FORWARD

SPRING 2020

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

RESPONDING to COVID-19

Make It Easy TO MAINTAIN YOUR MEDICATION SCHEDULE

A SEAT AT THE TABLE

The Patient Voice & AiArthritis

In This Issue

Join Us on Facebook & Twitter

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

TAKING CARE, in Times of Crisis and During Your Day-to-Day

Thank you to the FORWARD participants who give their time and energy to make their voice known in the rheumatology community and research. Your support is making a difference.

We know that COVID-19, or coronavirus, is top-of-mind for many of our participants. You will see that we have included many resources in this issue of FORWARD magazine to make sure that you know how to find the latest information about taking care of yourself and your loved ones during this uncertain time.

We have recently added a short questionnaire to help understand how COVID-19 may affect individuals with arthritis and rheumatic diseases. This data will be used along with the questionnaire asked every six months. We thank those who responded to our first wave of questions on your experience with the COVID-19 virus. With your help, we have already been able to collect information from this additional questionnaire and share it with the rheumatology community and the general public. Initially, we will be sending out these questionnaires every two weeks, and we will likely increase the time between questionnaires. We will be adding some of these questions into the twice-yearly questionnaires.

Thank you again, and we hope to remind you that taking care of yourself, your loved ones, and your neighbors is always the most important—both in times of crisis and during your normal day-to-day.

INTERNATIONAL FOUNDATION FOR AUTOIMMUNE & AUTOINFLAMMATORY ARTHRITIS

The International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis) works with patients affected by autoimmune and autoinflammatory diseases that include arthritis as a major clinical component. The organization aims to help patients use their voices to impact education, advocacy, and research.

TO LEARN MORE ABOUT AIARTHRITIS AND THEIR WORK WITH FORWARD AND OTHER NONPROFITS IN THE RHEUMATOLOGY COMMUNITY, TURN TO PAGE 8.

A Letter to Our Community: **FORWARD's Response to COVID-19**

This is a challenging time, one in which most of us are having to take precautions and steps that have disrupted our usual daily life. Whether it's our health or our finances, things are changing quickly.

I wanted to remind you that your contributions to our research are more valued now than ever! We have listened to you and put in place a new web-based questionnaire to make it easier to complete our biannual questionnaires. It also allows us to add questions about high-priority topics such as COVID-19 on short notice.

FORWARD has joined an impromptu group of world experts studying how COVID-19 has affected people with rheumatic and musculoskeletal conditions. We are asking our participants about any new symptoms you may be experiencing, what treatments you may be using, and if you were tested for or developed COVID-19. This may provide valuable information to health care providers going forward to help make decisions about how to treat patients with rheumatic diseases who get COVID-19.

We also understand that this topic may be a source of anxiety for you. Anxiety can disrupt our physical health. Personally, my gut has been bothering me in ways I haven't felt since I was in the last few weeks of my PhD—another time of stress. So while these questions are always optional, do know that you are not alone (even if you are home alone) in having concerns and questions about what is best to do now.

Turn to page 4 to see some early insights into what you are telling us about your experience with COVID-19 and to find several resources providing the latest information about the situation. We also hope that during this time of greater physical isolation you'll continue participating by answering our questionnaire. We are happy to talk with you on the phone to answer questions you may have.

Your continued support makes it possible for us to do research on timely and critical topics that impact patients with rheumatic diseases. During this time your help is needed most.

Thank you again–be safe, be strong.

Kaleb Michaud, PhD

COVID-19 + You

COVID-19 has changed our day-to-day experience. FORWARD—The National Databank for Rheumatic Diseases, along with the rest of the rheumatology community, is working to understand how COVID-19 may affect individuals with rheumatic diseases. We want to share some of the early insights we've gathered, provide some helpful resources, and, most importantly, let you know that you aren't alone in this crisis.

COVID-19 has taken us all by surprise. The virus and pandemic have created a world of uncertainty at a global level, as well as in our homes. We are learning how to cope without our normal routines. We are limiting contact with family and friends. Given your health state, you may have friends or family delivering food and medicine to limit your exposure.

We recently sent out a new COVID-19 questionnaire. We have heard from some of you and are learning about how you are coping with these challenges.

We learned that you are concerned about getting access to your medications, especially hydroxychloroquine. Others are concerned about whether they should be stopping or reducing their medications to lower the risk of developing COVID-19.

We suggest connecting with your physician or health care provider.

WE NEED YOUR HELP: Answer Our COVID-19 Questionnaire

We have developed a short questionnaire, in addition to the regular biannual questionnaire, that is specifically related to COVID-19. This is a supplemental questionnaire and will ask questions about new symptoms you may be experiencing, treatments you may be using, and how you are coping with the pandemic.

This questionnaire, and the information you provide, will help the rheumatology community by providing valuable information about how to treat patients with rheumatic diseases during a COVID-19 outbreak. Participation is easy.

If you are already a FORWARD participant, simply visit forwarddatabank.org and log in to your patient portal. If you are not currently a participant, you can join FORWARD by visiting forwarddatabank.org/join-forward.

Research and further information on what we have and are collecting will be shared on our website at: forwarddatabank.org/covid-19/

Rheumatology associations are in the process of providing guidelines and recommendations to health care providers. You can also ask about specific medications you are taking or research your medication online. Most pharmaceutical companies are providing information about what they are doing to support COVID-19 research, as well as guidance and support for healthcare providers and patients on their medications.

We have learned that many of you are feeling anxious and hopeless. You are trying to occupy yourself and stay connected. Some of you are calling us with your questionnaire responses and we are happy to collect your information over the phone. Results from the first questionnaire have been accepted for publication. You can find the paper at **onlinelibrary.wiley.com/doi/10.1002/acr2.11148.**

Some of you may be home alone and feeling more isolated than usual. Spring is coming and nature does not know about COVID-19. Open the windows, open the door, feel the sunshine, sit on the porch, go for a walk. Don't forget to take care of your mental health and emotions, which can also be affected by the pandemic.

Headspace, a meditation app, is offering free meditation modules during the outbreak. Stanford psychiatrist Dr. David D. Burns has also been posting special podcasts about coping with the pandemic on his blog. You can find these at **headspace.com/covid-19** and **feelinggood.com/?s=coronacast+2.**

Let us know what you are doing to pass the time.

twitter.com/ndb_org
facebook.com/ndb.org
jacob@forwarddatabank.org

COVID-19: **THE LATEST INFORMATION**

AMERICAN COLLEGE OF RHEUMATOLOGY COVID-19 GUIDANCE

rheumatology.org/announcements

The ACR has provided guidance for patients with a documented COVID-19 infection, those who have may been exposed, and those who are not infected and have not been exposed.

EULAR GUIDANCE FOR PATIENTS

eular.org/rheumatism_and_covid_19.cfm

The European League Against Rheumatism (EULAR) provides useful information for patients with rheumatic diseases in the context of COVID-19.

CDC INFORMATION ON COVID-19

cdc.gov/coronavirus

The Centers for Disease Control (CDC) provides useful information regarding what you need to know, resources for the community, COVID-19 cases in the U.S., and more.

NIH INFORMATION ON COVID-19

nih.gov/health-information/coronavirus

The National Institutes of Health (NIH) provides a number of resources and latest news releases on COVID-19.

CORONAVIRUS AND ARTHRITIS: WHAT YOU NEED TO KNOW

arthritis.org/about-us/news-and-updates/coronavirus-and-arthritis-what-you-need-to-know

The Arthritis Foundation provides valuable information on what you need to know about how COVID-19 affects those with arthritis.

COVID-19 GLOBAL RHEUMATOLOGY ALLIANCE

rheum-covid.org

A new registry, Rheum-COVID, is being built and will be "a secure, de-identified, international case-reporting registry" for patients with a rheumatic disease.

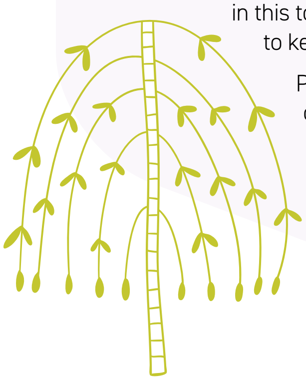
Hello Everyone,

TERESA SIMON, MPH,
SHARES HER EXPERIENCE

My name is Teresa and I work as a public health epidemiologist. Public health epidemiologists study how diseases (acute or chronic) like the flu, COVID-19, or RA and OA affect populations. I have been working with Fred, Kaleb, Rebecca, and the FORWARD team for the past 18 years. Public health experts have been anticipating and predicting a disease would come along and cause the world to stop. Many of us thought it would not happen in our lifetime, but it is happening right now. I have been reading comments from those that responded to the COVID-19 questionnaire and I understand all the emotions you are feeling.

As humans, we like to connect. We need a hug, a smile, a sense of purpose. When our human connections or our sense of purpose has been taken away, we may feel more lonely or isolated. It is for this reason I wanted to connect with you to say YOU ARE NOT ALONE!

I wake up every day and think about what I will do differently during these unprecedented times. Thank goodness for spring! I am reading more, drawing pictures of my garden, and journaling. I decided to look for a poem that describes these times for inspiration. I found Pandemic Panacea by Denis Bruce. For me, it describes an event that has taken over our lives. No one is exempt. Our vulnerability is tested. We are in this together, even as we are isolated. Thank goodness for technology (FaceTime, ZOOM, and HouseParty) to keep us connected; however, that gets old and does not replace the need for human contact.



Please continue to share your stories by responding to the questionnaire, writing your own poem, or let us know what you are doing to pass the time. It is great to meet each of you. Thank you for your continued dedication; without you we would have nothing.

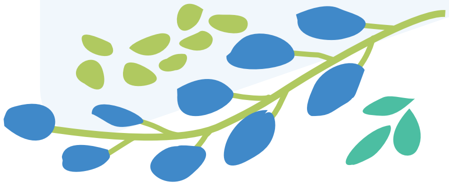
Stay Healthy,
Teresa

Pandemic Panacea

BY DENIS BRUCE

Disrespecter of borders, colour and creed | This pandemic reveals a truth we all must heed
To know that we are all but one and the same | Beneath our skin and culture in this life's game
Where we suffer the sad symptoms and the pain | To reclaim our common brotherhood again
From this dark cloud a silver lining brightens | So that belief in our unity heightens

Such grim moments see us drop our defenses | Allowing us clearly to come to our senses
Whether rich or poor, white or black, young or old | In shared humanity we find our true gold
So let this plain message ring out loud and clear | When acting together we have naught to fear.



The Diagnosis Process

If you or a loved one are currently going through the process of being diagnosed with a rheumatic disease, know that you are not alone. As many of our participants are well aware, the diagnosis process can be fraught with confusion and frustration. Even though the experience is different for every single person, we hope that the stages below may give you insight into the process.

1. **RECOGNIZING THE SYMPTOMS:** Typically, many individuals will realize that something is wrong and go see their primary care physician, who will, at some point, refer you to a rheumatologist. The length of time involved in this stage varies greatly. For some, they may be able to see a rheumatologist right away. For others, they may not be referred to a rheumatologist or may be unable to see one for a significant period of time.
2. **DETERMINING THE CORRECT DIAGNOSIS:** Based on your current symptoms, your family history, and various tests or examinations, your physician will attempt to determine what is causing your symptoms. The diagnostic tools that rheumatologists use are constantly being refined, updated, and improved upon. Even so, it can be difficult to determine a correct diagnosis.
3. **TREATMENT DECISIONS:** Once you've been diagnosed, your doctor will determine the first treatment they will use to lessen your symptoms and slow the progression of your disease. Many people find that throughout their life, they have to try many different treatments, as not all treatments work for all individuals. Likewise, treatment effectiveness can sometimes lessen over time.

When you share your experience as an individual with a rheumatic disease with FORWARD, you are giving rheumatologists the information they need to improve the diagnostic process. To learn more about making your voice heard as a FORWARD participant, turn to page 11.

Medication Madness

Whether you are new to taking medication on a regular basis or have been doing it for decades, it can be difficult to keep track. Read on to learn about some of our favorite, easy tips and tricks to help keep your medication schedule straight.

WRITE IT DOWN: Keep a regularly updated list of your medications, and be sure to include the time of day they are to be taken. You can refer to this list when you are organizing your medication or if you get confused.

KEEP IT SIMPLE: A tried-and-true method of keeping your medication organized is using a pillbox. Typically, these have enough room for seven days of medication, both day and night. Plan out a time each week to sit down, refer to your list of medications, and set your pillbox up for the week.

SET YOUR REMINDERS: If you have medication that isn't taken at the same time as the rest of your medication or if you have medication that is only taken on an as-needed basis, something as simple as a sticky note on the fridge can be a great visual reminder when you ought to be taking it. If you feel like going high-tech, there are plenty of apps or even the alarm function on your phone that you can use to keep yourself on schedule.

Patients CAN CONNECT

The International Foundation for Autoimmune and Autoinflammatory Arthritis (AiArthritis) doesn't just represent the patient voice. They are the patient voice.

FORWARD is not alone in striving to improve the diagnosis, treatment, and prevention of rheumatic diseases. The rheumatology community is filled with like-minded individuals and organizations, whose partnership with FORWARD and other organizations continue to drive rheumatic disease research. We sat down with Tiffany Westrich-Robertson, CEO and cofounder of the International Foundation for Autoimmune and Autoinflammatory Arthritis, as well as a self-proclaimed "problem-solving maverick."

What initially began as a hobby has grown into an international non-profit organization. When Tiffany, who has been diagnosed with non-radiographic Axial Spondyloarthropathy and various co-morbidities, found that she could no longer work in her previous profession of business development due to her condition, she began to spend her time creating bracelets designed to "raise awareness and re-brand arthritis as something that young people experience. All of the sudden, orders started coming in from all over the world. This was in 2009," says Tiffany. "In the email confirmations that I would send, I would include a little bit of my story, and ask people what their story was. I started to realize that so many other people with autoimmune or autoinflammatory conditions also had some form of arthritis. We all had shared symptoms."

This realization led to the founding of the International Foundation for Autoimmune and Autoinflammatory Arthritis (AiArthritis). The organization aims to help patients use their voices to impact education, advocacy, and research. The next step was the creation of the World Autoimmune and Autoinflammatory Arthritis Day. To achieve this, AiArthritis began to reach out to other organizations within the rheumatology community, and now, this event is recognized and celebrated in over 60 countries around the world.

"We realized that through storytelling, through conversation, we were able to connect the dots. This led us to our mission, which is to help those, like us, who are affected by autoimmune and autoinflammatory diseases with arthritis as a major early component, use their voices to impact education, advocacy, and research," says Tiffany. Like FORWARD, AiArthritis believes that no one can understand your disease experience better than you. You have the ability to connect the dots about your disease in ways that others, who don't have arthritis or a rheumatic disease, cannot.

Since that first initiative, AiArthritis has grown an incredible amount. They now have multiple initiatives, all working together to ensure that the patient voice is heard by the rheumatic disease community. "Each initiative is designed to provide another avenue for patients to take a seat at the table," says Tiffany. "This means that patients are viewed as equals to every other stakeholder who has a say in the rheumatology community." Initiatives include an award-winning podcast, AiArthritis Voices 360, an online platform, AiArthritis Voices Online Community, as well as other initiatives centered around education, advocacy, and research.

AiArthritis is using the availability of the internet to enable patients to participate, regardless of their geographic location, disease limitations, or prior advocacy experience. This will allow the AiArthritis team to gather data and information from a wide range of individuals. Additionally, AiArthritis is bringing industry, researchers, and nonprofit organizations to the table. This process is groundbreaking. In order to achieve big goals, like increasing access to precision medicine, innovative methodologies must be used. AiArthritis will be training patient advocates to moderate focus groups to strengthen community participation, provide support on the project, and collect data that is helpful and useful to researchers.

If you're ready to take your seat at the table, AiArthritis is ready to help. Visit **aiarthritis.org** or **aiarthritisvoices.org** to learn more.

FORWARD: **Taking a Seat at the Table**

FORWARD AND AiARTHRITIS have supported one another for years, since their first introduction in 2012. Now, FORWARD will be storing and analyzing all data from AiArthritis' research. "FORWARD is playing an integral role in this initiative," says Tiffany. "They are donating their services to ensure that our data is able to be used by researchers to improve the lived experience of individuals with rheumatic diseases."

When it comes to solving problems, AiArthritis is no stranger.

AiArthritis has developed a six-stage process that guides them in identifying problems and finding solutions for their community of people affected by autoimmune diseases or autoinflammatory diseases that include arthritis as a major clinical component early in onset.

STEP 1
Outstanding community issue identified.

STEP 2
Introduce the topic of focus to the community.

STEP 3
Invite the community to give feedback based on diverse perspectives.

STEP 4
Analyze responses and identify potential solutions.

STEP 5
Revisit the topic with other stakeholders and begin developing solutions or resources.

STEP 6
Develop resources, guidance, and education to improve community outcomes.

The FORWARD Databank: Not Your Average Research

As a research study that follows patients over time, often for many years, FORWARD provides valuable insight into the experience of individuals with rheumatic diseases. These data are used in analyses that address various aspects of rheumatic disease burden, patterns of treatment use, safety, and effectiveness. Here's why that's important:

THE DAY-TO-DAY MATTERS. Nobody has a better understanding of your daily experience than you do. By gathering data directly from the patient, FORWARD is helping fellow patients, doctors, and researchers better understand the experiences and challenges that those with arthritis and rheumatic conditions deal with each day.

INFORMATION IS GATHERED OVER TIME. Safety studies are used to determine whether or not a particular treatment has unexpected side effects over a long period of time. A study like FORWARD's provides a long-term view that is needed to understand how medications are used and if they are safe and effective over time.

EVERY VOICE IS HEARD. Many clinical trials have strict rules about who is allowed to participate. This is done to ensure that researchers are able to control as many aspects of the study as possible; however, databanks like FORWARD's ensure that every voice is heard, not just those that fit into the particular criteria created for clinical trials.

WE SHARE YOUR DATA WITH RESEARCHERS. FORWARD makes its data available for free to academic researchers. This means that no matter what question a researcher is asking, whether it be related to treatment, diagnosis, outcomes or any of the other important aspects of the research of rheumatic diseases, they have access to the important information that you, as a FORWARD participant, are providing.

IT'S ALWAYS EVOLVING. The FORWARD team often works with researchers to help them determine what questions they need to include in the questionnaire. This means that the questionnaire is regularly updated to capture current topics that are important to patients with rheumatic diseases and their health care providers.

Your participation in the FORWARD databank is important. Visit **forwarddatabank.org/join-forward** to make your voice heard.

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 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 when 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!

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 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 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, ext. 180.** 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/forward-patients/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, follow the links from our home page, **forwarddatabank.org**, and make the request, or send us an email at **webquest@ndb.org.**

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

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