

FORWARD

SPRING
2019

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

Travel Tips
& Tricks

Moving
FORWARD
in the Lab

Learn more
on page 9 >

INSIGHTS
into Your
Chronic
Illness

Spring Fever
**GET OUTSIDE
& GET ACTIVE**



Letter from the Co-Director

Dear Reader,

Hello, and thanks for picking up this latest edition of FORWARD magazine.



In this issue, you'll hear from one of our newest FORWARD team members, Kristin Wipfler, PhD. As the new Biobank Director with FORWARD, Dr. Wipfler joins us to share an exciting and easy way that FORWARD participants can further support rheumatic disease research and receive important information about their own health to share with their doctor. You'll also learn about some easy ways to approach spring travel and get some tips about how to get moving as we head into the warmer months.

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.

Sincerely,
Kaleb Michaud, PhD
 Co-Director, FORWARD

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).



FORWARD, The National Databank for Rheumatic Diseases



[@ndb_org](https://twitter.com/ndb_org)

In This Issue

- 3 **Arthritis Internet Registry (AIR) News**
- 4 **Rheumatic Diseases and Your Eyes**
- 5 **How to Get Moving**
- 8 **New FORWARD Research**
- 10 **Frequently Asked Questions**
- 11 **Reminders**

WAYS
TO HELP
FORWARD

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 betty@ndb.org or by calling 1-800-323-5871, ext. 143.

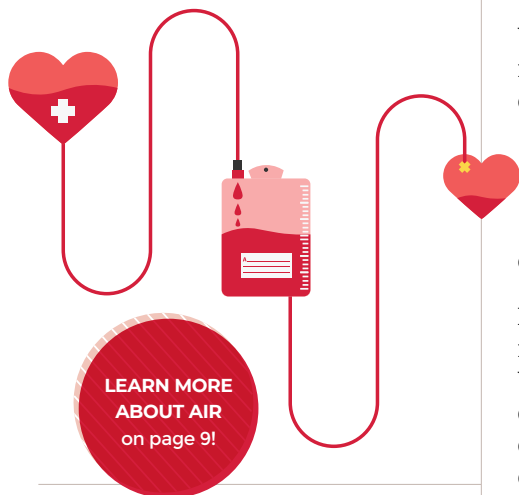


Give Blood for Research

Participants in the 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 6,812 participants join, and we have collected 1,546 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.



LEARN MORE
ABOUT AIR
on page 9!

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.



Thank You Participants!

To all of the participants who give your time every six months to share your experience and contribute to research about the diagnosis, treatment, and prevention of rheumatic diseases: Thank You. Whether you're a new participant who has only recently filled out their first questionnaire, or whether you've been contributing for years, you're making a difference for all individuals who have a rheumatic disease.

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. Furthermore, 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. By participating, you'll be helping to improve the treatment and outcome of rheumatic diseases.

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.



SMARTER TRAVELS

Spring has arrived, and with the warmer months comes Spring Break, beach vacations, and the opportunity for many to visit friends and family or an exciting new vacation spot. These tips can help you prepare to have a fun-filled and relaxing vacation:

PLAN AHEAD

If you're aware of things that trigger flares or pain, make a plan to deal with them. Do long walks cause a flare-up in your lower back? Find out your accessibility options at your local airport to catch a ride to your gate, and pre-plan your transportation at your vacation spot. Hop on, hop off trolleys are an exciting way to see a new city, or you can hire a driver, which will allow you to meet a local and learn about some off-the-beaten track places you should visit, all while maintaining your energy.

TOOLS + TACTICS

Whether it's a plane, a train, or an automobile, traveling in an uncomfortable space can pile on extra aches and pains. Feel extra achy in the cold? Bring an extra blanket. Try bringing an extra pillow for your lower back to maintain good posture. If possible, sit in an aisle seat on an airplane or schedule extra rest stops on a road trip so that you can stand, stretch, and walk around frequently. Bring hand warmers or an ice pack—whatever you prefer—to help with aches and pains mid-travel.

KEEP AN EYE ON YOUR VISION

The same inflammation that impacts your joints with a rheumatic disease can also impact other areas of your body... like your eyes. If you have a rheumatic disease, here's what you should be keeping an eye out for:

One of the most common ocular diseases for people with inflammatory conditions, **DRY EYE SYNDROME** (or keratoconjunctivitis sicca), limits your eye's ability to maintain a healthy film of tears, which is supposed to help protect the eye from foreign objects, lubricate the eye, and maintain good vision. If you're experiencing dryness, feel like something is always in your eye, or have new, blurry vision, your doctor may recommend eye drops, a humidifier, or tear duct plugs. Regardless of the treatment, it's important to discuss your options with your doctor, as dry eye syndrome can lead to infection or corneal scarring if untreated.

SCLERITIS is the inflammation of the white part of your eye, leading to redness that won't go away, eye pain, and sensitivity to light. Scleritis is often a sign that the inflammation in your body is excessive, which means that you need to work with your rheumatologist to control inflammation throughout the body, in addition to working with an ophthalmologist to treat the scleritis.

These are just a couple of the ocular diseases that you may experience as a result of a rheumatic disease. If you're experiencing vision problems, sensitivity to light, eye pain, or if something doesn't seem right with your eyes, talk to your rheumatologist, who can help you understand your risk factors and recommend an ophthalmologist for you. Regular checkups with an ophthalmologist can help you make sure your eyes stay healthy.



SPRING *into action* >

The sun is shining, the birds are chirping, and you are... indoors. We all know that low-impact, light exercise is an essential factor in maintaining our health, but sometimes it can be hard to get started. Here are some of our favorite outdoor activities and some tips to help you take advantage of the spring sunshine, head outside, and get some exercise.

LOOKING FOR SOMETHING SIMPLE?

One of the quickest, easiest ways to get outdoors is to grab your favorite companion and head out for a walk. We love going for walks, especially in the spring, because it's an excellent opportunity to experience nature, explore your neighborhood, and spend some time with those you love. Whether you're walking with a pet, a friend, or a family member, you're sure to have a great time.

Walking is also a great option for exercise because you can easily control how high-or low-impact it is. Feeling good? Walk briskly and head uphill! If you're not feeling great, no problem. Walk at a slower pace and choose a flatter route—just make sure you have enough energy to get back to your home or car once you turn around!

A LIFELONG HOBBY.

If you're looking for something a bit more involved, try starting a garden. Whether you're planting vegetables, flowers, or greenery, a raised garden bed is easily accessible and a great way to use your hands and get some activity in

your daily life. Just make sure you have the help you need with tougher tasks like moving bags or piles of dirt, and be sure to invest in lightweight, easily held tools.

Gardening is also a great hobby for the winter. Even though you may not be outdoors, you can use the colder months to plan for the upcoming growing season, choosing your plants and determining how and when you'll plant them!

KEEP LEARNING.

This unusual hobby is one of our favorites because it'll keep your body and your brain on their toes! Birdwatching is a great way to get out in nature, and all you need to get started is a pair of binoculars. There are great resources online and in bookstores to help you learn about the wildlife that lives in your area. Learning about them, searching for them, and recording what you've seen is a great opportunity to spend some time outdoors, stay active, and create memories!

WHY MOVE?

Ever wonder why low-impact exercise is recommended so often, especially for those with rheumatic diseases? According to the American College of Rheumatology, "people with arthritis who exercise regularly have less pain, more energy, improved sleep, and better day-to-day function." Even if you don't have a rheumatic disease, or a non-arthritic form of a rheumatic disease, individuals who are physically active are "healthier, happier, and live longer than those who are inactive."

Here's how low-impact exercise and activities can benefit you:



Prevent
Joint
Stiffness



Strengthen
Muscle



Improve
Range of
Motion



Benefit
Balance



Increase
Endurance



Boost
Energy



Promote
Quality Sleep



Control
Weight

ESSENTIAL GEAR

HEADED OUTDOORS? REVIEW THIS LIST OF NECESSARY GEAR THAT YOU MAY NEED TO HAVE AN ENJOYABLE AND SAFE EXPERIENCE.

Sunscreen + sun protection: A sunburn is never a fun experience, and the negative effects of too much sun exposure are well-documented. Have a friend or family member help you apply sunscreen or try a spray sunscreen making it easier to cover any exposed skin. Be sure to reapply!

Proper sneakers: A well-fitting, supportive shoe is crucial. They can help reduce pain, especially in your hips and back, and can support your balance, helping you stay upright at the right times. Make sure that you're getting a pair that make you feel stable and has the right amount of arch support.

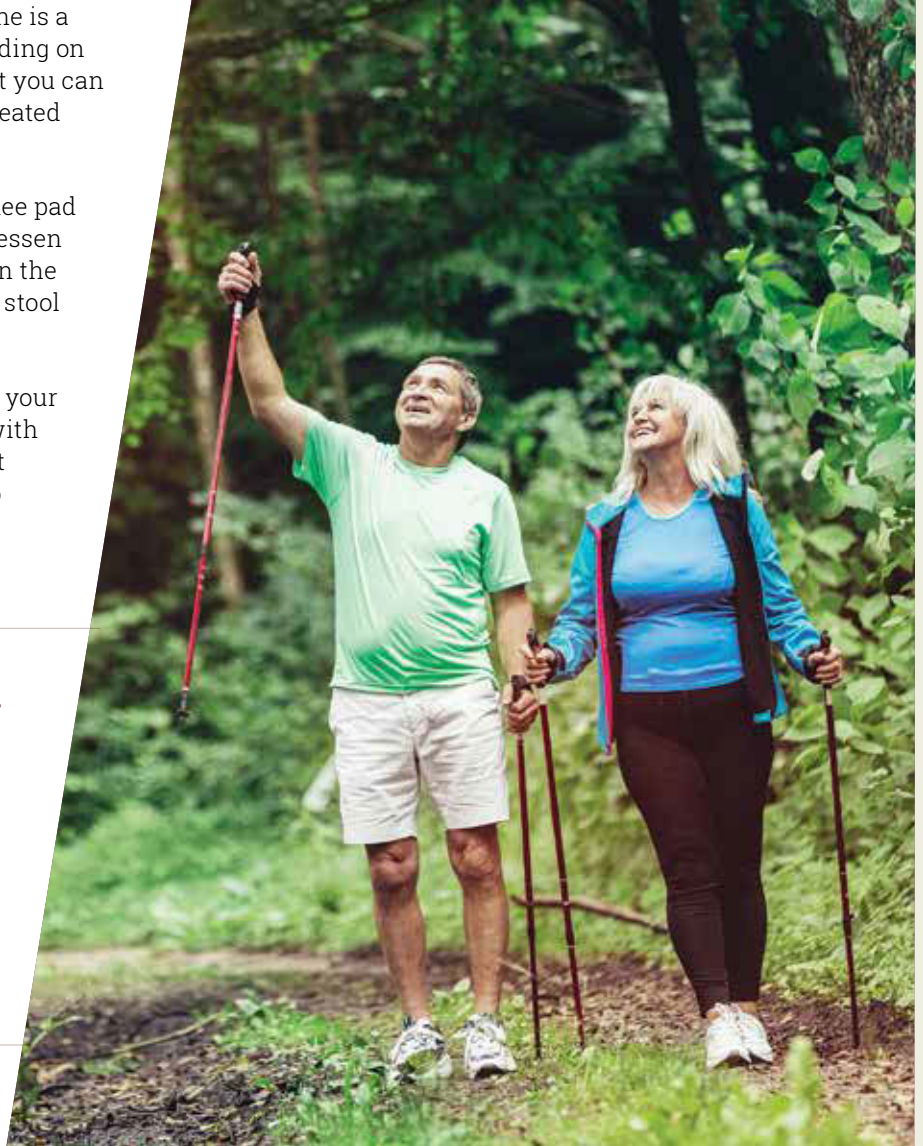
Walking cane: If you need extra support, a cane is a great, portable way to add some stability. Depending on your activity, you may need a standard cane, but you can also explore other options, like foldable canes, seated canes, and canes with different handle types.

Knee pad: If you're going to be gardening, a knee pad is a great tool that will support your joints and lessen the aches and pains associated with kneeling on the ground. If you want to stay off the ground, a low stool is also a great choice.

A helping hand: Having a partner join you for your outdoor exercise is a great chance to socialize with a friend, and you'll have someone there to assist you with whatever you need. If you choose to go alone, make sure you carry a cell phone for any emergencies.

WE WANT TO HEAR ABOUT YOUR EXPERIENCE WITH YOUR RHEUMATIC DISEASE!

If you have a favorite outdoor activity, method of staying healthy, or story about your health, we would love to share it with other FORWARD readers. Send it to us at jacob@ndb.org, and you may be featured in the next issue of FORWARD magazine!



Measure Up

IF YOU'VE TAKEN THE FORWARD QUESTIONNAIRE, YOU'VE PROBABLY NOTICED THAT WE ASK A LOT OF QUESTIONS ABOUT HOW YOU FEEL AND HOW WELL YOU'RE GETTING AROUND. HERE'S HOW YOUR ANSWERS AFFECT DOCTORS, RESEARCHERS, AND THE IMPORTANT WORK THEY DO FOR THE DIAGNOSIS, TREATMENT, AND PREVENTION OF RHEUMATIC DISEASES.

Measurements are crucial to improving the diagnosis and treatment of rheumatic diseases. Throughout the questionnaire, you'll find questions that are helping find new ways of measuring (or reporting) the effects of your rheumatic disease and treatments. Additionally, these questions help the rheumatology community know if certain measures being used in doctors' offices across the world are effective and correct, or if they need to be improved. If doctors and researchers weren't using

reasonable measures, the diagnosis and treatment of rheumatic diseases would not be as good as it is today. And, if we didn't work to have even better measures, the diagnosis and treatment of rheumatic diseases wouldn't improve.

That's one reason why it seems like we ask the same questions over and over again, even in the same questionnaire. When a question is worded slightly differently than another, it can provide valuable information about a

different measurement tool that doctors, nurses, and other health care professionals use to help with seeing how your disease is affecting you and if treatments are helping. When you answer these same questions every six months, your answers are added to the long-term Databank. Your data also allows researchers throughout the world to compare diseases and treatments and see how far we have progressed throughout the years of rheumatic disease research.

Here is one study that shows how your questionnaire answers are being used to test new and current measures of rheumatic diseases.

EXAMINATION OF PSYCHOMETRIC PROPERTIES OF THE PATIENT-REPORTED OUTCOMES MEASUREMENT INFORMATION SYSTEM FATIGUE 4-ITEM SHORT FORM IN PSORIATIC ARTHRITIS

BY: PATRICIA KATZ

WHAT IT'S ABOUT: The PROMIS system is used by doctors and researchers to measure and evaluate your physical, mental, and emotional state. A particular section focuses on fatigue, which is a significant aspect of diagnosing, evaluating, and treating rheumatic diseases. This study specifically focused on the fatigue measurements for individuals with psoriatic arthritis (PsA) to determine if they were able to measure and report individual's fatigue levels correctly.

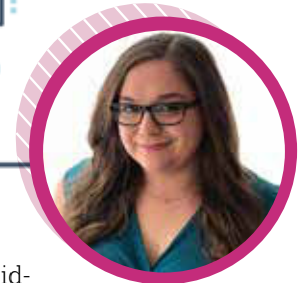
WHAT YOU NEED TO KNOW: Previously, there were no studies to check to make sure that these measures were appropriate for an individual with PsA. Every disease is different, even when they're in the same family (like rheumatic diseases). This study reviewed the reliability of these measures for PsA and determined that they were, in fact, reliable. This supports the continued use of these measures for PsA by your doctor or the researchers studying PsA.



Patricia Katz, PhD

Arthritis Internet Registry

Taking Research One Step Further



↑
Kristin Wipfler, PhD
FORWARD Biobank
Director

Many FORWARD participants are unaware of the Arthritis Internet Registry, an exciting partnership between FORWARD and Quest Diagnostics that provides valuable information for rheumatic disease research. We sat down with Kristin Wipfler, PhD, Biobank Director for FORWARD, to learn more about this program and how you can help.

FORWARD ➤: What is the Arthritis Internet Registry?

WIPFLER: AIR is a patient registry and biospecimen collection that combines the infrastructure of FORWARD and the nationwide availability of Quest Diagnostics blood collection sites. This partnership enables us to associate laboratory results with FORWARD's longitudinal questionnaire data for the patients who consent to give a blood donation. The research questions that can be asked and answered with this information are innumerable, and the knowledge gained is invaluable.

➤: Why is it important?

W: By analyzing your blood in combination with your answers to FORWARD questionnaires, we can examine associations between laboratory results and patient outcomes. We can investigate biological explanations for why some treatments work better for certain patients, identify prognostic factors, and gain a better understanding of genetic predisposition to rheumatic diseases.

➤: How can I help?

W: You can consider joining AIR and providing a blood sample! The data you provide helps us perform better research and make more discoveries.

➤: What happens to the information you learn from my donation?

W: De-identified samples are analyzed by QuestDiagnostics, and the laboratory results are linked to the FORWARD databank so that researchers can analyze the data. Your laboratory results will be available to you through a secure login on our website, and, if you would like to, you can print them out to take to your next doctor appointment.

➤: As Biobank Director, what role do you play with FORWARD?

W: While earning my PhD from the University of Nebraska Medical Center in 2017, my research was focused on genetics and bioinformatics. My passion is analyzing genetic and other biological data to learn more about diseases and improve outcomes for patients. I am currently analyzing the laboratory results of the more than 1,500 patients who have given a blood sample for our research, and I'm associating those results with the patients' questionnaire responses. One of my main roles is to devise new research questions and design new strategies to utilize the biological data we have to understand rheumatic diseases better.

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.

Frequently Asked Questions

EVERY SIX MONTHS, we send our questionnaires to you, our great participants who volunteer your time to add your information to the FORWARD Databank and your voice to rheumatic disease research. Each and every message we receive from you is read, and these comments often lead to changes to the questionnaire or provide an idea for a research project. We would like to take a moment to answer some of our most frequently asked questions.

Why should I participate?

People volunteer to participate in research for a variety of reasons. The primary reason people give for FORWARD participation is that they want to contribute to medical research that may help others with their disease. With a debilitating disease like arthritis or other rheumatic conditions, it can sometimes be difficult to volunteer in a traditional setting. FORWARD research allows you to volunteer in an important way. By learning about your condition over time, we hope to give researchers the tools to improve treatment for people with rheumatic conditions and improve their quality of life.

I'm in remission, or 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 you in the study so we can figure out what worked for you and whether it might apply to others. We can also 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.

When do I take my other medical problems into account?

Some questions ask about your rheumatic disorder, and others ask about your general health, which includes everything else, such as any other medical problems you may have. If it's not clear, you should answer with your general health in mind. In any case, don't worry about the difference too much or spend too much time on it. Your first thoughts on it are probably the most valuable to us.

In fact, many of the people in the study have more than one health problem. We are able to separate out the symptoms by using many of the answers you give us. There are many, many diseases and conditions that people in the study have in addition to their rheumatic diseases. It is currently beyond our capacity to study all or many of them, and the length of the questionnaire would probably cause many people to drop out, which would hurt the basic purpose of our research.

YOUR
VOICE
HELPS!





Reminders

While working on your questionnaire, if you have ANY questions, 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 goal of telling the rheumatology community about patient experience requires a large group of participants. Available for patient support groups/meetings, health fairs, offices, churches, or clinic waiting rooms – our pamphlets 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 jacob@ndb.org or **800-323-5871, ext. 180**. 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 participants 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

FORWARD

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

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