

FORWARD

WINTER
2024

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

Understanding Rheumatic Diseases & Autoimmune Conditions: FORWARD's Specialty Databanks and Registries

**FORWARD and
Clinical Trials: What's
the Difference?**

**The Legacy of
Frederick Wolfe, MD**

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Join Us on Facebook & Twitter

Currently, you can find us on Facebook as **"FORWARD, The National Databank for Rheumatic Diseases."** We will try to keep you up to date with any news items that occur between questionnaires. You can also connect with other participants and FORWARD staff who have joined our group. For those that may be on Twitter, but not on Facebook, we will be tweeting news items on Twitter as **@ndb_org**.



FORWARD, The National Databank for Rheumatic Diseases



@ndb_org



Letter from the Co-Director

Hello, and thank you for picking up the latest issue of FORWARD magazine. In this issue, you'll find that we've chosen to focus heavily on the mission and purpose of FORWARD—representing the patient voice and understanding the day-to-day lives of people with rheumatic diseases and autoimmune conditions.

There are exciting things going on in the world of FORWARD databanks and research, and also sad news to share. We hope that you enjoy reading about the life and work of Frederick Wolfe, MD, who was the founder of FORWARD, and who passed away on September 5, 2023. It was an honor to know Dr. Wolfe, to work with him, and to help continue his legacy through FORWARD.

We also discuss the many registries and specialty databanks that are now a part of FORWARD. These databanks, the individuals that lead them, and the patients who contribute to them are all an important part of understanding conditions and diseases that are not well-understood in rheumatology. I hope that you'll find learning about them to be not only interesting, but exciting, as they play an important role in improving the diagnosis, treatment, and prevention of rheumatic diseases and autoimmune conditions.

To all of our participants: thank you for your continued support. We hope that you find this issue of FORWARD magazine to be inspirational and insightful.

Sincerely,
Kaleb Michaud, PhD
Director, FORWARD

Non-Profit Spotlight

Looking for more information about rheumatic diseases and autoimmune conditions? These resources are known for providing fact-based, helpful information:

American College of Rheumatology (ACR)
rheumatology.org/patient-information

Mayo Clinic
mayoclinic.org/diseases-conditions

Arthritis Foundation
arthritis.org/about-arthritis

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

Johns Hopkins
hopkinsarthritis.org/arthritis-info/rheum.tv

Thank You to Our Participants

As we begin 2024—a New Year with lots of promise—we want to extend a big ‘Thank You’ to the participants who choose to spend their time and energy filling out the biannual questionnaires and also those who participate in our specialty databanks and registries.

Your support and willingness to share about your own experiences is making a difference in rheumatology and autoimmune condition research. We hope that you know how grateful we are to you, and how excited we are to continue to represent the patient voice through the FORWARD databank.

Some of you have been with us since your time as a patient in Dr. Wolfe’s clinic (some having participated for over 40 years!), and some of you have only joined FORWARD recently. We are grateful to all of you for your participation, as having a long-term understanding of the impact of conditions, treatments, and symptoms is very important to improving the diagnosis, treatment, and prevention of rheumatic diseases and autoimmune conditions.

As we kick off 2024, we hope that you will continue to work with us to make a difference.

To join FORWARD, visit:
forwarddatabank.org/join

JOIN FORWARD

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



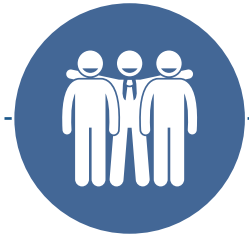
TO HELP OTHERS.

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 or call 1-800-323-5871 today!



Is a Clinical Trial Right For You?

At some point, your doctor may suggest that you consider participating in a clinical trial. It may be that your doctor believes that the clinical trial offers a promising new treatment option for your condition or symptoms, or your doctor may want to be sure that you know all the options that are available to you.

You and your trusted rheumatologist can make the best decisions for your healthcare, based on your specific illness, symptoms, and goals. Here are some questions that you may want to discuss with your doctor to help you make your decision:

Treatments and Symptoms

- + Why is this clinical trial right for me?
- + Are there other treatment options I should consider?
- + Will this treatment be added to my current plan, or used as a replacement?
- + How will participating in this clinical trial impact my healthcare costs?

Requirements

- + Are there additional requirements that I'll need to fulfill if I join the clinical trial, like extra appointments or tests?
- + Will there be other doctors or researchers that will assist with my treatment?
- + How long will I be a part of the clinical trial?

Safety

- + Has the treatment or subject of the clinical trial been studied before? What were the results?
- + What are the risks of this clinical trial?
- + If I have more questions about the trial, where can I find more information?

What is a Clinical Trial?

Has your doctor shared information about a clinical trial with you? Or have you wondered how being a FORWARD participant is different than clinical trial participation?

Within a clinical trial, patients are typically asked to use a specific treatment, like a medication, or occasionally make a lifestyle change, like adhering to a particular diet or exercise regimen. These trials may seek to learn things like whether a medication is effective or has harmful side effects, or if a particular course of treatment is better at preventing disease progression. Throughout the clinical trial, which may last for only a few months or for multiple years, doctors and researchers pay careful attention to the patient's symptoms and wellbeing, gathering data to help answer their research questions.

Unlike a clinical trial, participation in FORWARD doesn't require you to take any particular medications or adhere to a certain treatment plan. Instead, the FORWARD questionnaire gathers information from individuals with any rheumatic disease or autoimmune condition regardless of their treatment plan, symptoms, or disease status. FORWARD also collects this information for multiple years, with some participants now having provided data for over forty years!

Both types of research, and the people who participate, play an important role in improving the diagnosis, treatment, and prevention of rheumatic diseases and autoimmune conditions.

A woman with short, reddish-brown hair and a man with short, dark hair, both wearing white lab coats, are looking intently at something off-camera. The woman is in the foreground, and the man is slightly behind her. The background is blurred, suggesting a laboratory or clinical setting. A decorative pattern of overlapping hexagons is visible in the upper right corner of the image.

THE FORWARD DATABANKS

WORKING TOGETHER TO MAKE A DIFFERENCE

When you participate in the FORWARD Databank, you are supporting one part of a group of specialized databanks and registries that are intended to learn more about specific rheumatic and autoimmune conditions. These databanks bring together researchers, physicians, and patient advocates who work together to make sure that the day-to-day lived experiences of people with rheumatic and autoimmune conditions are represented in research. ➤

These specialized databanks work closely with the larger FORWARD databank and collect additional information specific to certain conditions that can be used by doctors, academic researchers, and pharmaceutical companies interested in all sorts of topics—treatment effectiveness, drug safety, prevention of disease progression, understanding characteristics of people who might be at a higher risk for a certain condition, and more.

We spoke with the individuals—including physicians, researchers, and patient advocates—leading these important projects about the role that each databank or study plays and how this ensures that important information about the day-to-day lives of patients is shared with researchers and doctors.

Dupuytren Databank

Dupuytren disease is the most common crippling hand condition that people have never heard of. This condition can cause fingers to be permanently bent, causing pain, functioning issues, and a myriad of other health problems.

Why It's Important: Many key aspects of risk factors, physical findings, and the personal impact of Dupuytren disease are not routinely documented in office records or hospital charts. The Dupuytren databank is a unique resource for this and other data relevant to developing preventive therapy for this common disabling condition.

Putting Data to Work: The Dupuytren Research Group is conducting a pilot study to discover blood biomarkers of Dupuytren disease to better identify if people with certain characteristics are at higher risk. Recruitment was only possible through the Dupuytren Databank. This study will be submitted for publication this year.

Psoriasis Registry

Psoriasis, sometimes thought to be nothing more than an annoying condition that can cause red or irritated patches of skin, can have a major impact on the day-to-day life of patients.



Charles Eaton, MD. Executive Director, Dupuytren Research Group. Director of the FORWARD **Dupuytren Databank**. dupuytren.org.



Joel M. Gelfand, MD, MSCE. Endowed Professor in Clinical Investigation, Perelman School of Medicine. Co-Director of the FORWARD **Psoriasis Registry**. forwarddatabank.org/psoriasis-registry

Psoriasis can also lead to psoriatic arthritis, which can cause permanent joint damage.

Why It's Important: The Psoriasis Registry is especially important because it is patient centered—collecting information directly from patients, so we can best understand their experience.

Putting Data to Work: This is a new and exciting initiative—over time the Psoriasis Registry will provide new insights into the patient experience living with psoriasis and will allow us to identify new strategies to help patients achieve better health outcomes.

Spondyloarthritis Registry

Spondyloarthritis (SpA) is an inflammatory arthritis that can cause long-term back pain and stiffness.

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

can use to better understand outcomes, outcome measures, and therapies.

Putting Data to Work: The evolution of new therapies to treat SpA patients makes patient participation in this registry all the more important. We need to understand how effective and safe the treatments are in the daily lives of our patients.

Lupus Registry

Lupus is an autoimmune condition, in which the body's immune system attacks its own tissues and causes inflammation throughout the body.

Why It's Important: While there are several clinical lupus cohorts around the country, the FORWARD databank is unique because it includes people across the US. We are trying to gather information that can express how lupus and its treatment affect the day-to-day lives of people with the condition. We are also able to look at lupus across the lifespan.

Putting Data to Work: Patti Katz, PhD, is currently planning a study to look at reports of cognitive symptoms—things like problems with memory or 'brain fog'—to better understand how common

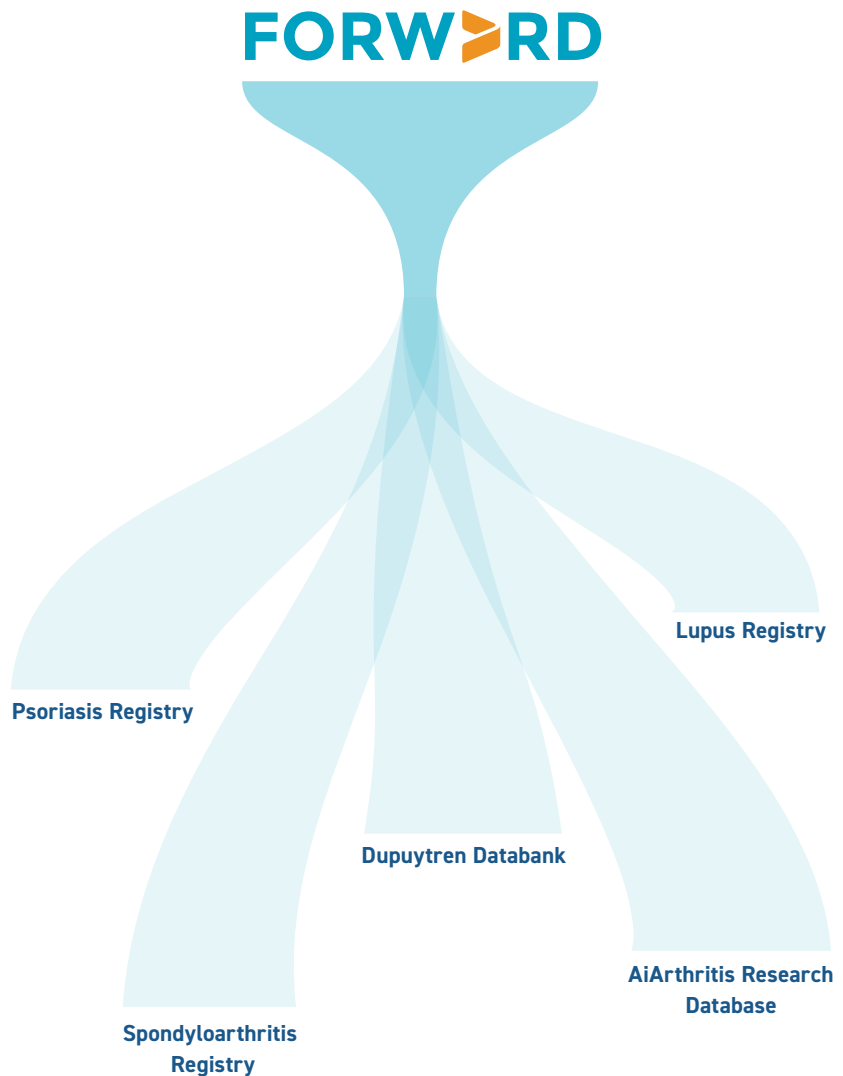
these are among people with lupus, whether there are age differences in how these symptoms are experienced, and the extent to which cognitive symptoms affect daily activities.

AiArthritis Research Database

AiArthritis is led by people affected by autoimmune and autoinflammatory arthritis (AiArthritis) diseases.

Why It's Important: We believe expedited diagnosis and access to early and effective therapy is vital to improve outcomes and increase rates of remission. The AiArthritis Research Database was established to address these issues by focusing on understanding symptoms, comorbidities, and individualized therapy responses, defining subgroups, and using data to drive public policy.

Putting Data to Work: We need real world evidence to prove the immediate need for biomarker testing and precision medicine. The same holds true for data to drive public policy. Clinical trial data only considers the average patient model and is not representative of the real community. Even though it is incomplete, it's still used and that results in laws and regulations that only benefit a portion of our community. The work we do will fill this gap and that's exciting!



Alexis Ogdie, MD, MSCE. Associate Professor of Medicine and Epidemiology, Perelman School of Medicine. Director of the FORWARD SpA Registry and Co-Director of the **Psoriasis Registry**.



Patti Katz, PhD. Professor of Rheumatology, UCSF. Director of the FORWARD **Lupus Registry**.



Tiffany Westrich-Robertson. Director of the **AiArthritis Research Database**. CEO of AiArthritis. aiarthritis.org.



A Mission Driven By Empathy

Frederick Wolfe, MD, started FORWARD because he had a mission to understand the patient experience.

Understanding the day-to-day lives of patients is a vital part of medical research. Unfortunately, for a long time, these experiences weren't considered by many researchers who instead relied on information from other doctors or short-term clinical trials. **Frederick Wolfe, MD, the founder of FORWARD—The National Databank for Rheumatic Diseases, was one of the first researchers in the rheumatology field to gather long-term information and data about the day-to-day lives of his patients.**

Dr. Wolfe passed away this past fall, on September 5, 2023. While many of you probably didn't get the chance to meet Dr. Wolfe in person, we want to tell you, the participants and supporters who make FORWARD possible, about Dr. Wolfe and his impact on FORWARD, the rheumatology field, and his patients, mentees, and peers.

Driven By Empathy

When you ask the people who knew Dr. Wolfe well about him, many will speak of his passion for his work, his expertise in the field of rheumatology, and, most importantly, the unique care and compassion that he had for people, including his patients.

Kaleb Michaud, PhD, director of FORWARD, met Dr. Wolfe when he was young—at age three, to be exact. Dr. Michaud was diagnosed with juvenile rheumatoid arthritis and has fond memories of Dr. Wolfe during the early years of their relationship: "I would see him regularly, although obviously going to the doctor as a kid was never that exciting. But we kept in touch throughout the years."

Dr. Michaud shares, "I've had the chance to look at my medical records and the notes from when he was treating me as a child, and the care and compassion that he had for me is so clear. He really took note of my pain and symptoms and was very thoughtful about the medications that he gave me, always balancing the benefits of the medications and the side effects that they would cause."

"Dr. Wolfe wanted to know the patient experience. That legacy continues at FORWARD because we believe strongly in that mission."

-Kaleb Michaud, PhD, Director of FORWARD

Getting Started—and Never Stopping

“When he first got started with tracking his patients’ symptoms and pain over time, he did it because he was frustrated with the results he was seeing,” Dr. Michaud says. “He wanted to make a real difference in those patients lives.”

As a rheumatologist in the 70’s, Dr. Wolfe purchased a computer to use for tracking bills in his medical office—but quickly learned that he could also track the pain and other symptoms that his patients were having over time, making it quicker and easier to understand the long-term symptoms that his patients had, and how those symptoms were affected by certain treatments or protocols.

“He used that data to say, ‘Hey, some of these patients are different than others,’ says Dr. Michaud. “There was this growing sense that questionnaires could be very helpful, and he started developing the whole sense of patient reported outcomes, which is still being used today in almost all areas of medicine.”

Over time, this work grew to become FORWARD—The National Databank for Rheumatic Diseases, a first-of-its-kind databank that obtains patient-reported data about the day-to-day experiences of people with rheumatic diseases and autoimmune conditions from tens of thousands of patients from all over the United States.

While Dr. Wolfe stopped seeing patients a number of years ago, it didn’t stop his work. Dr. Wolfe continued to ask questions and use patient-reported data in research, resulting in over 650 published papers (in the top 0.01% of published scientists!) and a lifetime of contribution to our understanding of rheumatic diseases.

A Lasting Legacy

Dr. Wolfe’s work went beyond data and publishing papers. His work as a mentor and informal educator informed

Remembering Dr. Wolfe

“[Fred’s] dedication to furthering our understanding of fibromyalgia and promoting its important place in rheumatology was inspirational.”

—Emma Guymmer, MBBS, FRACP from “The global rheumatology community is mourning the passing of US rheumatology professor Dr Frederick Wolfe.”
Rheumatology Republic

“Fred was an unusually generous and collaborative person ... [he] co-authored publications with hundreds of rheumatologists, and shared his ideas, data and interpretations consistently over the years.”

—Theodore Pincus, MD from In Memoriam: Remembering Frederick Wolfe, MD, The Rheumatologist

“Dr. Wolfe was a visionary but I’ll remember him for his generosity and unassuming manner when I was starting my own practice.”

—ACR President Douglas White, MD, PhD, from Celebrating the life of Frederick Wolfe, MD: “The consummate physician-scientist”, Healio Rheumatology

“He was a leader in so many areas, including the importance of listening to our patients, and of using patient reported outcomes. The most amazing thing is that Fred did all of this whilst being in private practice rather than being supported by the resources of a large academic medical center.”

—Daniel Clauw, MD, from Celebrating the life of Frederick Wolfe, MD: “The consummate physician-scientist”, Healio Rheumatology

“Dr. Fred Wolfe was a legend in the field of rheumatology and motivated me to be a better physician and be more stringent in assessment of outcomes.”

—Tim Shaver, MD, regarding his time with Dr. Wolfe

“My mom had severe rheumatoid arthritis and became a patient of Dr. Wolfe’s in 1975. She sang her praises of him until her passing in 1977. Through his care, she was able to enjoy a quality of life that she hadn’t experienced in many years.”

—Willa Applegate, regarding her mother’s relationship with Dr. Wolfe

the experiences of many researchers and clinicians. When Dr. Michaud initially worked with Dr. Wolfe, it was because his rheumatoid arthritis forced him to take a leave of absence during his early career pursuing a PhD in astrophysics. “I kept working late into the evening because I was so inspired by what he was doing and the fact that he was doing so much, seeing patients, and doing research simultaneously,” says Dr. Michaud. “The two years of that leave of absence were the most impactful in my life. And now, when I get up every morning and go do great work, it’s because of that time with Dr. Wolfe.”

Dr. Wolfe believed in supporting young researchers and clinicians, providing guidance and training to people who had the same passion that he had for doing excellent work that would ultimately help the patients. Dr. Michaud shares, “It was incredible to see all of the researchers and physicians that Dr. Wolfe helped—not for money or for a job, but because he wanted to help them continue to train and get better. That part of his work will never go away, because he impacted the lives of so many researchers who are continuing to work in the field.”

Unsurprisingly, Dr. Wolfe’s legacy also continues in FORWARD. “We know that the people who participate also believe in the mission,” says Dr. Michaud. “We’re asking a lot. We know that it isn’t always easy for participants to answer the questionnaires, and we’re incredibly grateful for them. That motivates us to keep on doing as much as we can with it, just like it did for Dr. Wolfe.”

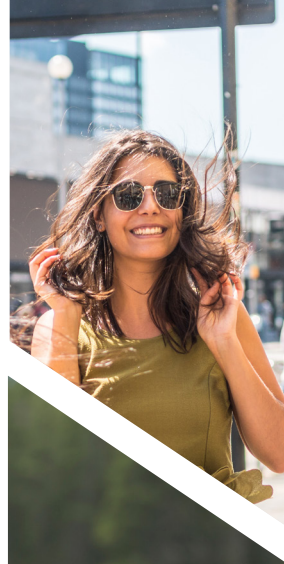
“There’s no research study like FORWARD. There’s no research study of the size and scope and approach that we take. And that’s all Dr. Wolfe. He wanted to know what happened to people beyond the clinic and wanted to know what happened to people who didn’t come back... he wanted to know the patient experience. That legacy continues at FORWARD because we believe strongly in that mission.”

In Your Words

The support of FORWARD participants allows us to continue Dr. Wolfe’s work and mission to understand the lived experiences and day-to-day lives of people with rheumatic diseases and autoimmune conditions.

We asked some of our participants why they volunteer their time and experiences to FORWARD, and here’s what we heard.

- + “I like to think that other people will benefit from my information... and I like receiving the newsletter with every questionnaire!”
- + “My pain is just so extreme. I hope that one day they’ll find a cure to help it.”
- + “My doctor got me started doing the questionnaires many years ago because I have rheumatoid arthritis. So, I just keep doing them every six months or so and hope that I can help someone else one day.”
- + “I want to help future generations—to help research learn more about arthritis.”
- + “I appreciate what FORWARD is doing... and I want to help others and myself by participating.”
- + “It makes me reflect on my own health and will hopefully help others with their arthritis.”
- + “I feel like it’s important to learn all that we can about RA, and to pass it on.”



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, 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!

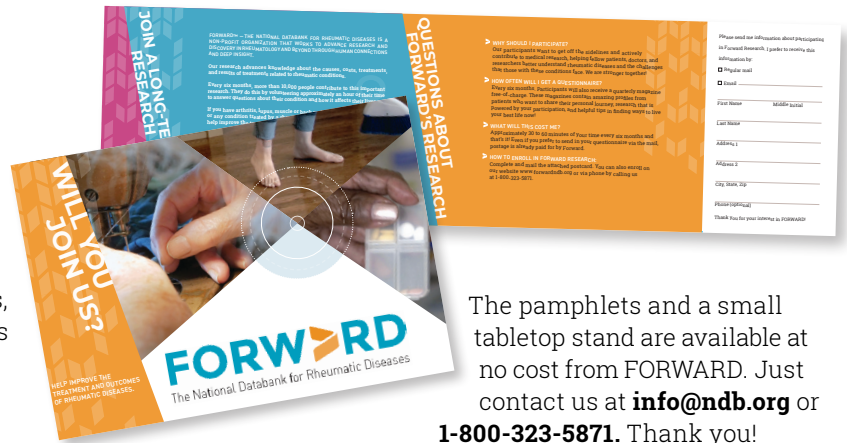
While working on your questionnaire, if you have ANY questions, please contact us right away by email (**webquest@ndb.org**) or phone (**1-800-323-5871**). These might be about technical difficulties or how to interpret a question. If you put your immediate questions in the comments section, we probably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

WAIT! WE WANT YOUR VOICE TO BE HEARD!

We need your help in filling out our questionnaires. We are a nonprofit research organization with a staff of 16 that combines the experiences of thousands of patients over time for use by rheumatologists, nurses, immunologists, epidemiologists, and even health economists. We are the **ONLY** longitudinal research study that asks the level of detailed questions we have with so many participants with rheumatic diseases, and we do this with a relatively small amount of grant funding. Please let us know what we can do to help you by phone (**1-800-323-5871**), email (info@ndb.org), or mail. We want to hear from you, as we are passionate about fighting these diseases!



For More Information or to Participate, Please Reach Out

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Director
Kaleb Michaud, PhD

Executive Director
Rebecca Schumacher, BS

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