Curious About Journaling? Learn more on page 4

Setting Smart Goals... & Achieving Them!

Insights into Your Chronic Illness

New FORWARD Research
SEE THE DIFFERENCE YOUR HELP MAKES
Letter from the Co-Director

Dear Reader,

Hello, and thank you for picking up this latest edition of FORWARD magazine. Here at the beginning of 2019, I’m excited to share with you some helpful tips about living with rheumatic diseases and some information about the impact that FORWARD, and all of the FORWARD participants, have had in 2018.

Inside, you’ll find a wide variety of topics we hope you’ll find interesting and informative, from how to make the most of new beginnings during the New Year’s season, to the incredible research that’s being performed because of your willingness to share your experience with FORWARD. For the past 20 years, we’ve been contributing to the diagnosis, treatment, and prevention of rheumatic diseases, and we hope that this issue will inspire you not only to continue contributing to research, but also to continue taking steps to contribute to your own well-being.

To all of our participants—thank you for your support! FORWARD wouldn’t exist without you.

Sincerely,
Kaleb Michaud, PhD
Co-Director, FORWARD

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.

New Study for FORWARD PARTICIPANTS

Are you starting or have you recently started one of the following medications?

* XELJANZ (TOFACITINIB)
* HUMIRA (ADALIMUMAB)
* ENBREL (ETANERCEPT)
* SIMPONI (GOLIMUMAB)

We have started a new study using a remote electronic Medication Event Monitoring System (MEMS) device to measure medication adherence (taking your medication as directed). The MEMS device is a cap on a medicine bottle that notes the day and time when the cap has been removed and put back on the bottle.

If you would like to know more, please contact us by email at info@ndb.org or by calling 1-800-323-5871, ext. 143.
THANK YOU PARTICIPANTS for Your Time and Voice!

Everyone who works with FORWARD, and all the doctors and researchers who benefit from our research, are incredibly grateful for your dedication to helping with this project. Many of you have been with us for several years. But every six months, we are also glad to see many new people join us.

Here is a quick primer on FORWARD for the newcomers. FORWARD is a nonprofit organization that studies rheumatoid arthritis, osteoarthritis, fibromyalgia, lupus, psoriatic arthritis, gout, and other rheumatic diseases. Our research is designed to improve the treatment and outcomes of these conditions.

We are an independent organization that conducts its own research without influence from pharmaceutical, insurance, or financial companies, or other outside interests. Our research is so well respected that we are often hired to provide independent drug safety verification to the government. Furthermore, if you participate in our studies, your personal information will always remain private. We do not sell or share any identifying information about Forward participants.

By participating, you’ll be helping to improve the treatment and outcome of rheumatic diseases.

FORWARD is different from other rheumatic disease databanks in that participants report on themselves. Data is not collected by doctors or medical staff. With patient-reported data, researchers get a perspective that short, small clinical trials cannot provide. Our long-term study offers a much broader view of treatment and results. Clinical trials are good at identifying common side effects, but rare or subtle problems, or problems that take longer to develop, are better detected by studies like ours.

Welcome to FORWARD, or thanks again for your continuing participation! If you ever have any questions or need help with your questionnaire, please contact us by email at webquest@ndb.org or call us at 1-800-323-5871.
JOURNAL
YOUR JOURNEY

Taking a little bit of time each day to take note of your symptoms, potential triggers, and activity levels may seem daunting, but it also may be worth it.

Keeping a journal of how you feel and what you’re doing about your chronic illness can help you better understand your disease and symptoms and may even help you identify triggers or better communicate your experience with your doctor.

Not sure where to start? Try tracking medications and supplements. Testing out a new anti-inflammatory supplement? Take note of your dosage and how swollen or inflamed your joints seem to be each day. After some time, you and your doctor can review and see if it’s having a positive effect on your illness.

Or, track your daily habits that help limit your symptoms, like exercise, by recording how long you are active for each day. Even these simple things can help you better understand the impact your day-to-day activities have on your condition. If you’re a FORWARD participant, you can even use the Health Diary we send every six months with your questionnaire to start tracking your health and medication. It’s a great, easy way to get started!

Consistency is key, so plan to keep entries simple and short. That way, you’ll increase your chances of filling it out when you feel at your worst, which could be the most important time to track your symptoms and daily activities.

Try taking note of these common activities and symptoms in your journal:

<table>
<thead>
<tr>
<th>Pain Rating</th>
<th>Exercise</th>
<th>Sleep Quality</th>
<th>Brain Fog</th>
<th>Nutrition</th>
<th>Medication</th>
<th>Other Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>30 minute run (yay!)</td>
<td>tossing all night, woke up at 3am</td>
<td>no brain fog today</td>
<td>only 1 glass of water</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

OTHER NOTES
Started a new medication today. So far I’m feeling okay, better than yesterday, although not sure if that’s the new meds or not.

Giving Back

After the holidays, and with 2019 feeling fresh and new, many people are feeling positive and looking to give back to their communities. However, if you’re living with a chronic illness, you know that it can sometimes be difficult to volunteer in the usual ways. That doesn’t mean that you can’t put your desire to give back to good use, however.

BE UPFRONT. The organization that you choose to volunteer with is grateful to have you on board! Informing them of your chronic illness—and any symptoms that may impact your ability to volunteer—early on will allow them to accommodate you properly.

START SLOW. Overcommitting yourself will only lead to exhaustion. Once you’ve found the organization that you want to volunteer with, try committing to one or two hours per week to start. You can always volunteer more time if you find you’re able to.

LOOK FORWARD. There may be ways that you’ve been giving back that you don’t even recognize as volunteering. Every time you fill out a FORWARD survey, you’re giving your time, energy, and voice to improving rheumatic disease research, which means you’re supporting improved treatments, earlier diagnoses, and better prevention of rheumatic diseases.

If you aren’t a FORWARD participant yet and are ready to support rheumatic disease research, or if you have any questions, email us at info@ndb.org or give us a call at 1-800-323-5871.
Experts say that if you want to achieve a goal, you should break it down into small, manageable steps. Now that we’re in the New Year, resolutions are everywhere, and we’re all taking a look at the small steps we can take to achieve our goals. However, this premise doesn’t only apply to New Year’s resolutions.
LIVING WITH a rheumatic disease or chronic illness, whether you’ve just been diagnosed or were diagnosed 25 years ago, can be overwhelming at times. Setting goals and milestones for yourself can help boost morale, give you more control over your treatment plan, positively influence your disease progression, and perhaps even improve your quality of life. Take a look at some ways you can set goals to manage your disease and symptoms, then map out some small steps you can take to achieve those goals.

Get Help Setting Goals
If you’re not sure what goals are right for you, talk to your doctor. They may recommend starting certain activities, like exercise, or avoiding potential triggers, like inflammatory foods. Whatever your situation is, your doctor can help you choose the right goals for you.

Make Your Goals SMART
Take a look at the list below of some long-term goals, and learn how to make them into smaller, manageable steps and goals that you can achieve.

+ Reduce morning stiffness
+ Stay active
+ Maintain your medication schedule
+ Limit joint pain
+ Track your disease symptoms and progression
+ Increase stamina

When you make a vague goal, you aren’t as likely to achieve it as when you make a SMART goal. A goal that is SMART is Specific, Measurable, Attainable, Realistic, and Timely.

So, how can you make a vague goal—like “keep track of my symptoms”—SMART?

Try this goal instead: “Spend five minutes every evening before bed writing down how I felt today to share at my doctor’s appointment in March.” It’s very specific—do this one thing every day at this time. It’s measurable—simply ask yourself, “Did I spend at least five minutes doing this thing?” It’s attainable—all you need is a method of tracking, like a paper and pen. It’s realistic—anyone can find five minutes in their day. It’s timely—it has a timeframe that lasts until a specific date.

The next time you make a goal for your rheumatic disease, ask yourself, “Is my goal SMART?” If not, adjust your goal until it reaches the necessary criteria.

Small Steps Make a Big Difference
Once you’ve taken your long-term goals, broken them down, and made your goals SMART, you should find that
According to a recent survey, these are the most common New Year's resolutions made in 2018. Take a look at these resolutions and some small steps anyone can take to move closer to achieving their goals.

**EAT BETTER:** Try adding one serving of vegetables to every meal and eat that serving before anything else on your plate.

**EXERCISE MORE:** If you don’t currently work out, try going for a short walk every day before dinner.

**GET MORE SLEEP:** Try heading to the bedroom an hour earlier than usual and reading for 30 minutes.

**LEARN A NEW SKILL:** Set aside time to try something new. Find 10 minutes during your lunch break to work on your new hobby.

Getting Motivated

Sometimes, it’s easy to ignore or avoid even the most achievable of goals if it requires additional effort or adjusting your schedule or routine. If this is the case, try these great tips to get started.

**PAIR UP.** Try pairing a new activity or task with something that you already do on a regular basis—like brushing your teeth or eating dinner. When you’re first incorporating something new into your routine, tell yourself, “I won’t eat dinner until I’ve walked the dog outside for 15 minutes.”

**BUDDY UP.** Finding a buddy to do your new activity with you is a great way to get motivated. Find a friend to go on a walk with you or ask your partner to sit down with you and help you review how you’ve felt that day when you’re trying to track your symptoms.

**WISE UP.** If you and your doctor work together to develop goals, make sure that you understand why you’ve been assigned a particular activity or task. If your doctor tells you to avoid alcohol, don’t hesitate to ask questions if you’re not sure why this specific goal is being made.

As you begin meeting your goals, take note of your successes, both on your own and with your doctor. Together, you can continue to create new goals and work to achieve the highest possible quality of life and manage your symptoms appropriately. Just think—if you take a quick walk this evening, you could have better endurance and be able to go on a longer walk next month. By this time next year, you may be able to go on a hike with the family or achieve your goal of walking a half-marathon.
Every year, thousands of rheumatologists, researchers, nonprofits, and more gather to explore the current state of rheumatic disease diagnosis, treatment, and prevention at the annual American College of Rheumatology meeting. This year, FORWARD data was used extensively in research, and a number of those projects were highlighted during the meeting. Take a look below at some of the projects that were made possible by FORWARD participants like you.

**DIAGNOSIS OF FIBROMYALGIA: DISAGREEMENT BETWEEN FIBROMYALGIA CRITERIA AND CLINICIAN-BASED FIBROMYALGIA DIAGNOSIS IN A UNIVERSITY CLINIC**

Recent studies indicate that fibromyalgia may be often misdiagnosed and that approximately 75% of individuals who report being diagnosed with fibromyalgia may not actually meet the criteria for a fibromyalgia diagnosis. This study had patients complete a questionnaire to see if they fit the diagnostic criteria for fibromyalgia before meeting with their doctor. While not as widespread as initially thought, nearly 50% of patients who met the criteria for fibromyalgia were not identified as such by their physician.

**What you need to know:** Diagnosing fibromyalgia can be difficult, and many within the rheumatology community disagree about the appropriate way to diagnose fibromyalgia. While the criteria for diagnosing fibromyalgia is easy to use, clinician bias, the meaning of a fibromyalgia diagnosis, and the validity of many diagnoses all present significant problems that need to be addressed by the rheumatology community.

FORWARD Research at the 2018 ACR Annual Meeting
CHANGES IN ALCOHOL USE IN PATIENTS WITH RHEUMATOID ARTHRITIS: ASSOCIATIONS WITH DISEASE ACTIVITY, HEALTH STATUS, AND MORTALITY

Prior studies have shown that RA patients who consume alcohol may have better control over their disease, increased quality of life, and fewer symptoms than those who do not drink alcohol. This study attempts to test these results and determine whether or not alcohol consumption has a positive, negative, or no impact on disease activity.

What you need to know: It appears that, amongst FORWARD participants, lessening or quitting drinking alcohol does happen at the same time as higher disease activity, poor quality of life, and increased symptoms. However, these observations don’t necessarily mean that alcohol improves rheumatic disease symptoms—rather, that as patients begin to feel worse, they often lower or completely remove their intake of alcohol. These results call into question previous studies that suggest otherwise and require more research.

CAN PASSIVELY-COLLECTED PHONE BEHAVIOR DETERMINE RHEUMATIC DISEASE ACTIVITY?

Cell phones now collect incredible amounts of data, most of which cellphone users are unaware of. Some of these data points include where you go, when you go, and how far you go. This study attempts to determine whether or not that information, which requires no extra work on the part of the cell phone user, can be used to indicate higher rheumatic disease activity.

What you need to know: The study found that these pieces of information can indicate when a patient with other rheumatic diseases may be getting worse. This means that, without any effort on the part of the patient, simply carrying around a cell phone could provide more information into the quality of life, disease progression, and symptoms the patient is experiencing.

What is ACR?

The American College of Rheumatology is a professional membership organization, dedicated to improving the care of patients with rheumatic diseases and advancing the rheumatology sub-specialty. They are a not-for-profit, global medical society that serves over 9,500 physicians, health professionals, and scientist’s worldwide.

FORWARD + ACR

The ACR Annual Meeting is a chance for all participants in the rheumatic disease field to come together and reflect on and share the developments of the past year and establish priorities, goals, and often research projects for the next year. FORWARD is proud to participate as a non-profit, and we use the annual meeting as a chance to connect with and begin working with new researchers, physicians, patients, and organizations, as well as support the researchers, physicians, patients, and organizations we already work with to advance rheumatic disease research. This year, FORWARD data was used in a number of research presentations during the annual meeting that were seen by thousands of researchers and physicians from all over the world.

ACR + You

What does this mean for you, a FORWARD participant? It means that when you choose to share your voice and experience with FORWARD by filling out a questionnaire every six months, you’re contributing to the knowledge of thousands of researchers worldwide who are working daily to improve the diagnosis, treatment, and prevention of rheumatic diseases like yours. Your experience, and your willingness to share that experience with FORWARD, is a vital part of rheumatic disease research.
View Your FORWARD Databank Results Online

MANY OF THE QUESTIONS WE ASK EVERY SIX MONTHS give researchers and doctors scores that show how you’re doing. We have heard from many of you that you want to see your results. You can now get your scores any time you need them on our website. If you don’t already have an account on our website, register today at forwardndb.org/user/register. Having an account keeps your information private and lets you access your scores.

You will be able to see scores for every questionnaire you’ve ever completed for the FORWARD Databank, as well as print them for your own information or to show to your doctor.

Frequently Asked Questions

EVERY SIX MONTHS, we send our questionnaires to you, our great participants who volunteer your time to add your voice and information to the FORWARD Databank. Each and every message we receive from you is read, and these comments often lead to changes to the questionnaire or provide an idea for a research project. We would like to take a moment to answer some of our most frequently asked questions.

Did you add new questions about diet and exercise?
In the current questionnaire, you will see some new questions regarding diet and physical activity. These questions were added at the request of researchers that work with the Databank, and they were also suggested by many participants who noted in comments that they would like to see questions regarding diet and exercise.

Diet and physical activity have been suggested by doctors and other health professionals as a way to help with the treatment of arthritis. These questions will provide an overview of the many diets and physical activity levels of the participants of the Databank and reveal if there is any connection between these measures and any of the other measures in the questionnaire.

Why are you asking about marijuana use?
There are also a couple of new questions regarding the use of marijuana. Many states have now legalized marijuana for medical or recreational use, but the current research on using marijuana for arthritis is limited. These questions will help researchers within the Rheumatology community explore its use and whether it has been helpful for patients.

What happens to the information I provide?
The information you provide will be entered into a computer data bank for use by medical researchers. Researchers describe their findings in articles that are published in medical journals and in presentations at national and international meetings. That way, all doctors who treat arthritis are able to receive the benefits of the research. What they learn will help them to provide better medical care to people with rheumatic diseases and similar medical conditions.

Some questions don’t apply to me. How do I answer?
If you come across a question you don’t understand or don’t see how it applies to you, we’d suggest that you try to choose the choice that best fits how it might apply to you. We’re always available to talk through the questions and your responses if you find that helpful. Otherwise, just know that we try to make sure the questions make sense for everyone and that all appropriate answers are listed. If not, simply select the best choice, even though it may not be completely correct for you.
Prize Drawing **WINNERS!**

FORWARD can best contribute to research when the questionnaires are completed and returned as soon as possible. We conduct random drawings as a token of our gratitude in help with rheumatology research. Our random drawings consist of:

+ 2 drawings for **$1,000 each** for those who complete a large questionnaire via mail, web, or phone within the first four weeks.
+ 2 drawings for **$500 each** for those who complete a large questionnaire via mail, web, or phone within the first four weeks.
+ 4 drawings for **$50 each** for those who complete a shorter questionnaire via mail or phone anytime within the first six months.

**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!

**Reminders**

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.
Who will see my questionnaire and information about me?

Only the NDB research staff. Once your information is in our research Data Bank your using the Data Bank for medical research cannot identify you. We have 25 years experience collecting arthritis data and protecting the confidentiality of what kind of questions will you ask?


What happens to the information I provide?

Presentations at national and international meetings. Information obtained from

The pamphlets and a small tabletop stand are available free from FORWARD. Just contact us at info@ndb.org or 800-323-5871, ext. 133. Thank you!

Refer a Friend

Here’s a really easy way to let a friend know about the Databank. Just give us your friend’s email address and we’ll send out an email invitation to join the study. Go to forwardndb.org/participate/tell-friend.

For More Information or to Participate

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

Directors
Kaleb Michaud, PhD
Frederick Wolfe, MD

Executive Director
Rebecca Schumacher

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, forwardndb.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 people with rheumatic diseases, and we do this with a relatively small amount of grant funding. So before you decide to not participate, please let us know what we can do either 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!

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.