

FORWARD

SUMMER
2022

NEWS AND INSIGHTS FROM THE NATIONAL DATABANK FOR RHEUMATIC DISEASES

Connecting the Dots

Psoriasis is More
Than Skin-Deep

Beyond Physical:
Chronic Illness
and Self-Care

**The FORWARD
Biobank**

Learn more
on page 9 ➤



In This Issue

3

Thank You

4

Taking Care of Your Chronic Illness

5

Condition Highlight: Psoriasis and Psoriatic Arthritis

10

FAQs: How Does FORWARD Help?

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



Letter from the Co-Director

Hello, and welcome to the latest issue of FORWARD magazine!

In this issue, you'll have the opportunity to discover some of the different areas of research to which FORWARD contributes valuable data and learnings—some of which might surprise you! We hope that you enjoy learning about an exciting new FORWARD research project and diving deep into the connection between psoriasis, psoriatic arthritis, and other autoimmune illnesses.

We also sat down with Dr. Kristin Wipfler, Director of the FORWARD Biobank to understand the role of the Biobank and the value that it adds to FORWARD's research contributions. You'll see that we've included an FAQ that brings us back to basics—what is FORWARD, and how do we help? If you've ever wondered what the point of FORWARD research is, or the type of research we perform and how that research impacts patients like you, turn to page 10 to learn more.

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

Sincerely,

**Kaleb Michaud, PhD
Co-Director, FORWARD**



Non-Profit Spotlight

The National Psoriasis Foundation

The mission of the National Psoriasis Foundation (NPF) is to drive efforts to cure psoriatic disease and improve the lives of those affected. As a non-profit organization, they seek to support research and advocate on behalf of individuals with psoriatic diseases, including psoriasis and psoriatic arthritis. The NPF also provides patient education resources, including information about psoriatic diseases, treatment, and care, and patient support resources to help guide you through your journey.

To learn more about the National Psoriasis Foundation, their work, and psoriatic diseases, visit psoriasis.org.



JOIN FORWARD

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



TO HELP OTHERS.

The information about your experience with a rheumatic condition is used by researchers to improve the diagnosis, treatment, and prevention of rheumatic diseases.



IT'S EASY.

Questionnaires are only sent out twice a year, and follow-up questions are only sent as needed to add more information to the data from the main questionnaire.



YOU'RE NOT ALONE.

Nearly every person is affected by a rheumatic disease, through a personal diagnosis or the diagnosis of a loved one. We know that together, we can continue to make a difference.

Visit forwarddatabank.org/join-forward or call **1-800-323-5871** today!

Thank you TO OUR PARTICIPANTS

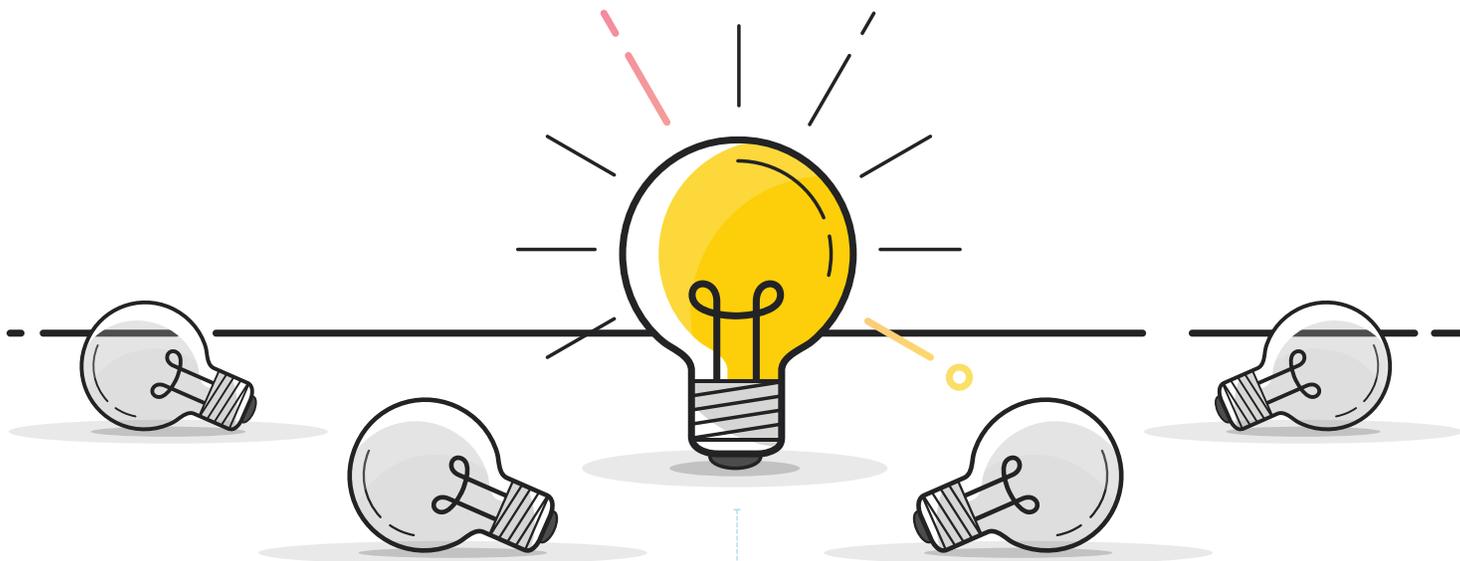
It is because of individuals like you—those who use their time and energy to fill out our bi-annual questionnaire, those who have donated blood to the FORWARD Biobank, and those who have shared FORWARD with their friends, families, and physicians—that we are able to make a difference. Because of you, we are able to participate in and support research designed to improve the diagnosis, treatment, and prevention of rheumatic conditions.

As you probably know, the rheumatology community studies many different conditions, some of which are intertwined with one another and some which have very similar symptoms. However, these conditions, while often connected to one another, will often have distinct differences. It is because of you that we are able to dive deep into the study of these conditions and to understand the unique experiences of individuals with many different conditions and treatments.

We'd like to share a very big THANK YOU to our participants who make this possible.

We hope that you know how valuable your participation is to FORWARD. To those who have been with us for years—thank you for your commitment. And to those who have only recently joined, welcome! Together, we're making a difference in the diagnosis, treatment, and prevention of rheumatic diseases.

To learn more about one of the diverse conditions studied by FORWARD, turn to page 5.



Beyond the Joints

When it comes to a chronic illness, the potential impact often goes beyond physical discomfort or pain.

Impacting Social Life

Some people may feel isolated from their inner circle following a diagnosis, whether from physical barriers—such as lack of mobility—or emotional barriers, like a lack of motivation or fear of the future.

Financial Burdens

You may find that you need extra help transporting yourself and completing household and personal tasks. Home care can be costly if not covered by insurance. Likewise, you may also be unable to work at the same pace as before, especially if your occupation is labor-intensive, high-stress, or time-demanding.

Increased Need for Accessibility

You may need to modify your living spaces to better accommodate your needs. Outside of this, having to consider accessibility in public spaces is necessary for people who use wheelchairs. All of this can add frustration and difficulty to your day-to-day life.

Communication Becomes Key

Navigating life with a chronic condition can feel overwhelming and chaotic. You may need to discuss accommodations with your work. Altering events and travel plans may happen more often because of frequent fluctuations in symptoms—and that's okay. **The ups and downs of living with a chronic rheumatic disease may make it tempting to avoid making plans altogether out of fear of disappointing others, but know that continuing to do the things you enjoy is one of the most important parts of your wellbeing!**

Taking Care

Managing chronic symptoms can sometimes feel impossible. However, understanding factors we can control in everyday life, like stress and diet, can have a positive effect on our overall well-being.

Manage Stress Levels

Engaging in physical activity or exercise is a great way to manage stress—even a walk around the block can help. Plus, it's good for your overall health! Physical activity is safe and beneficial for almost all people with rheumatic conditions, but ask your doctor if you have concerns.

Maintain an Anti-Inflammatory Diet

Individuals adopting a healthy, anti-inflammatory diet full of fresh vegetables and healthy fats may see a reduction in overall joint pain (and some studies show that this kind of diet may help slow the progression of damage).

Get Involved

Many individuals may find that supporting initiatives that bring awareness to chronic rheumatic diseases help them feel empowered and more in touch with their care journey.

Seek Community

Seeking connection with others can help you stay confident throughout your journey. Building and maintaining connections can bring awareness to the reality of living with a chronic rheumatic disease.

When you join FORWARD, you're joining a community of individuals dedicated to improving the prevention, treatment, and outcomes of rheumatic diseases. Learn more at FORWARDdatabank.org.

Psoriasis:

A LONG-TERM CONCERN



Psoriasis, a skin condition that ranges from mildly annoying to severely disruptive to one's life, can go deeper than the skin. Read on to connect the dots between psoriasis, psoriatic arthritis, and other autoimmune conditions.

Alexis Ogdie, MD, MSCE, Director of the FORWARD spondyloarthritis registry, shares what psoriasis is: "an inflammatory skin condition that is very common in the United States. It affects around 2 to 4% of adults. It is most commonly very mild and might just be a little bit of a plaque on an elbow or a knee. It could be on the scalp and is sometimes thought to be dandruff." ➤



"It can also be much more severe and cover larger areas of the body. It can sometimes be across the forehead or in the genital region. As you might imagine, that's much more bothersome. It can also affect the hands and feet and make those areas uncomfortable. The skin tends to be itchy and can be painful."

"Most people don't like the way it feels and looks. But in addition, psoriasis carries inflammation. When there's more psoriasis on the body, it is generally associated with more systemic inflammation as well. And that's where this condition can become very concerning when you consider the long-term impact."

Psoriasis, Psoriatic Arthritis, and More

According to Dr. Ogdie, those with psoriasis "are carrying around larger amounts of inflammation. That inflammation is associated with the development of psoriatic arthritis, which is an inflammatory arthritis. It usually causes joint swelling, tendon swelling, or inflammation of your back or spine, which generally manifests as stiffness in the morning or difficulty moving. You might experience joint pain and loss of some function—an inability to do the things you want to do. And there are other symptoms that many people experience, including fatigue and just feeling kind of run down."

"Looking long-term, psoriatic arthritis can lead to joint damage. When we're treating psoriatic arthritis, the swelling is

one thing we really focus on because we can bring that down with medications. What we're really trying to do is prevent damage so that in the long-term people can stay functional."

"Psoriasis is also associated with the development of heart disease and an increased risk for diabetes. Other things like fatty liver disease can travel along with it, too. So, there's these other co-morbidities that it is associated with and that is what we are concerned about."

New FORWARD Psoriasis Registry

FORWARD is excited to announce a new psoriasis registry, which is designed to ask specific questions to individuals with psoriasis. "We're going to start primarily as a questionnaire along with asking participants to provide some pictures of their psoriasis," shares Dr. Ogdie. "We rate the quality of psoriasis based on how red it is, how much scaling it has, and how thick it is, which you can often see on an image. We will also ask questions about where the psoriasis is located, how severe is it, how much it bothers them, as well as questions about some of their other co-morbidities."

"Our plan is to watch people over time for development of arthritis to try to figure out what factors are associated with developing one of those other autoimmune conditions. There are so many things we can learn from this type of



The Psoriasis Registry: What will you do with my information?

Like the usual twice-yearly FORWARD questionnaire, psoriasis registry participants will receive a twice-yearly questionnaire that includes questions about their condition, symptoms, treatments, and any other health conditions that they may be experiencing.

Participants will also be asked to share photographs of any psoriasis present on their skin so that researchers are able to better understand the severity of the condition.

This information will be made available to researchers who are studying psoriasis and its associated conditions. Like FORWARD data from the original questionnaire, this information will be vital to improving our understanding of and ability to treat this condition.

What to Look Out For

If you're not sure, these symptoms below may indicate that you should see your doctor about a potential psoriasis diagnosis:

- Red, inflamed rashes or patches on the skin
- Skin that is regularly itchy or painful
- Scaly sections of your scalp, which may seem like dandruff

registry, including who's at risk for heart disease and what we need to look out for to know who's at risk for these other autoimmune conditions, like psoriatic arthritis. We also want to learn about therapies and treatments—why people respond to certain therapies or don't respond to other therapies, how long the therapies are effective for... some of those basic things that we don't have a lot of data on. Having a large population study like this will be really helpful."

We Couldn't Do It Without You

"To many participants, it may seem like you're just filling out a questionnaire, that it isn't that big of a deal or maybe it feels tough because it takes a really long time. But we really appreciate that because in aggregate, with all of the other patients, that questionnaire can really help us learn a lot about these diseases. We're hoping to help solve some of these big problems, and that starts with one participant at a time."

Do you have psoriasis, or have a family member or friend with psoriasis? Please consider joining or sharing the FORWARD psoriasis registry! This registry will provide researchers with the important information they need to improve the understanding and treatment of psoriasis and the many conditions it is associated with. Visit FORWARDdatabank.org/psoriasis to learn more.



Alternative Treatments: Rheumatic Diseases and Cannabis Use

At FORWARD, we strive to study all aspects of rheumatic disease diagnosis and treatments—including new or alternative treatments that are not considered ‘mainstream.’ Below, we share the results of one such study, which was the first US-wide study to evaluate the cannabis usage in the rheumatic diseases population.

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

The study was performed using data from FORWARD questionnaires, with 11,006 respondents included. These participants were asked about both past and current cannabis use. Arthritis pain is cited as a common reason for medical use of cannabis. Knowing this, we set out to understand patterns of use within FORWARD participants.

WHAT WE LEARNED: There has been an overall increase in cannabis use in all states regardless of diagnosis or if cannabis was legalized (the largest increases were in the states where it was legalized).

WHY IT'S IMPORTANT: Participants who reported cannabis use had overall worse disease and condition activity, more comorbid conditions, and scored higher on pain, fatigue, sleep, anxiety, and depression scores compared to nonusers.

These characteristics suggest that those who use cannabis do so because they feel worse—and that their pain management needs may not be met by other therapies. FORWARD will continue to ask questions about cannabis usage in the twice-yearly questionnaire so that we are able, over time, to continue to learn more about cannabis and rheumatic diseases.

Future research will be able to dive deeper into the connection between cannabis and pain management to better understand the benefits and risks of using cannabis as a treatment for rheumatic disease symptoms, whether cannabis usage has the desired effect of improving symptoms and outcomes, and to help health-care providers give informed guidance to their patients about the use of cannabis-based products.

18.4%
of respondents
have used
cannabis

Before beginning any treatment for your condition or symptoms, discuss it with your doctor first! They have the knowledge necessary to keep you safe while helping to determine the right treatments for you.

The Importance of Researching Alternative Treatments

As the legality of cannabis and availability has increased, usage has increased as well—amongst respondents for this study, usage tripled between 2014 and 2019 (6.3% to 18.4%).

Because this alternative treatment is being used, it is important for doctors to understand it—how it impacts patients, how it interacts (if at all) with other treatments, and what the long-term effects of it might be.

According to the study, “arthritis pain is a commonly cited reason for medicinal cannabis use. However, little is known, and we set out to understand patterns of cannabis use in a US-wide rheumatic disease population.”

The Future of Personalized Medicine



We sat down with **Kristin Wipfler, PhD**, Biobank Director at FORWARD, to learn more about the power of the FORWARD Biobank when combined with the bi-annual questionnaires.

The FORWARD Biobank

"A biobank is a collection of biologic samples—they're usually collected for research purposes. It could include everything from blood, to urine, to biopsy tissue from an organ. FORWARD's biobank collects blood samples," shares Dr. Wipfler.

"Most people think of blood as a singular thing. But we can separate it into subcomponents. So, we have whole blood samples, but we can also look at plasma and white blood cells, and we can extract individual biomarkers that are present, including some that are specific to rheumatic diseases and autoimmune diseases. The blood is full of all different kinds of proteins and measures of immune function. At FORWARD, we can look at individual autoantibodies, we can look at already known biomarkers, and we can also explore potential new biomarkers."

When it comes to the future of rheumatic diseases, the data gathered from the FORWARD Biobank could be a game changer. "Having a biobank is important for things like genomic studies and for personalized medicine. You can't identify those biomarkers that allow for personalized medicine if you don't have a biological sample to identify biomarkers from." While this form of personalized medicine is already being used when treating patients, it still has a long way to go:

"There are millions of other markers to be assessed—things that could tailor treatment even further or inspire the development of a new drug. There are a lot of unknowns that we still want to identify."



Bringing Personalized Medicine to Life

Dr. Wipfler shares, "My love has always been looking at genomics and personalized medicine to help as many people as possible. With the research using the Biobank, we're able to look at specific biomarkers within a person's blood that allow us to better determine the success of a treatment or the risk-level of their disease's severity. We are able to make decisions based on their unique makeup as a person."

In order to do this, Dr. Wipfler and the FORWARD researchers consider both the questionnaire data and the biobank data. "The questionnaires alone are very informative, very powerful. But when we link the questionnaires with the biobank, we can really study the relationship between those lab results and patient outcomes."

Interested in donating blood to FORWARD's biobank?

Email kristin@ndb.org to be notified of upcoming opportunities.

"At this point, we are still using donated samples from as early as 2010 for new and ongoing research. Those who have donated to the FORWARD Biobank have made a very strong impact, and we're so grateful."

Back to Basics

Take a look at some of the most **common questions** we've received in the past six months.

What does FORWARD do?

FORWARD is the largest longitudinal, patient-reported research databank for rheumatic disorders in the United States. We report to the rheumatology community in medical and scientific peer-reviewed journals and at major scientific conferences such as American College of Rheumatology (ACR) and European League Against Rheumatism (EULAR).

So, what does that mean? At FORWARD, we collect important information from real patients about their daily lives—their disease, lifestyle, symptoms, treatments, etc.—over a long period of time. Some of our participants have been with us for over 40 years! We decide what information to ask for based on decades of experience supporting rheumatology research and regularly connect with researchers to understand what kind of information they need and are interested in.

We remove the identifying information from questionnaire data and compile it so researchers who are studying nearly any aspect of rheumatology diagnosis, treatment, and symptoms can use it. As a longitudinal research study, we're able to understand what participants experience throughout their life—not just at any one moment in time—which gives researchers a much better understanding of the impact of their disease, effectiveness of treatment, and progression of symptoms over time.

Why do you collect data from patients? Why not their doctors?

When it comes down to it, you are the expert on what your day-to-day experience is like. Because there are so many different types of rheumatic and autoimmune disorders and treatments, FORWARD will often confirm your diagnosis and treatments with your doctor. Otherwise, we know that you are the right person to ask about your own experience, because your doctor can't be at home with you or out running your errands when your symptoms are really impacting your daily life.

This is called real-world data—data that is gathered outside of the traditional medical setting. While physicians and researchers ultimately decide what to study, they need to have the best information possible about what is affecting real patients like you. That's why a patient-reported databank like FORWARD is so important to improving the diagnosis, treatment, and prevention of rheumatic diseases.

Why do you ask the same questions every six months?

It's important that we make sure we are collecting the same information from you and other participants for every questionnaire because that is what allows us to understand the long-term impact and experience of your disease and treatments. Because this data is used by scientific researchers, there are strict guidelines that require us to be very careful to not change the wording of a question in case it changes your interpretation and answer.





Random Drawing Information

FORWARD CONDUCTS RANDOM DRAWINGS as a token of our gratitude. Our random drawings consist of:

- + 5 drawings for **\$500 each** for those who return a large questionnaire via mail, web, or phone any time within six months for the current questionnaire.
- + 5 drawings for **\$100 each** for those who return a shorter questionnaire via mail or phone anytime within six months for the current questionnaire.

Email: What You Need to Know

FOR PATIENTS USING WEBQUEST, email is our primary method of getting in touch with you. Even if you're not using WebQuest, we'd like to be able to send you important information by email. **Here's an important step you can take to make sure our email gets to you:** add us to your email address book! Our address is **webquest@ndb.org**. This will ensure that our mail makes it through the spam blockers and into your inbox and not your spam or junk folder. You will need to do this every time you change your email address.

We cannot emphasize enough how important it is for you to let us know when you change your email address. To update your email address, go to our website, forwarddatabank.org, and click **"Update Contact Info"** under the **"Patients"** tab. You can also update your email address if you have set up an account in the FORWARD Patient Portal. If you have an account, you can login and click on your name in the upper right-hand corner, then click on "Change Email." Of course, you can always email or call us, and we will change it for you. Thank you!

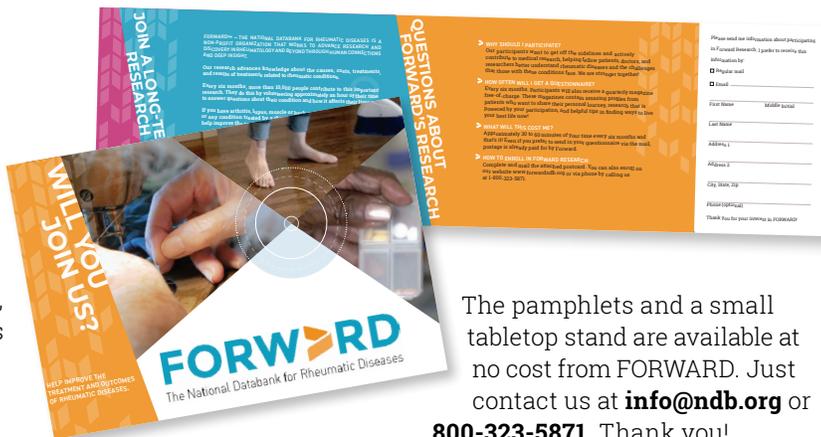
While working on your questionnaire, if you have ANY questions, please contact us right away by email (**webquest@ndb.org**) or phone (**1-800-323-5871**). These might be about technical difficulties or how to interpret a question. If you put your immediate questions in the comments section, we probably won't see it in time to answer.

Please use the comments section for any information you think we should have that isn't covered in the questionnaire. This could be about a change in medication that needs explanation or information about other considerations of your condition that you think we need to know. You may also ask general questions that don't require an immediate answer.

The Medical Information Release form is completely optional and does not need to be signed to be able to participate in the research. We use the medical records to help validate medical events that may be related to rheumatic diseases or the safety of medical treatments. The value of the research and the time people put into helping us is increased when we can confirm the details of such events—we thank those of you that have signed the form to add your medical record information to the FORWARD Databank. **Your information is always confidential**, and your participation is extremely valuable to the research with or without the signed medical information release form.

Helping FORWARD in Other Ways

FORWARD's goal of telling the rheumatology and medical community about patient experiences requires a large group of participants. Pamphlets are available to share with patient support groups/meetings, health fairs, offices, churches, or clinic waiting rooms—our pamphlets explain what we do and how you and others can help. Each one has a postage-paid postcard to register and become a participant of FORWARD.



The pamphlets and a small tabletop stand are available at no cost from FORWARD. Just contact us at info@ndb.org or **800-323-5871**. Thank you!



REFER A FRIEND

Here's a really easy way to let a friend know about FORWARD. Just give us your friend's email address, and we'll send out an email invitation to join the study. [Go to forwarddatabank.org/tell-a-friend](http://forwarddatabank.org/tell-a-friend).

About WebQuest

WebQuest is the online version of our questionnaire. The questions are the same as what you see on the paper questionnaire. People who are comfortable using computers may find it easier than the paper version. [If you would like to try it, contact us at webquest@ndb.org](mailto:webquest@ndb.org) and we will set you up with the online version.

WAIT! WE WANT YOUR VOICE TO BE HEARD!

We need your help in filling out our questionnaires. We are a nonprofit research organization with a staff of 16 that combines the experiences of thousands of patients over time for use by rheumatologists, nurses, immunologists, epidemiologists, and even health economists. We are the ONLY longitudinal research study that asks the level of detailed questions we have with so many participants with rheumatic diseases, and we do this with a relatively small amount of grant funding. Please let us know what we can do to help you by phone (**1-800-323-5871**), email (info@ndb.org), or mail. We want to hear from you, as we are passionate about fighting these diseases!



For More Information or to Participate, Please Reach Out

727 N Waco | Suite 200 | Wichita, KS 67203
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.