

FORWARD

WINTER
2022

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES



MAKING A DIFFERENCE:

**Your Impact
on Rheumatic
Disease Research**

Learn more
on page 8 ➤

Simple Steps
to Feel Better

*Find Your
Sun*

Preventing Extra Pain
During the Coldest Months



Letter from the Co-Director

Hello, and welcome to the first issue of FORWARD magazine in 2022. We, like many of you, are excited to begin a new year and hope that you will enjoy both reflecting on the past year and looking FORWARD to the new year in this issue.

You'll see that we have spent much of 2021 participating in rheumatology diagnosis, treatment, and prevention research, along with rheumatologists, scientists, and members of the academic community. We are grateful to our participants who made this research a possibility! We are also excited to share future research opportunities that FORWARD is creating to improve health and well-being research across multiple fields of study.

We hope that you will find our deep dive into the impact of winter on rheumatic conditions helpful, and that you will try some of the tips we have found helpful.

2021 has been quite a year—for FORWARD, for the rheumatology community, and we're sure, for you. To all of our participants: thank you for your continued support.

Sincerely,

Kaleb Michaud, PhD
Co-Director, FORWARD

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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**

JOIN FORWARD

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



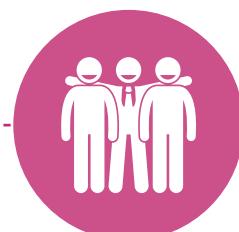
TO HELP OTHERS.

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-forward or call 1-800-323-5871 today!



thank you **TO OUR PARTICIPANTS**

FORWARD relies on the participation of individuals like you to make a difference. Every person who chooses to fill out our bi-annual questionnaire makes their voice heard and their experience known to the researchers and rheumatologists seeking to improve the diagnosis, treatment, and prevention of rheumatic diseases and conditions.

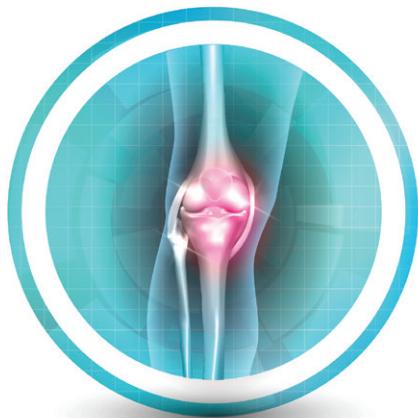
Along with the rest of the rheumatology community, FORWARD has spent much of 2021 concerned about the impact of COVID-19 on individuals with rheumatic diseases and conditions. That's why we'd like to share a very big THANK YOU to the individuals who have participated in our additional 'mini-questionnaires' specifically targeted towards understanding COVID-19 and the way it affects individuals with rheumatic conditions and their treatments and symptoms.

Additionally, many of you have chosen to participate in the Arthritis Internet Registry (AIR) by providing blood samples, allowing the FORWARD team to make incredible progress on a project that dives deep into the impact of an individual's genetic makeup on their risk of being diagnosed with rheumatoid arthritis (RA) and the potential seriousness of the disease. Thanks to your participation, we have also been able to begin researching the impact that one's genetics may have on the efficacy of different medications, which we hope will help improve future rheumatology treatment.

Thank you again to all FORWARD participants, our COVID-19 questionnaire participants, and to our AIR participants who provided blood samples and made these projects possible—it could not have happened without you!

To learn more about FORWARD research regarding COVID-19, turn to page 8.





The Many Types of Rheumatic Disease

There are more than 100 types of rheumatic diseases, which can be quite confusing for you as a patient. Let's clear things up by looking at ways they are connected.

Rheumatism & Arthritis

Rheumatism and arthritis are both umbrella terms that simply refer to joint pain and inflammation.

Autoimmune Disease

Some rheumatic diseases are autoimmune diseases, meaning your immune system mistakenly attacks your body's tissues. In the case of rheumatoid arthritis, the tissues that form the lining of your joints are attacked.

Symptoms

Inflammation, stiffness, pain, and swelling of the joints are all common symptoms of rheumatic disease. However, some types of rheumatic diseases can also affect your skin, heart, eyes, lungs, and kidneys.

Flares

Rheumatic disease symptoms often come and go, alternating periods of increased or decreased activity. A 'flare' is when a patient is suffering from increased activity (more inflammation).

Diagnosis

A doctor's visit is needed if you are experiencing symptoms such as aches, pains, and/or swelling of your joints for more than a few days, especially if it is affecting your everyday quality of life. Your physician will examine your symptoms, family history, and perform a physical exam, often leading to an imaging test such as an x-ray or MRI. Your physician may then refer you to a rheumatologist.

Keep it Simple: Managing Your Chronic Illness

Many types of rheumatic diseases are chronic conditions. The good news, however, is that most rheumatic diseases can be kept in check so that you can enjoy life just like everyone else. Here are a few tips for effective management:

Develop a Good Relationship with Your Doctor

Communication is key. Come prepared with a list of concerns. Doing so will show your physician that you are invested in your health, and it will also keep you from forgetting a question (it's easy to do!). Many patients bring someone with them to help keep things on track.

Cover the Basics

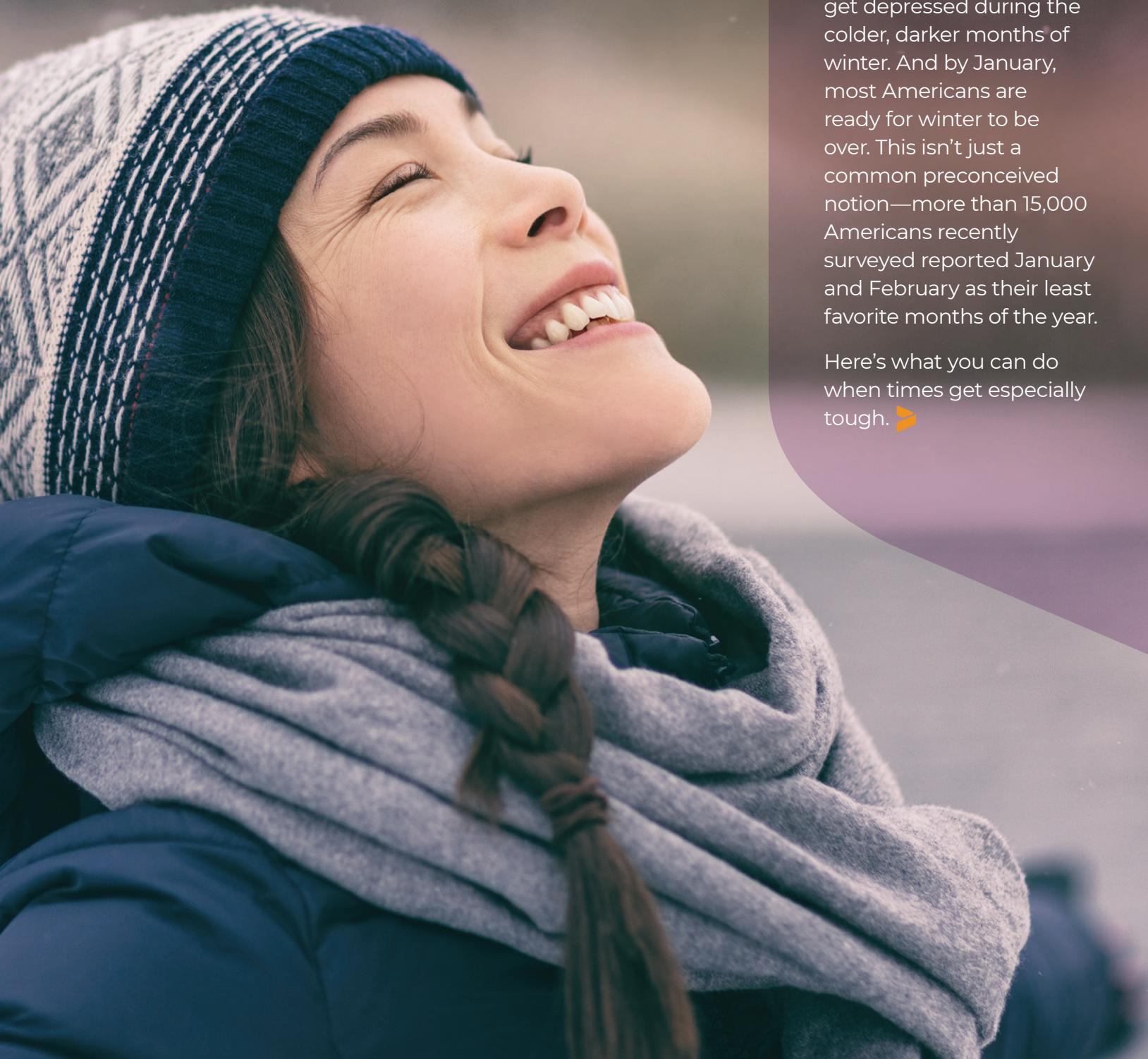
Exercise, rest, and nutrition are the big three basics to keep in mind on your management journey. Did you know exercise can decrease pain and reduce symptoms? Rest and nutrition are always important, especially once adding movement to your daily routine. The smallest routine can make the biggest difference.

Take Advantage of Resources

Knowledge is the best way to manage your condition and is one of the easiest ways to sustain a positive outlook—a critical aspect to living a healthy life. Our website ([forward-databank.org](#)) and the American College of Rheumatology ([rheumatology.org](#)) are great resources. The more knowledge you have about your medications, pain management, and joint protection—to name a few—the better you'll be able to manage symptoms.



Don't Let the *Winter Blues* Keep You Down



Let's face it: it's easy to get depressed during the colder, darker months of winter. And by January, most Americans are ready for winter to be over. This isn't just a common preconceived notion—more than 15,000 Americans recently surveyed reported January and February as their least favorite months of the year.

Here's what you can do when times get especially tough. ➤

As the weather turns cold, it's time to focus on doing what keeps you well—staying warm, staying active, and finding sunshine where you can.



There are many factors working against you that contribute to a winter's depression. Less sunlight results in lower serotonin levels, impacting your mood. A decrease in vitamin D can also affect your mood and serotonin levels. Finally, to top things off, your internal clock shifts with the season, affecting your hormones and sleep.

Depression and chronic pain are closely linked, so for those with rheumatic disease, these factors can make the winter months espe-

cially dark. In many ways they fuel each other: chronic pain can lead to depression and depression can exacerbate pain. According to Harvard Health, depressed patients have three times the average risk of developing chronic pain.

One possible reason for this connection is how pain and depression work. Pain is experienced by our nervous system where signals, or neurotransmitters, flow in both directions between your body and your brain. Meanwhile,

depression is tightly linked to special neurotransmitters called serotonin and norepinephrine, and pain can lead to poor regulation of them by our cells. This can result in even more pain, sadness, and anxiety than normal.

Chronic pain from rheumatic disease is made worse by low temperatures and pain receptors are more sensitive. Tissues, tendons, muscles, and bones are affected by the cold, which in turn worsens RA symptoms such as stiffness and pain.

On-Hand:

These practical items will keep you healthy, comfortable, and safe during the winter months.



Heating Pad > Allows you to rotate warming up specific joints



Resistance Bands > Exercising with resistance bands is low-impact and strengthens the muscles around your joints



Epsom Salt > Pour Epsom salt into your tub before taking a hot bath to reduce swelling and soreness



Foods with Omega-3 Fatty Acids > Walnuts, avocado, chia seeds, and fish are high in Omega-3 and reduce joint inflammation

Make Your Winter a Bit Brighter

Understanding this connection can better help you fend off the winter blues. While there are many factors going against your rheumatic symptoms, there are just as many things you can do to prevent flares and depression. While exercising in the colder months may seem an arduous task, it can aid your chronic pain and seasonal depression on many levels—even if it is beginner's yoga for only 15-20 minutes in the comfort of your warm home. Movement will improve circulation, warming up your body along with your joints.

If it's not terribly cold, layering up and going for an easy walk around the block is a great way to kick depression and flare symptoms back a notch. Call a friend while you walk—friends are a source of support and accountability and sharing a laugh can change the trajectory of your day. If staying inside, pull those curtains open and let in some sunshine to brighten your day. Take vitamin D supplements to boost your immune system, mood, and help fight pain sensitivity.

With chronic illness, it can be difficult to get out of bed in the morning regardless of the season or weather, especially if in a flare, feeling a sense of depression, or both. A nifty trick to get you excited about getting up and going is to find a new hobby. Learning a new skill reignites neurons, rewiring our brain and affecting our mood. This works great for winter months when staying inside and can be as simple as learning a new dish to cook for dinner, playing a new board game, or solving a puzzle.

Recognizing the close relationship between chronic pain and depression is a reminder to be especially proactive during months when there are so many factors working against your body and your mind. Remember, winter is only one season, and it doesn't have to be the longest one. Managing your rheumatic disease and its symptoms is difficult but employing some of these tactics can make surviving the colder months of the year much easier.

"Both pain and depression feed on themselves by changing both brain function and behavior. Depression leads to isolation and isolation leads to further depression; pain causes fear of movement, and immobility creates the conditions for further pain."

- HARVARD HEALTH

New Year's Resolutions Staying Active During Winter Months

When it's cold, getting active and staying active can be equally hard. Take advantage of these helpful ways to keep you moving:

Take a Bath

While it sounds like the opposite of moving, it actually helps get you going. Taking a hot bath will warm your body up along with your joints, alleviating stiffness and pain. If you're in a flare, this could be the one thing that gets you out of bed and your pain symptoms to a more manageable state. If you take pain medicine, it also gives it time to kick in.

Hydrate

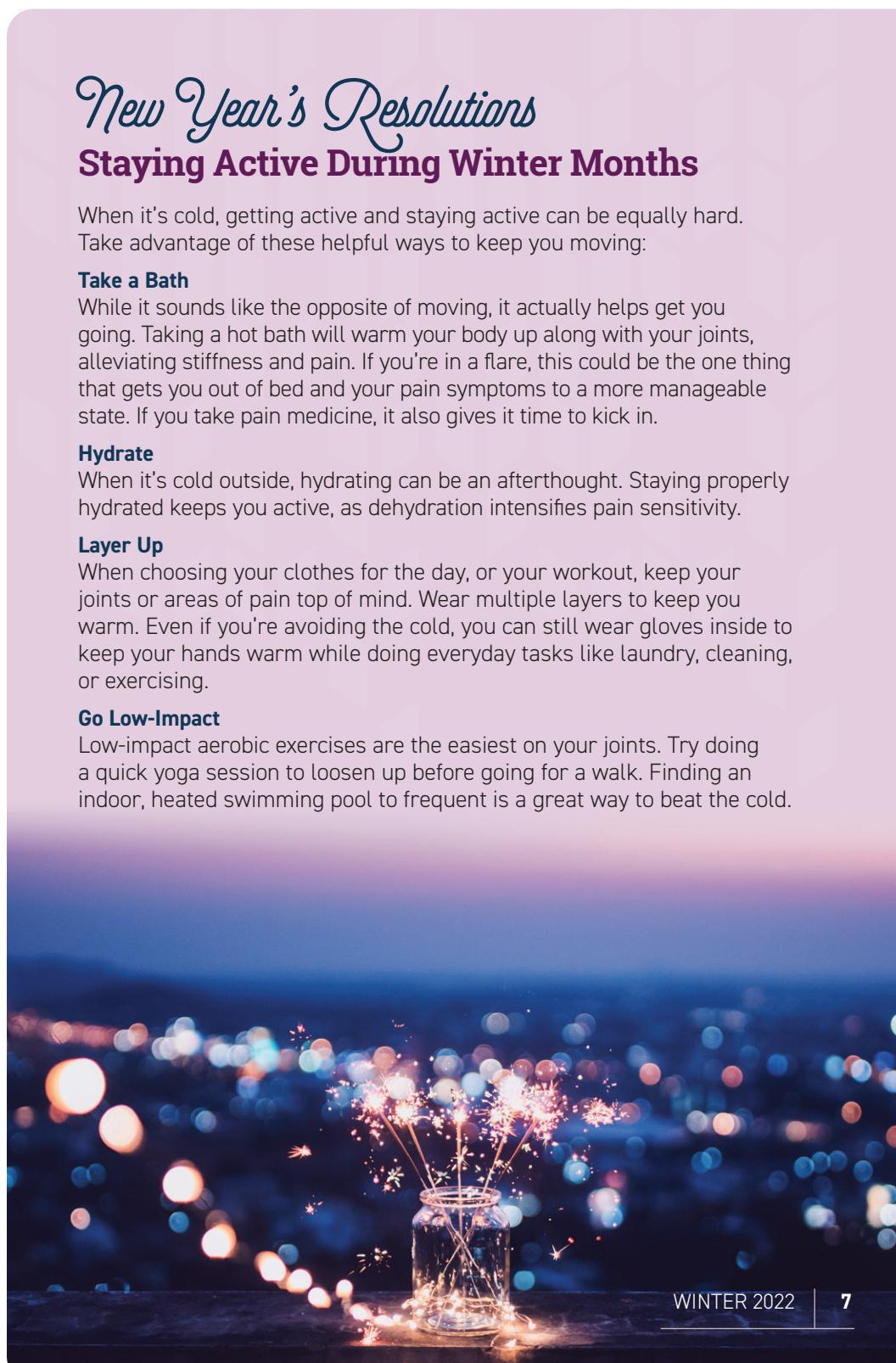
When it's cold outside, hydrating can be an afterthought. Staying properly hydrated keeps you active, as dehydration intensifies pain sensitivity.

Layer Up

When choosing your clothes for the day, or your workout, keep your joints or areas of pain top of mind. Wear multiple layers to keep you warm. Even if you're avoiding the cold, you can still wear gloves inside to keep your hands warm while doing everyday tasks like laundry, cleaning, or exercising.

Go Low-Impact

Low-impact aerobic exercises are the easiest on your joints. Try doing a quick yoga session to loosen up before going for a walk. Finding an indoor, heated swimming pool to frequent is a great way to beat the cold.





FORWARD has been busy in 2021. We have published over 10 papers in medical journals and also participated in two of the top research meetings within the rheumatology community—EULAR and ACR—to present our research projects covering many rheumatic diseases and treatments via 13 poster and oral presentations.

Research Review

Questions added to the FORWARD questionnaires in 2021 collected information on the effect of COVID-19 on individuals with rheumatic diseases and the usage and impact of cannabis or cannabidiol (CBD) products. Your support in completing these questionnaires allowed FORWARD to publish these papers and abstracts, sharing our findings with the rheumatology community:

The Association of General and COVID-19 Specific Stress with Changes in Patient-Reported Outcomes and Comorbidities

We found that individuals with rheumatic diseases experienced worse patient-reported outcomes (PRO) and comorbid conditions (when a person has more than one illness or disease at the same time or when one condition occurs right after another). Stress levels early in the pandemic were associated with these changes. These results suggest an important role for stress levels in patient outcomes and highlight the importance of the assessment of stress in the clinic and identifying effective stress management techniques.

Increase in Cannabis Use Among Adults with Rheumatic Diseases: Results from a 2014-2019 US Observational Study

Even though there have been advances in treatments among patients with rheumatic diseases, there is an unmet need in pain management. Cannabis has emerged as a potential alternative, with arthritis pain cited as a common reason for medical use. We set out to understand patterns of use within FORWARD participants. This was the first study to evaluate cannabis use in all rheumatic diseases and conditions across the United States. We found an overall increase in cannabis use in all states regardless of diagnosis or if cannabis was legalized, but did see the largest increases in the states where it was legalized.



Participants reporting cannabis use had overall worse disease/condition activity, more comorbid conditions, and scored higher on pain, fatigue, sleep, anxiety, and depression scores (PROs) compared to nonusers. Data will continue to be collected on this subject to possibly help determine precisely why individuals with worse PROs are using cannabis at higher rates, or if cannabis use does or does not achieve any desired effects in improving outcomes.

Continued research in this will help to improve our understanding of the benefits and risks of cannabis as a treatment for rheumatic disease symptoms and to support the education of health care providers, so they can provide guidance to their patients in making informed decisions about the use of cannabis-based products.

Mortality in 2020 Due to COVID-19 in U.S. Adults with Rheumatic Diseases:

Data from a Large, National, Multi-Rheumatic Disease Registry

Using FORWARD and National Death Index data, we found COVID-19 to be noted in 8% of all 2020 deaths and it was associated with respiratory failure, diabetes, and renal failure and not associated with cancer. Risks of respiratory death in 2020 were increased among inflammatory rheumatic diseases and non-inflammatory rheumatic diseases had an increase in cardiovascular death.

Factors Associated with COVID-19 Vaccine Hesitancy Among Individuals with Rheumatic Diseases

Most FORWARD participants had already been vaccinated or intended to be vaccinated when we sent out COVID-19 questionnaires in the spring of 2021. At that time, those that were hesitant reported reasons due to: the concern about sufficient testing on individuals with rheumatic diseases, distrusting information shared about the vaccines, and concerns of side effects.

You can find more research publications that have used this data on our website: forwarddatabank.org/research/research-library

Looking to the Future of FORWARD

IMPACTING PUBLIC HEALTH

FORWARD was first started as a non-profit organization to add the patient voice to rheumatic diseases and conditions research. We found that the data we collected was not only useful to the health care professionals, organizations, and researchers within the rheumatology community, but also to those working within public health. We are happy to announce that we are now helping expand general public health research by providing support to organizations with surveys, databanks, and research.

If you are interested in learning more or working with FORWARD, email Rebecca Schumacher, Executive Director of FORWARD, at rebecca@ndb.org.

NEW PSORIASIS REGISTRY

In 2022, we will be adding another condition-specific registry—the Psoriasis Registry.



This new registry is being added to the FORWARD Databank to expand the knowledge of psoriasis diagnosis and treatment and the effect it has on lives over time. We will not only be working with patients with psoriasis, but also primary care physicians, dermatologists, and rheumatologists. Psoriasis is a common, long-term (chronic) skin disease that causes red, itchy scaly patches, most commonly on the knees, elbows, trunk, and scalp. Psoriasis can also be associated with arthritis.

For more information on psoriasis, visit:

mayoclinic.org/diseases-conditions/psoriasis

hopkinsmedicine.org/health/conditions-and-diseases/psoriasis

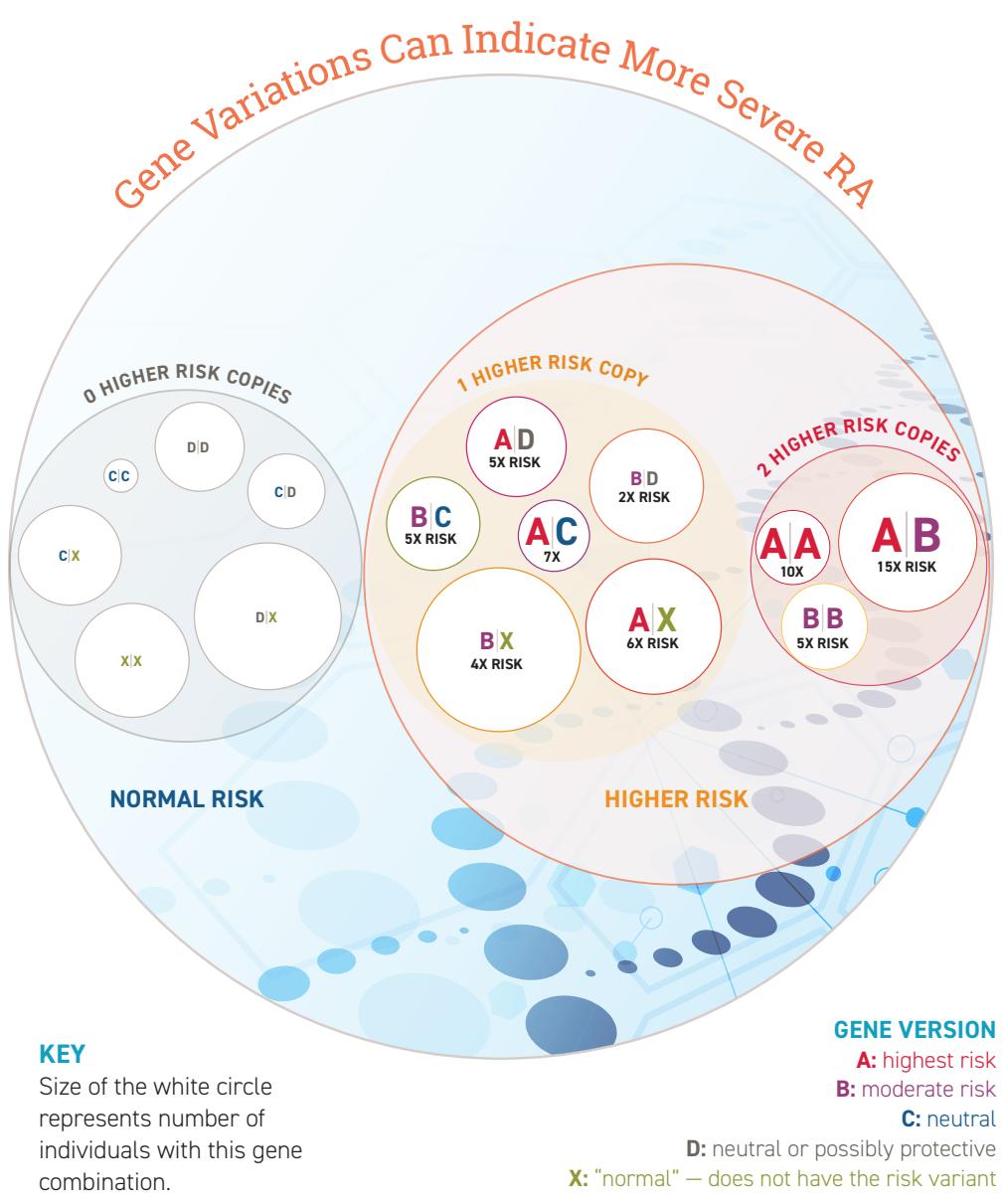
Beyond the Questionnaire: Arthritis Internet Registry

Thanks to our Arthritis Internet Registry (AIR) participants, FORWARD will soon complete a project that uses your FORWARD questionnaire responses and a portion of your donated blood samples.

For this project, we looked at a gene that is related to the immune system. Every individual has two copies of this gene and may have different versions of the gene. We hoped to learn more about predicting the potential severity of an individual's rheumatoid arthritis (RA), as well as potential medication response. So far, we have had two abstracts published and presented at the top annual rheumatology research meetings about this research.

THE FIRST ABSTRACT was focused on attempting to improve our understanding and prediction of RA severity. Researchers already know that certain versions of the gene indicate the level of risk that a person will develop RA. In this research, we learned that individuals with certain versions of the gene not only have a higher risk for developing RA but may also be more likely to develop blood markers that may cause a more severe disease. We also learned that some versions of the gene studied may help prevent the individual from more severe RA.

TO LEARN MORE, TAKE A LOOK AT THE FIGURE ON THE RIGHT.



FOR OUR SECOND ABSTRACT, we looked at how the different versions of this gene may show whether a person will respond well to certain medications. We found that the gene was not related to medication response, but that the blood markers (that may cause more severe RA) are sometimes also associated with a better response to certain medications.

We are also currently working on improving AIR and how to collect biospecimens, including blood samples, either through

labs or possibly at home. We are continuously trying to find the best way and the best time to collect biospecimens (e.g., blood, saliva, biopsy samples) to be able to provide the best research we can with the samples and questionnaire data.

We hope that this information will be used to better treat patients in the future.

Thank you to our AIR participants who provided blood samples and made this project possible—it could not have happened without you!



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!

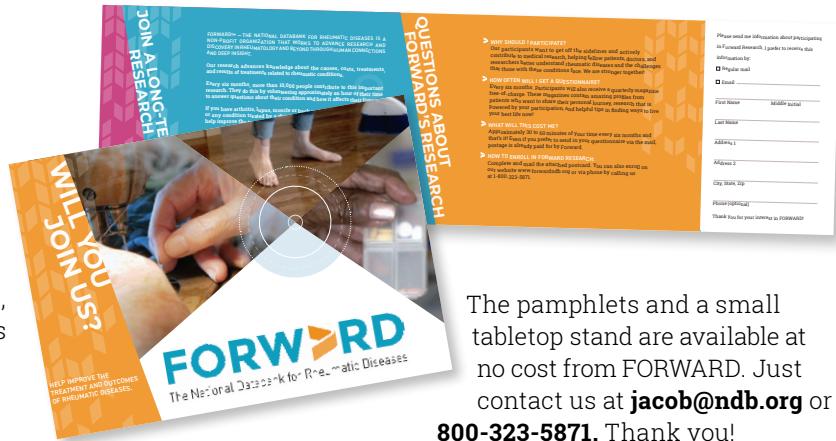
While working on your questionnaire, if you have ANY questions, please contact us right away by email (**webquest@ndb.org**) or phone (**1-800-323-5871**). These might be about technical difficulties or how to interpret a question. If you put your immediate questions in the comments section, we probably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