

FORWARD

SUMMER
2021

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES



Making Moves

A Story of Advocacy and the Patient Voice

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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**.



**FORWARD, The
National Databank
for Rheumatic Diseases**



@ndb_org



Letter from the Co-Director

Hello, and welcome to the latest issue of FORWARD magazine! For much of 2021, FORWARD, along with the rest of the rheumatology community, has been dedicated to understanding the impact of COVID-19 on rheumatology patients, and we thank you for your support and participation in this research.

In this issue, you'll see behind the scenes of FORWARD—The National Databank for Rheumatic Diseases and meet some of the important team members who have supported participants and the organization for many years.

You'll also hear from a patient, advocate, educator, and CEO of a non-profit about her own story of diagnosis and self-advocacy. We're excited to share some helpful tips about what advocacy may look like in your own life.

2021 has, so far, been a year of hope, insight, and constant striving to improve the diagnosis, treatment, and prevention of rheumatic diseases. To all of our participants: thank you for your continued support.

Sincerely,

**Kaleb Michaud, PhD
Co-Director, FORWARD**



Non-Profit Spotlight

The Spondylitis Association of America (SAA) was founded in 1983 by a small, dedicated group of volunteers who recognized a virtual standstill of spondylitis research in the U.S. At the time, there were no support networks, educational materials geared toward the patient, or even a single pamphlet for those affected by spondylitis. Now, for over 35 years, the SAA has held strong in their commitment to change the landscape of spondylitis in this country.

THE SAA IS A RELATIONSHIP-BASED NATIONAL NONPROFIT.

SAA's network of supportive programs ensures spondylitis patients do not have to face this disease alone. They also offer the most comprehensive hub of resources and material, providing support, education, advocacy, and funding for research in an effort to address the specific needs of spondyloarthritis patients and ultimately help them live their lives to the fullest.

To learn more about SAA, visit spondylitis.org.



Thank You

welcome

JOIN FORWARD

Why should you join FORWARD? Here are a few reasons why our participants choose to share their information and experiences with us.



TO HELP OTHERS.

The information about your experience with a rheumatic condition is used by researchers to improve the diagnosis, treatment, and prevention of rheumatic diseases.



IT'S EASY.

Questionnaires are only sent out twice a year, and follow-up questions are only sent as needed to add more information to the data from the main questionnaire.



YOU'RE NOT ALONE.

Nearly every person is affected by a rheumatic disease, through a personal diagnosis or the diagnosis of a loved one. We know that together, we can continue to make a difference.

Visit forwarddatabank.org/join-forward or call 1-800-323-5871 today!

You Make A Difference

FORWARD is proudly unique from other rheumatic disease databanks thanks to our long history of collecting patient-reported information (meaning that the data come directly from patients like you.) When needed to address certain questions, these data can work in concert with the FORWARD Biobank and clinical data (directly from rheumatology clinicians) to form a much clearer picture of total health and give us a one-of-a-kind perspective into long-term health for rheumatology patients. **It's FORWARD participants, like you, who make our contributions to rheumatic disease research possible.**

Whether you've been a contributor to FORWARD's questionnaires for over twenty years or are just getting started, we thank you. We're grateful for your time and energy each time you participate, and **we want you to know you are making a difference** for individuals who have been or will be diagnosed with a rheumatic disease.

If you are curious how your participation makes an impact, your information is paired with thousands of others' to advance research. Our comprehensive databank includes answers from all questionnaires since FORWARD's inception. The answers are used by rheumatic disease researchers all over the world who are trying to answer questions that help researchers, physicians, and pharmaceutical companies make improvements in each patient's diagnosis and treatment journey. We are an independent non-profit, nonpartisan organization, meaning we are not influenced by pharmaceutical, insurance, political, or financial companies. Access to our vital, patient-reported data is provided free of charge to academic researchers and physicians.

FORWARD's sole purpose is to champion your voice, the patient's voice, so that researchers can understand your diagnoses, treatments, side effects, and long-term benefits and risks to improve future care. Your participation makes all the difference.

If you are a new participant in our studies, welcome to FORWARD! If you ever have any questions or need help filling out your bi-annual questionnaire, please contact us by email at webquest@ndb.org or call us at 1-800-323-5871.

ON THE MOVE:

The Right Shoes for You

Shoes can be one of your most important decisions each day. The right shoe can increase mobility and slow down disease progression in your joints.



Flip-Flops & Flats

Surprisingly, flip-flops may create less knee stress for patients who suffer from knee osteoarthritis. If you struggle with foot pain or balance, however, flip-flops probably aren't the best option. A thicker, sturdy flat with some flexibility is a much better option than a flat you can bend in half.



Sandals

The more straps and support they have, the better. It's imperative your sandals have a strap wrapping around the back of your ankle so that the front of your foot isn't over-worked. The right pair of sandals can be a good option for walking because straps allow for a more custom fit.



Athletic Shoes

A neutral athletic shoe, without a lot of arch, may be best if you use custom orthotics. Stability shoes, on the other hand, provide good cushioning and support. If you're unsure, talk to your doctor or podiatrist so they can help.



Boots

Boots can be a great option for patients with ankle pain, especially hiking boots. Choose an option that has a low or flat, rubber-soled wedge that offers generous arch support.

Understanding Your Treatment Options

After being diagnosed with a rheumatic condition, there are several potential treatments your doctor may prescribe. To make it easy, here is an overview of the most common treatments.

ANALGESICS: specifically designed to relieve pain. These include acetaminophen or opioids, which are only available by prescription.



BIOLOGICS: designed to reduce inflammation and halt joint damage. Each biologic targets specific parts of the immune system that fuel inflammation.



NSAIDS (NONSTEROIDAL ANTI-INFLAMMATORY DRUGS): the most frequently used medications for rheumatic patients and often the first stop in form of treatment. These are used to reduce inflammation.



DMARDS (DISEASE-MODIFYING ANTIRHEUMATIC DRUGS): slow the disease process by blocking inflammation to help preserve joints. These are often prescribed alongside other medications listed here for quick pain relief.



CORTICOSTEROIDS: the quickest way to control inflammation but can sometimes cause serious side effects. They should not be used long-term.



Visit the Arthritis Foundation for more information: arthritis.org



Pushing Ahead, with SpA:

A Story of Advocacy, Education, and Connection

When Tiffany Westrich-Robertson knew something was wrong, she kept asking for the medical care she knew she needed. ➤



TIFFANY
WESTRICH-
ROBERTSON



"I WAS A MYSTERY PATIENT.

Like a lot of people with my illness, I was in my mid-thirties. I was an athlete, very physically fit, so the initial diagnosis was that I had injured myself. But I knew that something more was wrong." For Tiffany Westrich-Robertson, as it is with many people with spondyloarthritis (SpA), the diagnosis process was long and complicated.

Tiffany shares, "Eventually I was diagnosed with rheumatoid arthritis, but I was told that I didn't have the classic, textbook arthritis. There was no such thing as non-radiographic axial spondyloarthritis in 2009, so nobody knew what my actual disease was."

At the time, the "only disease in that category was ankylosing spondylitis, which has very specific criteria for diagnosis," which Tiffany did not meet. "I was put on a biologic that was indicated to treat rheumatoid arthritis, and I did OK for a couple of years. But then, in 2013, the lower back pain started coming back with a vengeance, and I remember just lying there in my bed. It was terrible to get up in the morning. And that's when I knew that something was really, really wrong with my diagnosis."

"Nobody wants limitations. We all eventually have them someday, but nobody thinks that it's going to happen in your 30s or your 40s."

—TIFFANY WESTRICH-ROBERTSON

A Textbook Case

In 2009, around the time of Tiffany's initial diagnosis of rheumatoid arthritis, she began the non-profit organization now known as The International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis). Expanding beyond its initial goal of raising awareness that rheumatic diseases are prevalent even amongst young people, AiArthritis now exists as an international patient organization designed to connect patients and professionals to solve problems that impact education, advocacy, and research within the rheumatology community.

Thanks to her experience leading AiArthritis, Tiffany was equipped with the knowledge and confidence she needed to advocate for herself when her back pain returned in 2013: "I went to the rheumatologist and I met with a physician's assistant and said, 'Something's wrong. You have to retest me for ankylosing spondylitis.' And they did, and of course, I didn't meet the criteria."

Tiffany shares, "I would not leave that office. I said, 'I don't accept this answer.' And eventually, the rheumatologist came in. I was very passionate, very adamant that this was not rheumatoid arthritis." Tiffany's rheumatologist had just returned from the annual European Alliance of Associations for Rheumatology (EULAR) conference and shared what he had learned. "He said,

Make your voice heard. To connect with other patients that experience autoinflammatory arthritis like SpA or RA, visit aiarthritis.org, and visit forwarddatabank.org/join-forward to become a FORWARD participant.

"There is now something called non-radiographic axial spondyloarthritis, and you are a textbook case."

Learning to Advocate

"To this day, I don't know what would have happened to me if I had not insisted that rheumatoid arthritis was the wrong diagnosis," says Tiffany. "And I don't know that the average patient would have been able to persist and even refuse to leave the office the way that I did."

"I remember, before receiving the correct diagnosis, lying in my bed staring up at the ceiling and thinking 'I don't know what this is going to turn out to be, but whatever it is, **I vow that I will make sure I do everything in my power to make sure this doesn't happen to other people.**'"

For Tiffany, as for many others with rheumatic diseases, personal advocacy is a frustrating (and ongoing) necessity. "I also want to point out that it's much more than being an advocate for yourself within the medical community. It's important to be an advocate amongst your own peers, your friends and family. Even though you may look fine on the outside, they don't always understand why you have to miss that birthday party or why you can't stand for longer than an hour, or whatever it is that you need."

How to Advocate



- **Tell Your Story:** Let your friends, family, and employer know if you require certain accommodations.



- **Make Connections:** Connect with patient groups, like AiArthritis, to hear other people's stories and to support one another.



- **Understand Your Needs:** Nobody wants limitations. But that doesn't mean you don't have them. Pay attention to what your body needs from you to feel your best.



- **Show Up:** One of the best ways to contribute to the rheumatic disease community is to participate in research—you can become a FORWARD participant today!

Spondyloarthritis (SpA) and You

Alexis Ogdie, MD, MSCE, director of the FORWARD SpA Registry, shares:

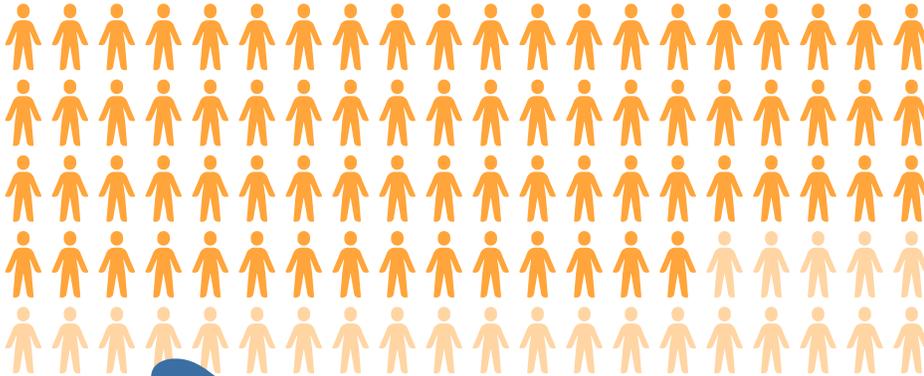
"There's lots of different symptoms and outcomes associated with the SpA family of diseases, compared to other rheumatic diseases, that we're able to study because of the FORWARD SpA Registry. We know that these questionnaires can be difficult because they are really long. But by filling these out, participants are really providing a wealth of information that we can use to better understand outcomes, outcome measures, and therapies."

"The evolution of new therapies to treat SpA patients makes patient participation in this registry all the more important."

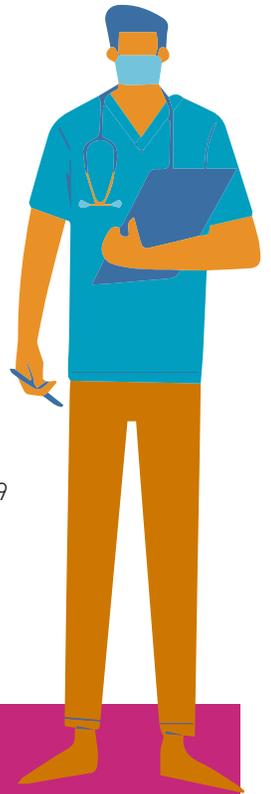
—ALEXIS OGDIE, MD, MSCE

FORWARD

COVID-19 Vaccination: By the Numbers



74.6% OF FORWARD COVID Questionnaire respondents received at least one COVID-19 vaccination by April 1, 2021. COVID-19 vaccines are effective at preventing COVID-19 disease, especially severe illness and death.



Millions of people in the United States have received COVID-19 vaccines, and these vaccines have undergone the most intensive safety monitoring in U.S. history. This monitoring includes using both established and new safety monitoring systems to make sure that COVID-19 vaccines are safe. — Key Things to Know About COVID-19 Vaccines, CDC

Vaccination Rates as of April 1, 2021

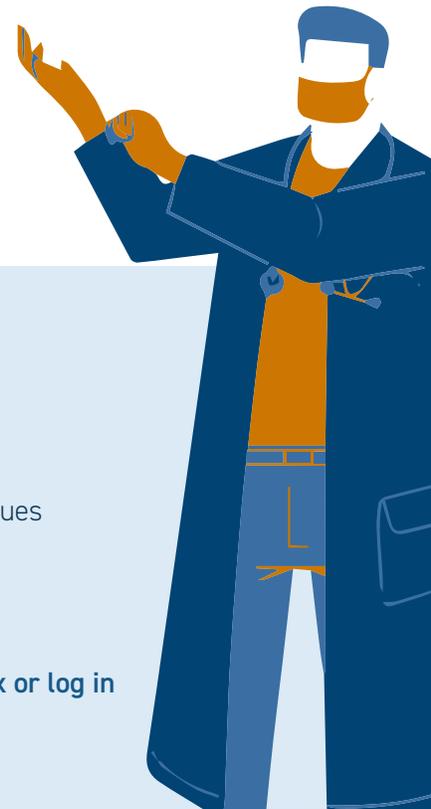


Mathieu, E., Ritchie, H., Ortiz-Ospina, E. et al. A global database of COVID-19 vaccinations. *Nat Hum Behav* (2021)

Vaccines are now more widely accessible in the U.S. Everyone 12 years of age and older is eligible to get a COVID-19 vaccination. The federal government continues to work toward making vaccines widely available for everyone at no cost.

Find a COVID-19 vaccine: Search vaccines.gov, text your zip code to 438829, or call 1-800-232-0233 to find locations near you.

To participate in the FORWARD COVID Questionnaire Study, check your email inbox or log in at forwarddatabank.org to get started.



Moving FORWARD, *with you*

You'll likely recognize the small, tight-knit team who supports the participants of the National Databank for Rheumatic Diseases.



**DEBRA
HARKNESS**



**ROSEMARY DUNBAR
BARBARA KELLEY
DANA KEELER**



**TWILA
HUDSON**

PLAYING AN INTEGRAL ROLE in aiding FORWARD participants with their questionnaires, the Research Support team ensures data collected are as pristine as possible. Twila Hudson has been with FORWARD for 36 years, and explains that each of the team members, or family, as they refer to each other, absolutely love their work. "This is a rewarding job. We spend more time with each other than anyone else... it's rare and valuable. We're hoping we'll come up with a cure."

All of the Research Support team members have been with FORWARD for years and know many participants well. "Participants' comments aren't shoved into a drawer or cabinet. We read them and we know them. That's the most rewarding part," says Rosemary Dunbar.

Barbara Kelley shares, "I've been a caregiver all my life... the most valuable part is being able to help patients. We listen to them, which is often what they need most. They are participating for free and don't complain. The least we can do is listen and help as best we can."

A rewarding job doesn't mean it's easy, though. Getting to know participants personally often makes it hard when they are suffering in their health journey. "Often, we're the only ones who understand how they feel. Everyone here has compassion for these participants," says Barbara.

This team walks through each questionnaire, recording and confirming data. Dana Keeler, who jokingly refers to herself as the newest member of the team (she's been with FORWARD for 14 years), calls patients to fill in missing questionnaire information. "It's almost like we're on the journey with them." On an RA and lupus journey of her own, Dana enjoys getting to know the partic-

ipants, and says sometimes when she calls, they'll answer, "Hello, Dana!"

Debra Harkness, having played a role on the FORWARD team for 38 years, emphasized the importance of data, calling it a gift: "Our participants give us a very huge gift—the gift of their time and data. They sit down and fill out this questionnaire; it may take days for them to do that. We don't take that lightly. They help us shed light on these systemic diseases... then turn around and thank US for helping find a cure. It's amazing, and extremely valuable." The appreciation, on both sides of the table, is a testament to the value that both participants and the FORWARD team members bring to this worthy cause.

The FORWARD team is grateful for our participants, without whom we wouldn't be able to make a difference. To join FORWARD, visit forwarddatabank.org/join-forward.

FAQS

FORWARD often receives questions from participants about our organization, research, and partners. Here are the most common questions we've received this year.

Q: Does FORWARD share my private information?

A: No, FORWARD does not share your private, identifying information. You can trust that the information you share with FORWARD is completely confidential.

FORWARD is not a government study—we are an independent, non-profit research group. Any personal information, like your name, address, phone number, email address, and more, is removed before any data or study information is seen by physicians, researchers, or other organizations.

The only people who know your name and can identify your information in the study are the FORWARD staff who contact you via phone, mail, or email. Ensuring that our participants are confident in the privacy of their personal information is of the highest concern to the FORWARD staff; in fact, we would not be allowed to conduct this research without guaranteeing complete confidentiality to participants.

FORWARD takes care to respect your privacy, and we comply with all privacy requirements to be able to conduct our research.

Q: Who funds FORWARD—The National Databank for Rheumatic Diseases?

A: FORWARD is an independent non-profit, non-partisan organization that currently receives funding from public donations, university grants, non-profit organization grants, and pharmaceutical or other research company grants.

FORWARD accepts pharmaceutical grants from multiple drug companies for research on specific medications or diseases, usually regarding whether medications are effective and safe. No matter the outcome of any research performed by FORWARD—good or bad—all research findings are published and shared with the public. As a non-profit organization, our goal is to ensure that all individuals and organizations have access to the information they need to improve the treatment, diagnosis, and prevention of rheumatic diseases.

Q: Why did I receive an extra or different questionnaire, other than my usual twice-yearly questionnaire?

A: Depending on what is happening in the world or in the rheumatology community, you may receive “mini” questionnaires, which are separate from the twice-yearly questionnaire all FORWARD participants receive.

Our goal with these mini questionnaires is to expand upon and gather new information to add to the data received from the twice-yearly questionnaire. Recently, we have a COVID vaccine mini questionnaire available to help collect data about whether vaccines are working and are safe for rheumatic disease patients. With this, and any research that we do, we are sharing our findings with the world-wide rheumatology community, including patients, doctors, nurses, researchers, companies, universities, and non-profit organizations. We thank you for your help with this research!

Have more questions? Learn more at forwarddatabank.org, call 1-800-323-5871, or email webquest@ndb.org.



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 FORWARD Databank. **Your information is always confidential**, and your participation is extremely valuable to the research with or without the signed medical information release form.

Random Drawing Information

FORWARD CONDUCTS RANDOM DRAWINGS as a token of our gratitude.

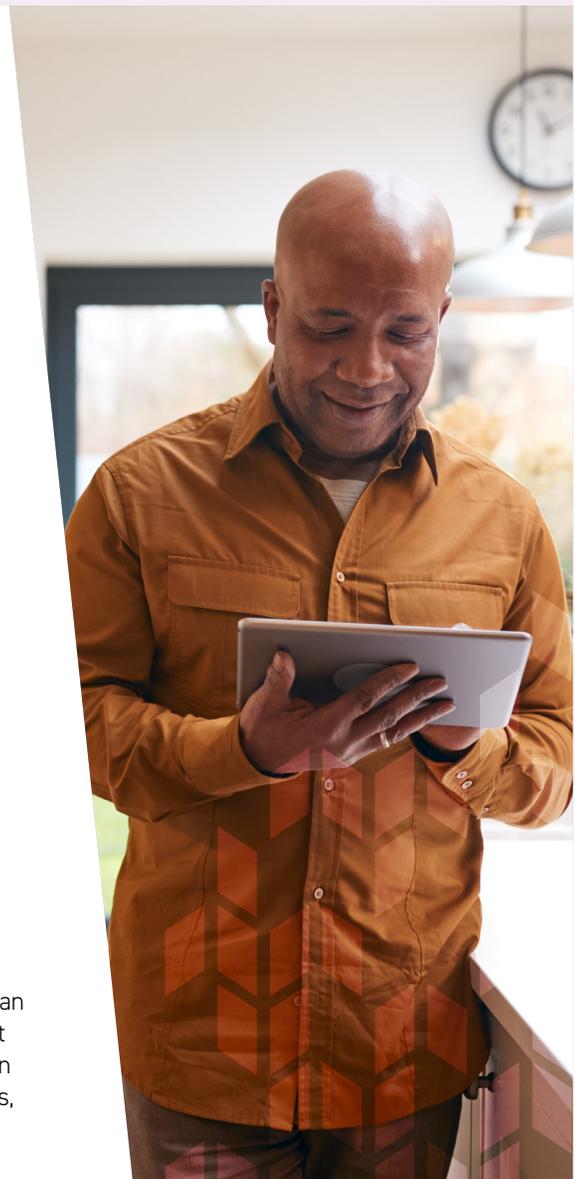
Our random drawings consist of:

- + 5 drawings for **\$500 each** for those who return a large questionnaire via mail, web, or phone any time within six months for the current questionnaire.
- + 5 drawings for **\$100 each** for those who return a shorter questionnaire via mail or phone anytime within six months for the current questionnaire.

Email: What You Need to Know

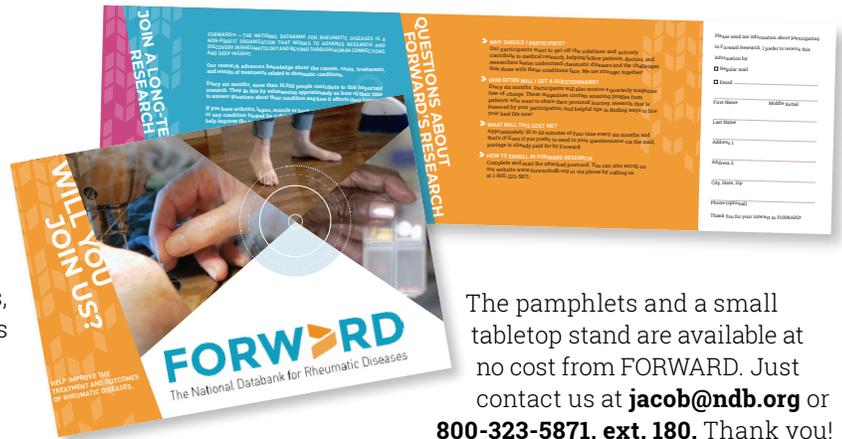
FOR PATIENTS USING WEBQUEST, email is our primary method of getting in touch with you. Even if you're not using WebQuest, we'd like to be able to send you important information by email. **Here's an important step you can take to make sure our email gets to you:** add us to your email address book! Our 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 when you change your email address. To update your email address, go to our website, forwarddatabank.org, and click **"Update Contact Info"** under the **"Patients"** tab. You can also update your email address if you have set up an account in the FORWARD Patient Portal. If you have an account, you can login and in the upper right-hand corner click on your name and then click on "Change Email." Of course, you can always email or call us, and we will change it for you. Thank you!



Helping FORWARD in Other Ways

FORWARD's goal of telling the rheumatology and medical community about patient experiences requires a large group of participants. Pamphlets are available to share with 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 at no cost 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 FORWARD. Just give us your friend's email address, and we'll send out an email invitation to join the study. [Go to forwarddatabase.org/tell-a-friend](http://forwarddatabase.org/tell-a-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, contact us at webquest@ndb.org and we will set you up with the online version.**

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. Please let us know what we can do to help you 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, Please Reach Out

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