Always Sunny
A double-whammy psoriasis and psoriatic arthritis diagnosis gave Summer Scirocco a new outlook on life

Steve Bieler, NPF Staff Writer

Summer Scirocco is a Louisiana native who has lived all of her life in the “itty bitty teeny town” of Vidalia, near the Mississippi border. In 2011, she became pregnant with her daughter, Emery. The pregnancy was difficult, and near the end of it, she required physical therapy for her hips and joints. Looking back, she believes these were undiagnosed symptoms of psoriatic arthritis.

Pustular psoriasis started the following year. She noticed a small patch of dry, red, scaly skin on her left heel, and in just a few weeks, it covered the bottoms of both feet. She had to quit her job because she couldn’t walk, and even when she could, she couldn’t wear shoes.

“I loved my job,” she said. “Knowing that a condition like this caused me to quit something that important to me was devastating.”

As her psoriasis spread, Scirocco began a grim march through the health care system. Her first doctors were uninformed and unsympathetic, she said. Once she was finally diagnosed and went through a trial-and-error series of meds until she found one that worked (Remicade [infliximab]), she endured five months when she couldn’t get the drug because of a dispute between her insurer and her doctor’s office.

“I was tired of being a guinea pig,” she said. “All the skin was gone off my feet and hands. My quality of life went from 11 to zero. I thought to myself, ‘I am only 27. I shouldn’t be unable to walk and be filing for disability.’”

In 2013, Scirocco found a dermatologist whom she calls her saving grace, and in 2015, she connected with a “fantastic” rheumatologist.

“If [a] doctor treats you like you’re a point on a chart, you are not bound to that doctor,” she said. “Don’t settle.”

She receives Remicade infusions from her new rheumatologist every six weeks. However, he can only administer these at the hospital where he’s affiliated — in Shreveport, a six-hour round-trip drive from Vidalia. It’s a 12-hour day (she brings her mother or a friend to drive), including the wait at the hospital, but the staff takes good care of her. “It’s worth it to me,” she said. “We don’t have that empathy in health care where I live.”

From the Fall 2016 issue of the National Psoriasis Foundation’s (NPF) patient publication, Psoriasis Advance. Reprinted with permission from NPF.
First Look:
Corrona Psoriasis Registry Data
Stacey Hirata Holmgren, Franchise Director
Psoriasis and Psoriatic Arthritis Registries
Corrona, LLC

Have you ever thought while completing your Corrona Subject Questionnaire, “How will my information be used? What do the other patients in the registry look like?” These are great questions, and we’ve finally collected enough initial data to be able to share the first snapshot with you.

The very first glimpse of data from the Corrona Psoriasis Registry was presented in two posters at the European Academy of Dermatology and Venereology Congress held in Vienna, Austria in September. The data from all patients who had enrolled by January 31, 2016 were included in this review. To be eligible for enrollment into the registry, patients must be at least 18 years old, have psoriasis diagnosed by a dermatologist, and have started or switched to an oral or injectable treatment for their psoriasis in the last 12 months.

At enrollment, these patients have had psoriasis for many years, tried several different therapies, and have other chronic diseases, called comorbidities.

- Of the 1,014 patients enrolled, 68% were receiving biologic medication, like Cosentyx, Enbrel, Humira, Remicade, Stelara, and Taltz, and 32% were being treated with an oral psoriasis medication.
- The average age of patients in the registry is 50.6 years, the average body mass index (BMI) is 30.5, and 45% are female.
- The average duration of psoriasis reported is 15.7 years.
- On average, patients had 8.5% of their body surface area affected by psoriasis, and about 1 in 5 of patients had more than 10% of their body surface area affected.
- Over half the patients enrolled had been treated with a biologic medication, and about one fourth of patients had received three or more biologic medications in the past.
- Of note, 44% of patients also reported a diagnosis of psoriatic arthritis. These patients tended to be older, have a higher body mass index, and were more likely to have used a biologic medication.

This is just the tip of the iceberg. As more patients enroll, and enrolled patients continue to come in for follow-up visits, the data collected on treatment effects, side effects, and how psoriasis affects your daily activities, will grow and some very interesting analyses can be performed. If you are already enrolled, thank you for participating and completing Registry follow-up questionnaires approximately every six months! If you haven’t enrolled yet, please speak with your dermatologist to see if you are eligible for enrollment so you can contribute your information to the registry.
Improving the Treatment of Psoriasis
One Follow-Up Visit at a Time

Deidre Sepavich, Sr. Dermatology Registry Manager
Corrona, LLC

Regular follow-up visits with your dermatologist are an important part of managing your psoriasis. Having this chronic disease requires you to actively participate in your own health care alongside your dermatologist. What you provide at each follow-up visit such as, how you are feeling, your day to day routine, and how you think your body is responding to the prescribed medications, plays an essential role in helping you and your dermatologist choose the best treatment regimen.

You have the opportunity to share this important information by completing the Corrona Psoriasis Registry Follow-Up Questionnaire. The information you provide at each follow-up visit, approximately every six months, begins to tell a story. You could think of each follow-up as one chapter in a novel. Each chapter tells a story about your health and how events, lifestyle, and your response to certain treatments may affect outcomes. By sharing your health ‘story’ at each follow-up visit, researchers and clinicians can better understand the disease and be better equipped to make the best decisions for your care today and in the future.

A very important part of the registry is to monitor and understand the safety of psoriasis treatments, often referred to as Drug Safety monitoring. How do you play a vital role in reporting safety events? During your follow-up visit, you will be asked about any medical problems that may have newly occurred since your last registry visit. It is always important that you let your dermatologist know right away (even in between visits) if you experience any of the following:

- Hospitalization
- A life threatening medical event
- A new medical problem that results in a disability
- Any new pregnancy
  - Any congenital anomalies or birth defects diagnosed in your baby

As you can see, you are providing a living history of your autoimmune disease. The information you provide by completing the follow-up questionnaire not only allows you and your dermatologist the opportunity to be able to discuss, develop, and maintain a more thorough plan of care for treatment of your psoriasis, but also helps advance the collective health of other patients with psoriasis. So, continue to actively participate in your psoriasis care, and remember to follow up!

Team NPF and the Role of Physical Activity in the Management of Psoriasis Symptoms

Paul Kinsella, Associate Dermatology Registry Manager
Corrona, LLC

On Saturday, September 10th, Team Corrona PSO came together at Carson’s Beach in Boston, MA for a great cause. The group participated in a 5k walk and community event, organized by Team NPF, dedicated to finding a cure for psoriatic disease. Approximately 100 walkers participated in raising almost $15,000 to help find a cure for psoriasis. Attendees learned about new ways to manage psoriatic disease, enjoyed free samples from food and healthcare vendors, and heard inspiring stories of people living well with psoriasis.

Team NPF is an organization of people with psoriatic disease and their supporters who come together to raise money and awareness by walking, running, and biking. Since 2007 Team NPF has raised over ten million dollars for psoriatic disease research. Information regarding Team NPF and a schedule of events can be found at http://npf.donordrive.com/.

These events promote the importance of physical activity in the management of the symptoms of psoriasis. Regular physical activity can help you fight stress, and help you maintain a healthy body weight, which may also decrease flares. Before starting an exercise plan, please consult your doctor; they may refer you to a physical therapist who can help you create a plan even if you have psoriasis pain. Physical therapists may recommend swimming, water aerobics, weight training, and working out with resistance bands.

Physical activity can also be incorporated into our everyday routines. Taking extra steps and doing a little stretching now and then adds up. The National Psoriasis Foundation recommends the following:

- Schedule 10-minute breaks in your planner or calendar and go for a short walk.
- Sitting at your desk? Do ankle rolls, heel/toe raises and knee lifts every hour or so.
- Watching TV? Do stretches and floor exercises or walk when commercials come on.
- Park further from the entrance when you go to work, go shopping, or go to doctor’s appointments.
- Avoid the drive-up ATM at the bank by getting out of the car and walking to the ATM.
- Take the stairs rather than the elevator.
Team Corrona @ the office...

Check out some of our Corrona staff taking an activity break at the office! Here are exercises you can perform at work or at home.

**Quad Stretch.** Support yourself with one hand against a wall. Bend your standing leg to grab the opposite foot and gently pull heel toward buttocks.

**Shoulder Stretch.** Press one arm across your chest at shoulder height. Hold for several counts and repeat with other arm.

**Calf Stretch.** Stand about two feet away from a wall. Place the ball of your right foot against the wall while your heel remains on the ground. Slowly and gently lean into the wall while keeping your knee straight. Repeat for other leg.

**Stair Climb.** Don't know which way to go? Hmm... What should Paul do?

Choose the stairs. Those extra steps can add up!

Photos courtesy of Paul Kinsella and Judith Tauriac

Crossword Puzzle

**Across**

2. On average, patients had 8.6% of their body_______area affected by psoriasis.
4. Of the 1,014 patients enrolled, 68% were receiving________medication.
7. Of note, 44% of patients also reported a diagnosis of psoriatic______.
8. Corrona staff came together for a _____walk.
9. Regular follow-up______with your dermatologists are an important part of managing your psoriasis.
10. Take the______rather than the elevator.

**Down**

1. Having psoriasis requires you to actively_______in your own health care alongside your dermatologist.
3. Since 2007, NPF has raised over 10______dollars.
5. Do stretches and floor_____or walk when commercials come on the television.
6. Regular physical activity can help you fight______.

Answer Key:

1. participate
2. surface
3. million
4. biologic
5. exercises
6. stress
7. arthritis
8. NPF
9. visits
10. stairs

"Across 2. 3. 4. 6. 7. 8. 9. 10. Down 1. 5. 6. 7. 8."

Corrona data to empower®

www.corrona.org