

FORWARD

SUMMER
2018

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

The Latest
FORWARD
Research

Insights
into Your
Chronic
Illness

Finding
Support
In Person
& Online

Learn more
on page 7 

Respecting
Your Limits
WITH **Spoon
Theory**



Letter from the Co-Director

Dear Reader,
Thank you for picking up the latest edition of FORWARD magazine. In this issue, you'll find conversations with some of the researchers who are using FORWARD data, as well as clinical data, to help prevent rheumatic diseases. You'll hear from a FORWARD member who has been filling out the FORWARD survey since her diagnosis nearly nine years ago, and you'll learn some great tips to help manage and maintain your energy levels during the summer months. We here at FORWARD are excited to be able to share with you some of the latest information and research about rheumatic diseases. Of course, this research wouldn't be possible without you. 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, we hope you'll find yourself inspired to continue helping us improve treatments and outcomes for rheumatic diseases.

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 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**.



**FORWARD, THE NATIONAL DATABANK
FOR RHEUMATIC DISEASES**



@ndb_org

Spotlight on Nonprofits & Organizations

Dupuytren disease, or palmar fibromatosis, is the most common inherited disabling hand condition, affecting at least ten million Americans. Not only does Dupuytren disease make a person's fingers permanently bent, but people with this disease also have a greater risk for cardiovascular disease, certain cancers, and early death.

The Dupuytren Foundation is working to cure Dupuytren disease by providing free patient support, hosting academic conferences, and authoring academic publications. They also developed the International Dupuytren Data Bank (IDDB), a research project with the goal of finding the cause and cure for Dupuytren disease and related conditions. The IDDB is hosted by FORWARD.

You can visit their website to find out more about Dupuytren disease and related diseases: **dupuytren.org**

If you have Dupuytren disease, you can help with the research by enrolling in the IDDB at: **dupuytren.org/iddb-dupuytren-patient-enroll**

Social Support: Dupuytren's Disease Support Group DDSG is a 3200-member (and growing) global Facebook support group dedicated to supporting research for a cure and providing education to patients with Dupuytren disease and related diseases. DDSG's eight expert physicians host monthly Q&A's with members. Their 100+ page DDSG Flipbook has become a resource to patients and physicians alike. DDSG is a closed Facebook group, but you may request membership by following this link: **facebook.com/groups/879351412113444**

**RESOURCES
FOR DUPUYTREN
DISEASE**

To Our 25-Year Participants, Thank You

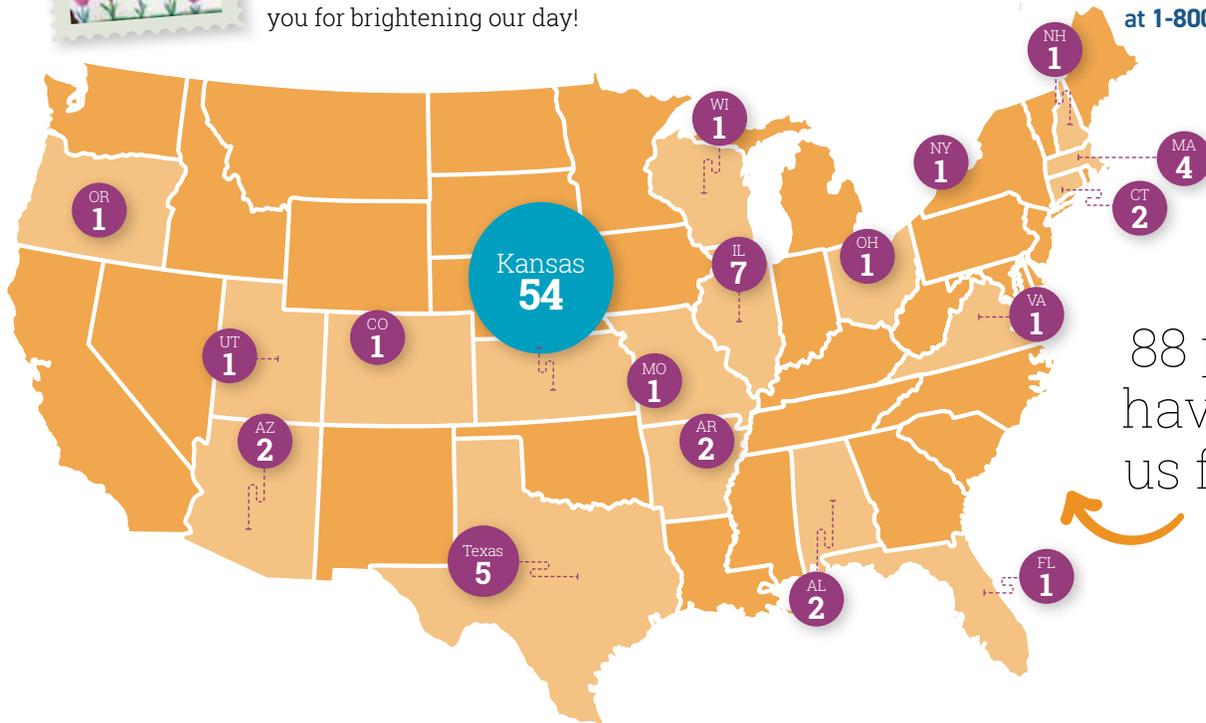
AS WE NEAR OUR 20TH ANNIVERSARY OF FORWARD, the National Databank for Rheumatic Diseases, we want to thank the 88 participants that have been with us since the very beginning and are still participating. These participants came from Dr. Wolfe's clinic when the databank first began and from other rheumatology clinics around the country. We would not be here without the clinics and patients that helped to start FORWARD and that continue to make it one of the largest databanks in the world—thank you!

FORWARD is a nonprofit organization dedicated to improving the treatment and outcomes of rheumatic diseases, and you can help us reach this goal by participating in our study. 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. 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.

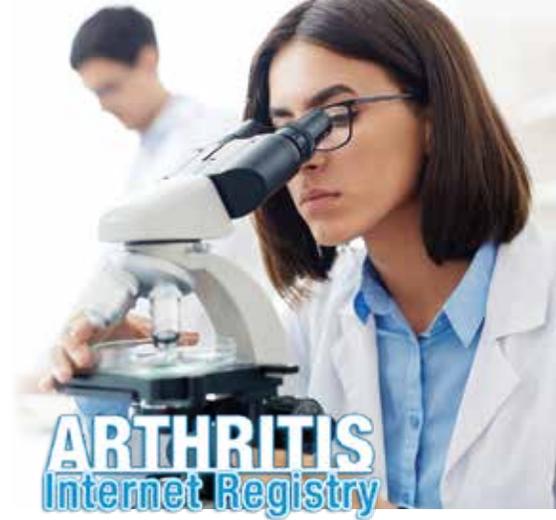
FORWARD is different than other rheumatic disease databanks because all of FORWARD's data is patient-reported, meaning that it comes directly from you, rather than a doctor or clinical staff. Our research depends on patients like you sharing their experiences to improve the treatments and outcomes of 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.



We also want to thank our participants that help bring a smile to our office with pictures, drawings, notes, comments, letters, and cards. Recently, a participant sent this card in with their questionnaire, and it now hangs in our break room for all to enjoy. Thank you for brightening our day!



88 participants
have been with
us for **25 years!**



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.



Pressing Pause on Symptoms

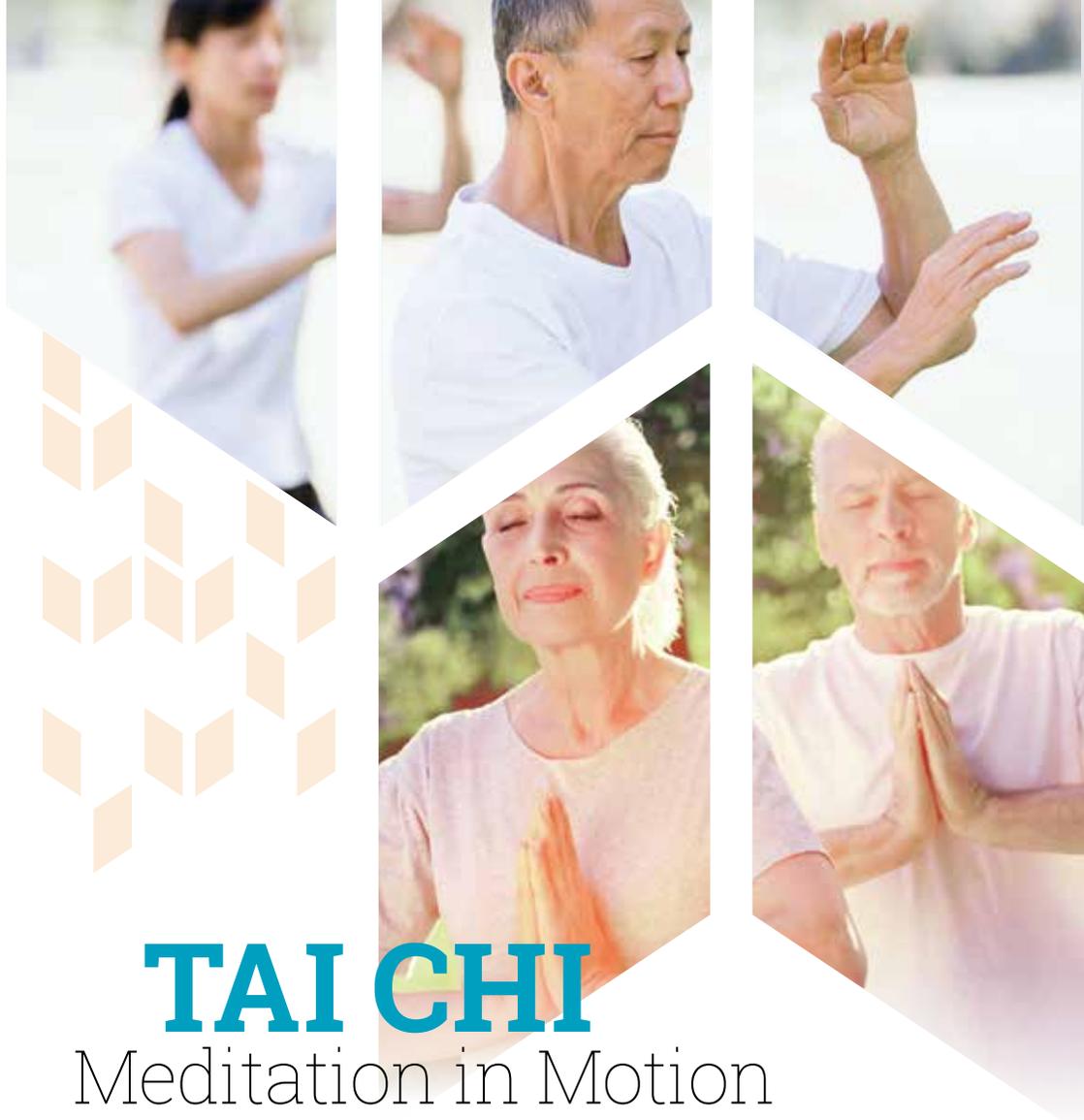
REMISSION IS the ultimate goal of all rheumatology patients and their rheumatologists. Studies show that 20–40% of patients will experience full remission as defined by the American Rheumatology Association (ARA).

Many rheumatologists and patients view remission as a significant decrease of symptoms, which is achievable for many through medication and lifestyle adjustments. If you and your doctor agree that you've reached remission, it's obviously time to celebrate. But after the celebration, what do you do?

Most importantly, don't cut out your medications. While it may be tempting to stop taking your medications—after all, you don't have any symptoms to treat anymore—doing so suddenly or on your own will likely cause a relapse of your symptoms. Always talk to a doctor before making decisions about medications.

Rheumatic disease treatments are evolving more and more every day—and FORWARD participants are helping. If you're currently in remission, make sure you keep filling out the FORWARD surveys. Your experience could shed light for researchers on how to help other patients achieve remission, too!

One study showed that patients in remission who stopped taking their medications were three times more likely to experience another flare-up than those who continued taking medication.



TAI CHI Meditation in Motion

HAVE YOU EVER SEEN groups of people at your local park slowly moving through what looks like a synchronized dance? There's a chance that they're practicing tai chi, an ancient Chinese tradition that, in many forms, focuses on slow, methodical movements. Considering trying tai chi? Here are some of the benefits that you might experience.

- + **BETTER BALANCE.** Tai chi requires constantly shifting your weight from one leg to another. This builds bodily awareness and helps many participants improve their balance over time.
- + **LESS PAIN AND STIFFNESS.** A study in *The Journal of Rheumatology* indicates that the slow, consistent movements of tai chi can help loosen joints and relax the muscles, meaning less pain.
- + **MORE STRENGTH.** Tai chi is a mild exercise that, over time, has been shown to increase strength just as much as a physical therapy regimen—without being overly taxing.
- + **REDUCED STRESS.** Sometimes called “meditation in motion,” tai chi offers a very accessible approach to meditation, which leads to greater relaxation and less stress.

As you gain better awareness of your body and achieve success during your tai chi practice, soon you'll begin to approach every difficult task as a challenge that you can master. Ready to try tai chi? Many local health or senior centers offer classes, or you can find a class using americantaichi.net.



SUMMER ACTIVITIES

From picnics to pool days, summertime can be very busy. Here's how you can help manage your energy levels during these sunny days:

CHOOSE YOUR TEAM. Let your friends and family know about your varying energy levels. If you're not having a great day, those close to you will want to help. Especially when it comes to large social gatherings, or events outside in the heat, you'll appreciate having a helping hand to take care of chores or cleanup after a big event.

DON'T SKIP YOUR TREATMENT.

Excess pain can play a big factor in your fatigue. Stick to the treatment plan you and your doctor have worked out, including medication, exercise, or any other therapy you have in place.

REST UP WHEN YOU NEED TO.

When you're managing a rheumatic disease or chronic illness, don't overtax yourself. Do less when you can, and you may have some extra energy to put into the next day.

Christine Miserandino created the Spoon Theory in a diner, when she was attempting to explain what life with lupus was like to a friend. Unable to explain the incredible toll of everyday actions, Miserandino handed her friend a bouquet of metal spoons, and showed her how each spoon represented the energy you had to use for every single task in a day, from opening your eyes and getting out of bed, to washing your face and brushing your teeth in the evening. Once all of your spoons are gone, you can't do anything else—you simply don't have the energy.

Think of it this way. You start your day with twelve spoons. You wake up, and swing your legs out of bed. One spoon—gone. Brush your teeth—one more spoon. Brush your hair—another spoon. You haven't even had breakfast, and you've already used up a quarter of your energy for the day. Now add in daily activities, like going to work or caring for your children, and consider other important holidays and events, and suddenly dealing with your chronic illness can seem overwhelming.

Many people with chronic illnesses experience this sort of fatigue and energy drain. The Spoon Theory isn't just a good way for you to explain your experience to others, it's also an excellent way to understand yourself, your limitations, and how you can make the most out of the energy that you do have.

USING THE SPOON THEORY

Know how many spoons you have. When dealing with a chronic illness, it's imperative that you pay attention to your energy levels. Overdoing it could leave you exhausted, which may lead to slower recovery times and longer periods of fatigue. The more that you pay attention to your energy levels, the more you'll be able to accurately read them.

WANT TO LEARN MORE ABOUT THE SPOON THEORY? CHECK OUT CHRISTINE MISERANDINO'S WEBSITE, BUTYOUdontLOOKSICK.COM.

FIND YOUR SUPPORT GROUP

Living with a rheumatic disease is about more than taking your medication on a regular basis. Many studies show that emotional support is vital to managing a disease, particularly when that disease impacts every part of your life, like rheumatic diseases do for many patients. If you're not comfortable with that support coming from a friend or family member, if that isn't an option, or if you find you need additional support, a support group could be a great option.

There are many different types of support groups, and it may take some time to figure out which is right for you:

- + **CLOSED OR OPEN GROUPS:** A closed group requires pre-registration and a commitment to show up.
- + **PEER GROUPS:** These are typically run by other rheumatic disease patients and are often used to share experiences.
- + **THERAPY GROUPS:** Run by a mental health professional, these often include support and education.
- + **EDUCATION GROUPS:** Rather than sharing experiences, these groups are largely educational about specific diseases and treatments.

If you're looking for support group, ask your doctor if they have any recommendations. You can also visit our Facebook page for information on starting your own support group.

Save your spoons. Once you know how much energy you have, it's important that you manage your time effectively. On days when you have low energy, conserve it by cutting corners wherever you can—wear slip-on shoes instead of shoes that you have to tie, have cereal or a frozen waffle for breakfast instead of making a meal, and so on. If you have a big, important event coming up, rest up as much as you can ahead of time.

Recognize the importance of your spoons. Don't forget—once your spoons are gone, they're gone. When you have the option, use your energy on the things that matter most to you—spending time with your family, doing hobbies that make you happy, and anything else that you find value in. When doing only things you want to do isn't an option, being intentional about not overdoing it is another way of recognizing the importance of the energy that you have.

Get Social

Not able to find the right in-person support group in your area? Never fear, the internet is here. As the internet has become more and more accessible, online support groups have risen in prominence. Accessible from anywhere, anytime, social media and online forums make it easy to connect with others with similar experiences. Want to try it? Here's how.

Choose your platform. Already have a Facebook? A simple search will reveal plenty of Facebook groups dedicated to specific diseases and rheumatic or chronic diseases in general. Or, if you're looking for something different, try doing an online search for a forum based on your illness. A forum is an open, online conversation that you can easily view or participate in. Whatever your platform is, most likely there is a community waiting for you.

Hashtags are a great way to organize content on social media—looking for information about other people's experiences with lupus? Searching for **#lupus** will bring up any post in the world that uses that hashtag, so it's a great way to expand your horizons and learn about other people's experiences. Other popular hashtags such as **#spoonie**, **#chronicillness**, or **#disability** can help you find others who share your experiences.

By contributing to research, you are helping to improve the lives of people with rheumatic diseases. Continue filling out your FORWARD questionnaire and let us know if you have any questions, comments, or concerns.

LOOKING TO
EXPAND YOUR
HORIZONS?



YOUR VOICE
HELPS!

“If there was anything I could ever do to give back and to try to help find a cure or better medication, I wanted to try to help.”

Contributing TO A CURE

Before Brandy Rogers was diagnosed with Rheumatoid Arthritis (RA), she began experiencing symptoms during her pregnancy with her first child.

Brandy's pain was impacting every aspect of her life, yet when she went to see her OB/GYN with the excruciating pain she was feeling, it was dismissed as typical pregnancy pains. At the time, the only treatment option available to Brandy was prescription narcotics for the pain, which would have resulted in Brandy's child being born addicted. You can imagine Brandy's reaction: “That's all you have to offer me? I can either help myself and hurt my baby, or live with this excruciating pain?”

Delayed Diagnosis

Like many patients, Brandy found the lack of clarity during the diagnosis process to be the most frustrating. As a new mom, Brandy found herself barely able to move due to her symptoms. “I had so many people questioning whether I had postpartum depression, and as a therapist, I knew that I didn't have postpartum depression,” she says. “I was just miserable in my life because I couldn't function.”

The Healing Process

For Brandy, self-empowerment was key to her journey towards successfully managing her RA. One thing she found healing was reading books on rheumatoid arthritis and educating herself about her disease and treatment options. **“The most hopeless point was when I didn't have options. Once I began to learn about the disease and the options I had, I felt much more empowered to make decisions about what I needed,”** says Brandy.

Additionally, Brandy found healing in those that she surrounded herself with. She found a doctor she could trust, and while Brandy didn't know anyone else with RA, she also found a community. She would often read posts on RA forums about other people's experience. “It was very healing for me to hear other people talk about their struggles, it made me feel not so alone,” she says.

The Value of Research

Brandy found out about the FORWARD questionnaires from an online RA forum. Having used research heavily in her own graduate studies, Brandy knows the value that this kind of research has. “I just kind of decided, if there was anything I could ever do to give back and to try to help find a cure or better medication, I wanted to try to help.”

“Being able to be a part of FORWARD has helped my mental and emotional health. I feel like I'm doing something more than just taking my medication every day. I'm contributing to, maybe, one day, a cure,” says Brandy. “If my answering those questions helps someone else, then that's the least I can do to try to prevent someone else from being in the place that I was in.”



RESEARCH

Forecasting Rheumatic Diseases

Since medical school, Dr. Kevin Deane has been interested in the prevention of diseases. With his new project, StopRA, he's aiming to one day stop rheumatoid arthritis in its tracks.

Motivated by the frustration he felt seeing patients diagnosed with diseases that, even with treatment, were still very difficult to manage, Dr. Deane began working in the field of disease prevention, often collaborating with researchers who use FORWARD's data. His latest project revolves around the prevention and testing for rheumatoid arthritis (RA).

Predicting an RA Diagnosis

StopRA is a clinical trial that will improve our understanding of the development and prevention of RA and other rheumatic diseases. Studies indicate that before someone gets their first swollen, painful joint from rheumatoid arthritis, they seem to have abnormal blood tests for three to five years that show a high level of the autoantibody CCP.

According to Dr. Deane, detecting these high levels of CCP "could give us an indication that someone will develop rheumatoid arthritis." He adds, "It's just like how high cholesterol can predict

that someone might have a heart attack in the future."

With participants at risk of developing RA, StopRA is testing the effects of Plaquenil, which has been shown to slow the progression of autoimmune disease. One of the safest drugs used in RA treatment, Plaquenil may hold high rewards for the future of RA treatment and prevention.

Reshaping the Future of Treatment

What does this mean for RA patients? The StopRA clinical trial could lead to a preventative medicine for individuals at risk for RA and other rheumatic diseases. "When approaching rheumatic diseases, we wait until people get sick and then we treat them," Dr. Deane says. "What if we got out in the population and started doing the tests to find people before symptoms begin?"

In the future, RA screenings, as well as screenings for other rheumatic diseases, might be as commonplace as screenings for cholesterol or colon cancer. Together,

WHAT
YOU NEED
TO KNOW



the work of FORWARD, independent researchers, and clinical trials like StopRA may find a way to stop autoimmune diseases before symptoms ever start.

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.

How to Participate in the Study

With 18 testing sites around the US, and two more coming soon, the StopRA clinical trial is funded by the National Institutes of Health through the Autoimmunity Center of Excellence.

Any individual over the age of 18 can be tested to see if they have high levels of CCP in their blood. Those who participate will not only be contributing to research, but will also have the chance to know their risk for RA.

If you're interested in participating in StopRA, email stopra@ucdenver.edu or go to stop-ra.org to find out more.

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 to see my full medical records, even when they might not be relevant to my rheumatic disease?”

First, it is always optional for you to sign the consent in the questionnaire to allow us to send for medical records, and we will still use the data you provided within the questionnaire regardless of whether or not you choose to share your medical records. We use medical records to make the data we collect even more convincing and accurate, which supports the research being published and provided to the healthcare community and public. Your medical records contain medical jargon and codes that we wouldn't expect participants to be able to report on our questionnaires—this information simply helps us confirm the information that you provided to us. Your medical records also contain information about other illnesses, comorbidities, hospital stays, and outpatient procedures. We have seen within the research that any of these may impact your primary rheumatic disease, and the only way it is possible to see these connections is with the data provided from medical records in addition to the questionnaires.

“You are only working to benefit insurance companies, the government, or pharmaceutical companies.”

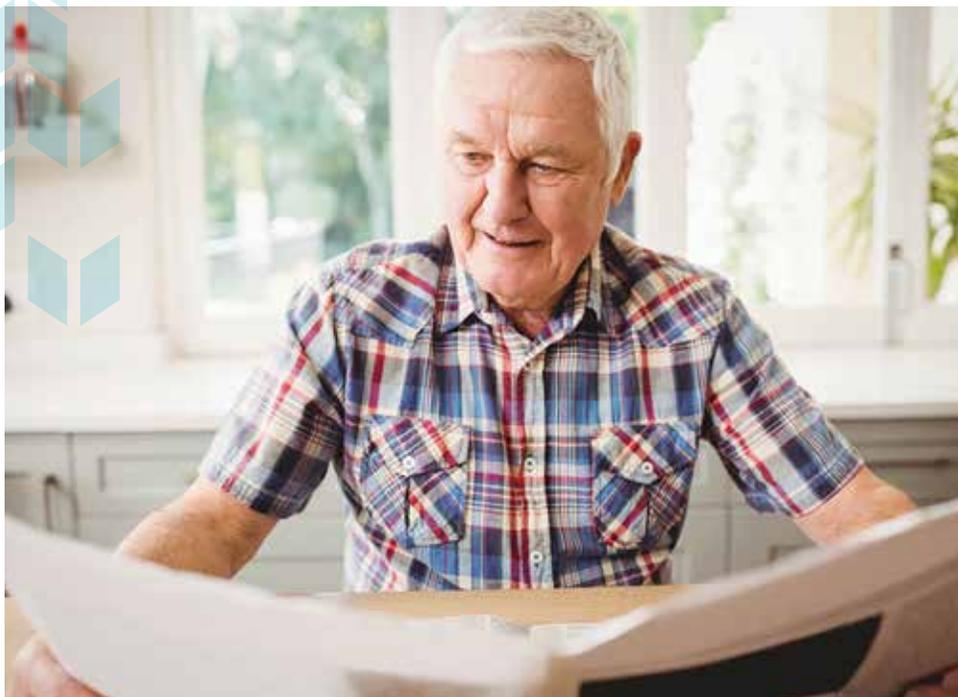
FORWARD is an independent research nonprofit organization, and we do not work to benefit insurance or pharmaceutical companies or the government. Instead, we are working to improve treatments for all rheumatic disease patients. Using your answers and those of thousands of other participants, we are able to advise doctors, lawmakers, and industries about drug safety, the likelihood of side effects, and the costs and burden of the diseases. We also want to stimulate new research by making data available to health professionals (i.e., doctors, students at universities, epidemiologists, nurses, and physician assistants), other organizations, and our participants. With the help of our participants, we are able to make suggestions to doctors about how best to care for a condition. And, we're able to help governments, employers, and policy makers understand how much these conditions affect people's lives, the community, and the economy. FORWARD research does shape the treatment and medications used in rheumatic diseases, and we could not do it without the help of each participant in the study.

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

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.

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 any time 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.

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 <https://www.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, ndb.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

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