FORWARD

SUMMER
2020

NEWS AND INSIGHTS FROM THE BANK FOR RHEUMATIC DISEASES

Moving FORWARD Together

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MEET Your Healthcare Team

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ANSWERING YOUR MOST COMMON QUESTIONS

Letter from the Co-Director

Dear Reader,

We're excited to share this issue of FORWARD magazine with you and hope that you will find it informative and helpful. You'll find an update about our COVID-19 questionnaire, learn more about the FORWARD team and the many important roles they play, and you'll also see that we have taken the chance to step back and answer some of the most common questions that we've received from FORWARD participants about research and rheumatic diseases.

Without individuals like you who are willing to give their time, energy, and effort to answer our twice-yearly questionnaire, we wouldn't be able to impact rheumatic disease research and improve 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

In This Issue

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

SPOTLIGHT

LOOKING for additional resources to learn about your rheumatic condition? Take a look at these non-profit organizations and institutions.

American College of Rheumatology (ACR)
rheumatology.org/I-Am-A/Patient-Caregiver

Arthritis Foundation
arthritis.org

John Hopkins Rheumatology
hopkinsrheumatology.org/rheumtv/

European League Against Rheumatism (EULAR)
eular.org

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
niams.nih.gov/health-topics/arthritis-and-rheumatic-diseases

thank you

First and foremost, the FORWARD team wants to say "Thank You" to all of the participants who fill out the FORWARD questionnaire, who call in to ask questions or share about their day-to-day experience with their rheumatic condition, and who share the FORWARD databank with their friends and family.

With the recent special COVID-19 questionnaire, we've had the opportunity to speak one-on-one with more participants than usual and have been reminded of how important each and every one of you are to the work that we do. If you're a newcomer, or if you're curious how your participation impacts rheumatic disease research, here's a quick primer. Every six months, FORWARD's participants complete a questionnaire about their experience with their rheumatic disease. These answers are added to a comprehensive databank. **The databank includes answers from all participants since FORWARD's inception in 1998.**

This databank is used by researchers all over the world who are seeking answers to questions that will help physicians, other researchers, and pharmaceutical companies improve the diagnosis and treatment of rheumatic diseases. **For academic researchers and physicians, this vital information is provided free of charge,** meaning that these individuals can devote their time and energy to studying your disease rather than seeking additional funding to gain access to this important information. **FORWARD is an independent organization and therefore not influenced by pharmaceutical, insurance, or other institutions, or other outside interests.**

JOIN FORWARD

Why should you join FORWARD? Here are a few reasons why our participants choose to share their information and experience 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. Once you've completed your questionnaire—you're done!

YOU'RE NOT ALONE.
Nearly every person is affected by a rheumatic disease, with either a diagnosis themselves or through a loved one. We understand that—and know that together, we can make a difference.

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

COVID-19 + FORWARD: **An Update**

We want to extend a massive "Thank You" to the many individuals who chose to fill out our recent COVID-19 questionnaires. Your information is being used by researchers to better understand the impact of COVID-19 on individuals with rheumatic diseases, their symptoms, and treatment. Many of you went above and beyond by including additional comments that give researchers deeper insight into your experience.

From now on, COVID-19 questions will be included in the regular six-month questionnaire. We ask that you continue to share your day-to-day experience and provide helpful information to the researchers whose work is dedicated to improving the diagnosis, treatment, and care of rheumatic diseases.

Avoiding the Doctor? **Don't.**

If you've been avoiding seeing your doctor, whether it's due to the ongoing COVID-19 pandemic or for any other reason, please reconsider! During the current pandemic, it's understandable that many individuals are avoiding the doctor in an attempt to further limit their social contact and lower their risk of contracting COVID-19.

However, your health depends on your physician's ability to treat your condition. If you have a regularly scheduled checkup soon or are experiencing symptoms that would normally cause you to go to the doctor, contact your physician's office. They'll be able to guide you to the best option, either an in-person visit or telehealth visit, to ensure that your healthcare needs are met while keeping you safe.

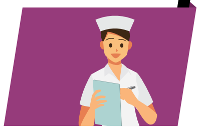
Your Healthcare Team

There are many individuals involved in your care. Here are some that you may run into during your doctor appointment, whether it's in person or online!

RHEUMATOLOGIST: A rheumatologist is a medical professional who has received extensive training in the diagnosis and treatment of rheumatic and musculoskeletal diseases. Often, these individuals perform important research, care for patients, and direct or collaborate with other caregivers to provide comprehensive medical care to their patients.

NURSE PRACTITIONER (NP): This individual, with a graduate degree in advanced practice nursing, works under the direction of a physician and can diagnose your condition, write prescriptions, refer you to another specialty, provide important education about your condition and treatment, and more.

PHYSICIAN ASSISTANT (PA): Often mistakenly thought of as a "physician's assistant," this highly trained individual with a graduate-level degree collaborates with a physician to manage all aspects of your care, including diagnoses, treatment, and ongoing condition management.



REGISTERED NURSE (RN): These individuals fill many vital roles in a rheumatologist office. Tasks from patient management to monitoring vital signs and blood work to providing important patient education are often performed by registered nurses.

RHEUMATIC & MUSCULOSKELETAL DISEASES

Just because RA has "Rheumatoid" in the name, it's a common misconception that this is the only disease we're referring to when we say, "Rheumatic diseases!" However, FORWARD collects data on many rheumatic and musculoskeletal diseases, and that list is very large. If you're seeing or have seen a rheumatologist, your experience is important and we need your participation. Here are just some of the conditions that FORWARD studies.

Osteonecrosis

Cryopyrin-Associated Autoinflammatory Syndrome (CAPS)

TAKAYASU'S ARTERITIS

Glucocorticoid-induced Osteoporosis

Dermatomyositis

Spinal Stenosis

Tumor Necrosis Factor Receptor Associated Periodic Syndrome (TRAPS)

ARTHRITIS (JIA)

JUVENILE

Familial Mediterranean Fever

Vasculitis

ARTHRITIS

SPONDYLOARTHRITIS

INFLAMMATORY MYOPATHIES

Kawasaki Disease (KD)

Granulomatosis with Polyangitis (Wegener's)

FIBROMYALGIA

CARPAL TUNNEL SYNDROME

Calcium Pyrophosphate Deposition (CPPD)

Hypermobility

Amplified Musculoskeletal Pain Syndrome (AMPS)

Osteoarthri

Hyperimmunoglobulin D Syndrome (HIDS) / Mevalonate kinase deficiency (MKD)

Osteoporosis

Osteoarthritis

Periodic Fever, Aphthous Stomatitis, Pharyngitis, Adenitis Syndrome (PFAPA)

Tendinitis & Bursitis

SCLERODERMA

IgG4-Related Disease (IgG4-RD)

Sjögren's Syndrome

Ankylosing Spondylitis (AS)

RHEUMATOID ARTHRITIS (RA)

Chronic Recurrent Multifocal Osteomyelitis (CRMO)

PSORIATIC ARTHRITIS (PSA)

LUPUS

Myopathies

Metabolic

Raynaud's Disease

Dupuytren's Disease

GIANT CELL ARTERITIS

Henoch Schönlein Purpura (HSP)

Paget's Disease of Bone

Gout

Antiphospholipid Syndrome

JUVENILE DERMATOMYOSITIS (JDM)

Polymyalgia Rheumatica

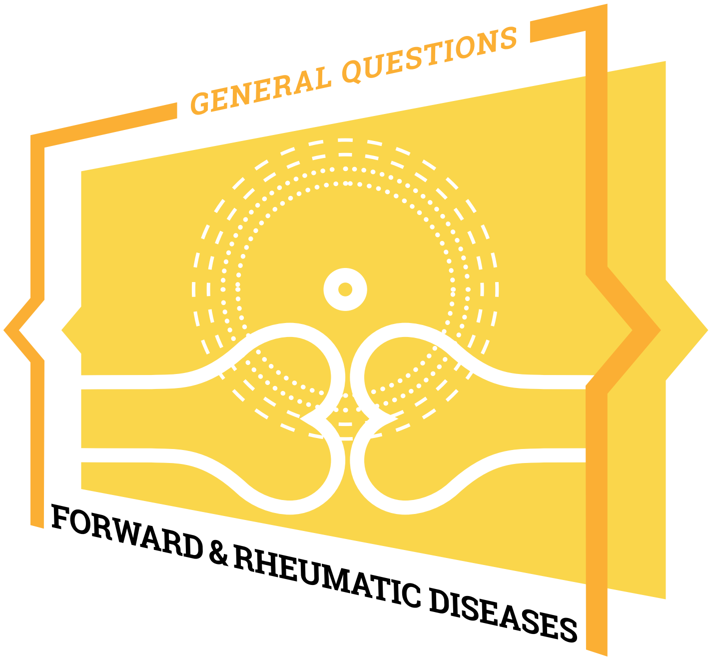
Reactive Arthritis

Still's Disease

Back to Basics

ADDRESSING SOME COMMON QUESTIONS: FORWARD, RESEARCH, RHEUMATIC DISEASES, AND YOU

FORWARD participants, and people who are interested in FORWARD, often have questions about the databank, research, and how it affects them. While we love talking with those individuals who reach out, we know that many other people probably have the same questions. Here are some of the most common questions we've received.



Q: WHAT IS FORWARD?

A: FORWARD—The National Databank for Rheumatic Diseases is a research databank that exists for people like YOU—individuals with rheumatic conditions or any condition that is treated by a rheumatologist or joint specialist. We collect data on your condition and your day-to-day experience via a questionnaire that is completed every six months, with the goal of advancing knowledge about the causes, outcomes, and treatments related to rheumatic conditions.

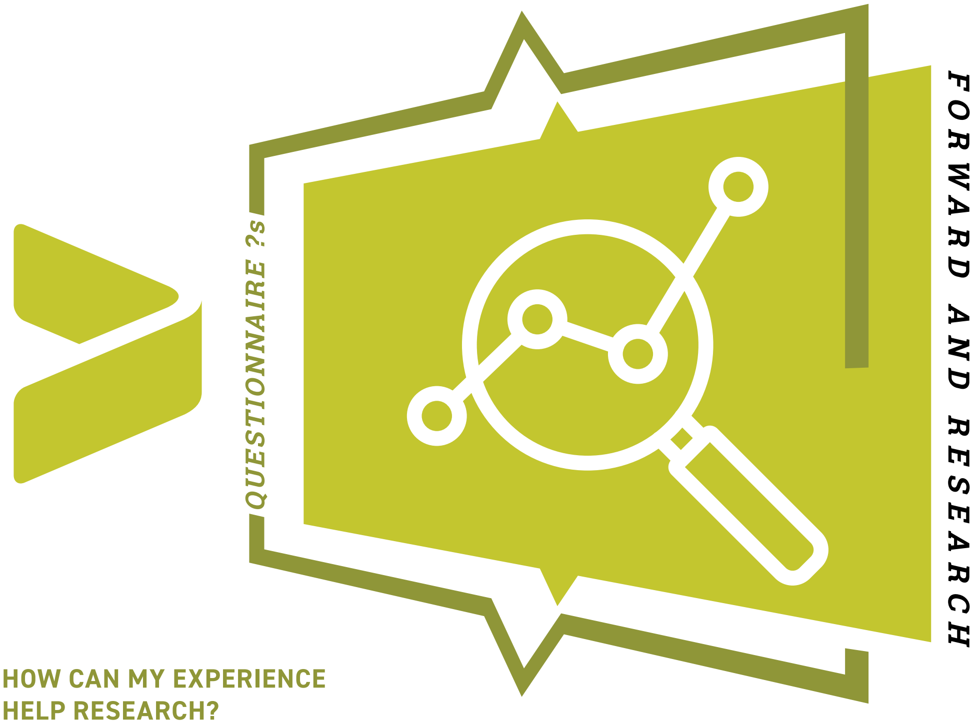
Q: WHAT DO YOU MEAN BY RHEUMATIC DISEASE OR CONDITIONS?

A: Throughout the questionnaire you may see the phrase, "arthritis or rheumatic disease." The term "rheumatic disease" encompasses a number of different conditions, many of which affect the joints and are commonly referred to as "arthritis". The official definition is: "Rheumatic and musculoskeletal diseases (RMDs) are a diverse group of diseases that commonly affect the joints but can also affect the muscles, other tissues, and internal organs. There are more than 200 different RMDs, affecting both children and adults. They are usually caused by problems of the immune system, inflammation, infections or gradual deterioration of joints, muscle, and bones. Many of these diseases are long term and worsen over time. They are typically painful and Iimit function. In severe cases, RMDs can result in significant disability, having a major impact on both quality of life and life expectancy."*

*Definition provided by the European League Against Rheumatism (EULAR). Visit EULAR.org to learn more.

Q: WHO RUNS FORWARD? HOW DO THEY KNOW WHAT INFORMATION RESEARCHERS NEED?

A: Over 20 years ago, FORWARD—The National Databank for Rheumatic Diseases was created as a formal nonprofit organization by Frederick Wolfe, MD, who had already been gathering information from his patients and others for the purpose of research. Since then, FORWARD has been run by and supported by rheumatologists, physicians, patients, administrative staff, and researchers from various academic institutions around the world, dedicated to improving the diagnosis, treatment, and prevention of rheumatic diseases or conditions. The varied expertise of these individuals, along with a constant commitment to provide helpful data to new researchers and institutions studying rheumatic conditions, allows FORWARD to ensure that the information being gathered from participants is relevant and helpful to researchers and the rheumatology community.



Q: HOW CAN MY EXPERIENCE HELP RESEARCH?

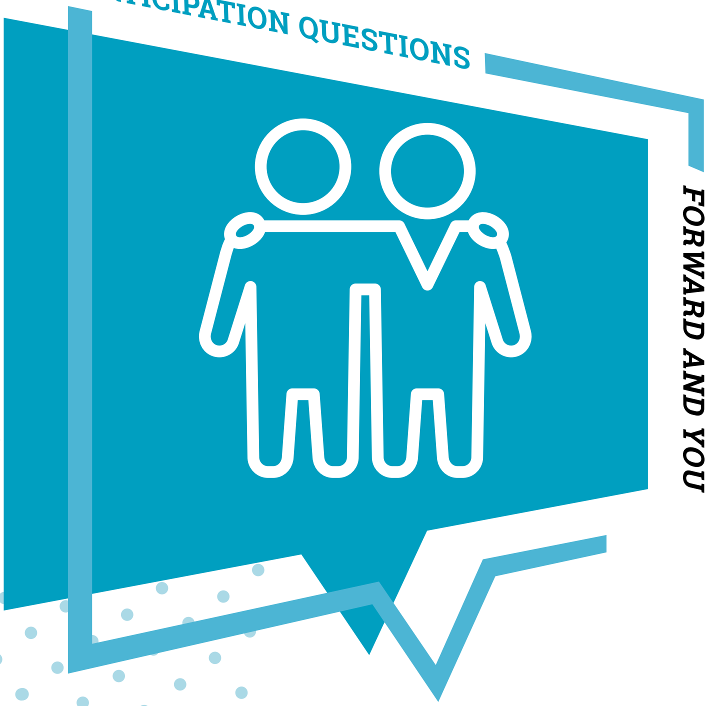
A: YOU are the expert on your experience with your disease or condition, symptoms, and treatment! There is no one better to let researchers know what is and isn't working for you. Once we remove your name and any identifying information, your data is entered into a computer databank used by medical researchers and the rheumatology community. This information is used to help better understand how your disease or condition and treatments are affecting you and your daily life and to help with improving treatment and care of your disease or condition. Researchers describe their findings in articles that are published in medical journals and in presentations at national and international meetings. That way, all doctors and other healthcare professionals who treat rheumatic and musculoskeletal diseases or conditions are able to receive the benefit from the research.

Q: WHY DO YOU ASK THE SAME QUESTIONS OVER AND OVER?

A: Often, a question that seems exactly the same as a previous question will actually have a small, but important difference. When it comes to research, the exact way that a question is worded can have a big impact on the information that researchers are able to gather from your answer. If you feel like you've already answered a question when you're working on the questionnaire, we ask for your patience and a thoughtful response.

Q: WHAT IF I DON'T KNOW THE ANSWER TO ONE OF THE QUESTIONS?

A: We understand that it may not always be possible for everyone to remember something that happened or started a long time ago. If you can't remember the answer to a question, we ask that you give it your best guess. You can also ask those around you to help you remember! Something as easy as, "Do you remember how bad my pain was around that time?" can prompt a conversation that might jog your memory. Another suggestion is to keep a short daily log of how you feel; you can then go back and see how you were feeling.



PARTICIPATION QUESTIONS

FORWARD AND YOU

Q: WHY SHOULD I PARTICIPATE?

A: People volunteer to participate in research for a variety of reasons. The primary reason that FORWARD participants have shared their experience with us is that they want to contribute to medical research and help others manage their disease or condition. With a debilitating disease like arthritis or other rheumatic or musculoskeletal 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 and the rheumatology community the tools to improve treatment for people with rheumatic conditions and impact their quality of life in a positive way.

Q: I DON'T HAVE A DIAGNOSIS. WHY DO YOU WANT ME TO PARTICIPATE?

A: If your physician or healthcare team recommended that you participate in FORWARD, they have a good reason! For some people, you may be showing symptoms similar to those of a rheumatic disease or condition, or perhaps you've visited a rheumatologist but they aren't sure what disease or condition you have yet. Regardless, having individuals like you in the databank allows researchers to compare your experience with the experience of other individuals with various rheumatic diseases, providing valuable information that can one day improve treatments for any individual experiencing symptoms like those of a rheumatic disease.

Q: I'M IN REMISSION. SHOULD I STILL PARTICIPATE?

A: 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 learn 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.

Still have questions? Learn more by visiting **forwarddatabank.org/about/FAQ** or contact us at **webquest@NDB.org** or **1-800-323-5871.**

MOVING FORWARD, **Together**

Many readers of FORWARD magazine may not be aware of the roles being played behind-the-scenes to support, grow, organize, and maintain the FORWARD databank and ensure that researchers are getting the data they need to answer important questions. The individuals and organizations that fill these roles, spread across the world, include physicians, researchers, nonprofits, and more.

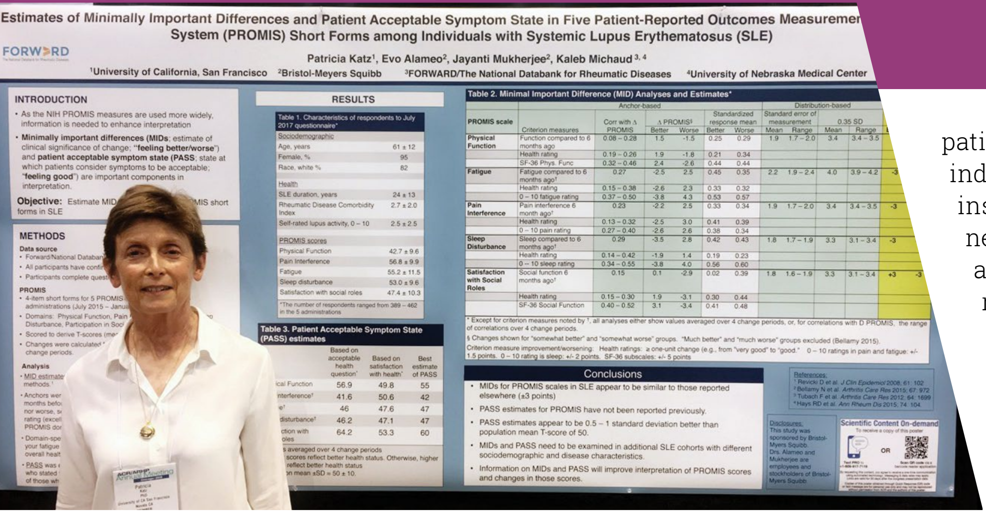
Take a look below at the many roles played by the FORWARD team to learn more about the individuals and organizations that have shared their expertise, time, and efforts to improve medical care for individuals with a rheumatic condition.

NONPROFIT ORGANIZATIONS

FORWARD regularly partners with other nonprofit organizations. In fact, you may have read about some of these nonprofits in recent issues of FORWARD magazine! Many of the organizations that we work with are patient-centric, often working to connect individuals with rheumatic diseases to important educational resources and to other patients with the same or a similar condition. Some of these nonprofits even have their own research initiatives! Together, we work to provide support to these nonprofits by sharing information about them with our own participants or providing data analysis important to their mission, and in turn, these nonprofits support FORWARD's goals by helping recruit participants and share data with even more researchers.

ACADEMIC INSTITUTIONS + RESEARCHERS

Without the support of academic institutions and researchers, FORWARD wouldn't be able to make a difference in the diagnosis, treatment, and prevention of rheumatic diseases. Researchers not only work with FORWARD to access the data, but also to lend their time and expertise in writing the questionnaire itself, spreading the news about the databank to institutions and researchers, and actively participating in research using FORWARD data, all while maintaining academic careers, seeing



Estimates of Minimally Important Differences and Patient Acceptable Symptom State in Five Patient-Reported Outcomes Measuremer
System (PROMIS) Short Forms among Individuals with Systemic Lupus Erythematosus (SLE)

Patricia Katz[1], Evo Alameo[2], Jayanti Mukherjee[2], Kaleb Michaud[3, 4]

[1]University of California, San Francisco [2]Bristol-Meyers Squibb [3]FORWARD/The National Databank for Rheumatic Diseases [4]University of Nebraska Medical Center

Conclusions

- MIDs for PROMIS scales in SLE appear to be similar to those reported elsewhere (±3 points)
- PASS estimates for PROMIS have not been reported previously.
- PASS estimates appear to be 0.5 – 1 standard deviation better than population mean T-score of 50.
- MIDs and PASS need to be examined in additional SLE cohorts with different sociodemographic and disease characteristics.
- Information on MIDs and PASS will improve interpretation of PROMIS scores and changes in those scores.

patients, and participating in other research. These individuals, with the support of their academic institutions, provide valuable insight into the needs of researchers and physicians who are actively working to better understand and treat rheumatic diseases.

ADMINISTRATIVE

The FORWARD administrative team fulfills many important roles needed to ensure the success of a nonprofit—everything from daily financial and clerical tasks to ensuring that every participant voice is heard via phone questionnaires to partnering with physicians and other nonprofits to enroll new patients into the databank. Many of these individuals have worked with FORWARD for over 20 years and have gained a unique level of expertise responding to the needs of a research databank like FORWARD. In fact, a number of the individuals on our Administrative team are physicians, researchers, and patients themselves! Having people with different areas of expertise working on tasks such as organizing and updating the questionnaire, promoting the databank, connecting with patients and other like-minded organizations, and providing access to other researchers is vital.

> **WE WANT TO EXTEND A SPECIAL THANK YOU TO THE MANY INDIVIDUALS AND ORGANIZATIONS WHO SUPPORT FORWARD'S MISSION TO ADVANCE RESEARCH AND DISCOVERY IN RHEUMATOLOGY, AND TO ULTIMATELY IMPROVE THE DIAGNOSIS, TREATMENT, AND PREVENTION OF RHEUMATIC DISEASES.**

YOU

As a team, those who support FORWARD share a common mission—to improve the diagnosis, treatment, and prevention of rheumatic diseases. While these individuals and organizations are spread across many different fields and areas of expertise, they all play very important roles in building and maintaining the databank. But we can't forget about the most important FORWARD supporter—our participants! Without individuals like you who are willing to share your experience with your rheumatic disease, the FORWARD team wouldn't be able to make a difference.

We thank you for each and every step you take to support rheumatology research. There are many ways that you can support the FORWARD databank and rheumatology research! Visit forwarddatabank.org to JOIN FORWARD and make your voice heard. You can also spread the word about FORWARD to your friends and family and make a monetary donation if you're able.

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

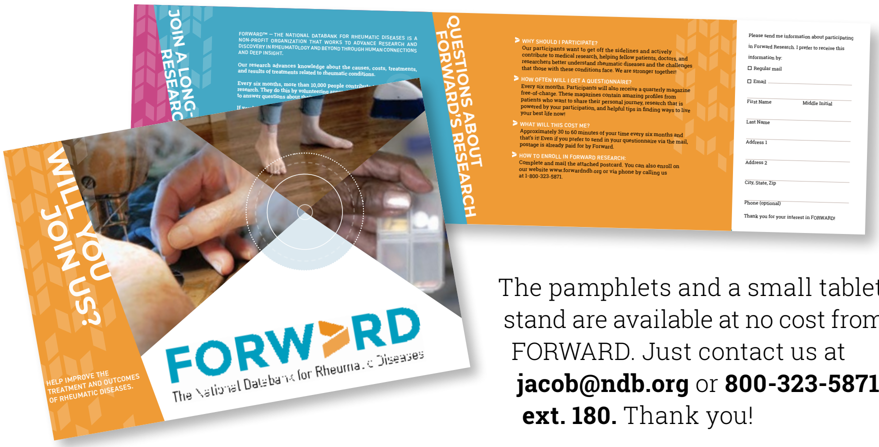
WHILE WORKING on your questionnaire, if you have ANY questions, please contact us right away by email (**webquest@ndb.org**) or phone (**1-800-323-5871**). These might be about technical difficulties or how to interpret a question. If you put your immediate questions in the comments section, we probably 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.

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.



JOIN A LONG-
RESEARC

FORWARD™ – THE NATIONAL DATABANK FOR RHEUMATIC DISEASES IS A NON-PROFIT ORGANIZATION THAT WORKS TO ADVANCE RESEARCH AND DISCOVERY IN RHEUMATOLOGY AND BEYOND THROUGH HUMAN CONNECTIONS AND DEEP INSIGHT.

Our research advances knowledge about the causes, costs, treatments, and results of treatments related to rheumatic conditions.

Every six months, more than 10,000 people contribut
research. They do this by volunteering appr
to answer questions about thei

QUESTIONS ABOUT FORWARD'S RESEARCH

- WHY SHOULD I PARTICIPATE?
  Our participants want to get off the sidelines and actively contribute to medical research, helping fellow patients, doctors, and researchers better understand rheumatic diseases and the challenges that those with these conditions face. We are stronger together!
- HOW OFTEN WILL I GET A QUESTIONNAIRE?
  Every six months. Participants will also receive a quarterly magazine free-of-charge. These magazines contain amazing profiles from patients who want to share their personal journey, research that is powered by your participation, and helpful tips in finding ways to live your best life now!
- WHAT WILL THIS COST ME?
  Approximately 30 to 60 minutes of your time every six months and that's it! Even if you prefer to send in your questionnaire via the mail, postage is already paid for by Forward.
- HOW TO ENROLL IN FORWARD RESEARCH:
  Complete and mail the attached postcard. You can also enroll on our website www.forwardndb.org or via phone by calling us at 1-800-323-5871.

Please send me information about participating in Forward Research. I prefer to receive this information by:

☐ Regular mail

☐ Email ______

First Name ______ Middle Initial ______

Last Name ______

Address 1 ______

Address 2 ______

City, State, Zip ______

Phone (optional) ______

Thank you for your interest in 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 forwarddatabank.org/forward-patients/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, follow the links from our home page, **forwarddatabank.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. 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

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

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