

FAQs about the FORWARD Psoriasis Registry

We invite you to help with this important research by joining the project. There are more details included in the following information:

What is the FORWARD Psoriasis Registry?

The FORWARD Psoriasis Registry is a project that collects data on psoriasis directly from persons who have this condition. The goals of the project are to advance our knowledge about the causes, outcomes, costs, treatments, and results of treatments related to psoriasis. Another important goal of the project is to stimulate data collection and study by health professionals and make FORWARD data available for medical research.

How often will I get a questionnaire?

Generally, FORWARD sends questionnaires to participants every 6 months and there will be a short monthly questionnaire. When you first register online, you will have a special questionnaire to obtain some background information about you.

Who will see my questionnaire and information about me?

Only the research staff. They look at the questionnaire to see if it is complete and make sure that your name, address, and email address are correct for mailing and emailing purposes. Once your information is in the FORWARD research data bank, your contact information is removed for research purposes. That way, any researcher using the data bank for medical research cannot identify you.

Will my name and medical information be available to anyone else?

No. FORWARD does not give away names, sell them, or make them available to anyone else. FORWARD has been collecting arthritis data for more than 25 years and no outside person has ever had access to anyone's name.

Does it cost me anything to participate?

No. Participation is absolutely free and there are no additional costs to you. FORWARD has a phone line for questions: **1-316-263-2171**.

How much time does it take to complete a questionnaire?

Questionnaires take approximately 5 to 30 minutes to complete, once a month and every 6 months.

Is there any compensation for participating?

- In general, participants will not be compensated. However, for questionnaires directed toward specific studies, participants will be compensated for completion of the questionnaires relevant for that study (e.g., \$50 per 6-month questionnaire to a maximum of \$200 for the study). Compensation will be done by either a gift card sent via email or by mail OR a check sent by mail and sent two times a year after each 6-month questionnaire period is reconciled and closed.
- Each participant will receive free issues of the *FORWARD Psoriasis Registry Newsletter* as long as they remain in the project. This newsletter contains information about psoriasis and psoriatic arthritis, new treatments, research in general, and the results of research that you have participated in by completing the questionnaires.
- There is the general compensation of knowing that by participating in this research project, you have helped to improve the understanding of psoriasis and psoriatic arthritis treatment and outcomes for future generations of people with the disease.

How do I participate?

Register online at: <https://www.forwarddatabank.org/psoriasis-consent/>

Fill out a brief background questionnaire online to finish the enrollment.

FORWARD will then contact you by regular mail, e-mail, or telephone, and follow up with short monthly questionnaires and a questionnaire every 6 months for a period of 5 years. To participate in the project, you must have psoriasis or

psoriatic arthritis. In addition, you must give your consent to participate.

What if I change my mind and don't want to participate?

It is hoped that you won't do so because this research depends on a continuing group of people, helping together, over a period of time. But, of course, you may discontinue participation at any time and for any reason. Just let FORWARD know by contacting them by any of the following methods:

- **Mail:** FORWARD
727 N Waco, Suite 200
Wichita, KS 67203
- **e-mail:** ForwardPsoriasis@ndb.org
- **Phone:** (316) 263-2171
- **Fax:** (316) 263-0761

What kinds of questions are asked?

Many different kinds of questions are asked. Here are some of the areas that questions are asked about:

- Pain
- Functional ability
- Work ability
- Disability
- Joints that are affected
- Symptoms
- Treatments with medications and surgery
- Side effects of treatments
- Other illnesses
- Questions about who you are
- Questions about how you manage with your illness

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 for articles that are published in medical journals and for presentation at national and international meetings. That way, all doctors who treat arthritis are able to receive the benefit from the research. What they learn will help them to provide better medical care to people with psoriasis and psoriatic arthritis and similar medical conditions.

Who is in charge of this project?

The primary investigator is Kaleb Michaud, PhD, Professor at the University of Nebraska Medical Center and Director of FORWARD. Associate Investigators are: Alexis Ogdie, MD, a rheumatologist at University of Pennsylvania (UPENN), and Joel Gelfand, MD, a dermatologist at UPENN.

Are any other health care professionals associated with this project?

Yes. More than 1,000 health care professionals from across the United States have helped in this research project by recruitment of participants and providing ongoing information about treatment and results of tests.

How many people will be participating?

There are over 10,000 participants in FORWARD. Each one is important because everyone's experience is unique. However, the FORWARD Psoriasis Registry's recruitment goal is to enroll 5,000 participants. With so many participants in the project, it is hoped that the results will make it possible to answer questions about treatment effectiveness and side effects that could not otherwise be obtained from just a few participants.

Can participating in the FORWARD Psoriasis Registry help me with my health problems?

Because this is a research project, FORWARD is unable to answer individual questions about treatments and symptoms. You may want to discuss any specific questions directly with your health care provider.