

# FORWARD

SUMMER  
2023

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

Finding the Joy in

*Life &  
Motherhood*

**A Treatment Plan  
that Fits You**

**FORWARD  
Data, Making a  
Difference**

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

Hello, and welcome to the latest issue of FORWARD magazine! We are excited to share some of the latest research that is being done with FORWARD data in this issue. To those of you who have chosen to use your time and energy completing our bi-annual questionnaire and additional surveys, thank you—your efforts are an important part of improving the diagnosis, treatment, and prevention of rheumatic and autoimmune conditions and are making a difference.

You'll also find an important topic in this issue—parenthood. We understand that many people with rheumatic conditions have concerns about the impact that their disease could have on their children or their own

ability to do the hard work of parenting. We're excited to share an interview with one parent who chooses to focus on the bright side of things... and we hope that you'll be able to see the bright side too.

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

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

Non-Profit  
Spotlight  
**MotherToBaby**



MotherToBaby is dedicated to providing up-to-date evidence-based information on exposures during pregnancy and breastfeeding to women, healthcare providers, and the general public. Common questions that we receive are about over the counter or prescription medicines, alcohol and drugs, vaccines, infections, chemicals, and health conditions that a parent has.

MotherToBaby's service is free and confidential. You can get in touch with a counselor by calling 866-626-6847, texting 855-999-3525 or visiting their website to start a live chat or email-an-expert at [mothertobaby.org](http://mothertobaby.org).

In addition to providing information, MotherToBaby also studies the effects of certain medications and diseases in pregnancy. These studies never require a mother-to-be to take a medicine or do anything different from her normal routine. These studies add to the knowledge base of the effects in pregnancy of rheumatic conditions and the medications used to treat them, so we can help future moms and babies.

MotherToBaby is a service of the non-profit Organization of Teratology Information Specialists (OTIS). MotherToBaby Pregnancy Studies are conducted by OTIS and coordinated by the University of California San Diego.

# Discover the Features of **WEBQUEST**

Did you know FORWARD has an online questionnaire platform called WebQuest? We are working tirelessly to improve it to make it as easy as possible for you to fill out our questionnaires. Here are some features that you don't want to miss:

## Existing Features

- Medications are automatically added to your questionnaire if you have previously filled out questionnaires with us in the past. This saves you time and ensures that your current medication list is always up-to-date.
- As you fill out a survey, questions are added and removed based on your responses to give you the most streamlined questionnaire possible. You won't have to answer unnecessary questions, and your questionnaire will be completed faster.
- You can download old questionnaires, so you always have a copy of your health history at your fingertips.
- You can see health reports based on your past questionnaires, which provides you with valuable insights into your health trends over time.

## Newly-Implemented Features

- You can change your email in the portal instead of sending the change to us directly. This gives you more control over your account information.
- When filling out a questionnaire, it will pull in your answers from past questionnaires where applicable. This saves you time and ensures consistency in your responses.
- Big improvements to our mobile interface mean that you can complete questionnaires on-the-go with ease.
- You can safely upload any files that you might want to reference at a later date, such as lab reports or medical imaging.

## Upcoming Feature

- Our upcoming digital diary will allow you to update your medications and hospital visits as they happen, so your health information is always up-to-date.

Our online questionnaire platform is dedicated to providing you with the best possible experience for managing your health information. Email us at [webquest@ndb.org](mailto:webquest@ndb.org) to switch to using WebQuest and try out these features that can simplify your health management today!

## 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!



## Making a Difference: Lifestyle Changes that May Impact Your Symptoms

With lifestyle changes, people can complement the effects of medication and improve their overall health. While not every lifestyle change will have the desired effect for every person, there are some changes that many people find beneficial.



### Regular Exercise

Keep moving to help to maintain joint flexibility and strengthen muscles, helping to reduce pain and increasing mobility.



### Anti-inflammatory Foods

Choose to eat a healthy diet with plenty of anti-inflammatory foods, such as fruits, vegetables, and omega-3 fatty acids, to help limit some symptoms that are connected to inflammation, like pain.



### Stress Management

Some techniques, such as meditation or yoga, help reduce anxiety, manage symptoms, and keep people focused on their own health and wellness.

## The Treatment Mix

Living with a rheumatic or autoimmune disease can be challenging, involving chronic pain, inflammation, fatigue, and more. While medication prescribed by a rheumatologist often forms the cornerstone of treatment, many people have found that a combination of treatment and lifestyle changes can often do the best job of managing their symptoms.

This holistic approach allows people to better understand and take charge of their own health and wellness. For many people, finding the best combination often requires some experimentation, over time, under the guidance of a rheumatologist that you trust and who understands your disease.

Medication prescribed by doctors plays a vital role in managing rheumatic and autoimmune diseases. These medications aim to control inflammation, lessen pain, and slow down disease progression. As the basis of many treatment plans, these medications often provide immediate relief from disease symptoms. However, some patients may experience side effects or find that medication alone isn't enough to manage their symptoms effectively.

Finding the right combination of treatments and lifestyle changes requires patience. What works for one person may not work for another, and individual responses to different interventions can vary significantly. With the guidance of an experienced healthcare professional, patients can work through the various options, monitor their progress, and adjust as needed.





# *Don't Hold Back*

## A STORY OF DIFFICULTIES, SURPRISES, AND RESILIENCE

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Stephanie doesn't let things get her down. Overcoming hardships early in life taught her to go after what she wants and be grateful for what she has—in her health, and in motherhood.

### **A Sudden Diagnosis**

"I turned 22 in September of '99," Stephanie shares. "Two weeks later, I got what I thought was pink eye. It ended up being uveitis, which is one of the viruses that commonly triggers rheumatoid arthritis (RA). Two weeks later, I completely lost the left side of my body. The doctors thought I had had a stroke." ➤





Stephanie, her daughter, and Mihail Moroianu, MD

"I was in college in Pennsylvania, and over the next two and a half months, I saw 13 different doctors and eventually I was diagnosed with seronegative RA. At the time, it felt like forever, but now I know that it was much faster than many people get the answers that they need."

"I was in college to be an English teacher, and my doctor really recommended that I didn't go to teach in a traditional classroom. He said, 'If this treatment doesn't work, I see you being disabled in two years.' And at the time, I believed him. I couldn't even brush my own teeth."

When Stephanie returned home to Queens, NY and transferred to a new doctor located nearby, she shared that her previous rheumatologist thought that she would be eligible for Remicade (a drug which improves the inflamma-

tion associated with RA) and that she wanted to try it, even though it had just come out of clinical trials and was still being studied for long-term risks and side effects.

"I had nothing to lose. I had 20 grand in student loans. I had to give up my dream job. I was like, 'I've got nothing. So yeah, I'll take the chance.'"

Stephanie began the Remicade in January of 2000 and six months later, she was in clinical remission—and has remained in remission for the past 20+ years.

### A Surprise Pregnancy

As an avid advocate for herself and an active participant in her healthcare, Stephanie is no stranger at her rheumatologist's office. In fact, when she realized that she was pregnant, Dr. Moroianu, who has been her rheumatologist since she and her husband

decided to start a family, was the first call that she made.

Unfortunately, getting to that phone call was not an easy process. When she and her husband first decided to start a family, Stephanie brought it up to the rheumatologist that she was seeing at the time: "She said, 'Ok, you need to stop the methotrexate for one menstrual cycle.' And I knew that wasn't right. I had seen the research—I knew I ought to be stopping the methotrexate for at least six months."

Having raised money for the Arthritis Foundation by running marathons, Stephanie had friends that she knew could connect her to a rheumatologist that was on top of the latest research. That's how she ended up working with Dr. Moroianu to prepare for parenthood. With Dr. Moroianu and a high-risk obstetrician in her court, she also





## Stephanie and her rheumatologist, Mihail Moroianu, MD

"Four weeks later, I discovered I was pregnant. Life is funny sometimes. I got my miracle baby."

### The Life-Changing Impact of Progress

For Stephanie, the ups and downs of life are just a part of the process, and all you can do is the best you can with what you've been given.

"I'm the longest RA patient in the world to be continuously treated on the Remicade. I got married. I have a kid. I have a full-time job that I love—I'm an environmental educator, so I get paid to play. I had a friend recently say something about all that I do—I dance, I have a family, I've run marathons, I work. To me it's like, 'Why not?'. Because I thought I was put on a clock when I first went on the Remicade."

"For so long, people like us were looked as 'Oh, they don't want to work or produce. You can't hurt that much, you look normal.' But now, all of the things that biologics treat...it's transformative in the treatment of autoimmune diseases. We can have full, complete, normal lives!"

agreed to participate in research with the organization now known as MotherToBaby, which studies the effects of health conditions and treatments during pregnancy.

Two and a half years later, and Stephanie still didn't have a pregnancy, and decided that perhaps adoption was the right move. During this time, she and her husband went on a cruise, celebrated the Christmas holidays, and then Stephanie lost her mom.

## Approaching Pregnancy

If you have a rheumatic or autoimmune condition and are concerned about family planning or looking to the future, keep these two important tips in mind so that you can address your concerns and aim for a healthy and successful pregnancy.

**Talk to Your Team:** Family planning with a rheumatic or autoimmune illness often requires the support of a team—made up of your rheumatologist, your OB/GYN, and potentially a fertility specialist. It is important to talk to your team early, when you are first considering family planning, to better understand what that journey may look like for you and to understand how your rheumatic or autoimmune condition might impact it.

**Recognize Your Risk:** Some, but not all, medications for rheumatic and autoimmune conditions can impact pregnancy, and some, but not all, conditions can also impact your risk levels. Every person (and their disease) is different, so it's important that you are relying on medical experts who know about your individual experience. Your doctors can help you recognize and reduce your risk in a way that is controlled and healthy for YOU.

## 3-6 Months

The amount of time an individual should have their rheumatic illness under control before attempting pregnancy.\*

\*As recommended by the American College of Rheumatology

## 3 Month Visits

How often a low-risk individual should visit their rheumatologist during pregnancy.\*





# FORWARD RESEARCH: What We're Learning

FORWARD is proud that research from the FORWARD Databank has been accepted as an oral presentation, two posters, and two abstracts at this year's annual European Alliance of Associations for Rheumatology (EULAR) Congress in Milan, Italy. Below, we've shared the research that was shared with the international rheumatology community this year.

## **Impact of Menopausal Treatments in Functional Decline on Women With Rheumatoid Arthritis (RA)**

Women with rheumatoid arthritis (RA) participating in the FORWARD Databank and using hormonal replacement therapy (HRT) were compared to those not using HRT to see if the therapy had an effect on functional status (an individual's ability to perform normal daily activities). We found that HRT use was associated with modestly better functional status, which means there needs to be additional research into the effects of HRT use on disease activity in RA.

## **Treatment Trajectories in Idiopathic Inflammatory Myopathies (IIM)**

Idiopathic inflammatory myopathies (IIM) are a group of rare diseases in which the hallmark feature is chronic inflammation of skeletal muscle leading to muscle weakness. We looked at participants with IIM in the FORWARD Databank to characterize real-world treatment paths among individuals with IIM. We found that despite published recommendations to combine glucocorticoids (a subgroup of steroids) with methotrexate, azathioprine, or mycophenolate as part of first line treatment for IIM, many individuals were only prescribed the glucocorticoids, meaning that many individuals do not receive the recommended treatment.



## Relationship Between Shared Epitope Status and Refractory Rheumatoid Arthritis (reRA)

Some people with rheumatoid arthritis (RA) do not respond to medications as well as others. Those who do not have reductions in disease activity after trying multiple medications are said to have "refractory" RA. Among FORWARD participants who donated a blood sample to the FORWARD biobank, we looked to see if there was a relationship between having refractory RA (reRA) and a specific genetic marker, the shared epitope (SE). The findings showed that individuals with RA who were SE positive were less likely to be refractory to multiple biologic medications. This suggests that SE positive individuals with RA are more likely to find success with their first biologic medication, while SE negative individuals may be more likely to have to try multiple biologic medications to find success in treating their RA.

## Association of Glucocorticoid Use with Healthcare Utilization among Persons with Systemic Lupus Erythematosus (SLE)

Glucocorticoids (GCs) have been a main treatment for systemic lupus erythematosus (SLE), and while they provide benefit, side effects to these medications have been linked to significantly increased healthcare costs. We looked at participants with SLE in the FORWARD Databank and saw that greater GC use is associated with greater healthcare use.

## Are Changes in Self-Reported NSAID Dose Associated with Meaningful Changes in Pain or Other Health Outcomes in Rheumatic Diseases?

Using data from participants with rheumatoid arthritis (RA) and osteoarthritis (OA) in the FORWARD Databank, we looked to see if nonsteroidal anti-inflammatory drugs (NSAIDs) are associated with changes in pain. We found that any increased NSAID use was significantly associated with increased pain, and to a greater degree in RA than OA.

## FORWARD Psoriasis Registry

FORWARD is excited to announce the FORWARD Psoriasis Registry, launched in June 2023 after three years of planning and discussions with researchers, doctors, and patients.

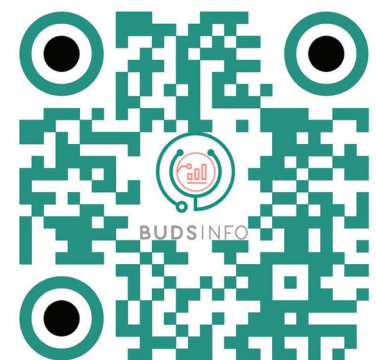
The FORWARD Psoriasis Registry seeks to understand what factors are associated with developing psoriasis or other autoimmune conditions, like psoriatic arthritis. We also want to learn about medications and treatments—why people respond or don't respond to certain ones, how long they are effective for, and the safety of the medications and treatments. This registry will provide researchers and health care providers with the important information they need to improve the understanding and treatment of psoriasis and the many conditions it is associated with.

**Do you have psoriasis, or have a family member or friend with psoriasis? Please consider joining or sharing the FORWARD Psoriasis Registry! Visit [forwarddatabank.org/psoriasis](http://forwarddatabank.org/psoriasis) to learn more.**

## Want to Contribute to Research? Cannabis Study Available.

A team of public health students and researchers created a short survey to better understand experiences with cannabis, cannabis-derived products, hemp and cannabidiol (CBD) products. The data will be used to inform product safety and public health guidance related to legalization. For more information about this project and the students conducting the research or share feedback on the survey tool, please visit [www.budsinfo.com](http://www.budsinfo.com) or email them at [prctrials.info@gmail.com](mailto:prctrials.info@gmail.com)

Please participate in this anonymous cannabis, cannabis-derived, hemp and cannabidiol (CBD) consumer project by scanning the QR code or visiting [budsinfo.com/adverse-event-page](http://budsinfo.com/adverse-event-page).



# Q+A

## Learning About the Importance of Sleep, with Patti Katz, PhD

We sat down with Dr. Katz to learn about important research regarding the connections between poor sleep, rheumatic diseases, and increased symptoms.

**Q** As a researcher and advocate for the patient voice, can you tell us about why you've chosen to study sleep?

**A** "I've always been interested in behavioral modifications and their impact on rheumatic disease and disease activity. Sleep is something that may have a huge impact on disease activity and on how people feel. For example, people who have poor sleep tend to have more pain. The question is: Is that because the pain is causing sleep problems or because sleep problems are causing lower pain thresholds? For many people, both of those things are probably true. Even in the general population, sleep disturbances do result in a lower pain threshold. It's a vicious circle."

**Q** Is this something that is unique to people with rheumatic diseases?

**A** "It may not be unique, but it is consistent across all of the analyses that I've done. In RA, we find a substantial number of people, about half, who are reporting less than seven hours of sleep, on average. For individuals with lupus, we find a substantial number who are reporting six hours or less."

"There are a lot of reasons why people may not be getting enough sleep, whether it be because they're uncomfortable, they're taking a nap during the day, or they just have trouble falling asleep. But whatever the cause is, short sleep has the potential to lower pain thresholds and increase fatigue and

brain fog, which are symptoms that people with rheumatic diseases report."

**Q** What can people do to solve the problems?

**A** "In general, our society undervalues sleep. I think, because of that, it's not given a lot of attention, either by patients who aren't getting enough sleep, and sometimes by their rheumatologists, who are juggling a lot of different needs when they're meeting with their patients. But solving the issue of sleep is difficult. Often, sleep aids don't lead to restorative sleep."

"There are people who specialize in sleep—including cognitive behavioral therapy to help retrain people to go to sleep at night. But the problem is, that sort of thing isn't widely available. Unless you are someone who experiences sleep apnea, which can be helped greatly by a device, I would recommend that you start to consider the things in your life that may be impacting your sleep quality and your sleep habits and trying to improve those aspects."

"I would recommend that patients really focus on getting those eight hours of sleep, or as close to it as they can. If you're napping during the day and not sleeping during the night, try to start weaning yourself off those daytime naps. If you're not walking or getting some sort of exercise every day, start going for a 20 minute walk, which might help improve your sleep."





## 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!

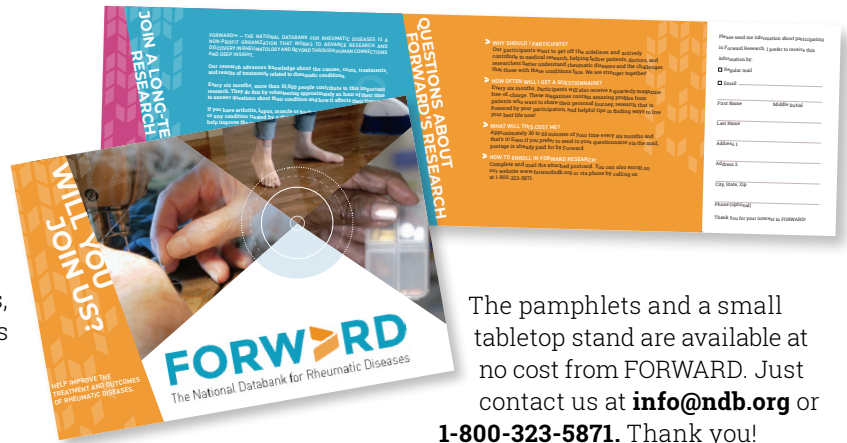
**While working on your questionnaire**, if you have ANY questions, please contact us right away by email (**webquest@ndb.org**) or phone (**1-800-323-5871**). These might be about technical difficulties or how to interpret a question. If you put your immediate questions in the comments section, we probably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

727 N Waco | Suite 200 | Wichita, KS 67203  
Please call 1-800-323-5871 or email [info@ndb.org](mailto:info@ndb.org)

### Directors

Frederick Wolfe, MD  
Kaleb Michaud, PhD

### Executive Director

Rebecca Schumacher, BS

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