SUMMER 2019 NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

The FORWARD Lupus Registry
Learn more on page 8

Dry Eyes? Here’s What You Need to Know
Insights into Your Chronic Illness

SLEEPLESS NIGHTS WITH A RHEUMATIC DISEASE
Letter from the Co-Director

Dear Reader,

Hello, and thanks for picking up the latest edition of FORWARD magazine.

In this issue, we’re excited to share all about the FORWARD Lupus Registry. You’ll hear from Dr. Patricia Katz, the FORWARD Lupus Registry director, about the importance of disease specific questions in our twice-yearly questionnaire, and about the research that she is most passionate about. You’ll also hear from a lupus patient who can give us all insight into the surprising, sometimes frustrating symptoms many lupus patients experience, as well as some of the most common shared experiences of many rheumatic disease patients. We’re also excited to share some great insight and tips to help you beat the heat and get some sleep this summer.

We hope that this issue will inspire you, the individuals who make everything we do possible. Without people like you who are willing to give their time, effort, and energy into answering the FORWARD questionnaires, we would not have the pleasure of adding to and supporting the research and understanding of the diagnosis, treatment, and prevention of rheumatic diseases. To all of our participants: thank you for your support.

Sincerely,
Kaleb Michaud, PhD

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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.

If you would like to learn more, please visit www.LADAinc.org, or find us on Twitter @LADAorg.
Thank You Participants!

To all of our participants, THANK YOU for volunteering your time every six month and sharing your experience and contributing to the research into the diagnoses, treatment, and prevention of rheumatic diseases. Whether you’re a new participant who has only recently filled out their first questionnaire, or whether you’ve been contributing for years, you’re making a difference for all individuals who have a rheumatic disease.

Here is a quick primer on FORWARD for the newcomers. FORWARD is a nonprofit organization that studies rheumatoid arthritis, osteoarthritis, fibromyalgia, lupus, psoriatic arthritis, gout, and other rheumatic diseases. Our research is designed to improve the treatment and outcomes of these conditions.

We are an independent organization that conducts its own research without influence from pharmaceutical, insurance, or financial companies, or other outside interests. Our research is so well respected that we are often hired to provide independent drug safety verification to the government.

FORWARD is unique from other registries, questionnaires, and surveys in that participants report on themselves. Data is not collected by doctors or medical staff. With your patient-reported data, researchers have an opportunity to understand your diagnosis, treatments, side effects, and long-term benefits and risks that may have an impact on future care.

Your privacy is important to us. If you participate in our studies, your personal information will always remain private. We do not sell or share any identifying information about FORWARD participants. By participating, you’ll be helping to improve the treatment and outcome of rheumatic diseases.

Welcome to FORWARD, or thanks again for your continuing participation! If you ever have any questions or need help with your questionnaire, please contact us by email at webquest@ndb.org or call us at 1-800-323-5871.

Unique Study Opportunity for FORWARD PARTICIPANTS AND OTHERS

Are you or someone you know, starting or taking one of the following medications?

+ XELJANZ (TOFACITINIB)
+ ENBREL (ETANERCEPT)
+ HUMIRA (ADALIMUMAB)
+ SIMPONI (GOLIMUMAB)

We have a study using our questionnaire data and a remote electronic Medication Event Monitoring System (MEMS) device to measure medication adherence (taking your medication as directed). The MEMS device is a cap on a medicine bottle that notes the day and time when the cap has been removed and put back on the bottle.

The MEMS device will help give us a different way to view how medications are taken in the real-world and to also see if there are any patient characteristics that are collected in the questionnaires that link to how medications are taken in a real-world setting.

If you, or someone you may know, have started or have recently started one of these medications within the past 6 months and are interested in the study, please contact Betty Pew via email at betty@ndb.org or by calling 1-800-323-5871, ext. 143.

Thank You
DRY EYES AND RHEUMATIC DISEASES

DRY EYES ARE a common annoyance, whether it be from allergies, certain medications, or even a long night with little sleep. You might be dealing with burning, itchy eyes, blurred vision, or extra sensitivity to light. Even though these symptoms can be bothersome, for many people, they’ll go away within a couple of days or with over-the-counter eye drops. However, if you have a rheumatic condition, this small irritation may be a symptom of a much larger problem.

You already know that your rheumatic condition causes inflammation that results in achy joints and pain throughout your body. But did you know that it can also cause inflammation in your eyes? If this happens to you, the only symptom to alert you might be dry eyes. If you experience dry eyes, don’t start with over-the-counter treatments—tell your doctor and get a comprehensive eye exam.

Why does the same inflammation that makes your joints ache cause dry eyes? Essentially, your normal tear production will be inhibited, meaning that your cornea doesn’t receive the moisture and nutrients it normally receives from your tears. While over-the-counter medicines may help relieve this symptom, you’ll most likely need additional treatment.

These treatments may come in the form of anti-inflammatory eye drops, eye inserts that will create artificial tears, special contact lenses, or even autologous blood serum drops, which use a sample of your own blood to add nutrients similar to those found in your own tears. Whatever treatment you end up with, it’s important that you and your doctor decide the best course of treatment before your irritating dry eyes become a much bigger problem.

How to Minimize Fall Risks

According to the Center for Disease Control and Prevention, 1 out of 5 falls causes a serious injury. Even if you have good mobility, it’s always good to be proactive about avoiding fall risks. Instead of worrying constantly about avoiding situations that could cause you to fall, try these simple fall-prevention tips and tricks instead:

Talk to Your Doctor: When it comes to your rheumatic disease, your doctor should always be your first line of defense. Review your fall history, current medications, and health conditions and symptoms.

Ask for Help: Sometimes, you’ll need something extra to help you stay steady. Whether that’s a helping hand, a cane, a raised toilet seat, or a grab bar in your tub, don’t hesitate to find what you need and make use of it.

Pay Attention to Your Feet: Make sure you’re wearing sturdy, non-slip shoes at all times. Not only can a pair of well-fitted shoes keep you upright, they can also help reduce joint pain.

Pick Up and Prepare: Pay attention the next time you walk around your home. What could you easily trip over or slip on? Pick it up and put it in an out-of-the-way yet easily accessible spot instead. Also, be sure to secure easily movable rugs with slip-resistant backing.

Don’t Stop Moving: Staying active is a great way to keep your muscles strong and improve your balance. Your doctor may recommend gentle physical exercise, a carefully monitored program, or refer you to a physical therapist.

Want to learn more? The Arthritis Foundation has lots of helpful information about preventing falls, protecting your eyes, and rheumatic diseases. Visit www.arthritis.org/living-with-arthritis to learn more.

*www.cdc.gov/homeandrecreationsafety/falls/adultfalls.html
SLEEP ON IT

HOW RHEUMATIC DISEASES AFFECT SLEEP
FOR ALMOST ALL RHEUMATIC DISEASES, tossing and turning at night is a common occurrence. Learn more about what this means, why this happens, and what you can do about it.

We all know that sleep is incredibly important, but when you have a rheumatic disease, it becomes even more important. A well-rested body is better equipped to manage stress, fight common illnesses, and possibly limit flares. When you are not getting enough sleep, your body may be more fatigued and not be as capable at reducing and managing pain.

There are many different causes of sleep issues, according to Dr. Patricia Katz, Director of the FORWARD Lupus Registry. “There’s a general poor sleep cycle, during which people are waking up throughout the night, called sleep fragmentation. There is also a pain aspect that keeps people awake—which is no surprise when you think about how severe pain can be sometimes for rheumatic disease patients—or pain that wakes you up whenever you move in the night. Medications are also a concern, particularly steroids, like prednisone.” Sometimes, insomnia can be caused by anxiety or worry, which may be the result of a new diagnosis, an uncertain future, or concerns about maintaining your day-to-day activities.

When it comes down to it, the best thing you can do is talk to your doctor. By addressing potential medications that might be causing sleep issues, learning ways to handle anxiety or worry, or figuring out how to better manage your pain, you can take the steps necessary, both in and out of the doctor’s office, to improve your sleep.

Obstructive Sleep Apnea

If your head is hitting the pillow early, and you don’t notice long bouts of being awake during the night, you might not understand why you’re so tired all of the time. If you’re constantly fighting daytime drowsiness, ask your bed partner... “Do I snore?”

“Obstructive sleep apnea does appear to potentially be more common in lupus and RA patients,” says Dr. Katz. Commonly referred to as sleep apnea, this condition causes a lack of oxygen in the bloodstream because the patient will stop breathing for 10 or more seconds at a time throughout the night. Even if you don’t realize it, you may be waking up multiple times throughout the night if you have this condition.

Symptoms to look out for include severe snoring, pauses in the breath, and snorting in your sleep. The connection between sleep apnea and rheumatic diseases requires more research, but, if you are experiencing some of the symptoms, it may be worth talking to your doctor about, as the condition is treatable.

Want to learn more about the FORWARD Lupus Registry and read about one FORWARD participant’s experience with lupus? Turn to page 8.
TRYING TO GET BETTER REST?

Daytime Tips

TAKE IT EASY
A lack of quality sleep, combined with your usual aches and pains, can make any activity more difficult than usual. Instead of always pushing through it, give yourself plenty of time to accomplish tasks and reward yourself for a job well done.

STICK TO A SCHEDULE
It’s easier for your brain and body to adjust to your resting hours if they know what to expect. If possible, stick to a similar sleeping and waking schedule every day (even on weekends!).

Nighttime Tips

MAKE THE MOST OF YOUR PILLOW
Based on your sleeping position, try placing a pillow between your knees, in the small of your back, or even underneath your stomach to relieve common pressure points and ease some of your aches and pains.

WATCH THE TEMPERATURE
While most people sleep better in a cool room, you want to make sure your feet, hands, and head aren’t too cold. Pull on some socks and adjust the thermostat, or take a hot bath right before bed.

Bonus: the hot bath might even serve to help soothe some of your aches and pains!

CUT THE CAFFEINE
Avoid stimulants, like caffeine, energy, exercise, and bright lights before you head to bed. It is suggested to avoid caffeine after 4 or 5pm, and limit alcohol consumption, which can negatively impact your sleep.

MOVE WHEN YOU CAN
Try to incorporate physical activity into your daily life. People who are physically active tend to have better sleep.

WANT SOME MORE TIPS TO HELP IMPROVE YOUR SLEEP? CHECK OUT THIS GREAT ARTICLE: WWW.MEDICALNEWSTODAY.COM/ARTICLES/323053
The FORWARD Lupus Registry

When it comes to different rheumatic diseases, it’s easy to oversimplify the similarities between them. Think of some of the main symptoms—pain and fatigue—that are almost universally experienced by individuals with a rheumatic disease. When you think about those symptoms, it’s clear why so many people lump all rheumatic diseases into the same pot. Here at FORWARD, we have heard from many of our participants about how important they feel it is to represent all rheumatic diseases—and the unique symptoms and challenges they present—in the FORWARD magazine, questionnaire, and research done with the Databank.

Meet Dr. Patricia Katz, Director of the FORWARD Lupus Registry. As a Professor of Medicine at University of California San Francisco and researcher who focuses on lupus and rheumatoid arthritis, Dr. Katz knows first-hand how important it is to understand "the unique aspects of lupus" that are different from other rheumatic diseases.

**On the FORWARD Lupus Registry:**
Dr. Katz joined the FORWARD team about five years ago. Based on her previous experience and research about lupus, "it was clear that we needed to make some changes to the questionnaire to reflect the unique aspects of lupus that had not really been covered before," she said. Now, Dr. Katz spends much of her time with FORWARD ensuring that the questionnaire accurately represents the experience of lupus patients.

**On the importance of the patient voice and agency:**
When asked where she finds the most value in her work, this is what Dr. Katz had to say: "It’s about two things, really. One is making sure that the voice of the person with lupus is heard. And we do that primarily by making sure that patient-reported outcomes are included in the questionnaires. Often, that’s through questions about symptoms, but it can also be about other quality of life issues.

The other thing that I’m really passionate about is looking at self-management. There are things that people can do to improve their health, perhaps, improve their condition and definitely improve their quality of life through behavioral changes. I think this gives people some options other than just medications."

When this writer suggested that self-management could provide some sense of “control” in the patient’s life, Dr. Katz was quick to correct: "It’s more about the sense of agency, which refers to the feeling of control over actions and their consequences, than control. In research, it’s unclear to what degree lifestyle changes can affect symptoms or the disease itself... but even so, a sense of agency lets patients know that they’re doing everything that they can. This is an area of research that I hope to spend more time in—how lifestyle changes can impact disease activity and symptoms, because there are reasons to think that they may."

**On her Lupus research:**
"We have recently been looking at some new types of patient-reported outcomes so that we can really expand what we’re asking people about. That’s been pretty successful. We’ve also done some preliminary research on sleep and lupus. I think that is going to be a really interesting thing to follow up on, now that we know who was reporting sleep problems [in the questionnaire] two years ago and see how those sleep problems may be impacting their disease and symptoms today. People with lupus are often on steroids, and steroids are known to disturb sleep, so we’re trying to learn how that affects the overall quality of life of the individual. It’s a really complicated picture, so we’re hoping to use the data from FORWARD to start teasing out some of those answers."
Quick Questionnaire Q’s

Have questions about the FORWARD questionnaire? Here, Dr. Katz shares her insight into some of the most common queries we receive:

Q: Does every participant answer the same questions, or do Lupus patients have different questions?
A: There is a specific questionnaire that is sent to people that identify as having lupus, and on that questionnaire, there are lupus-specific measures. These measures are about the disease and symptoms that are specific to lupus. There are also scales to measure disease activity and what kind of long-term effects the disease may have as people go through their lives with the condition.

Q: What are some of the different symptoms explored by the Lupus questionnaire?
A: A lot of lupus patients, unlike other rheumatic disease patients, experience skin issues and kidney issues. Before we updated the questionnaire, these specific symptoms—and the effect they may have on disease progression and quality of life—weren’t really represented.

Q: How often is the questionnaire updated?
A: While it’s important to ensure that the questionnaire questions have longevity (i.e., the same question is asked during every questionnaire to see how things change over time), it’s also important to make sure that the questionnaire is giving researchers the information they need. We do look at responses from previous questionnaires to see if anything stands out that shows us that perhaps we don’t have the right questions, or we aren’t asking the question correctly to get the information that we need.

On the value of the FORWARD participants:
“Having a large data set with lots of information from lots of different patients is very important when you’re trying to understand complicated questions. That’s the value of FORWARD, because we hope to have enough people enroll that we can sort out some of these issues. With a small data set that you would get at a single clinic or institution, it’s hard to have enough people to really look at. We’re always trying to increase the number of people that participate in FORWARD, so that we can address some of these really complex issues.”
Meet Elizabeth B., who was diagnosed with lupus in 1990 at age 60. Read on to learn more about Elizabeth’s experience with strange symptoms and lifestyle changes—and her best advice for people with a chronic illness.

The Diagnosis Process
Elizabeth is no stranger to the confusion and difficulty that accompanies the diagnosis process for many individuals with rheumatic diseases. She began experiencing problems when she was 28: “I would get different symptoms, but I was young and healthy and active, so they wouldn’t be chronic. But, over time, the symptoms increased, and I would get strange infections that would take up to a year to heal.”

Even after being diagnosed with arthritis, as Elizabeth got older, “stranger and stranger things kept happening. I would get blisters just from sitting in my kitchen near the window or from fluorescent lights.”

Constant Adjustments
"Mostly, when something happens, we just have to treat that thing," says Elizabeth. "We don’t say, ‘Oh, she’s a lupus patient, she has arthritis…’ It’s all about the symptoms or the new issue that I’m dealing with. A certain medication was working really well for me, my miracle medication, but I had to go off of it because I developed macular degeneration, so it was really a loss for me. We’ve tried to find something else that will help."

Lifestyle Changes
Like many individuals with rheumatic diseases, Elizabeth is no stranger to adjusting her day-to-day activities to accommodate for her illness. Some are common and expected, like giving herself plenty of time to accomplish tasks when she’s not feeling well. "I try to pay attention to my tiredness, and I’m lucky because I don’t work and my husband helps with the housework, so I can take my time to get something done," she says. "I’ve had to give up a lot of my activities, which I hate. I used to be very active—rode my bicycle every day, mowed the lawn, did yard work, played badminton. Now, I can go out for maybe twenty minutes and do a little bit of yard work."

When asked about how she deals with the chronic pain, constant fatigue, and unexpected symptoms of her disease, Elizabeth shared, “The biggest thing you can do is just try to be patient and try to be positive. Be positive, be willing to listen to your doctors, have friends that you can talk to, and, if you need help, ask for it.”

Want to share your story with FORWARD, and potentially be featured in FORWARD magazine?
Send an email to jacob@ndb.org!
Random Drawing Information

FORWARD CONDUCTS RANDOM DRAWINGS as a token of our gratitude in help with rheumatology research. 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 any-time within six months for the current questionnaire.

Important Information About Email

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 whenever you change your email address. To update your email address, go to our website and click “Update Contact Info” under the “Participants” tab. Of course, you can always email or call us, and we will change it for you. Thank you!

Important Information
Helping FORWARD in Other Ways

Achieving FORWARD’s goal of telling the rheumatology community about patient experience requires a large group of participants. Pamphlets are available for 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 free 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 the Databank. Just give us your friend’s email address and we’ll send out an email invitation to join the study. Go to forwardndb.org/participate/tell-friend.

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. So before you decide to not participate, please let us know what we can do either 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

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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, follow the links from our home page, forwardndb.org, and make the request, or send us an email at webquest@ndb.org.