

FORWARD

WINTER
2021

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

Your Impact on Current Research

Learn more
on page 8 ➤

The Updated FORWARD Questionnaire

Together,
**WE CAN MAKE
A DIFFERENCE**



Letter from the Co-Director

Hello, and welcome to 2021! It has been a strange year for us all, but we still thank you for picking up this latest edition of FORWARD magazine and for continuing to be a FORWARD participant.

In this issue, you'll learn about what FORWARD has been up to in 2020 and about how some changes to the questionnaire will impact the data that we are gathering in 2021. You'll see that we, like you, have spent a large portion of this year learning about COVID-19 and striving to support the rheumatology and medical community in the fight against COVID-19. However, you'll also see that we have not lost sight of our ultimate mission—to improve the diagnosis, treatment, and prevention of rheumatic diseases. We hope that you will enjoy reading about the many ways we've strove towards that mission with our community partners this year.

To all of our participants: thank you for your continued support.

Sincerely,

Kaleb Michaud, PhD
Co-Director, FORWARD

In This Issue

- 3 Looking Back
- 4 Meet FORWARD's Founder and Co-Director
- 5 The Rheumatology Community, FORWARD, and You
- 10 Expanding the FORWARD Questionnaire
- 11 Reminders

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

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.



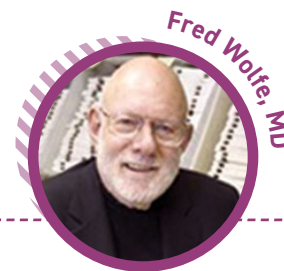
YOU'RE NOT ALONE.

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!

"In rheumatology, we didn't have particularly good therapies when I started. Some days I'd come home and wonder if I'd helped anybody during the day. In 1974, I began to collect data... on every single patient that I had ever seen. It was my opportunity to find out if I actually helped people or not."

-FRED WOLFE, MD, FOUNDER AND CO-DIRECTOR OF FORWARD



FORWARD FOUNDER:

Fred Wolfe, MD

While FORWARD was established as an official nonprofit research organization in 1998, founder Fred Wolfe, MD, was making a difference long before that, and continues to do so.

As a rheumatologist in Wichita, KS, Fred Wolfe, MD, was looking for a way to improve the care he provided to his patients. "In rheumatology, we didn't have particularly good therapies when I started. Some days I'd come home and wonder if I'd helped anybody during the day," Dr. Wolfe shares. With the goal of understanding how his patients were actually doing—not just during their appointments, but in their day-to-day life and over time—Dr. Wolfe began gathering and compiling information from his patients.

Dr. Wolfe thought about how to measure the impacts of a rheumatic condition and invented measurement scales still in use today. Dr. Wolfe also began to work with other rheumatologists and physicians, gathering information for a larger array of patients and ultimately founding the National Databank of Rheumatic Diseases as a nonprofit in 1998, known today as FORWARD. Creating a nonprofit like FORWARD ensured that even if a patient switched doctors or moved, they would still be able to share their experience with the databank.

Throughout the years, Dr. Wolfe has maintained his own research interests and contributed much to the rheumatic disease community. Over time, he has also begun to leave much of the day-to-day business of running a research nonprofit to FORWARD co-director Kaleb Michaud, executive director Rebecca Schumacher, and the FORWARD team, giving him the opportunity to dedicate his time to research. Dr. Wolfe's personal contributions to rheumatology research are best described as: **pioneering and impactful.**

Dr. Wolfe is largely responsible for the diagnostic criteria for fibromyalgia created in 1990, as well as an important update in 2010. These codified criteria help physicians better diagnose, and therefore better aid, their patients. His list of publications, while incredibly long, also shows an enduring interest in focusing on research topics that may have a significant impact on patients. Making a positive difference in each patient's life has always been Dr. Wolfe's goal. With FORWARD, he has ensured researchers and physicians have important information about rheumatic conditions as well as the impact that therapies and treatments have on patients.

FORWARD needs your help. By filling out a twice-yearly questionnaire, participants are making their voices heard and helping to improve the diagnosis, treatment, and prevention of rheumatic conditions. Join FORWARD today by visiting forwarddatabank.org/join-forward.



**"It's a very
important voice
that patients
have, directly
providing their
perspective
to research."**

Liron Caplan, MD, PHD
University of Colorado
School of Medicine

THE RHEUMATOLOGY COMMUNITY:

Working Together to Make a Difference

FORWARD—The National Databank for Rheumatic Diseases is proud to be a part of the rheumatology community, and proud to ensure that the voice of the patient is heard as we work to improve the diagnosis, treatment, and prevention of rheumatic diseases. If you are a FORWARD participant, here are some of the ways your information is making a difference.



“Patient-reported data is very important—to have the patient’s insight and have their take about what the disease means to them. [What is important] is what the patient is experiencing.”

TED R. MIKULS, MD, MSPH
UNIVERSITY OF NEBRASKA
MEDICAL CENTER

Making Medicine Safer

FORWARD is proud to provide meaningful information to healthcare companies and academic researchers related to the short- and long-term impacts of various treatments and therapies. While all medications and treatments undergo extensive testing and approval from the Food and Drug Administration in the U.S., which is dedicated to protecting public health and ensuring the safety of medications, it’s important to continue to make sure that medications and treatments are effective and, most importantly, safe, over long periods of time.

One of the best ways to do this is by following the experience of medication users over time—this is where a long-term, longitudinal data set like FORWARD is so valuable. This way, researchers from academic institutions and healthcare companies can see the impact a medication or treatment has with a wide variety of people and understand if there are any other factors that impact the safety or efficacy, ensuring that patients are receiving the right medication for them.

Supporting Non-Profits Focused on the Patient

Within the rheumatology community, there are many incredible non-profit organizations whose sole purpose is to improve the experience of individuals with rheumatic diseases. FORWARD works with a number of these organizations in a variety of ways, including providing support and research through the databank.

While some of these organizations, such as the Arthritis Foundation (arthritis.org) and the American College of Rheumatology (rheumatology.org) are focused on the large community of rheumatic conditions, there are many dedicated to specific diseases. These groups provide support to researchers of those conditions, as well as patients, such as the Dupuytren Foundation (dupuytren.org), the Spondylitis Association of America (spondylitis.org), the Lupus and Allied Diseases Association (ladainc.org), and AIArthritis—the International Foundation for Autoimmune and Autoinflammatory Arthritis (aiarthritis.org).

As somebody who’s been a part of this for decades, I’ve really seen this improve patient care. I’ve really seen this help me in making decisions. The biggest value I see is helping people move FORWARD. And if we can do that with therapies, and if we can document that we’re doing that with therapies and have confidence in what’s happening because we’re measuring those outcomes, then I think that’s very rewarding.”

-TIM SHAVER, MD, FACP, ARTHRITIS AND RHEUMATOLOGY CLINICS OF KANSAS

Helping Doctors Make Better Treatment Decisions

FORWARD works with a number of physicians who share information about the databank with their patients and encourage them to become a FORWARD participant—and we are very grateful to those physicians and their teams for supporting FORWARD and the patient voice. We also work with physicians who are improving their own patient care with help from FORWARD.

“We’ve used the tools that FORWARD [provided] to understand how our patients are functioning... I really have seen this improve patient care, I really have seen this help me in making decisions,” shares Tim Shaver, MD, FACP, a rheumatologist with the Arthritis and Rheumatology Clinics of Kansas.

Center, the University of California San Francisco, the University of Pennsylvania, the University of Michigan, and more, FORWARD is proud to assist in important studies related to the diagnosis, treatment, and prevention of rheumatic diseases.

FORWARD works with these researchers by providing access to important patient-reported data and also collaborates on larger studies and projects, such as those centered around FORWARD biobank data, where biological samples from FORWARD participants are used in addition to questionnaire data to better understand the impact of rheumatic conditions on the human body.

FORWARD participants are proud members of the rheumatology community, dedicated to improving the lives of people with rheumatic conditions by providing information about their own experiences in a twice-yearly questionnaire. If you’re ready to join FORWARD and make a difference, visit forwarddatabank.org/join-forward.

Asking (and Answering) the Important Questions

Working together with researchers from institutions like the University of Nebraska Medical

“The benefit of FORWARD is that you’re engaging people early on in their condition, so you’re gathering data for many, many years, so you can look at long-term outcomes that you can’t really look at in other settings.”

JOSHUA BAKER, MD, MSCE, PENN MEDICINE

“I think most patients are a little surprised to think that they can contribute this much to research. It really opens their eyes, that we can learn from them.”

BRYANT ENGLAND, MD, PHD
UNIVERSITY OF NEBRASKA MEDICAL CENTER

If You’ve Had COVID-19, Research Needs Your Help

iTakeControl Health has launched a new public health study, the COVID-19 @Home Patient Survey, for individuals who had COVID-19 and managed their illness and treatment primarily at home. FORWARD was grateful to be asked to assist with setting up this study and making sure the information being collected would be useful for all researchers, not only those in the rheumatology community.

The study hopes to analyze the disease symptoms and experiences of patients who, for many reasons due to the scale of the pandemic, will remain outside the healthcare system while managing their illness with self-care, telemedicine, and at-home circumstances. The study takes approximately 10 to 15 minutes to complete via an online informed consent process and an easy-to-use mobile app.

Please feel free to share this with your family and friends, as this mobile-based IRB approved study is open to anyone, regardless if they have a rheumatic disease or not, that is 18 years of age or older with a suspected or confirmed case of COVID-19. The mobile app study consists of a survey and the option to contribute a brief video story of their experience.

Researchers are particularly interested in individuals from vulnerable and marginalized communities where economic disadvantages, race, or cultural norms may affect infectious disease cases.

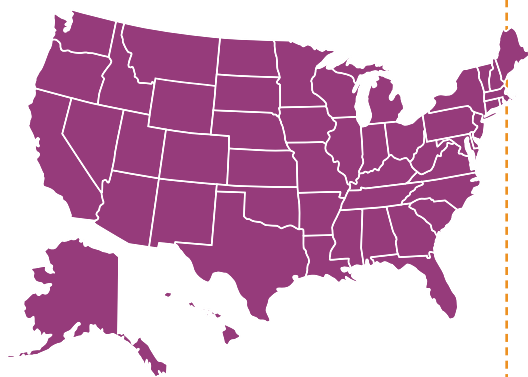
For more details or to enroll in the study, please visit covid19athomesurvey.com.

Convergence

at the American College
of Rheumatology



FORWARD research was shared in an online format with the rheumatic disease community at the annual American College of Rheumatology meeting for physicians, researchers, non-profits, and other members of the rheumatic disease community. Here are some of the important pieces of research made possible by FORWARD participants.



Experiences of Patients with Rheumatic Diseases in the U.S. During the Early Months of the COVID-19 Pandemic

WHAT WAS STUDIED: Early in the pandemic, there was a concern that patients with rheumatic diseases may have an increased risk of COVID-19 infection. While the medications they take may protect against COVID, their underlying health due to accompanying conditions like lung disease, hypertension, and diabetes leaves them at risk for a more severe COVID infection. Likewise, the steroids used to treat rheumatic disease flares could also worsen a COVID infection. FORWARD expanded on the published work about the first few weeks of the COVID-19 pandemic to look at the first few months of the pandemic. Our goal was to better understand how patients have been impacted. Participants in FORWARD with active email addresses were sent five COVID-19 surveys every two weeks between March 25, 2020 and June 2, 2020. These surveys asked about new symptoms, COVID-19 testing, changes in rheumatology care, safety measures, social contact, economic impact, and more. These responses were linked to the participant's most recent six-month questionnaire to be able to see a full picture of the participant and the impact of COVID-19 on them.

WHAT WE LEARNED: In the early few months of the COVID-19 pandemic, most patients with rheumatic diseases had important changes to their healthcare including: many appointment changes

from canceling, postponing, or switching to teleconference appointments; an inability to access prescriptions; and altered medications, including dosage changes and medications being added or removed from the treatment plan by either the physician or patient.

Utilization of Telehealth Among Patients with Rheumatic Diseases in the Early Months of the COVID-19 Pandemic

WHAT WAS STUDIED: Many health care providers replaced in-person clinic visits with telehealth visits—over the phone, online meeting, video calls, etc. We wanted to better understand these changes and levels of satisfaction with telehealth appointments among patients with rheumatic diseases during the first months of the COVID-19 pandemic in the United States. Using data from FORWARD participants, we found that about half of the participants had one or more telehealth appointments during the first months of the COVID-19 pandemic in the United States. Most reported being “satisfied” or “very satisfied” with their telehealth appointment.

WHAT WE LEARNED: Patients with more comorbidities (when a person has more than one illness or disease at the same time or when one condition occurs right after another) and a higher disease activity were more likely to use telehealth services. As clinics continue to adapt to having more telehealth visits, it is important to ensure quality of care and that satisfaction is met for populations that are most at risk.

Gene Expression Signatures in C-reactive protein (CRP) High and Low Rheumatoid Arthritis (RA)

WHAT WAS STUDIED: Transcriptomics, the study of all RNA molecules within a cell, has expanded our ability to identify biomarkers, which can be used to diagnose or give information about rheumatic diseases, and drug or therapy targets, used to treat or improve a patient's rheumatic condition.

Using biosamples from the FORWARD Biobank, our aim was to identify differentially expressed genes in CRP high and low patients with RA. CRP, which can be measured in your blood, is a marker of inflammation in the body and increases when there is inflammation in your body.

WHAT WE LEARNED: Inflammation is a way your body fights against infections, injuries, and diseases and some symptoms include swelling, redness, pain, and tenderness of an area on your body. By identifying genes responsible for these symptoms, clinicians will be better able to recognize them and consequently improve patient care.



Prevalence of Frailty and Associated Factors in a National Observational Cohort of Rheumatic Diseases

WHAT WAS STUDIED: Frailty, which is a medical condition of reduced normal function and health in older individuals, occurs more frequently and at a younger age in persons with rheumatic diseases. Self-reported frailty has not been widely studied in rheumatic and musculoskeletal diseases (RMDs). Katherine Wysham, MD, at the University of Washington, Joshua Baker, MD, at the University of Pennsylvania, Sarah Leiber, MD, at the Hospital for Special Surgery, and Patricia Katz, PhD, at the University of California San Francisco, worked with FORWARD to help describe self-reported frailty across RMDs and to determine factors associated with frailty in the FORWARD Databank. In January 2020, the six-month questionnaire included the FRAIL scale, a 5-item validated patient-reported frailty index, including:



Fatigue:
Time spent
feeling "tired"
in past 4 weeks



Resistance:
Ability
to climb
10 stairs



Ambulation:
Ability to
walk several
blocks



Illness:
≥5/11
comorbidities



Loss of weight:
>5% body
weight in
the last year

Those that had greater than or equal to 3 out of 5 of these were categorized as frail.

WHAT WE LEARNED: Understanding frailty—and the factors that increase the likelihood or severity—is vital to preventing or improving it for patients. Self-reported frailty was present in 30% of the participants and obesity and being overweight both appeared to increase the odds of frailty. Systemic Lupus Erythematosus (SLE) had the highest odds of frailty in RMDs. Further research needs to be done by gathering more data, and further review of the association between increased weight and frailty is needed.





Why are there new questions in the FORWARD questionnaire?

Expanding Our Research and Your Impact

If you are a long-term FORWARD participant, you may notice new questions that have been added to the latest questionnaire. These new questions are intended to improve our understanding and knowledge in three research areas: your experience with different medications, the way that COVID-19 is affecting individuals with rheumatic diseases, and the usage and impact of cannabis or cannabidiol (CBD) products.

CONFIRMING OLD INFORMATION

In 2006, a study was performed with FORWARD participants regarding certain medications. These questions have been added to the latest questionnaire and updated. Re-asking these questions, over 14 years later, will improve our

understanding of the acceptance and satisfaction with medications, willingness to change medications, and reasons why a person might not want to change their medication. This will allow health-care companies to better understand the impact of their medications and physicians to learn how they can better support their patients and those patients' medication plans.

GAINING NEW INFORMATION

We have also revised and added new questions regarding COVID-19, COVID-19 vaccines, and your personal experience with COVID-19. We need this information to provide doctors, nurses, patients, and researchers with important knowledge about how COVID-19 affects patients with rheumatic conditions. This will allow us to improve COVID-19 treatment for patients with rheumatic conditions, and also allow us to learn if there are any long-term effects, of the illness

or potential treatments, on patients. We are also considering setting up a monthly COVID-19 mini-questionnaire that will support the medical community by providing the latest information directly from patients, guiding treatment and care for individuals with rheumatic conditions during this pandemic.

In past questionnaires and in this current questionnaire we continue to ask about cannabis or cannabidiol (CBD) products (products derived from hemp or cannabis that do not cause a "high"). These questions are very important, as more states continue to legalize use of cannabis and CBD products and we need to gather data on these to provide information regarding how they are being used and if they are helpful for patients within the rheumatology community. These questions will also provide information on the safety of the usage of cannabis or CBD products.

There are many things that can affect the experience of an individual with a rheumatic condition. At FORWARD, it's our goal to provide information to the rheumatic disease researchers, physicians, and community that will allow them to improve this experience. If you'd like to be a part of the FORWARD databank, please visit forwarddatabank.org/join-forward.



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

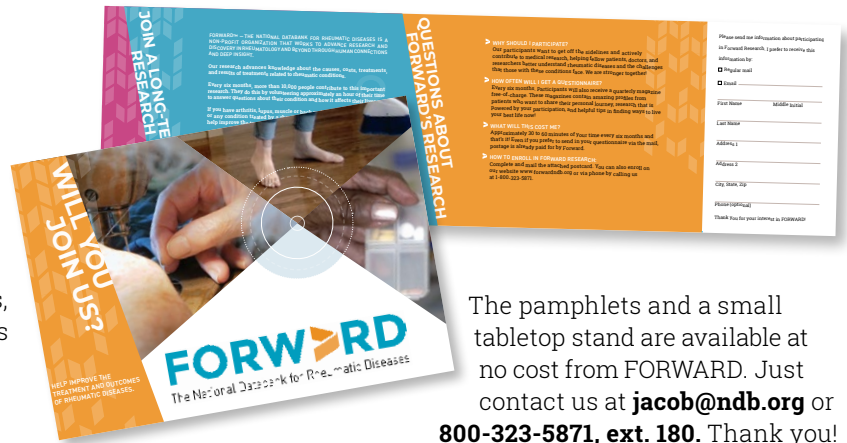
FOR PATIENTS USING WEBQUEST, email is our primary method of getting in touch with you. Even if you're not using WebQuest, we'd like to be able to send you important information by email. **Here's an important step you can take to make sure our email gets to you:** add us to your email address book! Our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

1035 N Emporia | Suite 288 | Wichita, KS 67214
Please call 1-800-323-5871 or email info@ndb.org

Directors

Frederick Wolfe, MD
Kaleb Michaud, PhD

Executive Director

Rebecca
Schumacher, BS

The contents of this magazine, such as text, graphics, images, information obtained from FORWARD contributors and licensors, and other material contained in FORWARD magazine are for informational purposes only. The content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in FORWARD magazine.

