


Rheumatic Diseases

AT ANY AGE:

Psoriasis and
Psoriatic Arthritis

**Keep Moving,
Even with Your
Rheumatic
Disease**

**The Research
You Support**

Learn more
on page 8 



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Join Us on Facebook & Twitter or X

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 or X, but not on Facebook, we will be tweeting news items as **@ndb_org**.



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



@ndb_org



Letter from the Director

Hi there—thank you for picking up this issue of FORWARD magazine. I hope that you are enjoying the summer season and that you will find this issue to be both engaging and educational. You'll see that we've chosen to share the stories of FORWARD participants throughout different stages of life, with different rheumatic diseases and conditions, who are all managing their illness as best they can.

We wanted to highlight how these conditions can impact people of any age. As I've written to you before, I was first diagnosed with "juvenile rheumatoid arthritis" at age 3, and I know some participants who were newly diagnosed

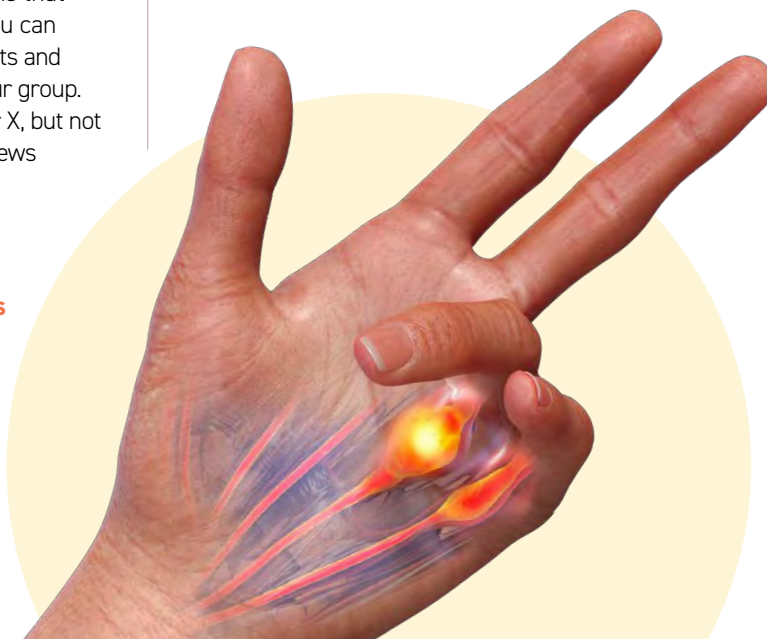
with lupus and gout in their 80s. We also wanted to share important and exciting information about the FORWARD Psoriasis Registry, one of our fastest-growing national registries. Understanding psoriasis and psoriatic arthritis is an incredibly important research topic that will allow doctors and researchers to improve prevention, treatment, and management of these conditions, that can cause pain, embarrassment, and frustration for those who experience them.

Finally, you'll see that we've included updates on each of the FORWARD registries and the important research going on with the information that you, FORWARD participants, provide. Thank you for your contributions!

Sincerely,
Kaleb Michaud, PhD
Director, FORWARD

Non-Profit Spotlight

Dupuytren disease is a unique illness that can cause an individual's fingers to stay bent inwards, making everyday tasks difficult.



Want to learn more about Dupuytren disease, the ongoing efforts to find a cure, and what the risk factors are? The Dupuytren Research Group is performing groundbreaking research and have information to share with you.

Visit dupuytren.org to learn more.



Thank You

TO OUR PARTICIPANTS

The FORWARD team would like to extend a big 'Thank You' to all of the participants willing to share their experiences and fill out the biannual questionnaire for the FORWARD databank, as well as those who participate in the specialty databanks and registries. As you'll see in the Research Highlight on page 8, your efforts are supporting important research that aims to better understand, diagnose, treat, and prevent autoimmune and rheumatic diseases.

We understand that filling out the questionnaires takes time and energy and can be a difficult task for many participants who are dealing with symptoms of pain, stiffness, fatigue, or brain fog. If you have difficulty, please

reach out to the FORWARD team at (316) 263-2125. There are multiple ways to participate in FORWARD, including paper questionnaires, a web-based questionnaire, and phone-based questionnaires in which a FORWARD team member will share questions with you over the phone and fill out the form for you.

Your continued participation is very important, as having information about your experiences over a long period of time provides researchers with very valuable insight into the long-term impact of your condition, medications and other treatments, and symptoms. Once again, thank you so much for your participation!

To join FORWARD, visit forwarddatabank.org/join-forward 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 or call **1-800-323-5871** today!

Don't Hold Back

"Many years have been spent trying to find answers, however rheumatoid arthritis remains a mysterious autoimmune disease with no cure in sight," shares Patricia, a FORWARD participant.



As one of the most common rheumatic diseases, affecting over 1.3 million adults* in the US, rheumatoid arthritis (RA) has a significant impact on the day-to-day lives of many FORWARD participants and readers.

"During the first seven years after my diagnosis, two rheumatologists informed me that my immune system was working overtime ... [they] prescribed various meds as well as physical therapy and acupuncture," says Patricia. "I tried a few folk remedies ... but nothing worked." Throughout the years, Patricia, with the support of her doctors, managed her symptoms and illness in a variety of ways, including switching careers to better support her needs, trying a variety of medications, and constantly adjusting her lifestyle to help better manage her pain and issues with mobility.

In 2006, Patricia told her doctor about the limited mobility she had started to experience: "I could not raise my hands to feed myself or comb my hair. My doctor recommended a drug research study. I felt miraculously well within a month and could move again."

Throughout her life, Patricia hasn't let herself be held back by her illness. She shares, "I knew I could be productive as long as I was sitting down." While building a thriving business selling hand-sewn baby blankets, pursuing a new career in tax preparation, and teaching others the skill of wool embroidery, Patricia managed her symptoms as best she could at the time and didn't let her illness prevent her from living her life to the fullest. Even now, she shares, "A wonderful church and ... classes keep me connected with some terrific people, and I continue preparing the monthly newsletter for my local garden club. Recently, I rejoined a local Panhellenic group that gives scholarships to OC girls, and I'm not done yet!"

*Data collected by the National Health and Nutrition Examination Survey (NHANES) and the National Health Interview Survey (NHIS).

Managing Pain, in the Long-Term

Understanding how your pain levels may have changed over time is a valuable tool when talking to your doctor or considering other lifestyle adjustments to better support your needs. You can track pain levels in a notebook, on the computer, or on your phone.

When making note of your pain, consider these tips:

- » If your pain levels change throughout the day, make note of how you feel morning, noon, and night.
- » Use a consistent scale that works for you, like 0-10, to rate your pain.
- » Make note of any changes that may affect your pain, like a bad night of sleep or new or additional exercise in your routine.



Below the Skin:

PSORIASIS AND PSORIATIC ARTHRITIS

Many people assume that any form of arthritis is an old person's disease—but many people begin experiencing these conditions at a much younger age. For one FORWARD participant, their journey with psoriasis and psoriatic arthritis started as early as high school. ➤



At just under 30 years old, John already has a long history with dermatologists and rheumatologists. John shares, “I was first diagnosed with topical psoriasis in high school. I have seen three different dermatologists since then with various treatment [efforts] as my psoriasis got worse over the years. I have tried creams, pills, and light therapy—some worked for a short amount of time but couldn’t keep up as my topical psoriasis got worse.”

According to the Mayo Clinic, having psoriasis—an inflammatory skin condition that can lead to scaly rashes on the skin—is the biggest risk factor for developing psoriatic arthritis. Psoriasis, on its own, can range from mild to severe, with people like John experiencing significant impacts on their day-to-day lives due to the symptoms. Psoriatic arthritis is a type of rheumatic disease that causes people with psoriasis to experience other inflammatory issues throughout their body, including painful and swollen joints, back pain, eye inflammation, or foot pain. Like psoriasis, the symptoms of psoriatic arthritis can range from mild to severe.

Getting Ahead of Psoriatic Arthritis

Understanding the progression from psoriasis to psoriatic arthritis is very important to researchers who are developing tests, treatments, and preventative measures for people who have, or are at risk for, psoriatic arthritis. Without understanding how psoriasis and psoriatic arthritis are connected, researchers cannot prevent psoriatic arthritis from developing in individuals with psoriasis. Unless they can see how psoriasis and psoriatic arthritis respond, long-term, to certain treatments or medications, researchers cannot refine those treatments and medications to better support people with psoriasis. Finally, identifying indicators that let doctors know if an individual with psoriasis is more or less likely to develop psoriatic arthritis will ensure that doctors can come up with a prevention and treatment plan early.

These are just some of the reasons why it is so valuable for people with psoriasis to participate in the FORWARD Psoriasis Registry. Following people with psoriasis long-term can give FORWARD and other researchers a good look at all stages of the disease, including the progression to psoriatic arthritis.

To learn more about the FORWARD Psoriasis Registry, turn to page 8 or visit www.forwarddatabank.org/psoriasis-registry.

"In 2018, I started feeling the effects of what I ultimately came to learn was psoriatic arthritis," John says. "For most of a year, I was confused why I struggled to get out of bed in the morning and participate in routine activities, and couldn't participate in sports at all—especially as someone in my mid-20's. Eventually, my dermatologist diagnosed me with psoriatic arthritis."

Once connected to a rheumatologist, John tried multiple treatment options to get his psoriasis and psoriatic arthritis under control. Over the years, he and his doctors have developed a treatment and lifestyle plan that works for him. In addition to starting a systemic treatment, John occasionally uses an over the counter medication when he has a flare up from pushing his body too hard and has adjusted his diet to be one of mostly "fruits, vegetables, and limited protein."

Even though John now has his symptoms under control, he participates in the FORWARD Psoriasis Registry to contribute to research about psoriasis and psoriatic arthritis. He shares, "Outside of psoriatic arthritis, which I would say is largely under control now thanks to my treatment plan and new lifestyle changes, I would consider myself very healthy. I don't have any other issues and do not get treated for anything else. No one in either side of my family has ever had psoriasis or psoriatic arthritis, so I'm always intrigued by why I got it. Anything I can do to give back or be a very small part of ultimately finding a cure for this disease would be very rewarding."

You're Not Alone: Stories from FORWARD Psoriasis Registry Participants

"I suffered through 32 years of being embarrassed by the red, scaly blotches from neck to ankle and the constant white flakes from my scalp. It dictated what I wore at all times. Suffering in slacks in the heat and sunshine. In the workplace, friends would brush the scalp flakes off my shoulders. Appreciated, but embarrassing."

"It took forever for the doctors to connect my psoriasis with my arthritis and my digestive system issues, which have worsened within the last two years."

"33 years of this, and I'm tired. I still exercise to the best of my ability daily. I have, in the past two years, had six surgeries. My skin is at its worst in the summer, which will cover around 85%+ of my body. Yes, this is depressing and yes, it affects how I dress and feel when I am out in public."

"My psoriasis was diagnosed this year after I got a biopsy. The worst part of my body is the backs of my ears, which has both plaque and inverse psoriasis. I have been testing medications for almost two full years with no huge results."

"I feel like it worsens with additional stress. My job is demanding, and it takes all my strength to perform my job, so I do not have energy to maintain house or have a social life."

"My skin was clear for 20 years, then came back about two years ago. I coat my feet with Vaseline or Aquaphor and wear socks and cotton gloves to bed. I use a sunbed two to three times a week. My hands and feet itch and burn."



FORWARD RESEARCH: In Use

There are some exciting things happening with the FORWARD databank and registries. Read on to learn about the important research that your participation is supporting.

The FORWARD Psoriasis Registry

Alexis Ogdie, MD, and Joel Gelfand, MD, co-directors of the FORWARD Psoriasis Registry, presented the first research abstract* produced by the registry at the Society for Investigative Dermatology (SID) in May of 2024. The abstract, shared with other rheumatologists, dermatologists, physicians, and researchers interested in the diagnosis, treatment, and prevention of skin diseases, reported important information learned from 702 participants in the Psoriasis Registry.

Some important statistics learned from participants:

- 27% have psoriatic arthritis (PsA)
- 62% use topicals (creams, lotions, etc.) for their symptoms
- 23% are “very dissatisfied” with their treatment
- 6% are “very satisfied” with their treatment

Prior to the launch of the Psoriasis Registry, Dr. Gelfand shared, “This is a new and exciting initiative—over time the Psoriasis Databank 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.”

The Psoriasis Registry is accepting new participants—if you have psoriasis or psoriatic arthritis, please consider joining! It's easy to participate, and the information that you provide could play a major role in improving the diagnosis, treatment, and prevention of these diseases.

To learn more, visit www.forwarddatabank.org/psoriasis-registry.

*Ogdie A, Gelfand J, N'Dri L, Wu Y, Scharnitz T, Michaud K. Treatments used among patients with psoriasis: a first look at a novel patient-centered psoriasis registry. Poster presented at: The Society for Investigative Dermatology; May 15-18, 2024; Dallas, TX.

Identifying and Predicting Flares in Rheumatoid Arthritis

Many people with a chronic illness know that a flare is a period of time in which already unpleasant symptoms intensify or get worse. For individuals with rheumatoid arthritis, a flare may mean increased pain and stiffness, and more difficulty going about one's day-to-day activities.

Research using the FORWARD databank* was presented at the European Alliance of Associations for Rheumatology (EULAR) 2024 annual meeting. This research aimed to improve researchers' ability to identify, and possibly predict, flares. This is important for people with RA whose quality of life is impacted by flares.

Researchers believe that there may be ways to monitor symptoms and predict when a flare is coming, without ever stepping into a doctor's office. Participants agreed to have passive data collected using a smartphone—which

means that the information was taken directly from their phone, rather than reported by the participants—including mobility distance, number of calls or text messages, length of calls, and the number of missed calls. This data was then compared to information that participants provided about any flares they experienced.

Researchers found that shorter, or less texting, and less mobility (specifically, moving less distance than usual) were associated with higher odds of having a flare. This information is important—it can help researchers who are trying to identify how to predict when a flare is coming, which could help physicians better treat or help people with RA prevent a flare.

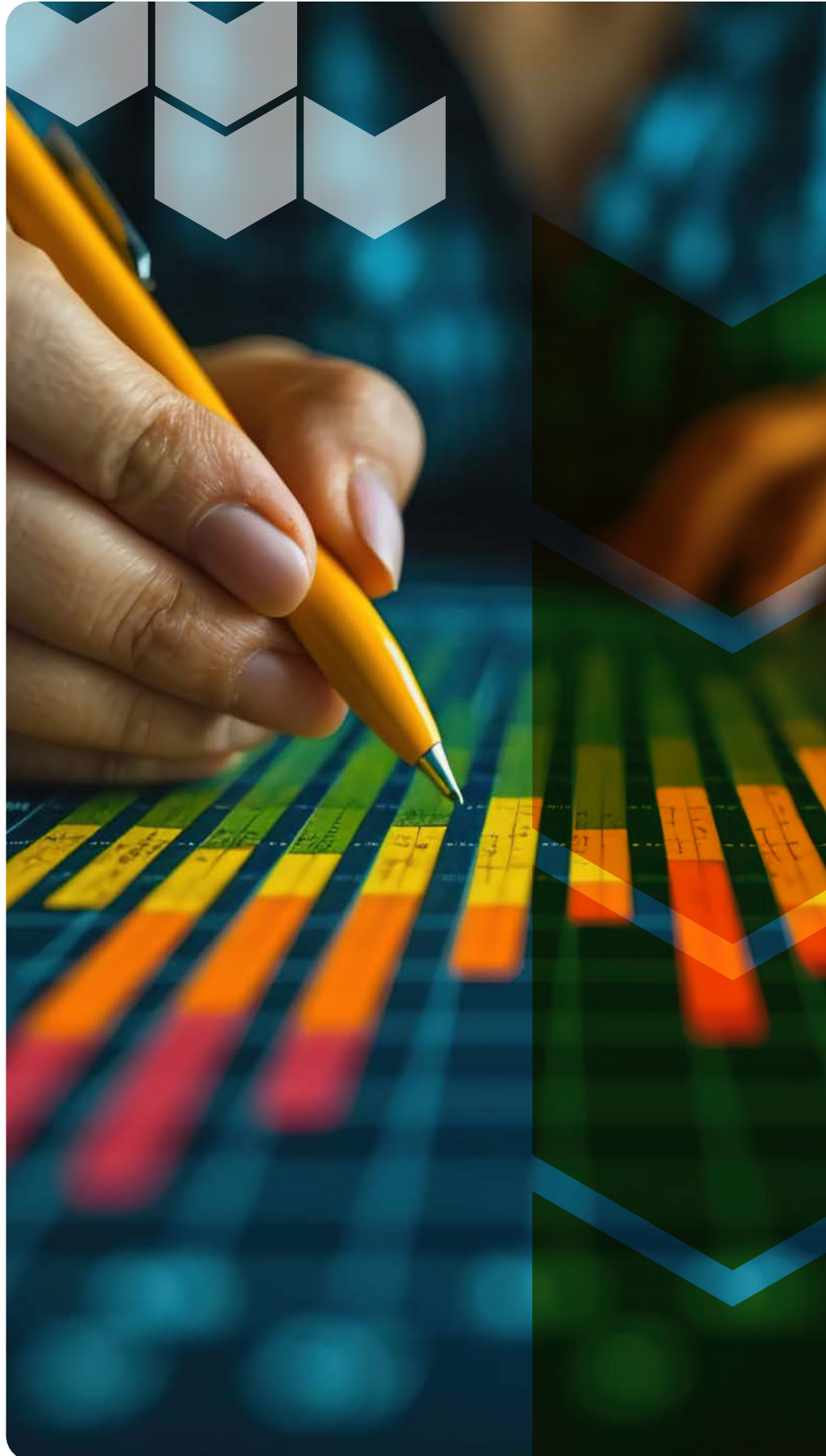
*Pedro S, Mollard E, Michaud K. Smart-phone-based behavioral monitoring of rheumatoid arthritis flares. Poster presented at: EULAR; June 12-15, 2024; Vienna, Austria.

Brain Fog in Lupus, Compared to Other Rheumatic Diseases

One common symptom of systemic lupus erythematosus (SLE) is “brain fog” or forgetfulness. Research using the data collected from the FORWARD Lupus Databank* was presented at the EULAR 2024 meeting and explored how older people with SLE experienced cognitive symptoms when compared to older people with rheumatoid arthritis (RA), osteoarthritis (OA), and fibromyalgia.

The research uncovered that older people with lupus have much worse cognitive symptoms compared to older people with other conditions. This is connected with worse lupus symptoms overall, worse health overall, and, importantly, worse social and role functioning. Understanding the burden of symptoms—the impact on an individual’s quality of life, day-to-day—is an important part of developing appropriate treatments.

*Katz P, Pedro S, Michaud K. Self-reported cognitive function among older adults with systemic lupus erythematosus compared to other rheumatic and musculoskeletal conditions. Poster presented at: EULAR; June 12-15, 2024; Vienna, Austria.



Maintaining Mobility and Independence: The Story of One FORWARD Participant

Like many people, the first indication that Linda had osteoarthritis were her aching knees. "Participating in any school or scout events was troubling," Linda shares. "Doing one day led to not being able to walk the next. I missed many family festivities because I hurt too much."

After being diagnosed in her 40's, Linda was told by her diagnosing provider that surgery wasn't an option until she lost a significant amount of weight and reached 60 years of age. "That meant a lot of years of taking pain killers, but after a few years I had to give up after having an allergic reaction to the drug that was actually working."

This led Linda to finding a doctor who aligned better with what she was looking for in a provider. "My advice would be to trust and like the doctor that you are seeing. I still see the second doctor that I found, and I recommend him to my friends and family always," shares Linda. "He first listed all of the possible treatments: more drugs, exercises and physical therapy to strengthen muscles, shots in my knees, and knee replacement surgery. He had me list them in the order that I wanted to do them and explained that my plan would be followed so that I never felt like saying, 'I wish we had tried that first.'"

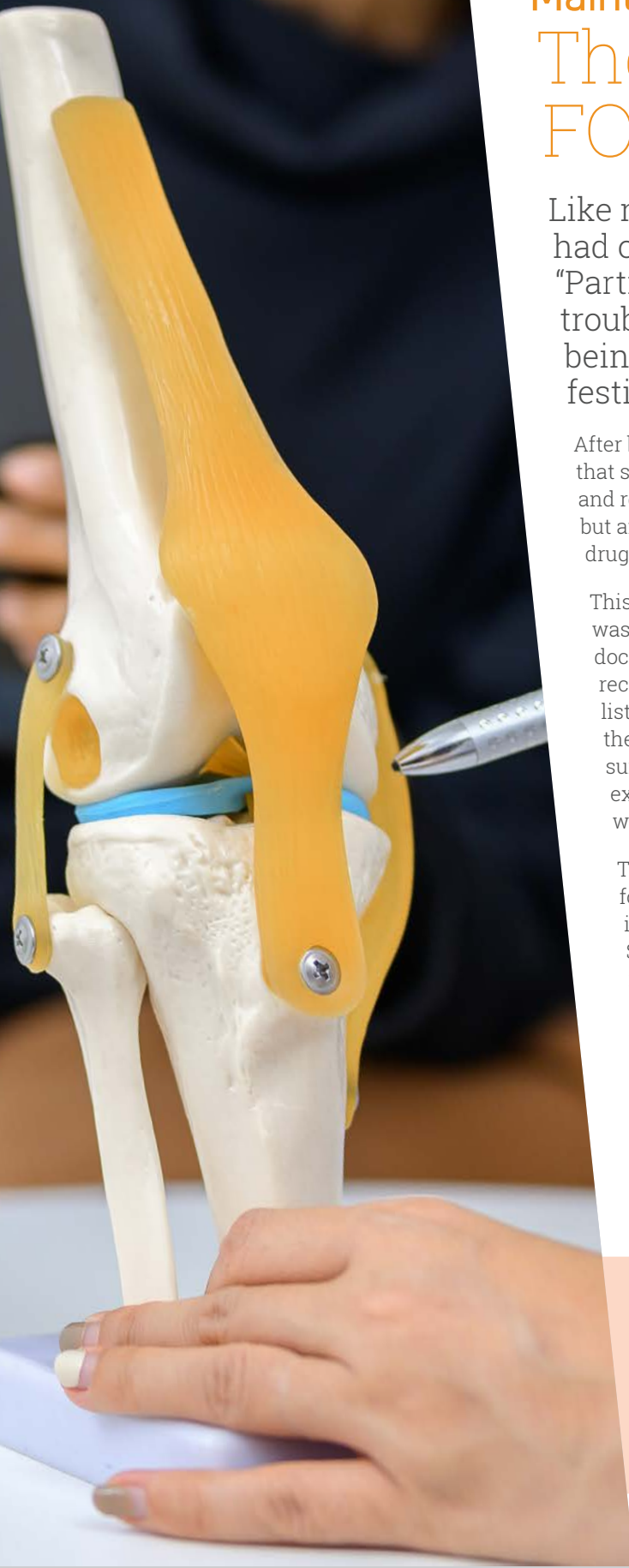
Together, Linda and her provider followed a treatment plan that worked for her until she reached the age of 59, and it became clear that less-invasive treatments were no longer effective to manage her pain. Supporting her own mobility is a priority for Linda. "Mobility is an issue as we age and is so important to remaining independent," says Linda. There was "a trip to Ohio, where the first thing I had to do was buy a cane so I could get around. So, in 2008 and 2009, I had knee replacement surgeries. Both successful."

Thanks to these surgeries, Linda found her step and continues to explore. "Our family is currently planning a trip to Minnesota to find the 'troll' statues," shares Linda, excited about exploring a unique art installation in the woods around Detroit Lakes in Minnesota. "Many years ago, I'm not sure I would have been able to do that!"

"I have found it rewarding to check the graphs of my history and see how my mobility has improved."

—Linda, FORWARD Participant

Participants in the FORWARD questionnaires are provided with reports that show their progress over time, tracking common symptoms and allowing participants, and their doctors, to easily see how things have changed throughout the years.





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!

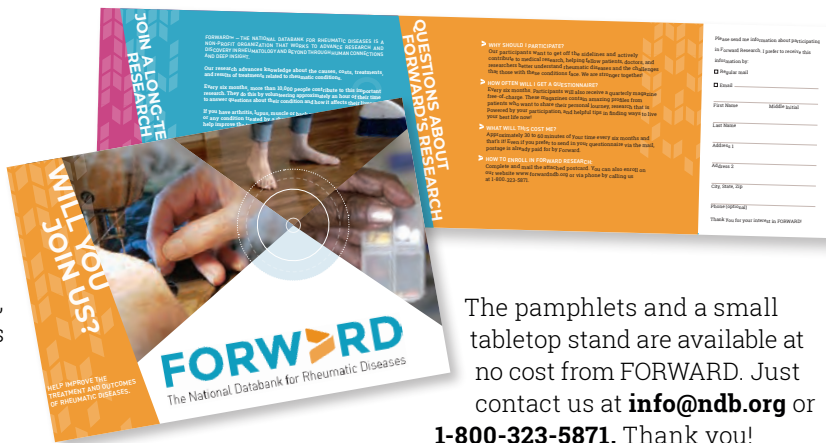
While working on your questionnaire, if you have ANY questions, please contact us right away by email (**webquest@ndb.org**) or phone (**1-800-323-5871**). These might be about technical difficulties or how to interpret a question. If you put your immediate questions in the comments section, we probably 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 forwarddatabase.org/tell-a-friend](http://forwarddatabase.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 11 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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