

FORWARD

FALL
2020

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES



**Disparities
in Rheumatic
Disease Research**

Learn more
on page 8 >

**Making the
Pain Scale Work
for You**

THE OSTEOARTHRITIS
Experience



Letter from the Co-Director

Dear Reader,

This issue of FORWARD magazine highlights the most common form of arthritis: osteoarthritis. We often choose to share important information on and patient experiences with different rheumatic conditions, because learning about any and all conditions diagnosed by a rheumatologist is vital to understanding and improving treatment for every rheumatic condition.

We've also included some important information about racial disparities in rheumatic disease registries and the impact these disparities have on treatment. FORWARD knows how important it is to work to correct these disparities, to improve rheumatic disease treatment for all. You can learn more about this important work by visiting page 8.

To all of our participants: thank you for your support. Together, we can make a difference in the diagnosis, treatment, and prevention of rheumatic diseases.

Sincerely,

Kaleb Michaud, PhD
Co-Director, FORWARD

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Join Us on Facebook & Twitter

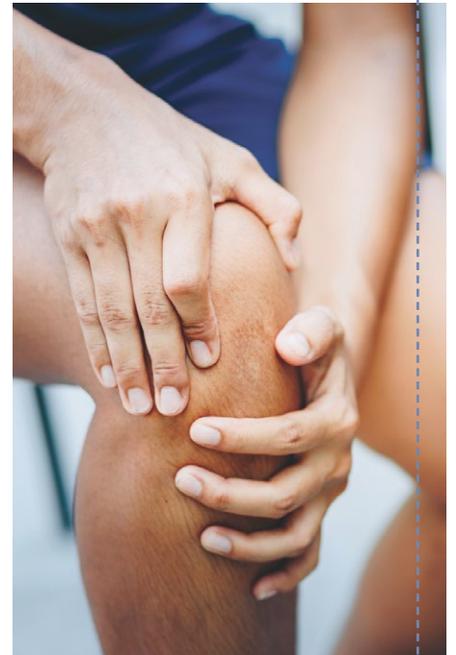
Currently, you can find us on Facebook as **"FORWARD, The National Databank for Rheumatic Diseases."** We will try to keep you up to date with any news items that occur between questionnaires. You can also connect with other participants and FORWARD staff who have joined our group. For those that may 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



NONPROFIT SPOTLIGHT RESOURCES

LEARN from the experts about the diagnosis and treatment of osteoarthritis.

ACR - American College of Rheumatology

[rheumatology.org/i-am-a/patient-caregiver/diseases-conditions/osteoarthritis](https://www.rheumatology.org/i-am-a/patient-caregiver/diseases-conditions/osteoarthritis)

Arthritis Foundation

[arthritis.org/diseases/osteoarthritis](https://www.arthritis.org/diseases/osteoarthritis)

NIAMS - National Institute of Arthritis and Musculoskeletal and Skin Diseases

[niams.nih.gov/health-topics/osteoarthritis](https://www.niams.nih.gov/health-topics/osteoarthritis)

CDC - Centers for Disease Control and Prevention

[cdc.gov/arthritis/basics/osteoarthritis.htm](https://www.cdc.gov/arthritis/basics/osteoarthritis.htm)



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. Once you've completed your questionnaire—you're done!



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!

Thank you to the many participants who choose to spend their time and energy every six months filling out the FORWARD questionnaire. Sharing your experience provides valuable information to researchers and physicians who are working to improve the diagnosis, treatment, and prevention of rheumatic diseases.

We especially want to thank those that continue to participate even when they are feeling better or have entered remission. Sharing information about your treatment, lifestyle choices, and current situation, along with the many other factors that might have improved your health, is so important. This allows researchers to understand what may help other people with the same or a similar condition. We are excited for you and hope that you stay feeling better for as long as possible!

For those that may be new to the databank or are considering joining, 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. **FORWARD data 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 outside interests such as pharmaceutical companies, insurance companies, or other institutions.

WORK WORKAROUNDS: Making the Most of Your Desk Setup at Home

Whether you're working from home due to the COVID-19 pandemic, are a full-time remote worker, or have hobbies that require you to spend large amounts of time at a desk or computer, consider these tips to improve your at-home workstation and limit the aches and pains that come with poor posture and extended periods of sitting.



Laptop Level-Up

➤ Invest in an **external keyboard and mouse** to more easily type and navigate without causing strain.

➤ Raise your laptop, using a stand or stack of books, so that the screen is approximately **level with your eyes**.

Chair Transformation

➤ A **firmer chair**, like a dining chair, will provide better support than a comfy living room lounger.

➤ Try rolling up a hand towel to add **extra support** for your low back.

Tabletop Maneuvers

➤ Don't limit yourself to the dining room table—the **kitchen countertop** can make a great base for a standing desk.

➤ If you are sitting, make sure you have **plenty of leg room** at the table to slide in close to your laptop and computer.

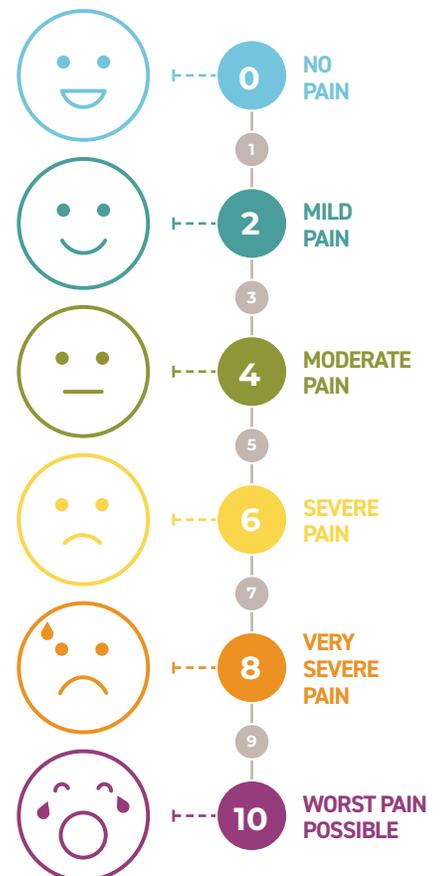
Answer the Question: "How's Your Pain?"

While your doctor will likely use a scale for disease activity, functional impairment, and physical damage caused by your condition to make a number of treatment decisions, it's also very likely that many of your doctor's appointments will include the seemingly simple question, "How's your pain, on a scale of 1-10?"

For many people, it may feel like this question is difficult to answer. The next time you are asked this question, consider these basic tips below to ensure you're giving your doctor the information they need.

- 1. Consider the worst.** If you're struggling to determine the right number to express your pain, try remembering the most terrible pain that you experienced at some point in your life (like a bad fall that caused a fracture, giving birth, or having a kidney stone) and compare your pain now to your pain then.
- 2. Share the details.** Don't hesitate to share more information about your pain with your doctor. If your pain level is a 3 right now, but was an 8 this morning, that's important information that your doctor needs to know.
- 3. Compare against the past.** Your last appointment can be a useful benchmark to help your doctor know if your pain has improved or declined. Sharing this information with your doctor can help them understand if your treatment is helping you manage your symptoms.

FORWARD participants receive a Health Diary printout, which can be a great tool for keeping track of your pain levels over time. To receive your Health Diary, sign up as a FORWARD participant at forwarddatabank.org/join-forward.





+



32.5 MILLION
adults have osteoarthritis

\$71.3 BILLION
in annual earning losses

\$65.5 BILLION
annual medical costs

18.7 MILLION
adult workers have
osteoarthritis

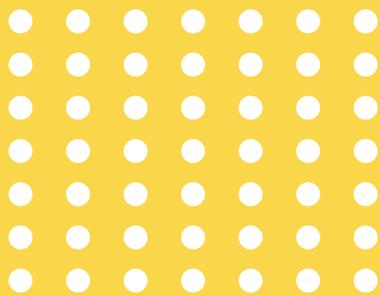


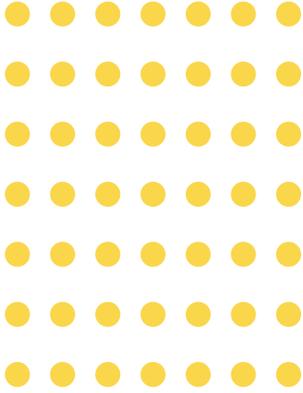
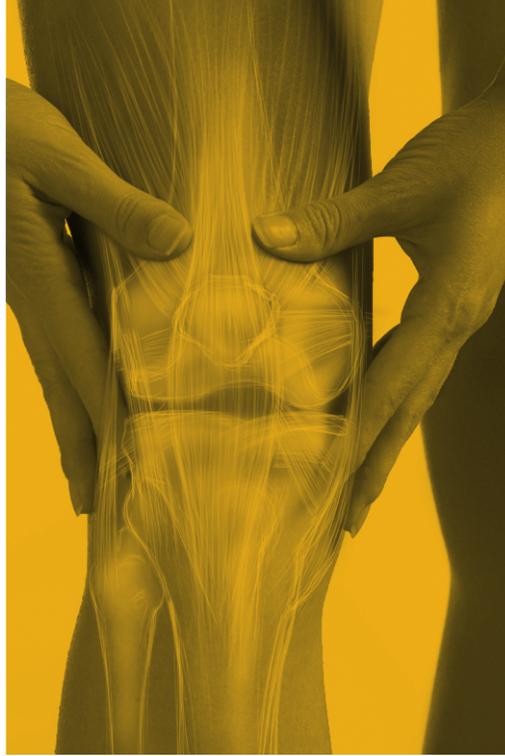
\$2,018 AVERAGE
per person per year
in medical costs



FORWARD Cares, and Wants to Learn More About Your Experience

Osteoarthritis (OA) is the most common form of arthritis, affecting over 32 million adults in the United States—1 in 7! That's why it's important for rheumatic disease registries like FORWARD to include the experiences of people with osteoarthritis in the information they share with researchers. A better understanding of this disease will help doctors diagnose, treat, and prevent osteoarthritis. Here, we've included information about this common disease to help you understand and better manage your symptoms and condition.





WHAT IS OSTEOARTHRITIS?



Osteoarthritis (OA) is a musculoskeletal disease that can cause pain, stiffness, and swelling in affected joints, resulting in reduced function and movement in some people. Often, these symptoms include a gradual onset of pain that is triggered by an activity like knitting or typing on a computer. Stiffness may occur in the morning, after waking up, or after a period of inactivity, like watching a movie.

PRIMARY OA may be localized to certain joints and is generally subdivided by location: hands, feet, hip, or knees. If you have many areas affected, it may be called generalized OA.

SECONDARY OA may result from other causes like trauma, congenital diseases, infection, rheumatoid arthritis, or gout.



WHAT CHANGES THE RISK OF GETTING OA?

- + **JOINT INJURY OR OVERUSE**—Repetitive stress on a joint, like bending your knee often, can cause damage and increase the risk of OA in that joint.
- + **AGE**—The risk of developing OA increases with age.
- + **GENDER**—Women are more likely to develop OA than men, especially after age 50.
- + **OBESITY**—Extra weight puts more stress on joints, particularly weight-bearing joints like the hips and knees. This stress increases the risk of OA in that joint. Obesity may also have metabolic effects that increase the risk of OA.
- + **GENETICS**—People who have family members with OA are more likely to develop OA.
- + **RACE**—Some Asian populations have lower risk for OA.

UNIQUE OPPORTUNITY FOR FORWARD PARTICIPANTS AND OTHERS

We need your help with new and existing projects centered on patients with osteoarthritis (OA).

IF YOU ARE ALREADY A FORWARD PARTICIPANT, we thank you for your continued support of these projects by completing the questionnaires.

IF YOU HAVE A FRIEND OR FAMILY MEMBER THAT HAS OA or has been newly diagnosed with OA, please introduce them to the Forward registry:

forwarddatabank.org/forward-patients

We will welcome them into our family. If it was not for you taking the time to complete the questionnaire, we would not be able to advance the science and research for OA. Thank you again for all your help and the time you volunteer for the FORWARD registry.



Recommended therapies for the management of osteoarthritis (OA). Strongly and conditionally recommended approaches to management of hand, knee, and/or hip OA are shown. No hierarchy within categories is implied in the figure, with the recognition that the various options may be used (and reused) at various times during the course of a particular patient's disease.

	HAND	KNEE	HIP	
PHYSICAL, PSYCHOSOCIAL, AND MIND-BODY APPROACHES	Exercise*			Strongly Recommended
	Self-Efficacy and Self-Management Programs			Conditionally Recommended
		Weight loss		
		Tai Chi		
		Cane		
	1 st CMC Orthosis	TF Knee Brace**		
	Heat, Therapeutic Cooling			
	Cognitive Behavioral Therapy			
	Acupuncture			
	Kinesiotaping			
	Balance Training			
	Other Hand Orthoses***	PF Knee Brace**		
	Paraffin	Yoga		
		RFA		
PHARMACOLOGIC APPROACHES	Oral NSAIDs			
	Topical NSAIDs	Topical NSAIDs		
	I-A Steroids	I-A Steroids (Imaging-Guidance for Hip)		
	Acetaminophen			
	Tramadol			
	Duloxetine			
	Chondroitin	Topical Capsaicin		

REFERENCE: Treatment Guidelines by the American College of Rheumatology (ACR) Arthritis Care & Research Vol. 72, No. 2, February 2020, pp 149–162 DOI 10.1002/acr.24131 © 2020, American College of Rheumatology <https://www.rheumatology.org/Portals/0/Files/Osteoarthritis-Guideline-Early-View-2019.pdf>

*Exercise for knee and hip OA could include walking, strengthening, neuromuscular training, and aquatic exercise, with no hierarchy of one over another. Exercise is associated with better outcomes when supervised. **Knee brace recommendations: tibiofemoral (TF) brace for TF OA (strongly recommended), patellofemoral (PF) brace for PF OA (conditionally recommended). ***Hand orthosis recommendations: first carpometacarpal (CMC) joint neoprene or rigid orthoses for first CMC joint OA (strongly recommended), orthoses for joints of the hand other than the first CMC joint (conditionally recommended). RFA = radiofrequency ablation NSAIDs = nonsteroidal antiinflammatory drugs IA = intraarticular.

HOW IS OA TREATED?

The focus of any arthritis treatment is to

- + **REDUCE** pain
- + **MINIMIZE** joint damage
- + **IMPROVE OR MAINTAIN** function and quality of life

There is no cure for OA, so doctors usually treat OA symptoms with a combination of therapies, which may include the following:

- + **INCREASING** physical activity
- + **PHYSICAL THERAPY** with muscle strengthening exercises
- + **SUPPORTIVE DEVICES** such as crutches or canes
- + **WEIGHT LOSS**
- + **MEDICATIONS**, including over-the-counter pain relievers and prescription drugs
- + **SURGERY** if other treatment options have not been effective

In addition to these treatments, people can gain confidence in managing their OA with self-management strategies. These strategies help reduce pain and disability so people with osteoarthritis can pursue the activities that are important to them. Take a look at **STRIVE FOR FIVE** (right) to learn more about how you can manage your OA symptoms.

STRIVE FOR FIVE



→ **LEARN NEW SELF-MANAGEMENT SKILLS.** There are CDC-recommended self-management education programs that improve the quality of life of people with arthritis, which can be found at [cdc.gov/arthritis/interventions/self_manage.htm](https://www.cdc.gov/arthritis/interventions/self_manage.htm).



→ **BE ACTIVE.** The Physical Activity Guidelines for Americans recommend that adults be physically active at a moderate intensity for 150 minutes per week. If you're unsure where to start, ask your doctor about any medically recommended programs near you, or look for a local community health program that will allow you to get out and get moving with others.



→ **TALK TO YOUR DOCTOR.** Being involved in your treatment plan is very important. Make sure that your doctor knows about your specific pains and other symptoms, and that you're both on the same page about the best steps you can take to improve your symptoms.



→ **MANAGE YOUR WEIGHT.** For people who are overweight, losing weight can reduce stress on your joints. In fact, losing as little as 10 to 12 pounds can improve pain and function for people with arthritis. Focus on healthy eating and staying active. You can also learn more by visiting [cdc.gov/healthyweight](https://www.cdc.gov/healthyweight).



→ **PROTECT YOUR JOINTS.** Joint injuries can cause or worsen your arthritis. Make sure that you choose activities that are low-impact and easy on the joints, like walking, bicycling, and swimming. Wear protective equipment and avoid doing the same movement over and over in a short time whenever possible.

REFERENCE: www.cdc.gov/arthritis/basics/management.htm

Disparities IN RHEUMATOLOGY

In order to improve the diagnosis, treatment, and prevention of rheumatic diseases, we need to improve the diversity of individuals represented with rheumatic disease registries—including FORWARD.

RACIAL, SOCIOECONOMIC, AND GENDER DISPARITIES ARE, unfortunately, all too common in all areas of healthcare, including rheumatology. For example, one study published in 2013 followed individuals diagnosed with rheumatoid arthritis (RA) and found that white participants experienced better outcomes—fewer symptoms or longer remission times—than minority participants.¹ There are many reasons as to why this might be, including a lack of access to proper care and treatment, unconscious bias within members of the medical community, ongoing discrimination, and more. One potential reason, however, is the lack of understanding about the experience of minority individuals with a rheumatic disease.

We've chosen to focus on this reason because this is the goal of FORWARD: to help individuals with rheumatic diseases share their experiences, providing researchers with the information they need to improve diagnosis, treatment, and prevention of rheumatic diseases.

Disparities in Rheumatic Disease Research

Whenever a researcher begins a study about a particular rheumatic disease, they need to ensure that it is representative of the population of individuals who have that disease. For example, women and people of color are much more likely to have lupus and studies show that genetics have





**TURN TO PAGE 10 TO
LEARN MORE ABOUT
THE IMPACT FORWARD
PARTICIPANTS HAVE
ON RHEUMATIC
DISEASE RESEARCH. >**

a large impact on the development of lupus. However, lupus study participants often aren't reflective of the affected populations—there aren't enough minority individuals included in most lupus studies.

When individuals aren't appropriately represented in studies, we aren't able to truly grasp their experience—we don't know if there's something that needs to change in the diagnosis process, treatment options, or recommended lifestyle adjustments that could improve the outcomes for these individuals. There are so many aspects of a person's life—in their genetics, in the doctor's office, and out in the world—that can potentially impact the likelihood that they have a rheumatic disease, and whether or not they receive the correct diagnosis. These also impact the outcome of the disease, including the severity of symptoms and whether or not they achieve remission, as well as the length of remission, and any comorbidities (meaning more than one disease or condition is present in the same person at the same time) or associated conditions they may experience.

This is why it is so important that research adequately represents the population of individuals with a particular condition. Studies performed on diseases that disproportionately affect minorities must represent those groups better.

Disparities in Rheumatic Disease Registries

How can FORWARD and other registries impact and improve minority representation within rheumatic disease research? By providing researchers with the information about the experience of minority individuals with rheumatic diseases. This means that any rheumatic disease registry, including FORWARD, needs to work hard to ensure that the databank includes a proportional amount of minority individuals for the diseases they gather data on.

A recent review of FORWARD participants shows that participation of ethnic and racial minorities is lower than expected given the prevalence of rheumatic diseases in minority populations. Not only is participation lower, but discontinuation rates are higher: individuals who are a part of an ethnic and racial minority are more likely to join the databank for a shorter period of time than white individuals. We would like to improve our understanding of how to recruit, enroll, and maintain minority individuals in the FORWARD databank. That way we can ensure they receive the care that everyone deserves when visiting their physician.

At FORWARD, we celebrate the diversity found amongst our participants. Currently, FORWARD actively and intentionally seeks to further empower

minority participation in the databank. If you've joined the databank, it's highly likely that it was recommended to you by your doctor's office, a patient group, a family member or friend, or a rheumatic disease nonprofit. We intentionally work with a wide variety of these organizations, both big and small, to reach as many patients as possible. These organizations, spread across the world and found online, are interacting with, providing support for, or treating a diverse group of people with many different rheumatic diseases. We interface with these groups to offer multiple ways to participate, including our online web questionnaire, mailed questionnaires, and phone interviews. The goal of this is to provide as many people as possible the opportunity to participate, regardless of socioeconomic status, internet access, location, or physical capabilities.

When it comes to improving the diagnosis, treatment, and prevention of rheumatic diseases, minority voices and experiences are important. Appropriately representing those impacted by these diseases is vital to the success of any study. Ethnic and racial minorities are not adequately represented and it is the job of every researcher and healthcare provider in the rheumatology community to help make this change.

Your voice and experience is vital to understanding and improving the diagnosis, treatment, and prevention of rheumatic diseases. Please visit forwarddatabank.org/join-forward to participate today.

FOOTNOTES: Greenberg JD, Spruill TM, Shan Y, et al. Racial and ethnic disparities in disease activity in rheumatoid arthritis patients. *Am J Med.* 2013 Dec;126(12):1089-1098.

The FORWARD Databank: Sharing Research, Virtually

We sat down with Sofia Pedro, MS, a FORWARD biostatistician to learn how FORWARD data impacts research and how the rheumatology community works together in a virtual setting.

TELL US ABOUT YOUR WORK WITH FORWARD:

I have been working for FORWARD as a statistician since 2012, with formal training in Statistics, Mathematics, and Computer Science. My main roles are to translate applied questions into statistical procedures and communicate the findings to other collaborators, both informally and through conference presentations and research papers.

In other words, **working as a statistician means dealing with data and helping to find practical solutions to problems.** As this is interdisciplinary work, it also requires a clear understanding of the basics of the science in question, i.e. clinical research and rheumatology.

HOW DOES FORWARD HELP FIND PRACTICAL SOLUTIONS TO PROBLEMS IN RHEUMATOLOGY?

FORWARD is a large study that follows patients over time, also called a longitudinal study. These studies are particularly important related to safety studies, where the goal is to estimate causal effects of medical treatments. This objective is limited and sometimes impossible in randomized controlled trials, as they have stringent patient inclusion criteria, short follow-up periods, etc. **Data from registries such as FORWARD can supplement medical trials to broaden understanding of the risks of treatment over time** with more heterogeneous clinical populations. **Patient-reported data also improves the understanding of diseases over time using real-world data.**

HOW DO YOU SHARE THE INFORMATION YOU GATHER WITH OTHER RHEUMATOLOGISTS AND RESEARCHERS?

Our findings, including the evidence and methods we used to arrive at them, are shared regularly in peer-reviewed academic journals. In more normal times, we also participate in-person at scientific meetings such as the ACR annual meeting, which bring together people from all over the world, who share a common field of interest. These meetings are an opportunity to engage in professional collaborations and are where we share our findings with other researchers. These meetings are also very important to **expand our knowledge in the field and learn from others about the latest research** such as new methods, unpublished data, etc.

GOING VIRTUAL AT ACR CONVERGENCE 2020

The annual American College of Rheumatology (ACR) meeting is a vital part of the work done by FORWARD and other rheumatic disease registries, researchers, non-profits, physicians, and more. Due to public health and safety concerns related to the COVID-19 pandemic, the annual ACR meeting will be held completely online this November.

FORWARD is excited to participate as a non-profit patient registry and will be attending the meeting to engage in conversation with other non-profits, universities, and physicians. Our primary goals are to share our research, learn from others, and support our research and academic partners who are presenting their findings using FORWARD data all to deepen our understanding of rheumatic diseases.

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

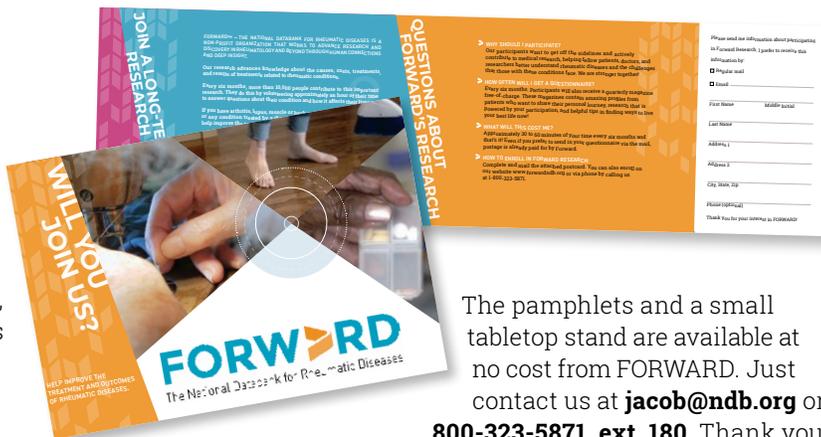
FOR PATIENTS USING WEBQUEST, email is our primary method of getting in touch with you. Even if you're not using WebQuest, we'd like to be able to send you important information by email. **Here's an important step you can take to make sure our email gets to you:** add us to your email address book! Our 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 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!



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 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, 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

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