What is the Corrona Psoriasis Registry?

- Corrona, LLC is a company that develops and operates registries in autoimmune diseases to advance medical research and improve patient care.
- In 2014, Corrona partnered with the National Psoriasis Foundation to begin planning the Psoriasis Registry and enrolled its first patient in April 2015.
- The registry collects and analyzes data to help dermatologists, researchers, and the pharmaceutical industry compare the safety and effectiveness of psoriasis treatments, which may benefit patients like you.
- The Registry has a network of 120 U.S. dermatology sites and is continuing to grow.
- Over 1650 patients have enrolled as of July 1st, 2016.
- Anticipated total recruitment is more than 10,000 patients.

Who can enroll in the Registry?

- Patients must be at least 18 years old,
- Diagnosed with psoriasis by a dermatologist, and
- Have started a biologic medication for psoriasis within the last 12 months.

*Corrona Sites from Inception of the Psoriasis Registry

* as of May 31, 2016
PSOaring UPWARD

Why Start an Independent Registry?
Stacey Hirata Holmgren, PharmD, MBA
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Corrona, LLC

Clinical trials are a necessary and important step in developing new drugs for psoriasis, but they don’t always tell the whole story. Studies often have strict requirements about who can be included in the trial, what other medications are allowed while in the trial, and when patients must return for follow up visits. These types of trials provide valuable information about the safety and effectiveness of medications. However, they do not show these medications will be used in the real world by patients who may have other diseases, who may be taking other medications, or who cannot come back for follow up on a set schedule. In addition, clinical trials usually do not include enough patients, nor do they follow them for enough time to fully ascertain side effects that are very rare or occur after taking the medication for a long period of time.

The Corrona Psoriasis Registry was conceived and launched to collect real world data on psoriasis patients over a long period of time — at least 8 years — and, hopefully, beyond. Corrona also has a Rheumatoid Arthritis Registry which began in 2001 and has been following patients for 15 years. By observing the treatment and outcomes of thousands of psoriasis patients over many years, the Psoriasis Registry will provide answers to questions about the long-term safety and effectiveness of these medications.

Similar psoriasis registries exist in many European countries, including Germany, Italy, Spain, France, and the UK. Registration is recommended or, in some cases, required by each country’s national health system for patients on biologics or other systemic medications. Although registration is not required for the Corrona Psoriasis Registry, Corrona recommends that you ask your dermatologist if you are eligible to enroll, so that you can contribute valuable information to help better understand psoriasis and improve treatment.

About the National Psoriasis Foundation®

“The National Psoriasis Foundation (NPF) is a non-profit organization with a mission to drive efforts to cure psoriatic disease and improve the lives of those affected.

Founded in 1966 from a tiny classified ad in a Portland, Ore. Newspaper, the Psoriasis Foundation has evolved to become the leading patient advocacy group for the 7.5 million Americans living with psoriasis and psoriatic arthritis.”

—From the website of National Psoriasis Foundation®
What to Expect at a Registry Visit
Deidre Sepavich, MBA
Senior Dermatology Registry Manager
Corrona, LLC

At your enrollment registry visit, information will be gathered during your routine office visit with your treating dermatologist. You will be asked to provide informed consent to participate in the registry and complete a questionnaire about your health, such as symptoms you are experiencing and medications you are taking. Your dermatologist will also be asked to complete a questionnaire and respond to questions about your health, such as your laboratory results, recent hospitalizations, or new or worsening medical conditions that may be related to psoriasis or medications you are taking for psoriasis.

How much time will it take to complete an enrollment registry visit?
It is estimated that it will take you about 30 minutes to complete the enrollment registry visit. However, the length of the visit may vary by the dermatology practice.

How often will I need to complete a registry follow-up visit?
Registry follow-up visits will take place at your regularly scheduled visits, about every 6 months. Similar to your enrollment registry visit, follow-up information will be gathered during your routine office visit with your treating dermatologist. You will be asked to complete a questionnaire about your health, such as medical conditions or symptoms you may have experienced since your last registry visit.

How much time will it take to complete a follow-up visit questionnaire?
The follow-up visit is expected to take less of your time than the enrollment visit. It is estimated that it will take you about 10 minutes to complete the subject follow-up visit questionnaire.

Why are registry follow-up visits necessary?
The Corrona Psoriasis Registry is collecting data over a period of time. In research, this is often referred to as a “longitudinal study”. This type of study provides data about the same individual, like you.

You could think of it as a photograph album rather than a single snapshot. By capturing information from you at each follow-up visit, approximately every 6 months, it tells a story about your health and how it has changed over time.

Your participation is essential to helping researchers better understand psoriasis, which may lead to more effective treatments with an end goal of helping all of us impacted by the disease. The more research conducted on the topic of psoriasis, the better the awareness and treatments will be.

From the Red Carpet!
Paul Kinsella, BS
Associate Dermatology Registry Manager
Corrona, LLC

Did you know that 7.5 million Americans have psoriasis?
Psoriasis is a disease that does not discriminate and can affect anyone. What you might not know is that many celebrities—from stage and screen to the playing field—live daily with the disease.

Jon Lovitz, comedian and former Saturday Night Live cast member, has campaigned for psoriasis awareness and has written and starred in a psoriasis campaign called, “Are You Serious?” Do you remember the 50’s TV hit “Leave it to Beaver?” The star of the show, Jerry Mathers, has lived with psoriasis for over 20 years. Another famous TV personality with psoriasis is CariDee English, Cycle 7 winner of America’s Next Top Model in 2006. CariDee was diagnosed at age five and, at one point, psoriasis covered 70% of her body. Some famous athletes also have psoriasis. Perhaps the most famous is professional golfer Phil Mickelson. Another is Olympic swimmer Dara Torres; she’s won 12 medals in five different Olympic games. NFL great, Mark Gastineau, also has the disease.

Lastly, there are some notable singers that have the disease. LeAnn Rimes was diagnosed at age two and, by age six, it covered 80% of her body. She has publicly campaigned for psoriasis awareness with her campaign motto, “Stop hiding. Start living.” Some other musicians include Art Garfunkel, Cyndi Lauper, and Liam Gallagher of Oasis.

Most of the celebrities above have been outspoken about their condition and have helped spread awareness for the disease. They have noted that limiting stress in their lives, finding a medication that works for them, exercising, and eating healthy are ways in which they have kept their condition under control. They have also shown that you can live an extraordinary life, even in the public eye, with psoriasis.
If you have any questions about the Corrona Psoriasis Registry, please see your health care provider. The PSOaring UPWARD Patient Newsletter is for distribution by Corrona Psoriasis Registry sites only, following IRB approval.

1. Psoriasis is a disease that involves the immune system. T or F
2. The first patient was enrolled into the Corrona Psoriasis Registry in December 2015. T or F
3. You can catch psoriasis from other people. T or F
4. Corrona partnered with the National Psoriasis Foundation® to begin the Psoriasis Registry. T or F
5. My participation in the Corrona Psoriasis Registry is contributing valuable information. T or F

Psoriasis is an autoimmune immunodysregulatory disease that causes raised, red, scaly patches to appear on the skin. The Corrona Psoriasis Registry enrolled its first patient in April 2015. Corrona partnered with the National Psoriasis Foundation® to begin the Psoriasis Registry. Your participation in the Corrona Psoriasis Registry is contributing valuable information to help better understand psoriasis and improve treatment. By observing the treatment and care of thousands of psoriasis patients over many years, the Psoriasis Registry will provide answers to questions about the long-term safety and effectiveness of psoriasis medications and care of thousands of psoriasis patients. The Psoriasis Registry is not contagious and cannot be passed from person to person. It can occur in members of the same family. Psoriasis is in an autoimmune immunodysregulatory disease that causes raised, red, scaly patches to appear on the skin. The Corrona Psoriasis Registry enrolled its first patient in April 2015.