

# FORWARD

WINTER  
2020

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

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

**2019/2020  
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](http://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](http://www.forwarddatabank.org).**

## NEW YEAR

new  
youMAKING  
YOUR  
NEW YEAR'S  
RESOLUTIONS  
WORK FOR YOU

While a New Year's resolution can be a great tool to help propel you towards your goal of a healthier you in 2020, it can be frustrating if you feel limited by your rheumatic disease.

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:

**ARTHRITIS FOUNDATION** [www.arthritis.org/health-wellness/detail?content=healthyliving](http://www.arthritis.org/health-wellness/detail?content=healthyliving)

**AMERICAN COLLEGE OF SPORTS MEDICINE** [www.acsm.org/read-research/resource-library](http://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](mailto:Jacob@ndb.org) telling us about you and your New Year's resolution, and you may be featured on our Facebook page!



# 2019/2020 LOOKING BACK & FORWARD

“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

## FORWARD

The National Database for Rheumatic Diseases

### Probiotic Use and Psoriatic Arthritis Disease Activity

Madison Grinnell<sup>1</sup>, Kristin Wipfler<sup>1</sup>, Alexis Ogdie<sup>1</sup>, Caleb Michoud<sup>1,2</sup>

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## Nebraska

Medical Center

## Nebraska

Medical Center

#### BACKGROUND

- Probiotics have been hypothesized to mediate inflammation through gut microbiome modulation.
- Growing evidence has suggested that our intestinal gut microbiome may play a role in the development or persistence of spondyloarthritis.
- We aimed to evaluate associations between probiotic use and patient-reported outcomes in patients with psoriatic arthritis (PsA).

#### METHODS

- We examined probiotic use among patients with PsA in FORWARD, The National Database for Rheumatic Diseases. Patients with rheumatoid arthritis (RA), in which gut inflammation is less clearly related to pathogenesis, acted as a comparison group.
- For comparisons made between probiotic users and nonusers, we used propensity score matching (separately performed for PsA and RA) to balance confounders. The scores were calculated based on age, sex, race, education, income, RDI, tumor use, fish oil use, vitamin D use, DMARD use, NSAID use, and PPI use.
- Descriptive statistics were calculated for patient demographics, clinical characteristics, and five outcomes of interest (PASI-4, HAQ-I, pain VAS, SF-36 PCS, and SF-36 MCS). Significance was assessed with Student's t-tests and Fisher's exact tests as appropriate.
- Paired comparisons were made among PsA probiotic users before and after initiating a probiotic.

#### RESULTS

- More patients have reported probiotic use over the past decade, with less than 1% prior to 2010 to approximately 7% in 2018.
- Probiotic users are more likely to be Caucasian women with higher education, income, and supplement use.
- Following propensity score matching, probiotic users with PsA had significantly lower SF-36 PCS scores and higher pain VAS scores than nonusers with PsA.
- There were no significant differences in PASI-4, HAQ-I, pain VAS, or SF-36 PCS/MCS among probiotic users with PsA before and after probiotic initiation.

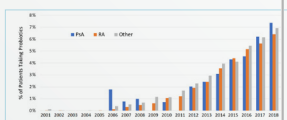


Figure 1. Probiotic use over time by primary rheumatic disease diagnosis in FORWARD. Average % per year was 1.8% for PsA, 5.7% for RA, and 4.0% for Other.

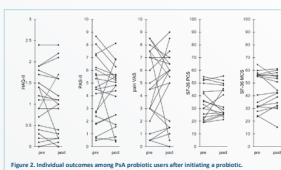


Figure 2. Individual outcomes among PsA probiotic users after initiating a probiotic.

Table 1. Baseline demographics and clinical characteristics by primary diagnosis at enrollment.

	PsA (n = 721)	RA (n = 2078)	p value
Demographics			
Probiotic use ever, %	5.7	5.7	0.93
Age, years	52.1 (12.2)	52.2 (12.3)	0.71
Female, %	86.2	86.0	0.96
Caucasian, %	86.2	85.5	0.71
Education, years	16.0 (2.2)	16.1 (2.2)	0.36
Household income, USD/1000	62.1 (18.8)	61.4 (18.8)	0.55
RDI, 0-4	2.2 (1.3)	1.8 (1.3)	0.22
Tumor use, %	4.4	3.7	0.23
Vitamin D use, %	20.7	20.2	0.53
DMARD use, %	65.7	66.0	0.92
PPI use, %	62.1	60.7	0.19
NSAID use, %	65.7	66.0	0.92
Pain VAS, 0-100	5.1 (3.8)	4.1 (2.8)	0.001
HAQ-I, 0-100	30.1 (11.5)	40.8 (11.1)	0.001
SF-36 PCS, 0-100	40.7 (12.8)	49.1 (13.7)	0.001
SF-36 MCS, 0-100	41.5 (12.4)	43.5 (12.7)	0.001
PASI-4, 0-100	14.0 (7.7)	14.0 (7.7)	0.99

Table 2. Demographics and clinical characteristics by primary diagnosis at enrollment.

	PsA (n = 721)	RA (n = 2078)	p value
Demographics			
Age, years	52.1 (12.2)	52.2 (12.3)	0.71
Female, %	86.2	86.0	0.96
Caucasian, %	86.2	85.5	0.71
Education, years	16.0 (2.2)	16.1 (2.2)	0.36
Household income, USD/1000	62.1 (18.8)	61.4 (18.8)	0.55
RDI, 0-4	2.2 (1.3)	1.8 (1.3)	0.22
Tumor use, %	4.4	3.7	0.23
Vitamin D use, %	20.7	20.2	0.53
DMARD use, %	65.7	66.0	0.92
PPI use, %	62.1	60.7	0.19
NSAID use, %	65.7	66.0	0.92
Pain VAS, 0-100	5.1 (3.8)	4.1 (2.8)	0.001
HAQ-I, 0-100	30.1 (11.5)	40.8 (11.1)	0.001
SF-36 PCS, 0-100	40.7 (12.8)	49.1 (13.7)	0.001
SF-36 MCS, 0-100	41.5 (12.4)	43.5 (12.7)	0.001
PASI-4, 0-100	14.0 (7.7)	14.0 (7.7)	0.99

## FORWARD

The National Database for Rheumatic Diseases

### Comorbidities in Patients With OA and RA: Results From a Large US Rheumatic Disease Registry

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#### BACKGROUND

- The burden of comorbid conditions can impact the overall quality of life in patients with RA and OA. However, the presence of common comorbidities in inflammatory and degenerative arthritis is not well described.
- We sought to compare comorbidities in the two patient groups.

#### METHODS

- We identified patients with physician-diagnosed OA and RA in FORWARD, The National Database for Rheumatic Diseases.
- FORWARD is a large US registry with comprehensive 6-month questionnaires from 1998 through 2018, with patients primarily recruited through rheumatology clinics.
- Each patient with OA was age- and sex-matched to two patients with RA at study entry.
- We compared demographics, clinical characteristics and current and past comorbidities between the OA and RA groups.
- Patient status at the last observation was further categorized as active (if they had a full follow-up questionnaire collected in the last 2 years), not active, or lost to follow-up/deceased. T-tests and Chi-square tests were used as appropriate to assess differences.

#### RESULTS

- 9,463 patients with OA were matched to 18,926 patients with RA.
- Patients with OA experienced more pain compared to patients with RA (4.6 vs 4.2), but patients with RA had slightly worse HAQ scores (1.0 vs 1.1; Table 1).
- Higher use of NSAIDs was reported for patients with OA.
- Except for pulmonary and liver disorders, which were more prevalent among patients with RA, patients with OA had a higher prevalence of the majority of comorbidities, with an average overall disease comorbidity index of 2.3 vs 2.1 for patients with RA.
- The most frequently reported comorbidities (OA vs RA) were hypertension (69% vs 66%), gastrointestinal disorders (67% vs 63%) and psychiatric disorders (55% vs 48%) (Figure 1).
- Patients who were lost to follow-up/deceased had worse outcomes and more comorbidities than active and non-active patients both with OA and RA. Patients who were not active had more comorbidities than active patients, revealing an informative drop-out (Table 2).

Figure 1. Comorbidities During Study or in the Past for Patients with OA or RA at Last Observation

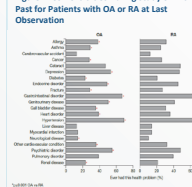


Table 1. Clinical Measures and Treatment of Patients with OA and Age- and Sex-Matched RA, Characterized at Last Observation

Variables	Patients with OA (n = 9,463)	Patients with RA (n = 18,926)	p value
Age, years	67.1 (10.1)	67.1 (10.1)	0.98
Female, %	87.1 (10.1)	87.1 (10.1)	0.98
White, %	87.1 (10.1)	87.1 (10.1)	0.98
Household income, USD/1000	20.0 (10.1)	20.0 (10.1)	0.98
RDI, 0-4	2.0 (1.0)	2.0 (1.0)	0.98
Tumor use, %	2.0 (1.0)	2.0 (1.0)	0.98
Vitamin D use, %	2.0 (1.0)	2.0 (1.0)	0.98
DMARD use, %	2.0 (1.0)	2.0 (1.0)	0.98
PPI use, %	2.0 (1.0)	2.0 (1.0)	0.98
NSAID use, %	2.0 (1.0)	2.0 (1.0)	0.98
Pain VAS, 0-100	4.6 (3.8)	4.2 (2.8)	0.001
HAQ-I, 0-100	1.0 (0.8)	1.1 (0.8)	0.001
SF-36 PCS, 0-100	40.7 (12.8)	49.1 (13.7)	0.001
SF-36 MCS, 0-100	41.5 (12.4)	43.5 (12.7)	0.001
PASI-4, 0-100	14.0 (7.7)	14.0 (7.7)	0.99

Table 2. Comorbidities During Study or in the Past for Patients with OA and Age- and Sex-Matched RA at Last Observation and Active Status

	Patients with OA (n = 9,463)	Patients with RA (n = 18,926)	p value
Active	8,463 (89.3)	17,926 (94.8)	0.001
Not active	1,000 (10.7)	1,000 (5.2)	0.001
Lost to follow-up/deceased	1,000 (10.7)	1,000 (5.2)	0.001
Comorbidities			
Hypertension	69.0	66.0	0.001
Gastrointestinal disorders	67.0	63.0	0.001
Psychiatric disorders	55.0	48.0	0.001
Respiratory disorders	4.0	4.0	0.98
Liver disorders	4.0	4.0	0.98
Other comorbidities	4.0	4.0	0.98
NSAID use, %	2.0	2.0	0.98
Vitamin D use, %	2.0	2.0	0.98
DMARD use, %	2.0	2.0	0.98
PPI use, %	2.0	2.0	0.98
Pain VAS, 0-100	4.6	4.2	0.001
HAQ-I, 0-100	1.0	1.1	0.001
SF-36 PCS, 0-100	40.7	49.1	0.001
SF-36 MCS, 0-100	41.5	43.5	0.001
PASI-4, 0-100	14.0	14.0	0.99

#### CONCLUSION

- Patients with OA reported more comorbidities than patients with RA, even after age- and sex-matching.
- Although RA has a much more complex etiology, affecting more organ systems, our data suggest that the burden of comorbidities among OA patients is not negligible in comparison.
- Advancement in treatment for RA may have lessened the burden of disease and comorbidities when compared with OA.
- This OA cohort receives care from a rheumatologist and may have more severe disease.

Professional medical writing: Katherine Kampen, Coude, Funded by Bristol Myers Squibb.

# 2019 Research Highlights

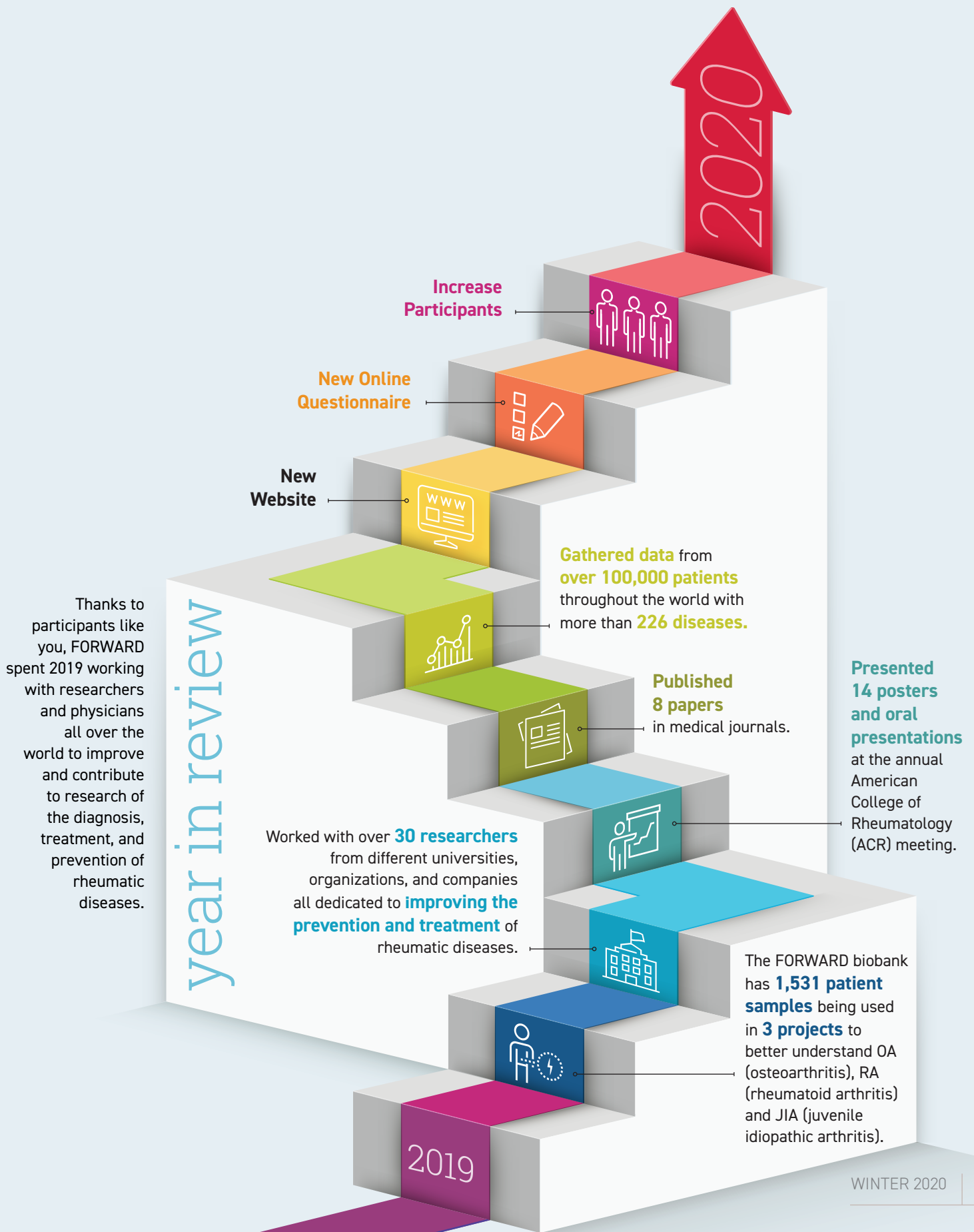
All research listed below was only possible with the continued support of all of our participants —this could not be done without you. THANK YOU!

## 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.

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.





### 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.

PROBIOTICS ARE SUSPECTED TO AFFECT INFLAMMATION IN PATIENTS, BUT OUR RESEARCH SHOWS THAT FURTHER STUDIES ARE NEEDED TO BETTER UNDERSTAND THE IMPACT OF PROBIOTICS ON PATIENT DISEASE ACTIVITY.



**RHEUMATOID ARTHRITIS PRESENTS A HIGHER RISK FOR SERIOUS INFECTIONS THAN RHEUMATIC DISEASES THAT ARE NON-INFLAMMATORY. THIS IS A RISK THAT PATIENTS WITH RA (AND THEIR PHYSICIANS) OUGHT TO BE AWARE OF AND PREPARED TO TREAT, IF NECESSARY.**

### 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.

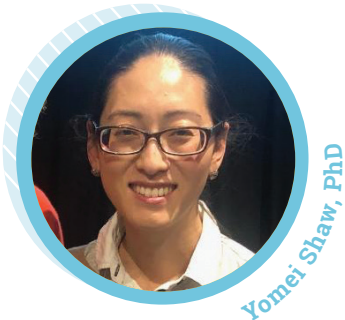
THE SAFETY OF DRUGS IS AN IMPORTANT PART OF ANY MEDICAL RESEARCH. THIS STUDY SHOWED THAT ABATACEPT, A POPULAR BIOLOGIC USED TO TREAT RHEUMATIC DISEASES, DOES NOT PRESENT AN INCREASED RISK WHEN COMPARED TO SIMILAR DRUGS.

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](http://www.forwarddatabank.org/join-forward) to get started.





**WHILE WORKING** on your questionnaire, if you have ANY questions, please contact us right away by email ([webquest@ndb.org](mailto: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.

## 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](mailto: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!

# 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/](http://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](http://forwarddatabank.org), and make the request, or send us an email at [webquest@ndb.org](mailto: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](mailto: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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