

FORWARD

WINTER
2025


NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

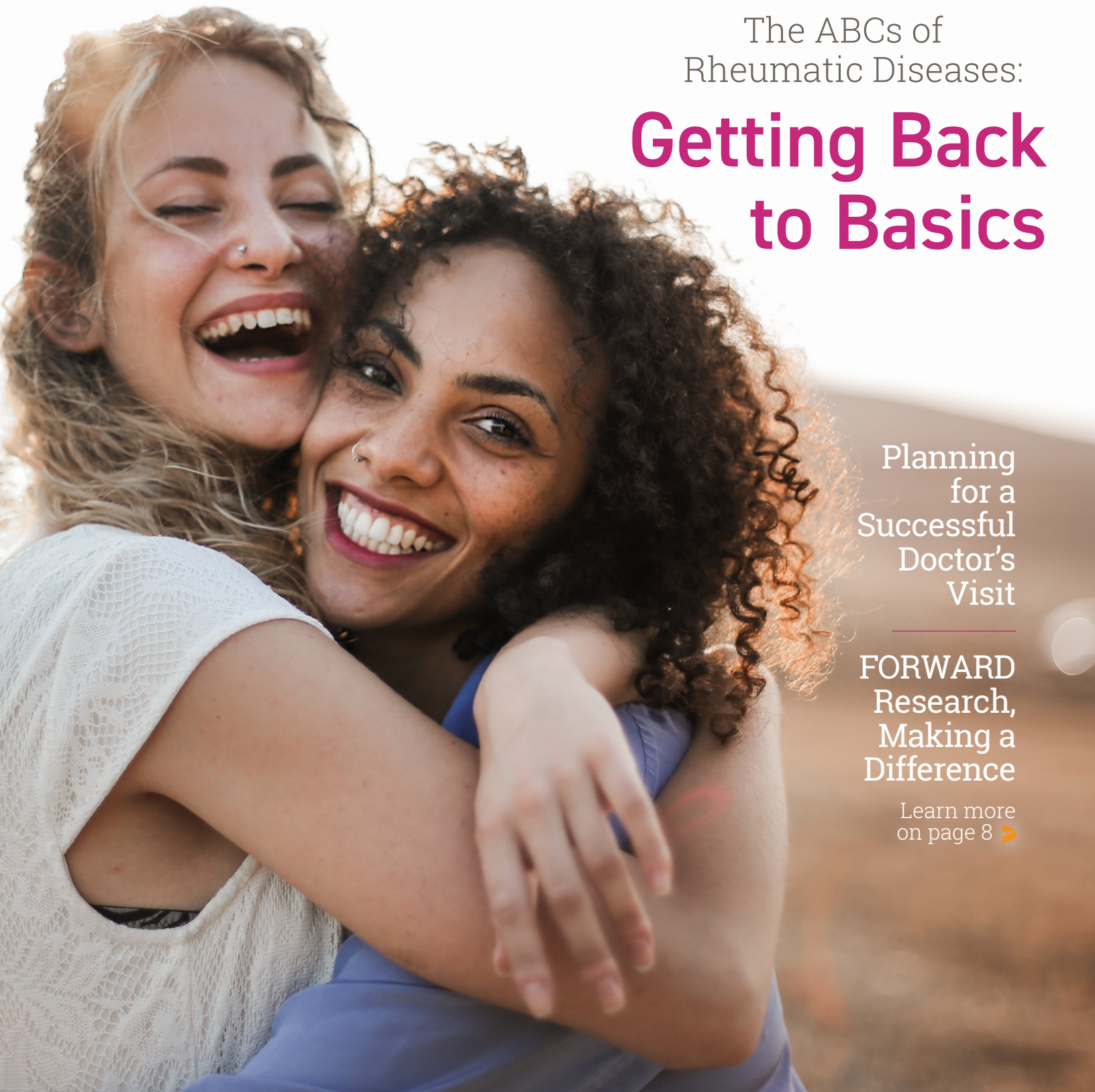
The ABCs of
Rheumatic Diseases:

Getting Back to Basics

Planning
for a
Successful
Doctor's
Visit

FORWARD
Research,
Making a
Difference

Learn more
on page 8 



Letter from the Director

Welcome to this special issue of FORWARD magazine, where we are excited to share some of the impactful work happening at FORWARD—the National Databank for Rheumatic Diseases. In this issue, you'll learn more about the important role that FORWARD participants play in advancing research and improving care for people with rheumatic diseases.

We are excited to take a step back to the basics, discussing some of the most common rheumatic and autoimmune diseases and symptoms, as well as common treatment pathways. You'll also find insightful articles discussing the best ways to prepare for a successful doctor's visit, and tips on managing your symptoms.

Additionally, this issue will dive into some of the exciting ongoing research that is being powered by FORWARD data. From exploring new treatment approaches to improving quality of life, your participation is helping to shape the future of rheumatic disease care.

Thank you for being a part of this journey with us. Your voice truly makes a difference!

Sincerely,
Kaleb Michaud, PhD
 Director, FORWARD



FORWARD In The News

FORWARD recently sat down for a conversation on Health Uncensored with Dr. Drew. In the feature, FORWARD Director Kaleb Michaud, PhD, shines a light on the groundbreaking work being done to improve the lives of those with rheumatic diseases. The segment spotlights how participants' data, like yours, is helping researchers make continued advancements in treatments and care.

Tune in to learn more and watch the feature by visiting www.FORWARDdatabank.org.



In This Issue

- 3 Thank You to Our Participants
- 4 Getting the Most Out of Your Doctor's Visit
- 5 Back to Basics: Understanding Rheumatic Diseases
- 8 FORWARD Research Update
- 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 sharing news items as **@ndb_org**.



**FORWARD, The
National Databank
for Rheumatic Diseases**



@ndb_org



A **Thank** BIG **You** TO FORWARD PARTICIPANTS!

Your involvement is truly making a difference in the lives of people living with rheumatic diseases.

To everyone participating in FORWARD—the National Databank for Rheumatic Diseases—we just want to say thank you.

Every time you take a few minutes to fill out surveys and track your health, you're helping to move research forward. FORWARD is the largest research databank for rheumatic and autoimmune diseases, and it's because of your participation that researchers and doctors can learn more about conditions like rheumatoid arthritis, lupus, fibromyalgia, and others. This data helps create better treatments, improve care, and even make new discoveries.

We know dealing with a rheumatic or autoimmune disease isn't easy, but your effort to share your experiences with us is incredibly valuable. By being a part of FORWARD, you're helping millions of people worldwide who live with these conditions. Your voice deeply matters!

We just want you to know how much we appreciate your time and dedication. Thanks to you, we're building a future where rheumatic and autoimmune diseases are better understood, and care is more effective.

So, from all of us—thank you! You're making a huge difference.

JOIN FORWARD

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



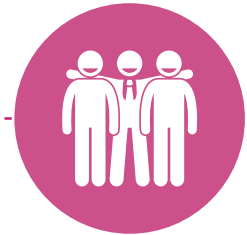
TO HELP OTHERS.

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!



Making the Most of Your Doctor's Visit

Going to the doctor can be difficult, especially if you have a condition or symptoms that you are particularly concerned about. Consider the questions and answers below to make your next appointment successful.

Q: What should I do before my doctor's appointment?

A: One of the best things you can do is write down your questions beforehand. It's easy to forget what you want to ask during the visit, especially if you're feeling anxious or rushed. Make a list of any concerns—whether it's about your symptoms, medications, or treatment options—so you can stay organized and ensure you don't leave without the answers you need.

Q: How should I track my symptoms?

A: Pay attention to the details. Write down when your symptoms started, how often they occur, what makes them better or worse, and how they're impacting your daily life. Being specific about your symptoms will help your doctor understand your situation better and make the diagnosis process smoother.

Q: Should I bring anything with me to the appointment?

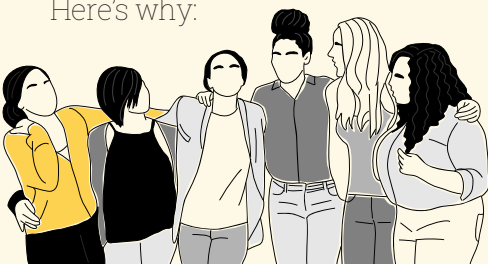
A: Yes! Bring a list of all your current medications, including dosages, as well as any vitamins or supplements you're taking. This ensures your doctor has the full picture of your health and can avoid potential interactions with new medications.

Q: Any tips for remembering the doctor's advice afterward?

A: Consider bringing a notebook with you. Taking notes during the visit allows you to review the doctor's advice later and to help you follow the treatment plan as prescribed. By being prepared, you'll have a more productive and stress-free doctor's visit.

The Right Support

Having a friend or family member with you can make your doctor's visit easier, less stressful, and more productive. Here's why:



Ask the Right Questions

A friend or family member can ask questions you might forget or feel unsure about.



Catch Important Details

They can take notes, acting as a second set of ears when medical terms start flying around.



Emotional Support

Having someone by your side can ease stress, especially if it's a tough or complex appointment.



Stay Present

Bringing someone along ensures you get the most out of your visit, helping you stay calm, focused, and fully informed.



➤ Back *to* Basics

UNDERSTANDING AND MANAGING RHEUMATIC DISEASES

Rheumatic and autoimmune diseases affect millions of people across the world. While every person's experience is unique, we also know certain diseases and symptoms tend to be more common. Let's take a look at some of the most basic, but important, information about rheumatic and autoimmune diseases. ➤

What Are Rheumatic and Autoimmune Diseases?

At their core, rheumatic and autoimmune diseases involve inflammation in the musculoskeletal system. Some affect only the joints, while others are more systemic, impacting your organs, skin, and blood vessels. Here are a few of the most common ones:

- **Rheumatoid Arthritis (RA):** An autoimmune disease where the immune system attacks the lining of the joints, causing pain, swelling, and eventually joint damage. It often starts in the smaller joints, like fingers and toes, and can progress to larger joints over time.
- **Osteoarthritis (OA):** Osteoarthritis occurs because of wear and tear of cartilage between bones, leading to stiffness, swelling, and pain. Most OA usually occurs in the knees, hips, and hands.
- **Lupus (Systemic Lupus Erythematosus):** A complex autoimmune condition affecting multiple organs. Joint pain is a big part of it, but lupus also brings fatigue, rashes, and sometimes serious organ damage.
- **Psoriasis and Psoriatic Arthritis:** Psoriasis is a skin condition caused by an overactive immune system, resulting in scaly, inflamed skin. Psoriatic arthritis occurs when the inflammation also affects the joints, creating pain and stiffness.
- **Fibromyalgia:** Though not exactly a form of arthritis, fibromyalgia shares similar symptoms like widespread pain, fatigue, and sleep issues. Fibromyalgia affects how the brain processes pain, which can make even light touch feel painful or uncomfortable.

Spotting the Symptoms

Though each rheumatic disease is different, there are many common symptoms shared across many diseases. Being able to recognize these early signs can make all the difference when it comes to managing the disease and preventing it from getting worse.



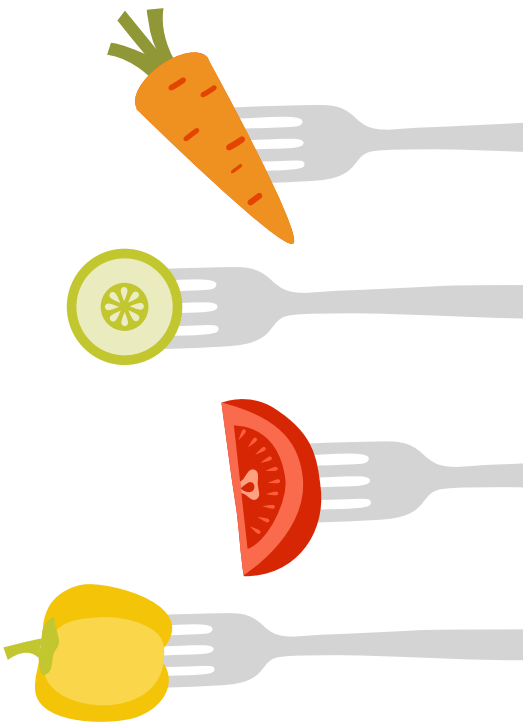
- **Joint Pain:** Persistent or intermittent joint pain is one of the most common symptoms experienced by people with rheumatic diseases. The pain might get worse after activity or after sitting still for a while.
- **Swelling and Stiffness:** Joint swelling and stiffness, especially after periods of rest like first thing in the morning, can be a sign of infection and can cause difficulty going about normal daily activities.
- **Fatigue:** Chronic exhaustion is very common, especially with diseases like lupus and fibromyalgia. This kind of fatigue is more than getting a bad night of sleep... it is an ongoing symptom that can impact every aspect of a person's life.
- **Redness and Warmth:** Inflamed joints might become red and feel warm to the touch, a classic sign in conditions like RA and gout.
- **Limited Range of Motion:** As inflammation progresses, moving the affected joints can become difficult, limiting everyday activities.

Commonly Used Treatment

Thanks to advances in medical science, treating rheumatic diseases has come a long way. Today, there's a wide range of treatments that target both symptoms and the disease itself. Remember to always talk to your doctor about treatments for your condition, because they understand your unique situation and needs. Here's a look at some of the most common options:

1. Medications:

- **NSAIDs (Nonsteroidal Anti-Inflammatory Drugs):** These over-the-counter drugs, like ibuprofen and naproxen, are often the go-to for easing pain and reducing inflammation. They're particularly useful in mild cases of rheumatic diseases.
- **Corticosteroids:** Corticosteroids are anti-inflammatory medicines, like prednisone, that are used for short-term relief of severe inflammation. They work fast but can have side effects, so they're usually not a long-term solution.



- **DMARDs (Disease-Modifying Antirheumatic Drugs):** These drugs target the immune system to slow the progression of diseases like RA and lupus.
- **Biologics:** These are newer medications designed to block specific proteins in the immune system responsible for inflammation. Biologics have revolutionized treatment for autoimmune diseases.
- **Topical Treatments:** Anti-inflammatory medications applied to the skin can help lessen inflammation and improve the appearance of skin and pain and stiffness in joints.

2. Physical Therapy: Staying active is one of the best things you can do to manage rheumatic disease. Physical therapists can design exercise plans that build strength and flexibility without overloading the joints. .

3. Lifestyle Changes: Our day-to-day choices can help improve the symptoms or progression of a rheumatic or autoimmune disease. Lifestyle changes are also often paired with medication or other forms of treatment.

Taking Care, at Home

While medical treatments are important, many of the best ways to manage rheumatic diseases happens outside of the doctor's office. Here are some simple, back-to-basics strategies for managing your symptoms at home:

1. Stay Active, but Don't Overdo It:

Moving your body regularly can ease joint stiffness and improve your strength and flexibility. Focus on low-impact exercises like walking, swimming, or gentle yoga. Remember, though, that rest is just as important—overdoing it can lead to flare-ups, so it's crucial to listen to your body.

Why it helps: Movement keeps your joints lubricated and can strengthen muscles, making it easier to support your joints and reduce pain.

2. Use Heat and Cold Therapy:

Applying heat can help to relax tight muscles and soothe stiff joints, while cold therapy reduces inflammation and numbs pain. A warm bath or heating pad is great when you're feeling stiff, while a cold pack can help with sudden flare-ups.

Why it helps: Heat increases blood flow and reduces stiffness, while cold constricts blood vessels, decreasing inflammation and pain.

3. Maintain a Healthy Weight:

Excess weight puts additional strain on your joints, especially your knees, hips, and lower back. Even small weight loss can lead to significant improvements in pain and function.

Why it helps: Every pound of weight lost takes pressure off your joints, particularly weight-bearing ones, which can help decrease pain and stiffness.

4. Manage Stress:

Stress can exacerbate rheumatic disease symptoms. Mindfulness techniques like meditation, yoga, or deep-breathing exercises can help you stay calm and reduce stress levels.

Why it helps: Stress causes your body to release chemicals that promote inflammation. Keeping stress in check helps reduce flare-ups and manage pain.

5. Eat an Anti-Inflammatory Diet:

Focus on foods that fight inflammation, like fruits, vegetables, whole grains, and omega-3-rich fish. Avoid processed foods, sugary snacks, and anything high in unhealthy fats, which can worsen inflammation.

Why it helps: Certain foods contain nutrients that combat inflammation at the cellular level, helping to manage symptoms naturally.

The Bottom Line

Living with a rheumatic disease can be tough but getting back to basics with a few simple strategies can make a world of difference. By learning to recognize early symptoms, sticking to your treatment plan, and adopting healthy habits, you can reduce pain, slow disease progression, and improve your quality of life. It's about taking small, sustainable steps toward managing your health and well-being.



FORWARD Research: Some Learnings from 2024

The Power of Long-Term, Real-World Data

Mining for Gold: Big Data in 2024

Kaleb Michaud, PhD, Director of FORWARD and Professor at the University of Nebraska Medical Center, provided a fresh perspective of Real World Data (RWD) to better understand rheumatic disease. He highlighted how new technologies are changing, how we collect information and the challenges that come with it, offering valuable insights from a nonprofit and academic viewpoint.

Understanding Social Security Work Disability in Fibromyalgia: 25 Years of Patient Follow-up

At the ACR Convergence 2024, Dr. Shreena Kamlesh Gandhi, a fellow at the University of Kansas and researcher



with FORWARD, presented findings from a long-term study alongside other fibromyalgia experts at FORWARD. This research was built upon a 2014 study led by Dr. Fred Wolfe and other fibromyalgia experts.

For many with fibromyalgia, debilitating symptoms can make it hard to work. Disability benefits are crucial for individuals unable to work and are often provided through programs like Social Security Disability Insurance (SSD) in the United States, with similar programs globally. While fibromyalgia is recognized under immune and musculoskeletal disorders, proving eligibility remains challenging.

The study found that perceptions and care for fibromyalgia have evolved over the past decade, though social security disability rates for individuals with fibromyalgia remain high—but not higher than those living with rheumatoid arthritis (RA) or osteoarthritis (OA) who also meet SSD criteria. The research also found that asking functional status questions in surveys helps as the main predictor of work disability.

Understanding Symptoms Exploring Post-Exertional Malaise (PEM) in Rheumatic Diseases

At the ACR Convergence 2024 meeting, Kaleb Michaud, PhD, Director of FORWARD, presented the first study to understand and report PEM rates in adults with rheumatic diseases. PEM refers to abnormal and prolonged responses to even small amounts of physical, mental, or emotional activities. The findings uncovered associations that impact PEM status, such as higher disease activity, as depression, widespread pain, and exposure to COVID-19. These results open new doors for understanding how adults with rheumatic conditions are impacted by PEM and the importance of addressing it in their care.

Understanding Pain and Associated Factors in People with Idiopathic Inflammatory Myopathies

Pain has long been overlooked in **Idiopathic inflammatory myopathies (IIM)** – a group of rare muscle diseases including myositis, polymyositis, dermatomyositis, and sporadic inclusion body myositis. IMM was traditionally believed to cause a painless weakness, but new research shows otherwise.

A recent study **found that 86% of people with IIM reported pain**—individuals who were black and obese had significantly higher pain levels. Those with severe pain were also more likely to have additional health challenges, including depression, anxiety, and diabetes. The study also revealed a strong link between pain and how patients reported their myositis disease activity.

These findings underscore the critical importance of recognizing and addressing pain experienced by those living with IMM. By better understanding individuals' pain, healthcare providers can deliver more effective, patient-focused care.

Working Together to Make an Impact

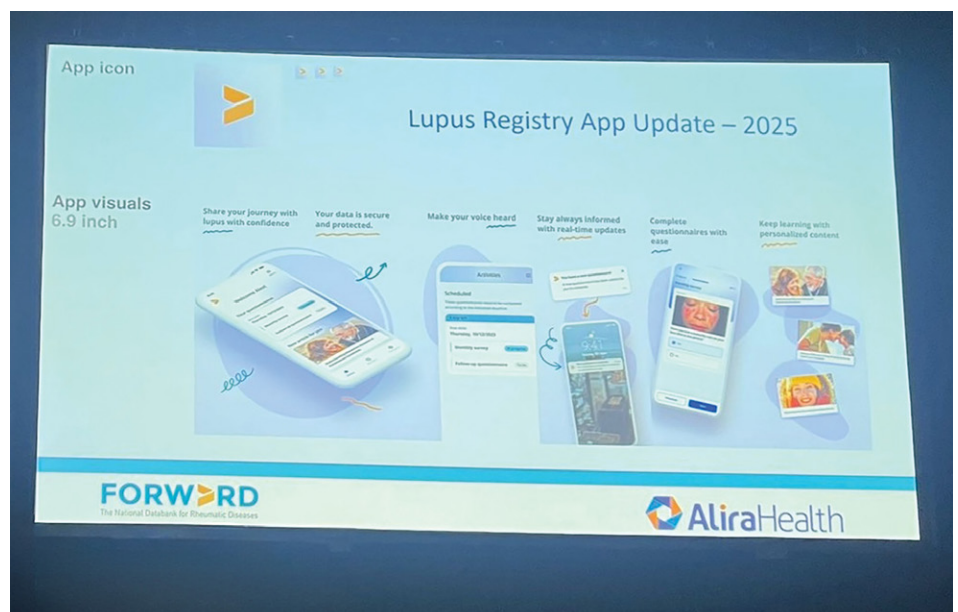
Strengthening the Lupus Registry

We are excited to announce our partnership with Alira Health, a global advisory and clinical research firm, to improve the FORWARD Lupus Registry.

Lupus is a complex disease that can affect people differently. Symptoms vary widely, and treatment options are limited. Because of this, understanding people's experiences and long-term health outcomes is particularly challenging. That's why the Lupus Registry is such a vital tool—and our partnership will create new opportunities to support new discoveries in lupus.

The registry offers a safe and secure way to share health and symptom data, all de-identified. **This not only helps people with lupus better manage their condition, but also helps researchers develop better treatments and improve the overall quality of life for those with lupus.**

With Alira Health, we're creating an app that allows people with lupus to easily share their health experiences, answer surveys, and even upload their medical records if they want to contribute further. The registry will continue to serve as





a worldwide digital collection for lupus data. Members of the registry will receive reporting results, offering additional insight into the collective outcomes experienced by the lupus community.

We plan to launch the new registry app in early 2025 and will send out updates as we get closer to the big day. Together, we are driving real progress and discoveries for those impacted by lupus.

The LupusNet Federated Data Network: Bringing the World Together to Understand Lupus Better

Real-world data about people with Systemic Lupus Erythematosus (SLE) is collected consistently, but until now, has been scattered across multiple registries worldwide. To change that, the Lupus Federated Data Network (LupusNet) was created. This initiative combines information from existing lupus registries to create a global network. Our goal is to deepen our understanding of lupus with a larger number of patients, greater data consistency, and address potential gaps in knowledge.

SLE FORWARD is one of five registries in LupusNet, representing North America and providing direct data from people with lupus. Other registries include APLC (Asia Pacific), RELESSER (Europe), and Almenara and GLADEL (Central and South America), representing over 10,000 lupus patients.

LupusNet uses a data-network approach and privacy-by-design method. That means personal data remains within the registries and analysis occurs locally, only combined results are shared.

This ongoing study aims to give a clearer picture of lupus, the patient populations affected, and treatment patterns, ultimately helping improve the lives of people with lupus around the world.

A New Tool and Registry to Identify Psoriatic Arthritis Risk

Identifying people at risk for developing psoriatic arthritis (PsA) early may allow for faster diagnosis and treatment. The Psoriasis Epidemiology Screening Tool (PEST) is designed to help spot people who might have undiagnosed PsA. The PEST score may also be associated with and predict future risk of PsA in individuals who don't yet have the condition with a higher chance.

As part of this effort, the FORWARD Psoriasis Registry is a new program that collects data directly from individuals with psoriasis. In its first year of data collection, researchers found that participants with high PEST scores (3 or more) shared similarities with those diagnosed with PsA.

These findings suggest that PEST could be a useful tool for identifying PsA or determining PsA risk in research studies – and will continue to be tested in the FORWARD Psoriasis Registry.





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!

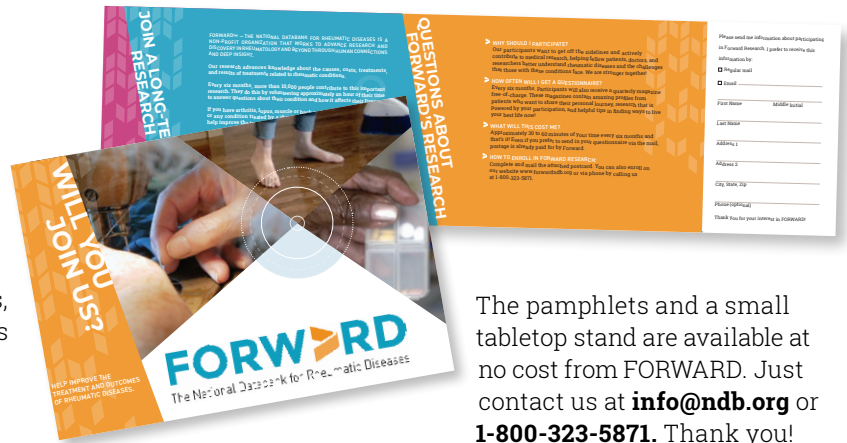
While working on your questionnaire, if you have ANY questions, please contact us right away by email (**webquest@ndb.org**) or phone (**1-800-323-5871**). These might be about technical difficulties or how to interpret a question. If you put your immediate questions in the comments section, we probably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