A New Online Questionnaire

HOW TO
Make Your New Year's Resolution Work for You

2019/2020
Looking Back & FORWARD
Letter from the Co-Director

Dear Reader,

Hello, and welcome to 2020! As always, thank you for picking up this latest edition of FORWARD magazine.

In this issue, we’re hoping to shed light on the impact that FORWARD participants had on the research completed in 2019 about the prevention, diagnosis, and treatment of rheumatic diseases. You’ll learn about some of the research projects and how they affect you as an individual with a rheumatic disease. You’ll also hear from some members of the FORWARD team about the role they play as researchers, and how valuable patient-reported data (like the data from the FORWARD questionnaire) are.

We’re also excited to share the updates we’ve made to the FORWARD website and online questionnaire. These updates are intended to make it easier for our participants to contribute to rheumatic disease research and we are excited for you to be able to experience them.

To all of our participants: thank you for your continued support.

Sincerely,

Kaleb Michaud, PhD

In This Issue

4 New Year, New You
5 Looking Back & FORWARD
7 Next Steps
10 A New Online Questionnaire
11 Reminders

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

FORWARD Website Update

Check out our updated website at www.forwarddatabank.org.
Thank You to Our Participants

As we enter into the new year and reflect on the previous, the FORWARD team is grateful to and thanks all the participants who dedicate time, energy, and effort in filling out the FORWARD questionnaire. It is one way to have your voice heard in rheumatic disease research.

As a non-profit organization, we are dedicated to improving the diagnosis and treatment of rheumatic diseases… but we wouldn’t be able to do it without you. Together, we’ve contributed to research by working with some of the best researchers and physicians around the world. FORWARD participants have the opportunity to share how their disease impacts their daily life. This is our way of documenting your experience (voice) in living with a rheumatic disease. Our goal in 2020 is to make this process easier for you. If you have had the opportunity to check out our new website, you may have noticed that it is more representative of the participants that make up the FORWARD Registry. We’ve made similar changes to our online questionnaire to make it even easier to make your voice and experience heard. To the many participants over the years who have given us feedback and suggestions about how we could improve your experience—thank you! Please know that your helpful comments made this update possible (head to page 5 to see how).

If you’re a newcomer, or if you are curious how your participation impacts rheumatic disease research, here’s a quick primer. Every six months, FORWARD’s participants fill out a questionnaire about their experience with their rheumatic disease. These answers are compiled, confirmed with the participant’s physician (if necessary), and added to a comprehensive databank that includes answers from all participants since FORWARD’s inception.

This databank is used by researchers all over the world who are trying to answer questions that will help researchers, physicians, advocacy groups, organizations, and pharmaceutical companies improve the diagnosis and treatment of rheumatic diseases. For academic researchers and physicians, this vital information is provided free of charge, meaning that these individuals can devote their time and energy to studying your disease, rather than seeking additional funding to gain access to this important information. FORWARD is an independent non-profit organization, meaning that we are not influenced by pharmaceutical, insurance, or financial companies, or other outside interests.

If you are not yet a participant or want to learn more about how FORWARD is making participation even easier in 2020, head to page 10 to learn more or visit www.forwarddatabank.org.
Keep these tips in mind to help you (and your doctor) improve your health and wellness, in and out of the doctor’s office, with these common New Year’s resolutions.

GET INVOLVED IN YOUR TREATMENT
Taking the steps needed to understand your treatment and how you can improve your rheumatic disease symptoms start with your doctor. Talking to your doctor can be tough, especially if they seem busy or rushed, or if you’re unsure about what it is that you need to discuss with them. If you want to be more involved in your rheumatic disease treatment, consider these tips the next time you’re in the doctor’s office.

PREPARATION IS KEY. Before your doctor’s visit, think about the questions that you might have, and write them down. Highlight the ones that you think are really important, such as those about your diagnosis, prognosis, or treatment.

SPEAK UP. If you have questions, be sure to bring them up at the beginning of your visit. If you ask at the start of the visit, the doctor may be able to answer the questions as they examine you and as you discuss your treatment. Try not to leave questions to the end, as your doctor might be busy. You can speak up early in the visit with something as simple as “Hello Doctor, how are you? I want you to know that I have a few questions to ask you.”

BRING YOUR SUPPORT. If you have a hard time remembering details or are nervous that you won’t be able to share your concerns, bring a family member or friend who is familiar with your day-to-day experience. They can help you remember your questions and the doctor’s answers and provide emotional support during tough conversations.

GET UP & GET MOVING
Exercising more can be a great New Year’s resolution for anyone who is looking to improve their health, but getting started (especially when you’re experiencing the symptoms of your rheumatic disease) can be tough. If you’re having a hard time getting up and getting moving, these tips may help:

TALK TO YOUR DOCTOR. Anyone beginning a new exercise program should discuss it with their doctor first. They can help identify if there is anything about your current health that may prevent you from exercising safely, and help you decide what your next steps ought to be if that’s the case.

TRY SOMETHING NEW. No matter your level of fitness is, you can always add something to your routine to help you maintain the strength and flexibility needed to feel good. If you’re just getting started, why not try adding a daily walk, or a twice-weekly strength training session?

ASK FOR HELP. Whether it be having a friend or family member join you on your daily walks or looking to the experts for assistance before trying a new strength exercise, you should always look for the right support that can help you stay on track to getting healthy. Here are a couple of sites that have information that may be helpful:

ARTHITIS FOUNDATION www.arthritis.org/health-wellness/detail?content=healthyliving
AMERICAN COLLEGE OF SPORTS MEDICINE www.acsm.org/read-research/resource-library

Want to share your New Year’s resolution with the FORWARD team and other individuals with a rheumatic disease? Send an email to Jacob@ndb.org telling us about you and your New Year’s resolution, and you may be featured on our Facebook page!
Monitoring what happens to patients with rheumatic diseases over time is essential... so that researchers and health care providers can identify what needs to be done to improve the quality of rheumatology care and well-being of patients.

Yomei Shaw, PhD, FORWARD Research Fellow
Comorbidities (presence of one or more additional conditions or diseases with a primary condition) in Patients with Osteoarthritis (OA) and Rheumatoid Arthritis (RA)

The burden of comorbid diseases can impact the overall quality of life in patients. FORWARD did a comparison of 9,463 OA patients with 18,926 RA patients to find out more. Patients with OA reported more comorbidities than patients with RA, even after matching by sex and age. Pulmonary (asthma, hardening of the lungs, bronchitis, etc.) and liver disorders were more prevalent among RA patients, but OA patients had a higher prevalence of the majority of comorbidities. The most frequently reported comorbidities were hypertension (high blood pressure), gastrointestinal disorders (constipation, irritable bowel, diverticulitis disease, inflammation of the colon, etc.), and psychiatric disorders (depression, anxiety, bipolar disorders, etc.). Although RA is more complex and affects more of the organs within the body, the study shows that the burden of comorbidities among OA patients is not negligible in comparison.

2019 Research Highlights

All research listed below was only possible with the continued support of all of our participants—this could not be done without you. THANK YOU!

WHEN IT COMES DOWN TO IT, THIS RESEARCH INDICATES THAT, WHILE RA IS A MORE COMPLEX DISEASE, OA PATIENTS CAN ALSO EXPERIENCE A SIGNIFICANT NUMBER OF OTHER DISEASES AND MEDICAL ISSUES RELATED TO THEIR OA.
Thanks to participants like you, FORWARD spent 2019 working with researchers and physicians all over the world to improve and contribute to research of the diagnosis, treatment, and prevention of rheumatic diseases.

Worked with over 30 researchers from different universities, organizations, and companies all dedicated to improving the prevention and treatment of rheumatic diseases.

Gathered data from over 100,000 patients throughout the world with more than 226 diseases.

The FORWARD biobank has 1,531 patient samples being used in 3 projects to better understand OA (osteoarthritis), RA (rheumatoid arthritis) and JIA (juvenile idiopathic arthritis).

Published 8 papers in medical journals.

Presented 14 posters and oral presentations at the annual American College of Rheumatology (ACR) meeting.

Increase Participants

New Online Questionnaire

New Website
Probiotic Use and Psoriatic Arthritis (PsA) Disease Activity
Growing evidence has suggested that our intestinal gut microbiome (the genetic material of all the microbes or microorganisms—bacteria, fungi, and viruses—that live in the gut) may play a role in the development or persistence of spondyloarthritis. Probiotics (live microorganisms—bacteria and yeasts—that are good for you) have been suspected to affect inflammation (when part of the body becomes reddened, swollen, hot, and often painful) through gut microbiome adjustments. We found that probiotic use has increased over the years, from less than 1% prior to 2009 to approximately 7% of FORWARD participants reporting probiotic use in 2018. In this real-world observational study, we found no significant change in patient function scores before and after starting a probiotic. Further studies are needed to examine whether probiotics affect disease activity (to measure the progress and improvement of a disease) and function in patients with PsA.

Serious Infection Risk in Rheumatoid Arthritis (RA) Compared with Non-Inflammatory Rheumatic and Musculoskeletal Diseases (NIRMDs): a US National Cohort Study
Serious infections (an infection that can cause the shutting down of organ systems and, in some cases, death) in patients are always a concern, and patients with RA are at an increased risk compared with patients without RA. This study followed more than 26,000 FORWARD participants, including those with RA and NIRMDs (which include osteoarthritis, degenerative spine diseases, back pain, and osteoporosis). RA patients had a greater risk for serious infections when compared to NIRMD patients. The risk of bacterial (examples are pneumonia, tuberculosis, food poisoning), respiratory (common cold, bronchitis), bloodstream, sepsis, skin, bone, and joint infections are significantly increased in patients with RA compared with patients with NIRMD. The infection risk appears to be greatest in those with higher RA disease activity, which is calculated from a set of questions asked in the FORWARD questionnaire.

Safety of abatacept compared with other biologic (medications that are made from blood, proteins, viruses, and organisms and are used to prevent, treat, and cure human diseases) and conventional synthetic (medications that are made from man-made chemicals rather than natural ingredients) disease-modifying antirheumatic drugs in patients with rheumatoid arthritis: data from an observational study
FORWARD participants that were enrolled through the RAlly study, either through their doctor's office or enrolled on their own, helped provide the data for this study. Data were reviewed between 2005 and 2015 for patients who started or switched to abatacept, other biologic disease-modifying antirheumatic drugs (bDMARDs), or conventional synthetic DMARDs (csDMARDs). Overall the data showed that abatacept was well tolerated and did not result in an overall increased risk of cancer, infections, or other autoimmune diseases when compared with other bDMARDs or csDMARDs.

Want to learn more about the research that FORWARD participants are supporting? See more at: [www.FORWARDdatabank.org/FORWARD-research/research-library/](http://www.FORWARDdatabank.org/FORWARD-research/research-library/)
USING RESEARCH TO MOVE FORWARD

WE SAT DOWN with Yomei Shaw, PhD, Research Fellow with FORWARD—The National Databank for Rheumatic Diseases to better understand the importance of the patient voice in rheumatic disease research and to learn more about her vision for the future of the patient perspective.

Why is patient-reported data (like what FORWARD collects) important?
Patients are a valuable source of information about how they are impacted by rheumatic diseases, other health conditions, and treatments (including aspects such as side effects and costs). Monitoring what happens to patients with rheumatic diseases over time is essential for understanding the effectiveness and safety of treatments and how the needs of patients are changing, so that researchers and health care providers can identify what needs to be done to improve the quality of rheumatology care and well-being of patients.

Why is it important to participate in events like the American College of Rheumatology (ACR) Annual Meeting?
Scientific meetings such as ACR and EULAR (European League Against Rheumatism) are where rheumatology health care providers and researchers go to learn about current research and new developments in treatments, approaches to diagnosis, and disease management. For the FORWARD staff and collaborators, these meetings are an opportunity to get up to date on the new research happening around the world, develop research collaborations, and communicate and share our research findings to the international rheumatology community.

Have you been working on anything interesting lately?
I have been working on an article that takes a closer look at patients’ perspectives (a particular attitude toward or point of view) on patient-reported outcome measures, which are surveys that are used to measure health status in patients. I feel very strongly that patient’s perspectives should be incorporated into research—including thinking about and deciding how we should approach research. In the future, I would like to see more research about patient perspectives on research and how to incorporate their perspectives into the research process.

Can you tell us what we can be looking FORWARD to in 2020?
I am working on a project to improve the design and presentation of FORWARD’s web questionnaire. While the questions themselves are already updated every six months, our goal is to make a more engaging web questionnaire that will communicate to participants the value of the data they are contributing, and hopefully motivate them to continue taking part in our questionnaires well into the future. We would like to give participants a better sense of the community of FORWARD participants that they are a part of, and the research that has been produced as a result of their participation.
A NEW ONLINE QUESTIONNAIRE

We are pleased to announce that, starting in 2020, we will be using a new online questionnaire system. In 2019 it was decided, from participant and researcher comments, that we needed to revamp the online questionnaire to provide a better experience for those who choose to fill out their questionnaire online, rather than via mail/paper or by phone.

The new online questionnaire is simplified and more accessible and should make the process of sharing your experience with your rheumatic disease quicker and easier. This new system will also allow the FORWARD team to create, update, and revise the questionnaires as quickly and easily as possible, allowing us to ask the right questions at the right time, as is needed by research. We appreciate all of our participants support and patience as we have worked, and will continue to work, to get the system to what we all need to best support and provide research to the rheumatology community.

How Can You Participate?

If you are not already a FORWARD participant, or if your current method of filling out the questionnaires is too difficult, we have many different ways that you can make your voice heard in rheumatic disease treatment.

ONLINE
For those that are comfortable with the internet, the online questionnaire is a great way to provide FORWARD with your information. We’ll make sure that your information is kept private, and, should you need a break while filling out the questionnaire, you always have the option of pausing and returning to the questionnaire at a later date.

PAPER QUESTIONNAIRES
Delivered to your mailbox with a prepaid return envelope, this is a great option for individuals who are more comfortable working with a paper questionnaire than online. You’ll be able to take your time and fill out the questionnaire at your pace, and can then drop it off with your postman to have it returned, at no cost to you, to FORWARD once you’ve finished filling it out.

OVER THE PHONE
Should a paper or online questionnaire prove to be too difficult, we also provide telephone questionnaires, during which a trained FORWARD staff member will walk you through each question over the phone and record your answers for you.

Visit www.forwarddatabank.org/join-forward to get started.
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.

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!

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.

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/.

FOR MORE INFORMATION OR TO PARTICIPATE

1035 N Emporia | Suite 288 | Wichita, KS 67214
Please call 1-800-323-5871 or email info@ndb.org

DIRECTORS
Frederick Wolfe, MD
Kaleb Michaud, PhD

EXECUTIVE DIRECTOR
Rebecca Schumacher, BS

THE CONTENTS OF THIS MAGAZINE, SUCH AS TEXT, GRAPHICS, IMAGES, INFORMATION OBTAINED FROM FORWARD CONTRIBUTORS AND LICENSORS, AND OTHER MATERIAL CONTAINED IN FORWARD MAGAZINE ARE FOR INFORMATIONAL PURPOSES ONLY. THE CONTENT IS NOT INTENDED TO BE A SUBSTITUTE FOR PROFESSIONAL MEDICAL ADVICE, DIAGNOSIS, OR TREATMENT. ALWAYS SEEK THE ADVICE OF YOUR PHYSICIAN OR OTHER QUALIFIED HEALTH PROVIDER WITH ANY QUESTIONS YOU MAY HAVE REGARDING A MEDICAL CONDITION. NEVER DISREGARD PROFESSIONAL MEDICAL ADVICE OR DELAY IN SEEKING IT BECAUSE OF SOMETHING YOU HAVE READ IN FORWARD MAGAZINE.

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!