

# FORWARD

WINTER  
2023

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES



Managing Muscle Pain  
and Weakness:

## *Myositis* *A Rare Condition*

**A Broad Spectrum  
Approach to Care**

**FORWARD,  
Contributing  
to Research**

Learn more  
on page 8 ➤

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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

Welcome to the latest issue of FORWARD magazine, the end of 2022, and the beginning of 2023.

I hope that you'll enjoy this issue. FORWARD is incredibly proud of the contribution we've been able to make to the rheumatology community throughout this past year and hope that you will find it beneficial as well—turn to page 8 to take a look.

We have also reviewed some of the less well-known rheumatic and autoimmune diseases and symptoms. You'll see that we consider this research to be valuable because we seek to improve the diagnosis, treatment, and prevention of any rheumatic or autoimmune condition, and that the research of one condition can support research in other conditions as well. Because most rheumatic and autoimmune conditions are incredibly complicated and multifaceted diseases, physicians need the support of research to improve the daily lives of people with those conditions.

Thank you for your support and your participation.

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



## Non-Profit Spotlight

### The Myositis Association

Myositis is a rare autoimmune condition that results in inflammation or swelling of the muscles, causing fatigue and muscle weakening over time.

The mission of The Myositis Association is to improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy. Their programs and services provide information, support, advocacy, and research for the myositis community.

Learn more about The Myositis Association at [myositis.org](https://myositis.org).



# Thank you

## TO OUR PARTICIPANTS

FORWARD would like to extend a big 'Thank You' to the individuals who take the time to participate in the databank by filling out our biannual questionnaires and occasional follow-up questionnaires.

It is because of you that we are able to support the rheumatology community with late-breaking research related to current events that impact people with rheumatic and autoimmune conditions. Your participation allows us to provide patient-reported data—data that is provided by you, the people who are experts in their own experiences—to researchers. Thanks to you we have gathered data over the course of 20+ years to generate a long-term look at the impact of conditions, treatments, and symptoms in a wide range of rheumatic diseases.

To the participants who have joined us recently or have been with us for years: thank you so much for sharing your experience with researchers. For those who fill out the biannual questionnaire and those who also complete our occasional follow-up questionnaires: we appreciate the time you take to contribute to our understanding of your experience and your condition.

Without you, FORWARD would not be able to do what we do.

To learn more about the research your participation allowed FORWARD to complete in 2022, turn to page 8.

## 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.

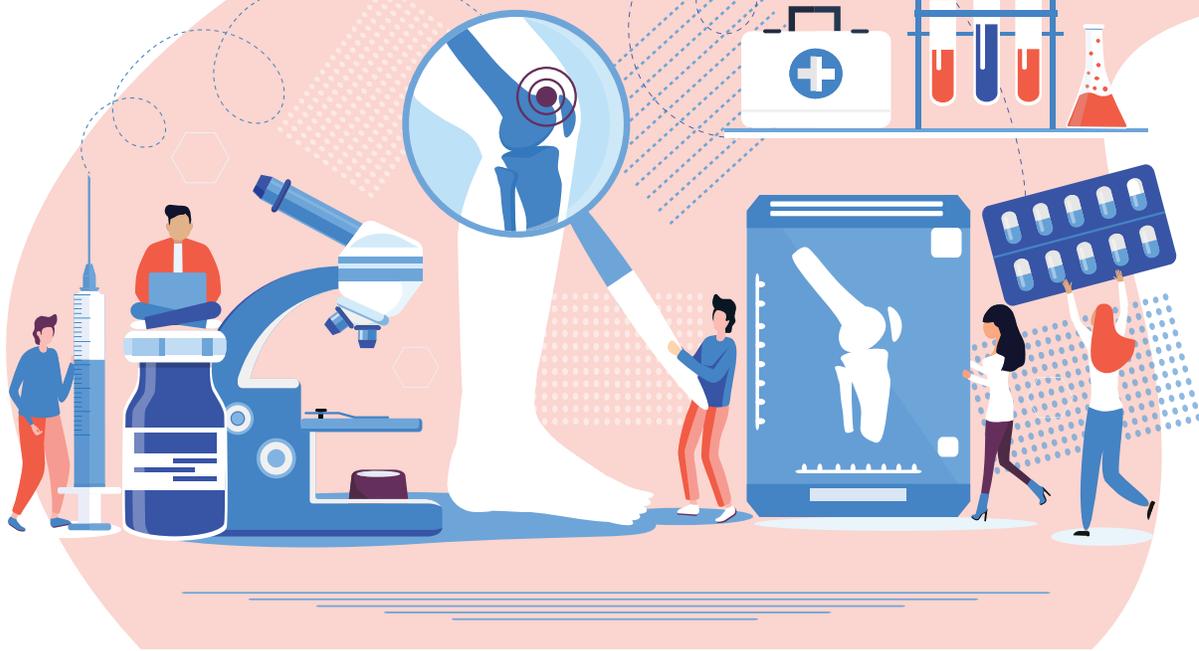
Questionnaires are only sent out twice a year, and follow-up questions are only sent as needed to add more information to the data from the main questionnaire.



### 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](https://forwarddatabank.org/join) or call 1-800-323-5871 today!



# Broad Spectrum Care: Why the Rheumatologist is the Right Choice

With over 80 types of rheumatic and autoimmune conditions, it's important that your physician has the ability to diagnose and treat a broad range of conditions—even those that may have similar or overlapping symptoms.

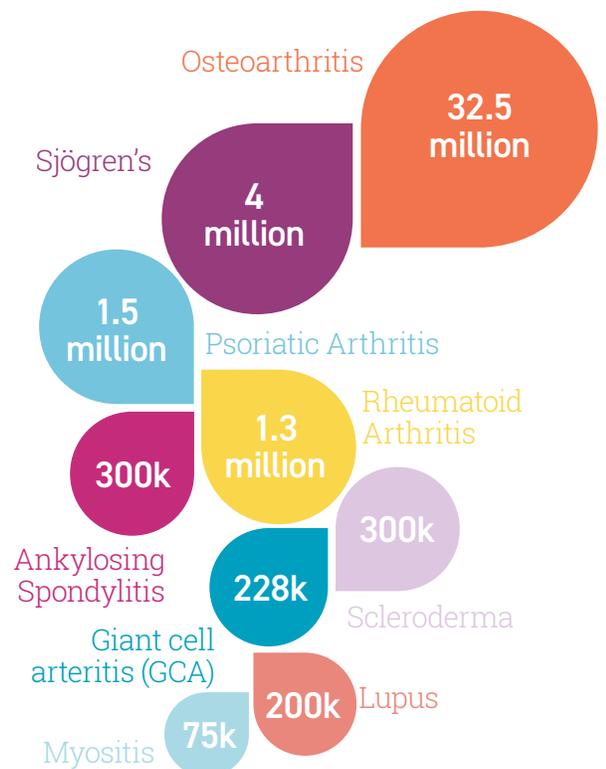
How is a rheumatologist different than your primary care provider or another specialist focused on a singular condition or organ?

A rheumatologist is a specialist who has continued their education to receive training specific to the broad array of potential rheumatic and autoimmune conditions. They are specially trained to identify the symptoms of these conditions and to address their complex nature through consistent and ongoing treatment. Due to the complexity of these conditions, many individuals with rheumatic and autoimmune conditions find that they require many treatment adjustments throughout the course of their condition—rheumatologists are trained to select the best course of treatment for a particular individual, their condition, their symptoms, and their lifestyle.

In comparison, your primary care provider plays a slightly different role than your rheumatologist, helping you manage multiple aspects of your health and ensuring that you have access to the correct specialists for your health needs. While they may assist with the management of your rheumatic or autoimmune condition, your primary care provider will often defer to or recommend you to a rheumatologist who can determine the best course of action, long-term.

## Rare Conditions

Did you know that some rheumatic and autoimmune conditions are considered to be very rare? This makes them difficult to study which makes improving diagnosis, treatment, and prevention a challenge. Take a look below at some of the rarest conditions, compared to some of the most common, in the United States.



A man with dark, wavy hair and a beard is shown in profile, looking down and to the right. He is wearing a light blue t-shirt and has his right hand pressed against his left shoulder, suggesting pain or discomfort. The background is a plain, light blue color.

# *Muscles, Joints, & More:*

## **THE MANY SYMPTOMS OF RHEUMATIC AND AUTOIMMUNE CONDITIONS**

For many people with a rheumatic or autoimmune condition, the journey to a diagnosis begins with joint pain and inflammation—but for many of them, muscle pain and inflammation becomes an everyday experience related to their condition.

While it is not uncommon nor incorrect to associate rheumatic or autoimmune conditions with joint pain, it is important to remember that many of these conditions have other symptoms associated with them—including muscle pain. ➤



### **A Result of Other Symptoms**

For some, muscle pain and stiffness may be a result of joint pain and fatigue limiting movement. This occurs in some of the most common rheumatic or autoimmune conditions, such as rheumatoid arthritis and osteoarthritis. When joint pain or stiffness makes it difficult to get up and move it can cause the muscles to stiffen up and weaken over time—eventually making it even more difficult to get up and get moving.

### **Muscle Pain and Fatigue: A Determining Factor**

For others, muscle pain and fatigue are caused by inflammation in their muscles and is not the result of other symptoms, such as sore and stiff joints.

Muscle pain and fatigue, like many symptoms of chronic conditions, can impact every part of a person's life. Whether it's making it difficult to do everyday tasks, causing trouble sleeping or getting comfortable due to pain, or causing frustration due to a lack of normal stamina, it's important to recognize and attempt to mitigate the impact of muscle pain and fatigue.

Muscle pain and fatigue can be a result of another symptom of your condition or it can be a determining factor in your diagnosis, so it is necessary to keep your muscles moving to manage and improve your symptoms. Remember, always speak with your provider before beginning an exercise regimen, as they

can make sure that you are able to exercise in a way that is safe and healthy and will not negatively impact your health or your symptoms. Your provider may ask you questions about your day-to-day life—how you spend your time, whether you currently engage in any sort of intentional movement or exercise, and what kinds of chores you manage on your own. If you're unsure where to start, let your provider know, so that they can give you the guidance that you need. Your doctor may provide a referral to a physical therapist who can help you develop the right exercise programs for your needs.

You can expect that your exercise program will likely include regular

## Myositis: A Rare Condition

**With symptoms that mimic aging or other autoimmune diseases, it can be very difficult for patients to receive the correct diagnosis of myositis.**

Depending on the patient and their specific needs, the symptoms of myositis can be difficult to identify. According to The Myositis Association, a nonprofit organization dedicated to improving the lives of people affected by myositis, these symptoms often include:

- + Difficulty standing or walking, with common trips or falls
- + Muscle weakness, causing difficulty climbing stairs or reaching for things above your head
- + Trouble swallowing

These symptoms are due to the chronic inflammation that individuals with myositis experience. Because many of these may appear over time, it can be easy to dismiss them as the common results of aging or slowing down as

a patient gets older. The rarity of the disease and overlap of its symptoms with getting older can unfortunately leave many patients undiagnosed or misdiagnosed. We hope that by shedding light on this condition, patients can receive the care they deserve.

### **FORWARD Research into Rare Conditions**

FORWARD encourages individuals with myositis, or any other rheumatic or autoimmune condition, to easily contribute to research by participating in our bi-annual questionnaires. By sharing your experiences with your disease, medication, and any other form of therapy your doctor may recommend, you'll provide researchers and physicians with the information they need to improve the diagnosis, treatment, and prevention of myositis as well as other rare rheumatic diseases.

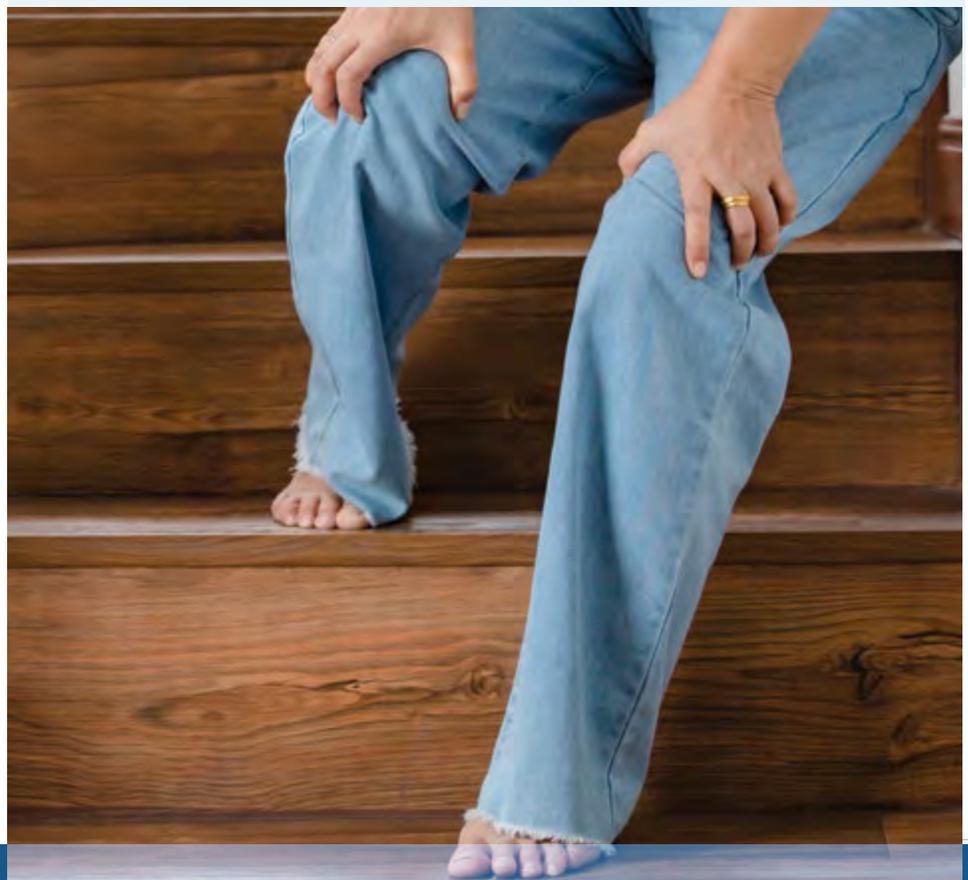
**Ready to share your experience and contribute to research? Visit [forwarddatabank.org/join](https://forwarddatabank.org/join) now.**

Learn more about why FORWARD researches rare autoimmune and rheumatic conditions by visiting page 10.

low-impact exercise that benefits both your joints and your muscles, helping you build or maintain strength and avoid the stiffness that is a common experience amongst people with autoimmune or rheumatic conditions.

It can be difficult to maintain an exercise regimen when you feel like you aren't seeing progress or continue to have day-to-day trouble keeping it up.

In this case, bring it up with your providers again. They may consider a medication or treatment adjustment, or be able to recommend other lifestyle adjustments that may ease the stiffness and pain that you are experiencing. Always remember that exercise and movement are a key part of managing your symptoms and helping you feel better in the long run.



# A Year in Research: FORWARD 2022



FORWARD research this past year has been rewarding in many ways: from being able to participate and attend the top rheumatology community research meetings, EULAR and ACR, in person again, to working with new researchers, and presenting vital research quickly to the rheumatology community when it was needed.

In 2022, FORWARD has presented and published over 15 posters, oral presentations, and papers at meetings and in medical journals. We were very excited that three of our posters were selected as Ignite Talks at the 2022 American College of Rheumatology (ACR) meeting. Only 225 of these are selected from the thousands of posters submitted each year. All of this is only possible with the entire team that makes up our organization—our participants, our staff, and the researchers, health care professionals, patient organizations, and companies that provide guidance and support for our research.

## A SELECTION OF FORWARD RESEARCH IN 2022

### **Side Effect Profile of Hydroxychloroquine Use in Patients with Rheumatoid Arthritis (RA), Systemic Lupus (SLE), and other Rheumatic Diseases (RMDs) over 20 Years**

During the COVID pandemic, hydroxychloroquine (HCQ) became infamous in the news and media, but it has been used to treat rheumatic diseases for many years. Unfortunately, very little is known about the overall side effects of HCQ. To remedy this, the FORWARD databank was used to look at 20 years of data on RA, SLE, and other rheumatic diseases. Type, severity, and rates of side effects of HCQ and HCQ paired with methotrexate—another widely used treatment for rheumatic diseases—was studied. We found gastrointestinal side effects were the most common for both—including side effects of vomiting, diarrhea, nausea, upset stomach, change in appetite, etc. *Only side effects impacting vision were higher for HCQ than methotrexate.*

### Impact on Access to Methotrexate in the Post-Roe Era

Following the US Supreme Court's June 24<sup>th</sup> decision to overturn Roe v Wade, some patients reported having difficulty filling their prescriptions for methotrexate to treat their arthritis. Methotrexate is a first line treatment for rheumatoid arthritis (RA) and is used to treat several other rheumatic and non-rheumatic disorders. In high doses, methotrexate can be used to treat miscarriage and ectopic pregnancy. We sent FORWARD participants a short follow-up questionnaire asking if they had any issues or problems filling any prescriptions after this decision. We found that within two months of the overturn of Roe v Wade, 1 in 17 individuals with a rheumatic disease who tried to refill a methotrexate prescription experienced an unexpected issue when trying to get their medication. The most common issue was a delay in prescription refilling while pharmacies contacted health care providers to confirm the reason for the prescription. Some patients were asked excessive questions about pregnancy, had to complete interviews, or could not get their prescription filled. We presented these findings at ACR as one of the top late-breaking research items. *We recommended that health care providers prescribing methotrexate or other medications that may affect pregnancy include the patient's rheumatic diagnosis on the prescription to help reduce or avoid pharmacy delays.*

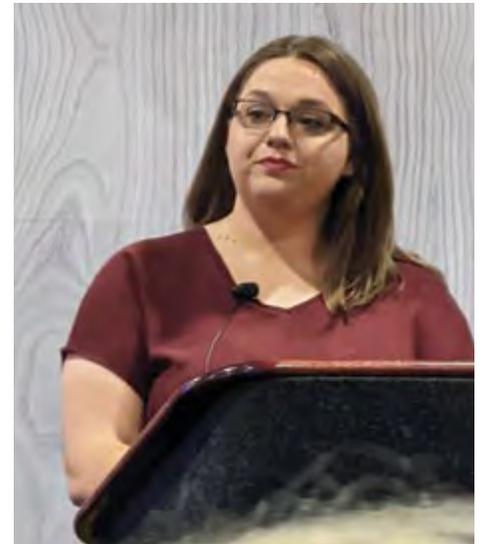


### Association Between Fatty Acid Amide Hydrolase (FAAH) Variants and Response to Cannabis Use for Pain Management in Rheumatoid Arthritis (RA)

Cannabis is used by many people to treat their pain. We looked at questionnaire and biological data from FORWARD participants who have rheumatoid arthritis (RA) to see if genetics might play a role in cannabis being more helpful for some people compared to others. We found that a particular change (also known as a "variant") in the gene FAAH is associated with 5x greater odds of effective pain management among cannabis users with RA. *This is the first study linking FAAH variants with cannabis use and real-world pain management in RA.*

### Mapping Long COVID-19 Patient Journeys for Rheumatic Disease Patients

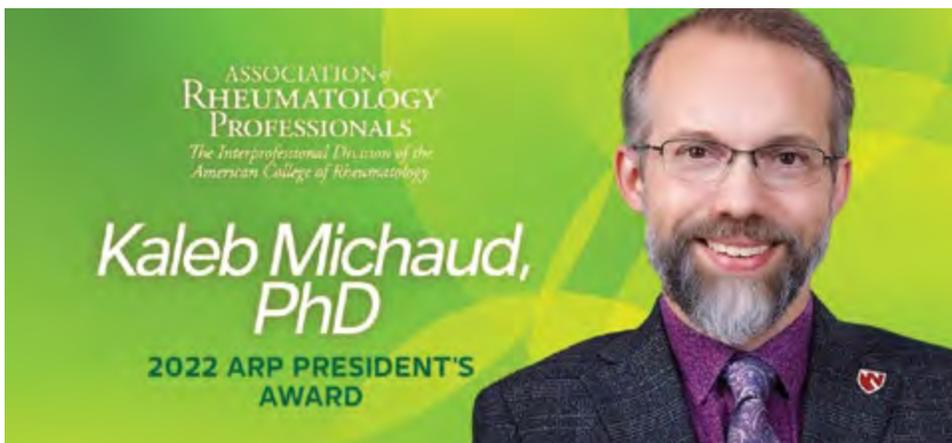
Underlying health conditions like rheumatic diseases increase long COVID risk and there is an increased need for health care services to address the needs of patients who develop persistent long COVID symptoms (e.g. fatigue, chronic pain, respiratory issues, etc.). These symptoms can impair physical and mental functioning and reduce the quality of life of pa-



Kristin Wipfler, PhD, presenting one of her two Ignite Talks at ACR.

tients. Working with researchers and patients at the University of Michigan and the New Mexico Department of Health, 16 patients allowed the researchers to closely read their electronic medical record documents to create a patient journey map showing their health status, interactions with health care providers, treatments, and decision making over time. They showed long COVID can be frustrating for patients, as it can cause new symptoms and require follow-up from multiple specialty providers. *These providers have the challenge of figuring out if it is long COVID, the patients' rheumatic disease, or other health problems that are causing the new symptoms. Patients also relied on assistance from health care providers for requests for work leave and improved working conditions to reduce their risk of exposure to COVID-19.*

These are just a few of the research projects we worked on in 2022. Find out more at [forwarddatabank.org/acr](https://forwarddatabank.org/acr).



Kaleb Michaud, PhD, Co-Director of Forward, receives the ARP President's Award

TURN TO PAGE 8 TO SEE SOME OF FORWARD'S RESEARCH RECENTLY SHARED AT THE AMERICAN COLLEGE OF RHEUMATOLOGY'S ANNUAL MEETING.



# About FORWARD and Our Research

Below, we've shared some of the most **common questions** that we have recently received about FORWARD and the conditions that we study.

## What kind of conditions does FORWARD study?

As a research databank, FORWARD studies rheumatic and autoimmune conditions. These conditions include those that are both common and rare, including rheumatoid arthritis (RA), osteoarthritis (OA), fibromyalgia, lupus, psoriatic arthritis, ankylosing spondylitis, polymyositis, low back pain, tendonitis, and many other problems—any condition treated by a rheumatologist or joint specialist. We collect data on these conditions (and more) directly from the people who experience these conditions and their impact on daily life. We do this in order to advance knowledge about the causes, outcomes, costs, treatments, and results of treatments related to these conditions.

## Why does FORWARD study rare conditions?

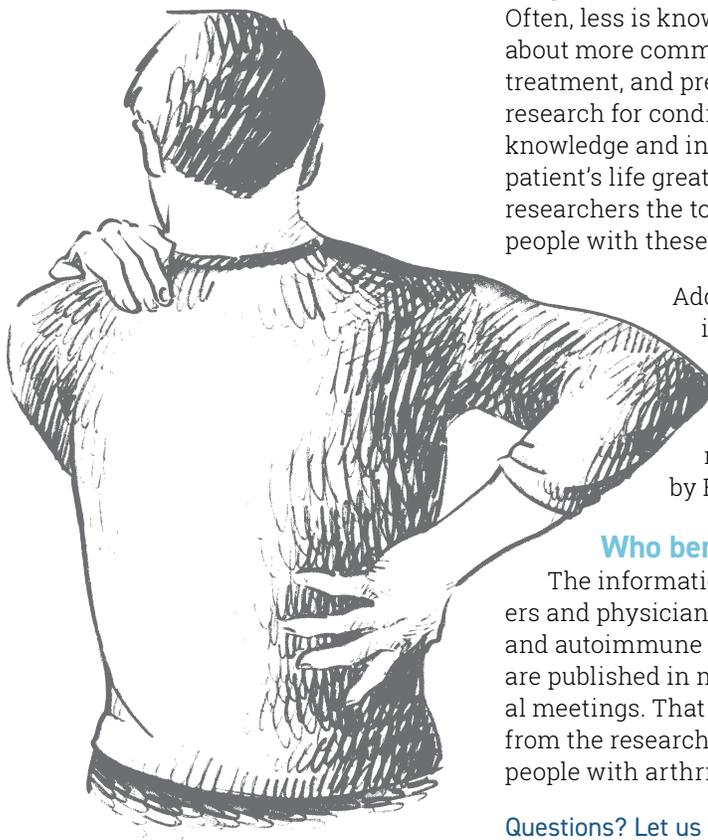
Often, less is known by physicians and researchers about rare conditions than about more common conditions—which can cause difficulty in the diagnosis, treatment, and prevention of those conditions. FORWARD hopes to contribute to research for conditions like these to ensure that patients and physicians have the knowledge and information they need about these conditions, which can affect a patient's life greatly. By learning about these conditions over time, we hope to give researchers the tools needed to improve treatment and improve quality of life for people with these conditions.

Additionally, many autoimmune and rheumatic diseases share similar symptoms and may affect patients similarly. Because of this, research related to one illness may also support research related to another illness. It is valuable to research all autoimmune and rheumatic conditions, no matter how rare, because they may be related to one another and, we hope, can all be benefited by FORWARD's research.

## Who benefits from FORWARD's research?

The information gathered during FORWARD's research is shared with researchers and physicians seeking to improve the diagnosis and treatment of rheumatic and autoimmune conditions. Researchers describe their findings in articles that are published in medical journals and in presentations at national and international meetings. That way, all doctors who treat arthritis are able to receive the benefit from the research. What they learn will help them to provide better medical care to people with arthritis and similar medical conditions.

Questions? Let us know at [info@ndb.org](mailto:info@ndb.org)!





## 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 into 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](http://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 click on your name in the upper right-hand corner, then click on "Change Email." Of course, you can always email or call us, and we will change it for you. Thank you!

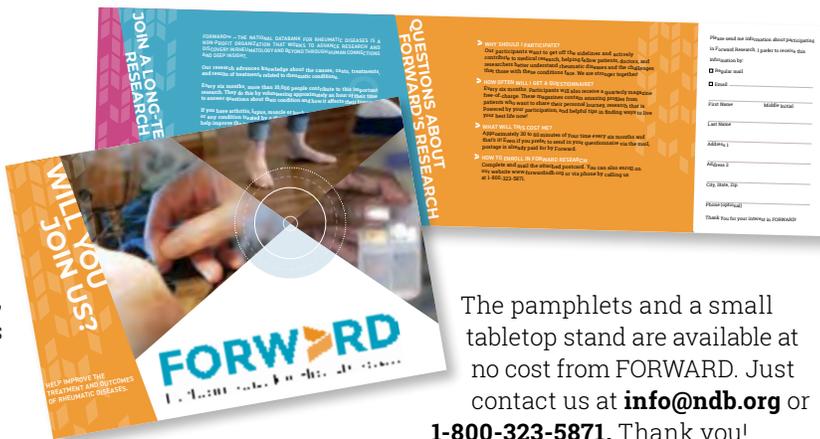
**While working on your questionnaire**, if you have ANY questions, please contact us right away by email (**webquest@ndb.org**) or phone (**1-800-323-5871**). These might be about technical difficulties or how to interpret a question. If you put your immediate questions in the comments section, we probably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

# 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 [info@ndb.org](mailto:info@ndb.org) or **1-800-323-5871**. 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/tell-a-friend](http://forwarddatabank.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](mailto: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](mailto: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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