insurance plan, their current doctor has retired or moved, or they simply need to find a specialized doctor to help with their disease. Visit the links below from the ACR for more information about what a rheumatologist can do for you, as well as a search link to help find a specialized doctor:

+ [rheumatology.org/I-Am-A/Patient-Caregiver/Health-Care-Team/What-is-a-Rheumatologist](http://rheumatology.org/I-Am-A/Patient-Caregiver/Health-Care-Team/What-is-a-Rheumatologist)
+ [rheumatology.org/Directories/Find-a-Rheumatologist](http://rheumatology.org/Directories/Find-a-Rheumatologist)
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 6,740 participants join, and we have collected 1,506 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.

Here’s where our 30+ year participants come from

Thank You for 30 Years

The National Databank for Rheumatic Diseases (FORWARD) is excited to extend a special thank you to the 40 participants who have dedicated their time and effort to furthering rheumatoid disease research for over 30 years. These individuals began their journey with Dr. Wolfe, the founder of FORWARD, at his clinic in Wichita, KS. Since then, the patient databank and FORWARD’s contribution to research have grown an incredible amount, and we couldn’t have done it without these pioneering patients.

For newcomers, here is a quick primer on FORWARD. FORWARD is a nonprofit organization that is independent from pharmaceutical, insurance, or financial companies and 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 contribute to rheumatic disease research by participating. Every six months, FORWARD provides participants with a questionnaire in which 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.

FORWARD 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 treatments, results, and the way they affect 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 is making a difference.
Work Smarter, Not Harder

Maintaining a clean household with a chronic illness can seem like an impossible task. Here are some tips to help you illness-proof your to-do list.

+ **RAISE IT UP:** Wherever possible, make it so things are accessible without bending over. Store commonly-used cleaning products at waist height. Instead of using a standard sponge to clean your shower, try using a sponge mop. Use an easy-reach grabber to help you pick things up. If possible, have someone put your laundry machine on risers so that you aren’t bending over multiple times per load.

+ **BREAK IT DOWN:** Instead of tackling the whole house, set yourself an achievable goal for each day. Try splitting up rooms or doing one general cleaning task whenever your best time of day is. If you find yourself getting tired, take a break to conserve your energy and try again later.

+ **CUT THE CLUTTER:** Cleaning around and under knickknacks is significantly more difficult than cleaning a clear surface—if you have sentimental pieces, try to limit them to one area. Have designated places for other things that may pile up, like mail, shoes, and outerwear, and implement a household rule to ensure those immediately go into their designated space.

TO CONTINUE RECEIVING GREAT TIPS LIKE THESE, KEEP COMPLETING OUR SURVEYS. YOU’LL GET A NEW ISSUE EVERY 3 MONTHS AS A FREE GIFT.

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Following your doctor’s recommended medication schedule is vital to managing your chronic illness. Take a look at these free apps that can help you stick to your schedule.

**Medisafe:** With this app, you can easily set up even the most complicated medication reminder schedule. It will also inform you of any potential drug interactions, making it a great option for someone taking multiple medications.

**CareZone:** This app includes a journal where you can record your symptoms, as well as medication schedules and a calendar to keep track of appointments and prescription refills.

**Round Health:** This app is great for people with a shifting daily schedule, as it will give you multiple reminders to take your medication until you do. This is one of the simplest, easiest-to-use apps available for managing medications.

If these apps seem like they’re a bit too much for you, don’t worry. Every phone has a great option to help you manage your illness: the alarm clock. You can set a daily alarm with a simple “Take Medication” reminder as the alarm title.

**Are you tech-savvy? If you’d rather complete the questionnaire online, visit ndb.org.**

Concerned about your privacy? Don’t worry—Consumer Reports states that each of these apps is HIPAA-compliant, meaning that your information is just as protected as it is at your doctor’s office.
GETTING PERSONAL

WITH DR. KALEB MICHAUD
In 1999, Dr. Michaud was a graduate student in his early twenties assisting with lab research. After he had his wrists replaced, he says he noticed that people suddenly treated him differently. "Everyone assumed that a wrist replacement was like an ACL tear and that I’d be back after a few weeks," he says. "When all of your work requires your hands, whether it’s behind a microscope or with chemicals or biological substances, it’s a major change." He began to realize he wasn’t enjoying the research like he once did. That’s why he said yes when Dr. Frederick Wolfe, the doctor who initially diagnosed him with rheumatoid arthritis (RA) back in 1977, asked him to be a statistician for his new arthritis research database in Wichita, Kansas.

The more he worked with Dr. Wolfe at the organization that would become FORWARD, the more he saw the impact their research was making in the field of rheumatology. And, says Dr. Michaud, the greater the impact, the more excited he became. "I decided that this was where I needed to be and this was what I needed to be doing... Looking at so many other people and studying what did or didn’t work really gave context to my own experience." Since then, Dr. Michaud has authored over 160 articles on rheumatology for various journals, becoming one of the most respected researchers in his field.

**Taking Charge, Taking Care**

In between researching rheumatology and co-directing FORWARD, Dr. Michaud sets aside time for taking care of himself and managing his RA. He’s a perfect example of someone who has taken an active role in his health journey. Of course, not everyone with a rheumatic disease will become a researcher, but they can still be their own health advocates. When asked why it’s important to be your own advocate, Dr. Michaud says, “There’s nobody else who is going to do it for you. Doctors want you to be well, but in the end, they only get so many minutes with you, so they don’t get the full picture of what’s affecting you.”

Communication with providers is key. For Dr. Michaud, it’s all about being transparent about your health goals and what’s working for you. “The doctors have to be a part of your team for your health, and they have to understand what your goals are and what’s important for you,” says Dr. Michaud. By the same token, it’s important to find a doctor who you trust and who trusts you.

In addition to being proactive and involved in his own healthcare decisions, Dr. Michaud makes sure to stick to a healthy lifestyle. While he’s not opposed to trying new things, he mostly avoids home cure fads and sticks to the tried-and-true methods of “following my medication schedule, getting a good night’s sleep, eating healthy, and exercising a certain amount” to manage his RA. "I think that, for me, it’s finding a balance with work, family, and hobbies, like watching movies and playing board games." (Actually, Dr. Michaud owns a board game café in Omaha, Nebraska, called Spielbound, with over 2,400 games available to play!)

**Forward March**

No matter how you decide to manage your health day-to-day, one
Being Your Own Advocate

When you’re managing a chronic illness, it’s important to have a group of people who can support you on your journey. But ultimately, you’re the one who knows your illness and symptoms best. Being your own advocate means taking an active role in your treatment. Here’s what you can do to start.

Studies show that patients who take a more active role in their treatment often fare better than those who don’t, with higher patient satisfaction rates and better treatment outcomes. No matter how long it has been since your diagnosis, follow these tips to boost your confidence as you navigate your healthcare journey.

**Treat Your Providers as Your Partners**

Every time you meet with one of your healthcare providers (HCPs), it’s a meeting of experts. Of course, your HCP is an expert on illnesses and treatment options, but you are an expert on your life and your goals for your illness. Trust your doctor, but don’t be afraid to speak up. You’re the only person who has attended every one of your doctor’s appointments, from primary care physicians to specialists, so trust yourself. If you feel that a provider isn’t listening to you or won’t answer your questions, consider seeking out a second opinion.

**Do Your Own Research**

It’s true—knowledge is power, so study up on your condition. If you sense that you might have trouble separating fact from fiction, ask your doctor for recommended resources and don’t be afraid to ask questions. Also, before making health decisions with your providers, it’s important to research what is and is not covered under your current health insurance plan. For example, different types of medications may require different copays. Talk to your insurance provider to be sure you fully understand your coverage.

Taking an active role doesn’t come naturally for everyone. Many of us feel anxious about even going to the doctor, let alone speaking up and being an active participant in making our own health decisions. Any step you take in your advocacy journey is a good one. Just remember: with time, you have the power to become your biggest health advocate.

Important way you can advocate for yourself is to participate in FORWARD research. By contributing your responses to the FORWARD Databank, you can help rheumatologists determine which treatments are most effective for people with your condition. “This study has been used and learned from by people around the world,” says Dr. Michaud. “I am contacted all the time by people all over the world asking to use our work. We’re actually making a difference. Without FORWARD, yes, there would be arthritis research, but it wouldn’t be nearly as good.”

Dr. Michaud stresses that none of the research would be possible without the help of FORWARD’s dedicated contributors. Even if you feel like your responses are no longer needed, please continue to answer the surveys. “People always say to us, ‘You don’t need to hear from me because my arthritis isn’t very bad,’ or, ‘I’m too busy with my job,’ or, ‘I’m not doing very well, so you don’t need to hear from me.’ All of those reasons are why we need to hear from you,” says Dr. Michaud.

**YOU CAN BE YOUR OWN ADVOCATE—AND AN ADVOCATE FOR OTHERS—BY TAKING THE TIME TO FILL OUT OUR SURVEY. THANK YOU FOR YOUR PARTICIPATION IN THIS IMPORTANT RESEARCH.**

Listen Up, Doc

One of the biggest challenges people face being their own advocate is communicating effectively with their doctors. Here are our tips for making the most out of your time with your doctor.

1/Bring Your Records.
Be sure to bring a hard copy of your personal health record, including medications you’re taking and recent symptoms you’ve experienced, to answer any questions about your medical history or treatments.

2/Take Notes.
When you feel nervous, it can be difficult to remember everything. Take good notes—or better yet, ask to voice-record the appointment.

3/Be Honest.
Especially when it comes to questions about lifestyle, don’t lie or fudge your answers. Similarly, don’t leave out important details like unexplained symptoms.

4/Ask Questions.
Often, patients come to the doctor with general questions in mind only to leave without having them answered. Avoid this problem by bringing specific written questions to every appointment.
FORWARD Research Highlight
Menopause and Disability in Women with RA

A new study published by the journal *Rheumatology* and conducted using FORWARD surveys found that women with rheumatoid arthritis (RA) experienced faster functional decline after menopause.

DID YOU KNOW that women are diagnosed with RA three times more often than men? In addition, women with RA experience more pain and RA-related fatigue than men with RA do. While researchers can't fully explain the difference gender makes on RA, they do know that when women experience major hormonal changes in their life, their RA can change.

About the Study
The mysterious connection between hormones and RA inspired researchers from the University of Nebraska Medical Center, led by Elizabeth Mollard, PhD, to study the impact of menopause on RA functional ability—a person's ability to complete daily tasks with ease.

The study was conducted using responses from women taking FORWARD’s Health Assessment Questionnaire (HAQ), which is distributed nationwide every six months. As those of you who have taken it know, the HAQ collects information about participants’ functional status, as well as their demographic information. A total of 8,189 women participating in FORWARD were eligible for the study. Of these, 24.5% were pre-menopausal, 7.5% transitioned through menopause during the study, and 68.0% were post-menopausal.

What Researchers Found
Researchers looked to see whether functional ability declined more quickly after menopause and found that it did, even taking into account age, medications, and other factors. They also found that women with RA who had ever been pregnant or undergone hormone replacement therapy during their lives experienced less functional decline.

This study represents an important step forward in understanding the impact of hormones on RA, and researchers are excited to study the effects of hormonal changes on other rheumatic diseases as well. This research could not have been possible without the continued support of our dedicated FORWARD participants. Thank you for partnering with us as we advance research and discovery in Rheumatology and beyond through human connection and deep insight.

A NOTE FOR RESEARCHERS: FORWARD collaborates with researchers worldwide and makes its data available to qualified investigators without charge. For more information on doing research with the FORWARD Databank, please complete the Research Request Form at forwardndb.org/research/research-request-form.

Key Takeaways
+ Women with RA had better functional status before experiencing menopause, even accounting for age, arthritis medications, and other variables.
+ After menopause, women with RA experienced functional decline at a faster rate than they had before menopause. Women who had ever been pregnant or undergone hormone replacement therapy had less functional decline.
+ Women who had longer reproductive years, meaning they started their period at a younger age or started menopause later, had less functional decline than those who didn’t.

Attention: New Study for FORWARD Participants
Within the next couple of months, we will be starting a 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 will be starting or have recently started Xeljanz (tocafitinib) and would like to know more, please contact us by email at info@ndb.org or by calling 1-800-323-5871 ext. 125 or 119.
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.

Why do you ask the same questions over and over? The Databank is called a longitudinal databank, which means it collects the same data over different points in time and provides long-term data. If we did not collect the same data over time, we would not be able to compare how participants are doing now to how they were doing 15 years ago. This long-term data can also help with treatments and show if there are any side effects that show up after many years of using a medication.

Why do you repeat questions within the same questionnaire? While it may seem that questions are being repeated within the same questionnaire, they actually are all different. Certain sections within the questionnaire are part of individual measurement tools that doctors, nurses, and other health care professionals use to help with seeing how your disease is affecting you and if treatments are helping. These questions being asked every six months and added to the long-term data also helps the researchers throughout the world to be able to compare diseases and treatments and see how far we have progressed throughout the years of rheumatic disease research.

My disease is in remission—why do you want me to continue filling out the questionnaires? We are always happy to hear when participants note their disease is in remission, as it helps in knowing we are all making a difference to hopefully find a cure for our diseases one day. Everyone’s journey is different with their disease, and we want to continue capturing data from participants that are in remission to help to see if there is anything different from that participant compared to others. This data also helps to see if certain treatments or lifestyles help to stay in remission.
Meet Dr. Mikuls

Meet the rheumatologist using FORWARD research to look for ways to predict and prevent rheumatoid arthritis.

DR. TED MIKULS is not like most other rheumatologists. An academic rheumatologist practicing at the University of Nebraska Medical Center (UNMC) and the Omaha VA Medical Center, Dr. Mikuls combines his rheumatology practice with epidemiology, the study and analysis of health and disease conditions in the general population.

He found his passion as a medical resident. “I worked in rheumatology and immediately knew this to be my career path. I then sought additional training in Rheumatology as a fellow while simultaneously pursuing my Masters in Epidemiology. I like the ‘intellectual puzzle’ often posed in rheumatology, and to me epidemiology provides a beautiful framework in attacking these problems that come before us every day in clinic,” Dr. Mikuls says. Today, Dr. Mikuls conducts research focused on understanding the risks for the development of rheumatoid arthritis (RA) and on methods to improve care for patients with gout.

Recently, Dr. Mikuls collaborated with two other UNMC professors, Dr. Geoff Thiele, internal medicine, and Dr. Dan Anderson, cardiology. The goal is to study malondialdehyde-acetaldehyde (MAA) adducts. A big name for a small molecule, MAA adducts play a role in the inflammation process of RA and other diseases. A test for MAA could detect inflammation in the body before major symptoms develop. In time, this has the potential to predict the onset of RA, diabetes, coronary artery disease, and more. “Our early work suggests that these MAA adducts could play a role in generating the inflammation and autoimmunity that characterizes RA and some of its common comorbid conditions such as cardiovascular disease and chronic pulmonary diseases.”

With this advancement and many others, Dr. Mikuls is optimistic about the future for patients with RA. “I think we’re going to continue to see exciting therapeutic advances, particularly as we uncover novel disease targets through a better understanding of the intricate biologic pathways at play. I think the future looks brighter—really—every day. The treatments that we have at our disposal continue to grow, and we’re now conceptualizing studies to understand ways to prevent the disease all together, a thought that really would have been unimaginable just two decades ago,” he says.

All of this would not exist if not for the scientific advancements made possible by FORWARD and patients who contribute to the registry. “FORWARD has really been at the forefront in helping us drive the science forward and understand how arthritis impacts the daily lives of the people it touches,” says Dr. Mikuls.
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.

Don’t 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, so we want to hear from you on what we can do to improve your participation with us. 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 questions with this level of detail and with so many participants who have rheumatic diseases, and we do this with a relatively small amount of grant funding. So, before you decide not to 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 making a difference!

Prize Drawing Winners!

The Databank 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 anytime within the first six months.
- 4 drawings for $50 each for those who complete a shorter questionnaire via mail or phone anytime within the first six months.
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 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 https://www.forwardndb.org/participate/tell-friend.

For More Information or to Participate

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

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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, ndb.org, and make the request, or send us an email at webquest@ndb.org.

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!

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