



psoriasis.org  
volume 17: number 2 | summer 2019

# NPF ADVANCE™

Live well with psoriatic disease

***The faces of  
our community***

**BATTLING  
ALCOHOLISM**

The naked truth about  
genital psoriasis

Honoring an NIH legend

**Plus** New psoriasis  
treatment guidelines

FOR ADULTS WITH MODERATE TO SEVERE PLAQUE PSORIASIS



ACTUAL PATIENT **GARY**

Gary has been compensated for his time.

“I was covered with psoriasis for years. It was awful.  
I tried so many different things...then I found COSENTYX®.  
I'm clear. Have been for 3 years. Look at these elbows...sexy, right?”

# CLEAR SKIN CAN LAST WITH COSENTYX.

In clinical trials, the majority of people taking COSENTYX 300 mg were clear or almost clear at 3 months. Approximately 8 out of 10 people saw 75% skin clearance. Many who saw results at 1 year maintained them at 3 years. For some people, a dose of 150 mg may be acceptable.

Ask your dermatologist about COSENTYX.

**INDICATION**  
COSENTYX® (secukinumab) is a prescription medicine used to treat adults with moderate to severe plaque psoriasis that involves large areas or many areas of the body, and who may benefit from taking injections or pills (systemic therapy) or phototherapy (treatment using ultraviolet or UV light, alone or with systemic therapy).

**IMPORTANT SAFETY INFORMATION**  
Do not use COSENTYX if you have had a severe allergic reaction to secukinumab or any of the other ingredients in COSENTYX. See the Consumer Brief Summary for a complete list of ingredients.

COSENTYX is a medicine that affects your immune system. COSENTYX may increase your risk of having serious side effects such as:

- Infections**  
COSENTYX may lower the ability of your immune system to fight infections and may increase your risk of infections.
- Your doctor should check you for tuberculosis (TB) before starting treatment with COSENTYX.
  - If your doctor feels that you are at risk for TB, you may be treated with medicine for TB before you begin treatment with COSENTYX and during treatment with COSENTYX.



Novartis Pharmaceuticals Corporation  
East Hanover, New Jersey 07936-1080

- Your doctor should watch you closely for signs and symptoms of TB during treatment with COSENTYX. **Do not take COSENTYX if you have an active TB infection.**

**Before starting COSENTYX, tell your doctor if you:**

- are being treated for an infection
- have an infection that does not go away or that keeps coming back
- have TB or have been in close contact with someone with TB
- think you have an infection or have symptoms of an infection such as: fevers, sweats, or chills; muscle aches; cough; shortness of breath; blood in your phlegm; weight loss; warm, red, or painful skin or sores on your body; diarrhea or stomach pain; burning when you urinate or urinate more often than normal

**After starting COSENTYX, call your doctor right away if you have any signs of infection listed above.** Do not use COSENTYX if you have any signs of infection unless you are instructed to by your doctor.

**Inflammatory Bowel Disease**

New cases of inflammatory bowel disease or “flare-ups” can happen with COSENTYX, and can sometimes be serious. If you have inflammatory bowel disease (ulcerative colitis or Crohn’s disease), tell your doctor if you have worsening disease symptoms during treatment with COSENTYX or develop new symptoms of stomach pain or diarrhea.

**Serious Allergic Reactions**

Serious allergic reactions can occur. Get emergency medical help right away if you get any of the following symptoms: feeling faint; swelling of your face, eyelids, lips, mouth, tongue, or throat; trouble breathing or throat tightness; chest tightness; or skin rash. **If you have a severe allergic reaction, do not give another injection of COSENTYX.**

**Before starting COSENTYX, tell your doctor if you:**

- have any of the conditions or symptoms listed in previous column for infections
- have inflammatory bowel disease (Crohn’s disease or ulcerative colitis)
- are allergic to latex. The needle caps contain latex.
- have recently received or are scheduled to receive an immunization (vaccine). People who take COSENTYX **should not** receive live vaccines.
- have any other medical conditions
- are pregnant or plan to become pregnant. It is not known if COSENTYX can harm your unborn baby. You and your doctor should decide if you will use COSENTYX.
- are breastfeeding or plan to breastfeed. It is not known if COSENTYX passes into your breast milk.

**Tell your doctor about all the medicines you take**, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Know the medicines you take. Keep a list of your medicines to show your doctor and pharmacist when you get a new medicine.

**How should I use COSENTYX?**

**See the detailed Instructions for Use that comes with your COSENTYX for information on how to prepare and inject a dose of COSENTYX, and how to properly throw away (dispose of) used COSENTYX Sensoready® pens and prefilled syringes.**

- Use COSENTYX exactly as prescribed by your doctor.
- If your doctor decides that you or a caregiver may give your injections of COSENTYX at home, you should receive training on the right way to prepare and inject COSENTYX. Do not try to inject COSENTYX yourself, until you or your caregiver has been shown how to inject COSENTYX by your doctor or nurse.

**The most common side effects of COSENTYX include:** cold symptoms, diarrhea, and upper respiratory infections. These are not all of the possible side effects of COSENTYX. Call your doctor for medical advice about side effects.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**Please see Consumer Brief Summary on the back of this page.**

**\$0 CO-PAY\***  
IF YOU'RE ELIGIBLE

   
LEARN MORE AT [COSENTYX.COM](http://COSENTYX.COM)

\*For commercially insured only. Limitations apply.



CONSUMER BRIEF SUMMARY

The risk information provided here is not comprehensive. This information does not take the place of talking with your doctor about your medical condition or treatment.

To learn more about COSENTYX® (secukinumab), talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 1-888-669-6682 or visit www.COSENTYX.com.

What is the most important information I should know about COSENTYX?

COSENTYX is a medicine that affects your immune system. COSENTYX may increase your risk of having serious side effects such as:

- Infections.** COSENTYX may lower the ability of your immune system to fight infections and may increase your risk of infections.
- Your healthcare provider should check you for tuberculosis (TB) before starting treatment with COSENTYX.
  - If your healthcare provider feels that you are at risk for TB, you may be treated with medicine for TB before you begin treatment with COSENTYX and during treatment with COSENTYX.
  - Your healthcare provider should watch you closely for signs and symptoms of TB during treatment with COSENTYX. **Do not take COSENTYX if you have an active TB infection.**

Before starting COSENTYX, tell your healthcare provider if you:

- are being treated for an infection
- have an infection that does not go away or that keeps coming back
- have TB or have been in close contact with someone with TB
- think you have an infection or have symptoms of an infection such as:
  - fevers, sweats, or chills
  - muscle aches
  - cough
  - shortness of breath
  - blood in your phlegm
  - weight loss
  - warm, red, or painful skin or sores on your body
  - diarrhea or stomach pain
  - burning when you urinate or urinate more often than normal

**After starting COSENTYX, call your healthcare provider right away if you have any of the signs of infection listed above.** Do not use COSENTYX if you have any signs of infection unless you are instructed to by your healthcare provider.

See “What are the possible side effects of COSENTYX?” for more information about side effects.

What is COSENTYX?

COSENTYX is a prescription medicine used to treat adults with moderate to severe plaque psoriasis that involves large areas or many areas of the body, and who may benefit from taking injections or pills (systemic therapy) or phototherapy (treatment using ultraviolet or UV light alone or with systemic therapy).

COSENTYX may improve your psoriasis, but it may also lower the ability of your immune system to fight infections.

It is not known if COSENTYX is safe and effective in children.

Who should not use COSENTYX?

Do not use COSENTYX if you have had a severe allergic reaction to secukinumab or any of the other ingredients in COSENTYX. See the end of the Consumer Brief Summary for a complete list of ingredients in COSENTYX.

What should I tell my healthcare provider before starting COSENTYX?

Before starting COSENTYX, tell your healthcare provider if you:

- have any of the conditions or symptoms listed in the section “What is the most important information I should know about COSENTYX?”
- have inflammatory bowel disease (Crohn’s disease or ulcerative colitis)
- are allergic to latex. The needle cap on the COSENTYX Sensoready® pen and prefilled syringe contains latex.
- have recently received or are scheduled to receive an immunization (vaccine). People who take COSENTYX **should not** receive live vaccines.
- have any other medical conditions
- are pregnant or plan to become pregnant. It is not known if COSENTYX can harm your unborn baby. You and your healthcare provider should decide if you will use COSENTYX.
- are breastfeeding or plan to breastfeed. It is not known if COSENTYX passes into your breast milk.

**Tell your healthcare provider about all the medicines you take**, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Know the medicines you take. Keep a list of your medicines to show your healthcare provider and pharmacist when you get a new medicine.

How should I use COSENTYX?

**See the detailed “Instructions for Use” that comes with your COSENTYX for information on how to prepare and inject a dose of COSENTYX, and how to properly throw away (dispose of) used COSENTYX Sensoready pens and prefilled syringes.**

- Use COSENTYX exactly as prescribed by your healthcare provider.
- If your healthcare provider decides that you or a caregiver may give your injections of COSENTYX at home, you should receive training on the right way to prepare and inject COSENTYX. Do not try to inject COSENTYX yourself, until you or your caregiver has been shown how to inject COSENTYX by your healthcare provider.
- COSENTYX comes in a Sensoready pen or prefilled syringe that you or your caregiver may use at home to give injections. Your healthcare provider will decide which type of COSENTYX is best for you to use at home.
- Your healthcare provider will prescribe the dose of COSENTYX that is right for you.
  - If your prescribed dose of COSENTYX is **150 mg**, you must give **1 injection** of COSENTYX for each dose.
  - If your prescribed dose of COSENTYX is **300 mg**, you must give **2 injections** for each dose.
- COSENTYX is given as an injection under your skin (subcutaneous injection), in your upper legs (thighs) or stomach-area (abdomen) by you or a caregiver. A caregiver may also give you an injection of COSENTYX in your upper outer arm.
- **Do not** give an injection in an area of the skin that is tender, bruised, red or hard, or in an area of skin that is affected by psoriasis.
- Each injection should be given at a different site. **Do not** use the 2-inch area around your navel (belly button).
- If you inject more COSENTYX than prescribed, call your healthcare provider or go to the nearest emergency room right away.

What are the possible side effects of COSENTYX?

**See “What is the most important information I should know about COSENTYX?”**

- **Inflammatory bowel disease.** New cases of inflammatory bowel disease or “flare-ups” can happen with COSENTYX, and can sometimes be serious. If you have inflammatory bowel disease (ulcerative colitis or Crohn’s disease), tell your healthcare provider if you have worsening disease symptoms during treatment with COSENTYX or develop new symptoms of stomach pain or diarrhea.
- **Serious allergic reactions.** Get emergency medical help right away if you get any of the following symptoms of a serious allergic reaction:
  - feel faint
  - swelling of your face, eyelids, lips, mouth, tongue, or throat
  - trouble breathing or throat tightness
  - chest tightness
  - skin rash

**If you have a severe allergic reaction, do not give another injection of COSENTYX.**

The most common side effects of COSENTYX include:

- cold symptoms
- diarrhea
- upper respiratory infections

These are not all of the possible side effects of COSENTYX.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

Keep COSENTYX and all medicines out of the reach of children.

General information about the safe and effective use of COSENTYX

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use COSENTYX for a condition for which it was not prescribed. Do not give COSENTYX to other people, even if they have the same symptoms you have. It may harm them.

You can ask your healthcare provider or pharmacist for information about COSENTYX that is written for health professionals.

What are the ingredients in COSENTYX?

**Active ingredient:** secukinumab

**Inactive ingredients: Sensoready pen and prefilled syringe:** L-histidine/histidine hydrochloride monohydrate, L-methionine, polysorbate 80, trehalose dihydrate, and sterile water for injection.

**Vial:** L-histidine/histidine hydrochloride monohydrate, polysorbate 80, and sucrose.



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To drive efforts to cure psoriatic disease and improve the lives of those affected.

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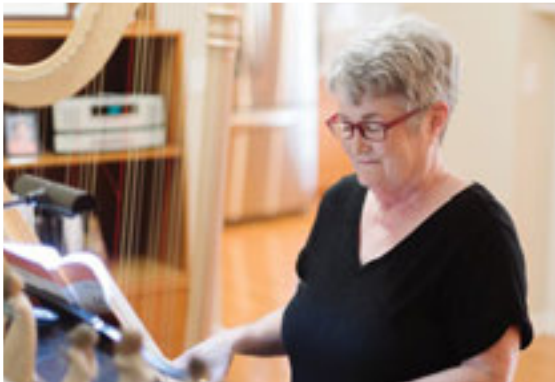
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NPF, a 501(c)(3) organization, relies on your tax-deductible donations to support the millions diagnosed with psoriatic disease. NPF is governed by a volunteer board of directors and is advised on medical issues by a volunteer medical board. To get a copy of NPF’s annual report, call 800-723-9166.

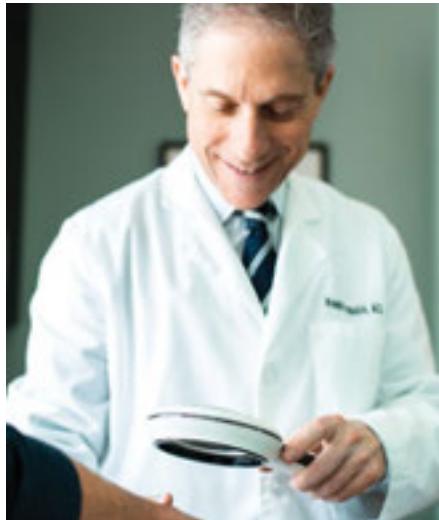


**26** Our  
lifeblood

Volunteers are the heart and soul of our organization. For 50-plus years, NPF has been powered by a river of patients, families, scientists and health care providers who repeatedly pitch in to help our cause.



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Aiming for the moon

By the time you read this, NPF will have put the finishing touches on our strategic plan for the years 2019 through 2024.

Under the strategic plan that just ended, we opened the Patient Navigation Center, the world's first personalized support center for individuals impacted by psoriatic disease. We expanded our funding for research and increased the number of scientists studying psoriatic disease and the number of patients participating in research. We dedicated ourselves to the creation of a diagnostic test for psoriatic arthritis. These are just a few of our recent achievements.

Our new five-year plan will give us an even more ambitious set of goals that, we believe, will transform the lives of individuals living with psoriatic disease. As usual, we are planning to do things within the field of psoriatic disease that have never been done before. One of the biggest, most exciting of these goals is our "moonshot" – preventing the onset of psoriasis.

To make this happen, we intend to fund a research collaboration: multiple people from multiple fields (genetics, biomarkers, immunology) at multiple institutions. This team of the best and the brightest will research the interventions that will someday head off psoriasis and all of its comorbidities, including psoriatic arthritis. We will invite applications for this transformative team beginning this summer. The five-year project will launch in July 2020.

When NPF was founded, there was no one who spoke for our community. We were the first people to stand up for ourselves, to ask questions, to demand better treatment and to fund research into psoriatic disease. From day one, we have aimed for the moon.

Can we change the course of the psoriatic disease community? We have to go for it. Because if we don't, who will?



**Randy Beranek**  
*President and CEO*  
National Psoriasis Foundation



**Pete Redding**  
*Chair, Board of Directors*  
National Psoriasis Foundation



# Nothing satisfies the soul like a sense of belonging

I've always believed in the importance of community. When I was younger, that meant belonging. I was a medium-sized nerd at a big, competitive high school. It wasn't hard to find my place: marching band, student council, French club, Odyssey of the Mind. Every student organization came with a built-in set of friends, a group of teenagers instantly bonded by a common interest.

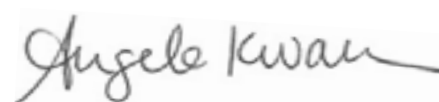
My perspective of community has shifted over time. I now place more emphasis on giving back. In recent years, I signed up to volunteer with my local alumni chapter and my son's school. And as a result, I found myself accidentally joining new communities. In retrospect, I shouldn't have been surprised.

I'm super excited to spotlight people who have joined the NPF community in this issue. The 10 folks featured in our cover story (page 26) represent just a tiny sliver of the passionate, empowered individuals who make up our community.

What I love about this collection of vignettes is the diversity among the stories. It doesn't matter if you're interested in research or policy or fundraising, we have many, many ways for you to get involved. And you don't need to make a huge commitment. Some opportunities require 10 minutes or less – literally.

If you're ready to take your relationship with NPF to the next level, contact [volunteer@psoriasis.org](mailto:volunteer@psoriasis.org) or visit [psoriasis.org/get-involved](https://psoriasis.org/get-involved).

I suspect you'll be pleasantly surprised.



**Angela Kwan**  
Editor  
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**P.S.** NPF Advance is launching two digital issues next year. Give us your email address and be the first to get notified when we unveil our online magazine in 2020.

Visit [psoriasis.org/digital-advance](https://psoriasis.org/digital-advance) and receive a thank you gift for completing the form.

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“Alone we can  
do so little,  
together we can  
do so much.”

— Helen Keller —



Catching up with NPF



Take control of your psoriasis

August is Psoriasis Action Month, and the goal is to help you live your healthiest life. Watch for inspirational stories and educational resources designed to help you take a more active role in managing your disease. Until we can find a cure, the journey continues. And we'll be there every step of the way to offer you support and keep you on the road to success.

psoriasis.org/psoriasis-action-month



Your summer plans start here

To help celebrate Psoriasis Action Month this August, we're hosting three regional volunteer conferences:

San Francisco, California: Aug. 3

Dallas, Texas: Aug. 10

Philadelphia, Pennsylvania: Aug. 24

These free events are designed to foster conversation and educate you about the fight against psoriatic disease. Be among the first to hear about the latest developments in research and treatments, new initiatives at NPF, and how to become more deeply involved in our community.

You can expect an exciting agenda packed with learning, networking and socializing. Come spend the day with us!

psoriasis.org/rvc/2019



Listen while you work

NPF has your summer covered with the newest episodes of our podcast, Psound Bytes, dropping every other Tuesday. Hear from experts in our community who offer advice on disease management and patients who provide insights into daily living with psoriasis or psoriatic arthritis.

Join us as we tackle a myriad of topics, including treatment options for ear psoriasis, the latest psoriasis treatment guidelines and tips for rapid pain relief.

psoriasis.org/podcast



Ready for a life on your own?

Senior year is over. You've had the big game, the prom, the ceremony and, of course, the parties. Now it's time to face life as a young adult with psoriatic disease. We can help you with a new webinar from longtime NPF volunteer Melissa Leelou: "Preparing for life on your own." This free, 30-minute webinar and Q&A for older teens is now available through Our Spot.

Leelou covers everything from how to get your medications and insurance to how to fill your fridge, stay healthy, and have fun. Check out all of Our Spot's resources for teens post-high school graduation.

psoriasis.org/our-spot/for-teens



For moderate to severe plaque psoriasis or psoriatic arthritis

little knot big hero



Otezla is different  
It's a pill—not an injection, cream, or biologic

When you're living with *plaque psoriasis* or *psoriatic arthritis*, little moments can be a pretty big deal.

- For **plaque psoriasis**, Otezla can help you **achieve clearer skin**
- Otezla can help **reduce the joint swelling, tenderness, and pain of psoriatic arthritis**
- The Otezla Prescribing Information has **no requirement for initial or routine blood testing**
- Most people pay nothing out of pocket through the **\$0 co-pay\* program**

APPROVED USE

Otezla is a prescription medicine approved for the treatment of patients with moderate to severe plaque psoriasis for whom phototherapy or systemic therapy is appropriate.

Otezla is a prescription medicine approved for the treatment of adult patients with active psoriatic arthritis.

IMPORTANT SAFETY INFORMATION

You must not take Otezla if you are allergic to apremilast or to any of the ingredients in Otezla.

Otezla can cause severe diarrhea, nausea, and vomiting, especially within the first few weeks of treatment. Use in elderly patients and the use of certain medications with Otezla appears to increase the risk of having diarrhea, nausea, or vomiting. Tell your doctor if any of these conditions occur.

Otezla is associated with an increase in depression. In clinical studies, some patients reported depression, or suicidal behavior while taking Otezla. Some patients stopped taking Otezla due to depression. Before starting Otezla, tell your doctor if you have had feelings of depression, or suicidal thoughts or behavior. Be sure to tell

your doctor if any of these symptoms or other mood changes develop or worsen during treatment with Otezla.

Some patients taking Otezla lost body weight. Your doctor should monitor your weight regularly. If unexplained or significant weight loss occurs, your doctor will decide if you should continue taking Otezla.

Some medicines may make Otezla less effective, and should not be taken with Otezla. Tell your doctor about all the medicines you take, including prescription and nonprescription medicines.

Side effects of Otezla include diarrhea, nausea, vomiting, upper respiratory tract infection, runny nose, sneezing, or congestion, abdominal pain, tension headache, and headache. These are not all the possible side effects with Otezla. Ask your doctor about other potential side effects. Tell your doctor about any side effect that bothers you or does not go away.

Tell your doctor if you are pregnant, planning to become pregnant or planning to breastfeed. Otezla has not been studied in pregnant women or in women who are breastfeeding.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-332-1088.

Please see Brief Summary of Prescribing Information on the next page.

\*Certain restrictions apply; eligibility not based on income.



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Sign up for the  
\$0 co-pay\*  
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Pay \$0 *for Otezla*



### The \$0 co-pay\* *program*

Most people with private insurance **pay nothing out of pocket** for their prescription. After you're prescribed, you have the same opportunity to save.

#### How to get the \$0 co-pay offer:

1. Go to [otezla.com/copay](http://otezla.com/copay)
2. Call **1-844-4OTEZLA** (1-844-468-3952)
3. Ask your doctor about the \$0 co-pay card

### More ways to *save*

If you have private insurance and are experiencing delays or your private insurance doesn't cover Otezla, you may be eligible for **free medication** through the **Otezla Bridge Program**.†

If you have government-issued insurance (Medicare or Medicaid) or are uninsured/underinsured, you may be eligible for the **Patient Assistance Program**.

For all Otezla savings questions:  
*call* **1-844-4OTEZLA** (1-844-468-3952)



\*Certain restrictions apply; eligibility not based on income, must be 18 years or older. This offer is not valid for persons eligible for reimbursement of this product, in whole or in part under Medicaid, Medicare, or similar state or federal programs. Offer not valid for cash-paying patients. People who are not eligible can call 1-844-4OTEZLA to discuss other financial assistance opportunities.

†To receive a free bridge supply of Otezla, you must have an on-label diagnosis and be denied or experiencing a delay in obtaining coverage. Federal, State, or similar plans are not eligible for Bridge. Once Otezla is approved by your commercial insurance plan, you will no longer be eligible for the Bridge Program.

### Brief Summary of Information About OTEZLA® (oh-TEZ-lah) (apremilast) Tablets

Rx Only

This information does not take the place of talking to your doctor about your medical condition or treatment. If you have any questions about OTEZLA® (apremilast), ask your doctor. Only your doctor can determine if OTEZLA is right for you.

#### What is the most important information I should know about OTEZLA?

OTEZLA may cause serious side effects:

**Diarrhea, Nausea, and Vomiting** have been reported in some patients taking OTEZLA and in some cases, patients required hospitalization. Most events happened within the first few weeks of starting OTEZLA and occurred more in patients 65 years of age or older and in patients taking certain medications. Tell your doctor if any of these occur.

**Depression** was reported by some patients taking OTEZLA. Before taking OTEZLA, tell your doctor if you have had feelings of depression, suicidal thoughts, or suicidal behavior. You, your caregivers, and family members should be alert for the development or worsening of depression, suicidal thoughts, or other mood changes. If such changes occur, contact your doctor. Your doctor will determine whether you should continue taking OTEZLA.

**Weight loss** occurred in some patients taking OTEZLA. Your doctor should monitor your weight regularly. If unexplained or significant weight loss occurs, your doctor will consider whether you should continue taking OTEZLA.

**Some medicines should not be taken with OTEZLA** as they may make OTEZLA less effective. Tell your doctor about all the medications you take, including prescription and nonprescription medications.

#### What is OTEZLA?

OTEZLA is a prescription medicine used for the treatment of adult patients with active psoriatic arthritis.

OTEZLA is a prescription medicine used for the treatment of patients with moderate to severe plaque psoriasis for whom phototherapy or systemic therapy is appropriate.

It is not known if OTEZLA is safe and effective in children less than 18 years of age.

#### Who should **not** take OTEZLA?

You must not take OTEZLA if you are allergic to apremilast or to any of the ingredients in OTEZLA.

#### What should I tell my doctor before taking OTEZLA?

Tell your doctor if you:

- have had feelings of depression, suicidal thoughts, or suicidal behavior
- have any kidney problems
- are pregnant or plan to become pregnant. It is not known if OTEZLA can harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if OTEZLA passes into your breast milk.

#### What are the side effects of OTEZLA?

- OTEZLA may cause serious side effects. See "What is the most important information I should know about OTEZLA?"
- **Common side effects** of OTEZLA are:
  - diarrhea
  - nausea
  - headache
  - vomiting
  - upper respiratory tract infection
  - tension headache

These are not all the possible side effects with OTEZLA. Tell your doctor about any side effect that bothers you or does not go away.

#### General Information about OTEZLA

Medicines are sometimes prescribed for purposes other than those listed in their package inserts. This is a Brief Summary of important information about OTEZLA. Ask your doctor or pharmacist for more complete product information, or visit [otezla.com](http://otezla.com), or call 1-844-4OTEZLA (1-844-468-3952).

OTEZLA (apremilast) tablets

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Based on APRPI.006

OTZ\_PsA-PsO\_Pt\_BSV.006 06\_2017

# Friends in high places

*Six longtime members of our community remember Stephen I. Katz, M.D., Ph.D., a tireless advocate for our cause and a champion to everyone who faces life everyday with psoriatic disease.*

By National Psoriasis Foundation

Throughout our history, we've been helped by a long line of doctors, scientists and administrators. Stephen Katz, M.D., Ph.D., who passed away on Dec. 20, 2018, at age 77, was among the best of the best.

Katz came to the National Institutes of Health (NIH) in 1974 as a senior investigator in the dermatology branch at the National Cancer Institute, where he initiated a research program in the immunology of skin diseases. In 1995, he became the director of the U.S. National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), one of the 27 institutes and centers that make up the NIH. NIAMS conducts and supports research into the causes, treatments and prevention of diseases of the bones, joints, muscles and skin.

The tributes to Katz that follow have been edited for length and clarity.

## Never stop having fun

*Steve was a true scholar and showed his most generous side when mentoring. I was a new tenure-track physician/scientist in the NIH Intramural Program in Bethesda. I was trying to characterize a connection between psoriasis and heart disease. Why were these two distinct diseases linked? I had limited knowledge of preclinical models in inflammatory conditions. My colleagues immediately said, "You need to talk to Steve Katz!"*

*Though he had never met me, shortly after I sent an email to him, Steve called me up, invited me to his office and spent an hour and a half with me sharing his journey and knowledge openly. He initially started by telling me what I was interested in accomplishing was a lofty goal, and I should accept failure as an expected outcome. But he said my goal was important.*

*He proceeded to tell me many anecdotes about experiences along the way so I could learn and not make the same blunders. He oozed kindness. Over the years, Steve and I met many times around D.C. and on campus. He shared more than science with me; he drove home what a special place the NIH Intramural Program was, letting people explore and study "tough science." But, most of all, he told me to never stop having fun. And I haven't.*

**Nehal N. Mehta, M.D.**

NPF Medical Board

Lasker Clinical Research Scholar

U.S. National Institutes of Health

Bethesda, Maryland

12  
13

summer 2019



## Frank, honest and kind

*I got very tearful when I heard about Stephen. He and I did our joint fellowships in London in the early 1970s. He was doing an immunology fellowship at the University of London and I was doing my fellowship at St. Johns Hospital for diseases of the skin. He would often come to our meetings. That's how we got to know each other. Even in those early days, my colleagues were amazed at his knowledge and understanding. When they had meetings, when they had cases, Stephen, in his own quiet way, was always in the forefront of the conversation. We remained friends ever since.*

*One of the real positive things about Steve was that he never talked down to anybody, whether they were a medical student or anyone else. He was frank, honest and kind.*

*From a scientific perspective, he has to be considered one of the most high-quality dermatologists in the history of American dermatology. I mean that sincerely.*

**Alan Menter, M.D.**  
NPF Lifetime Achievement Award 2013  
Dallas, Texas

## Compassion, empathy and active listening

*On behalf of the psoriatic disease communities, I would like to honor and thank Dr. Katz for his leadership in dermatology research and his dramatic and long-lasting support for all positively affected by NIAMS research. He was an exemplary leader who showed compassion, remarkable empathy and active listening, with a genuine interest in those he served. He was most generous in coordinating an all-day workshop at NIAMS on gaps and opportunities in psoriatic arthritis research, and allowing me to represent the patient population.*

*He was a wonderful human being.*

**Richard Seiden, J.D.**  
NIAMS Advisory Council  
NPF Lifetime Achievement Award 2016  
NPF Board of Directors  
Los Angeles, California

## An effective and tough advocate

*Steve was a dedicated scientist who was fair, caring and insightful. During my years at NPF, Steve was a frequent advisor and supporter. I met him when he attended our first interdisciplinary scientific workshop, held in 1989 in Deer Valley, Utah. At that time, he was the lead scientist in skin cancer research at the NIH.*

*I got a chance to establish a personal acquaintance with Steve when we broke off from a group of doctors hiking up the mountains during one afternoon meeting break. I was lucky to be in the same shape as Steve as it gave me the opportunity to sit with him on the edge of a cliff looking out over the scenery with our legs dangling. We talked for quite awhile about our views on research, and to share some of our personal history.*

*It was here that he told me how much he admired Ken Halprin, the Foundation's co-founder, and how much he respected his integrity and independence. Ken had been his mentor and professor when he was in medical school.*

*From that point on, Steve and I had a professional and friendly relationship. He was always there for the Foundation when I asked him to speak at our national conference.*

*Steve was a big advocate for the patient groups in skin. He was always welcoming when they visited NIAMS. Steve was a leader among a group of dermatologists at that time who worked hard to achieve recognition of skin disease research on a par with other disease research.*

*We are indebted to scientists like Steve, who in those early years were effective and tough advocates for skin research, including psoriasis. Without them, patients would not have gained a place at the table.*

**Gail Zimmerman**  
NPF Executive Director, President and CEO, 1979-2007  
Lake Oswego, Oregon

## A great friend to dermatology

*Steve Katz took me under his wing early in my career, and nominated me for membership in the American Dermatological Association. I learned very quickly that virtually everyone in dermatology with an interest in research was influenced by Steve in a positive way. He was always encouraging, but gave the best constructive criticism I've gotten from anyone. In my role as chair of the medical board of the National Psoriasis Foundation, there was no one in Washington, D.C., who was more supportive and had better ideas to move efforts to treat psoriasis forward than Steve Katz.*

*As president of the American Academy of Dermatology, my most pleasant day was the one I spent lobbying on Capitol Hill with Steve to raise funds for the NIH and for dermatology research. He had the respect of every lawmaker we encountered. That included individuals who were reluctant to support research, but nevertheless listened to Steve, who unquestionably influenced them to support the NIH.*

*As chair of the department of dermatology at Mount Sinai, he supported my efforts to find basic researchers for our department at many points, including Anne Bowcock, who in 2003 discovered the first psoriasis gene.*

*Steve Katz was a great friend to dermatology and to me personally, and he will be missed by many. He leaves behind an extraordinary legacy.*

**Mark Lebwohl, M.D.**  
NPF Lifetime Achievement Award 2012  
Chair Emeritus, NPF Medical Board  
New York, New York



Leah McCormick Howard with Stephen Katz

## A man who lived patient-centeredness

*I met Dr. Katz in 2012. I had recently joined NPF to head the government relations and advocacy team and learned from colleagues of the Foundation's long and collaborative relationship with the National Institute of Arthritis and Musculoskeletal and Skin Diseases. What I did not yet appreciate was how Dr. Katz drove this positive relationship between patient groups and NIAMS.*

*NPF was planning a congressional briefing on the connection between heart disease and psoriasis and we wanted Dr. Katz to present. He surprised me by quickly accepting. He delivered compelling remarks – one of many times we asked over the years. Having gotten to know him, I later jumped at the opportunity to work more closely with him by serving as co-chair of the NIAMS coalition, a group of 90 patient and provider organizations.*

*As I reflect on my interactions with Dr. Katz, what strikes me is how he always kept the purpose of his work – individual patients – at the forefront. "Patient-focused drug development" is the buzz term of the day in Washington, D.C., health policy. Dr. Katz is a man who lived patient-centeredness well before it became popular. We might not have known it, but we all benefited.*

**Leah McCormick Howard, J.D.**  
Chief Operating Officer, NPF  
Alexandria, Virginia



# NEW PSORIASIS TREATMENT GUIDELINES ANNOUNCED

*The first two AAD-NPF guidelines in a series of six tackle biologics and comorbidities.*

By Steve Bieler

In 2016, the American Academy of Dermatology and the National Psoriasis Foundation embarked on an ambitious project: updating psoriasis treatment guidelines for the first time in a decade.

That project is reaching a successful conclusion. The first two guidelines – for biologics and comorbidities – are now available to health care providers, insurers, patients and caregivers, via the *Journal of the American Academy of Dermatology*.

These guidelines will not simply reinforce dermatologists' knowledge of psoriasis and how to treat it. The guidelines will also give other health care providers a reference they may have been lacking when caring for people with psoriasis. They will give health insurance companies the up-to-date treatment information needed to design more appropriate coverage policies for folks like you. And the guidelines will help improve your knowledge of psoriasis and how to work with your doctor to achieve the best health outcome possible.

The evidence-based guidelines were developed by a joint AAD/NPF team composed of dermatologists, a cardiologist, a rheumatologist and patient representatives.

Alan Menter, M.D., is one of the two co-chairs of the guidelines team. Menter, chair of the Division of Dermatology and director of the Dermatology Residency Program at Baylor University Medical Center in Dallas, received an NPF Lifetime Achievement Award in 2013.

## Biologics

According to the guidelines, the majority of you with mild-to-moderate psoriasis are capable of controlling your disease with topical medications or phototherapy. However, this approach may be insufficient if you have moderate-to-severe psoriasis. Biologics may be more successful and have a high benefit-to-risk ratio.

"We in dermatology were late to the biologic revolution," Menter says. Biologics developed primarily for psoriasis weren't available to dermatologists until approximately 2004. Today, he notes, dermatologists have a slew of new biologics to choose from.

"We are very fortunate to have these biologic agents, with others still to come," he says. "Instead of clearing 60 to 70 percent of our patients like we did 10 to 15 years ago, most of our new biologics are now clearing 80 to 90 percent of our patients."

While he welcomes these new treatments, Menter looks ahead to the day when we also have a way of knowing which biologic works best for which patient. "That's the million-dollar question," he says. "If you came in to me with severe psoriasis, which biologic would I choose? We do not yet have what I call biomarkers to say that you are better suited for this biologic drug as opposed to that one."

The new psoriasis guidelines arrive on the heels of the new PsA treatment guidelines, a collaboration between NPF and the American College of Rheumatology. Together, both these guidelines mark a new era in the treatment of psoriatic disease.

## Comorbidities

There are various conditions associated with psoriasis. The most common are psoriatic arthritis (PsA), cardiovascular disease (diseases of the heart and arteries), metabolic syndrome (including type 2 diabetes) and mental health (depression and anxiety). These conditions are the most pressing to screen for.

PsA leads the comorbidity list because of the impact to your health and quality of life. "More doctors and more patients should be aware of the need to look for psoriatic joint disease at each visit," Menter says. "Left untreated, 50 percent of such patients will go on to permanent joint destruction, which we cannot allow. Once those joints are destroyed, they're destroyed."

Although the concept of comorbidities can be frightening, Menter believes that you can help your own cause to some extent with simple lifestyle changes. "Our psoriasis population is heavier than the population without psoriasis," he says. "That's not just driven by people eating too much or not exercising enough. If you are 20 pounds overweight, and you've been thinking it's due to your lack of discipline, it might also be due to having psoriasis. Psoriasis affects your metabolism.

"This is why it's very important that you make sure you have your blood pressure and heart checked regularly and treated if need be. It's also important that you keep your weight down to the best of your ability, that you exercise and cut back on fatty foods."

*Instead of clearing 60 to 70 percent of our patients like we did 10 to 15 years ago, most of our new biologics are now clearing 80 to 90 percent of our patients.*

Dermatologists are not specialized in treating heart disease, diabetes or hypertension. They can partner with colleagues in these areas, but also with primary care physicians. Menter encourages dermatologists to work with primary care physicians.

"Most PCPs are not aware of all the comorbidities associated with psoriasis," he says.

Menter points out that the guidelines do not dictate how doctors should treat their patients. They do not define the standard of care and they definitely do not take the place of the conversations you should be having with your doctor about your treatment plan.

Instead, the guidelines provide an education. "Thanks to these guidelines, your health care provider now has the clinical evidence of the past 10 years, including biologic treatments and the latest findings on comorbidities, at his or her fingertips. You can learn this, too. You should work in partnership with your doctor to find the treatment that works for you and that you want to do."

## Guidelines to come

In 2019, the AAD/NPF team will publish guidelines in four more areas:

- |  |   |
|--|---|
|  Phototherapy       |  Non-biologics |
|  Pediatric patients |  Topicals      |

If you would like to learn more about the new psoriasis guidelines, or if you need help finding a doctor with whom to discuss your psoriasis and its treatment, contact our Patient Navigation Center for free, personalized assistance.

**Visit [psoriasis.org/navcenter](https://psoriasis.org/navcenter).**



# The four faces of arthritis

Get to know the main types of joint disease and how to tell them apart.

By Chris Paoli

Knowing the difference between psoriatic arthritis, osteoarthritis, gout and rheumatoid arthritis can get hairy, especially when so many symptoms and causes overlap. Here, Arthur Mandelin, M.D., Ph.D., an NPF medical board member and a rheumatologist at Northwestern University School of Medicine in Chicago, helps clear up any confusion.

## Psoriatic arthritis

### Doctor's notes

In simplest terms, psoriatic arthritis (PsA) is a disease in which the body's immune system attacks healthy cells, specifically in the joints. About a third of people with psoriasis also develop PsA sometime in their lifetime. While PsA shares similarities with rheumatoid arthritis, osteoarthritis and gout, it is dissimilar, especially in the case of gout and osteoarthritis.

"Psoriatic arthritis is a disease," says Mandelin. "Something is going on in the body that shouldn't be going on, making the person ill and driving the arthritic process."

Rheumatoid arthritis and PsA share many similarities, as they are both caused by issues in the immune system. However, one of the ways in which PsA differs from rheumatoid arthritis is that it can affect the spine, where RA rarely strikes, Mandelin explains.

One major similarity between PsA and rheumatoid arthritis is how they are handled. For the most part, the two have similar treatment options (biologics, oral treatments, non-steroidal anti-inflammatory drugs, etc.) and the trial-and-error process to find what works best for each individual.

### Symptoms

- Swelling and pain in the joints
- Limited range of motion
- Tenderness and pain in the tendons (fibrous tissue that attaches muscle to bone)
- Morning stiffness and general fatigue
- Pain in the eyes and redness of the cornea

### Treatment options

- Biologics and biosimilars
- Oral treatments
- Non-steroidal anti-inflammatory drugs
- Disease-modifying anti-rheumatic drugs

## Rheumatoid arthritis

### Doctor's notes

Of all the joint diseases, rheumatoid arthritis is the most similar to PsA and operates in the same fashion – the body's immune system attacks healthy tissue. The biggest distinction between PsA and rheumatoid arthritis is that, while PsA is usually accompanied by psoriasis, there is no visible skin condition associated with rheumatoid arthritis.

Medical professionals can easily distinguish between rheumatoid arthritis and PsA during the diagnosis period. "The way that the bone gets attacked, the way that the bone degenerates, even the way that the bone looks in an X-ray, looks different for RA compared to PsA," says Mandelin. Blood tests can also be used to diagnose rheumatoid arthritis. While there are rare cases of individuals who have PsA and rheumatoid arthritis, Mandelin says that having one typically lowers your chance of having the other.

### Symptoms

- Swelling and pain in the joints
- Limited range of motion
- Tenderness and pain in the tendons
- Morning stiffness and general fatigue

### Treatment options

- Biologics and biosimilars
- Oral treatments
- Non-steroidal anti-inflammatory drugs
- Disease-modifying anti-rheumatic drugs



# Osteoarthritis

## Doctor’s notes

“OA is more classically wear and tear, related to aging or overuse,” says Mandelin. While he classifies osteoarthritis as degenerative, he is quick to stress that over time the medical community has come to understand that osteoarthritis is more complicated than simple overuse of the joint. Ongoing research is needed to understand the full picture of what causes degeneration.

Unlike PsA, rheumatoid arthritis and gout, osteoarthritis affects older adults more than any other age group. The majority of people over 60 typically have some form of osteoarthritis, ranging from mild to severe. Common causes of osteoarthritis at a younger age include physical joint injury or overuse of a specific joint. Professional athletes, for instance, are at a high risk for developing osteoarthritis in their 30s and 40s.

# Gout

## Doctor’s notes

While gout shares some similarities with PsA, the way in which the disease functions is quite different. “For gout, there is a very clear trigger,” Mandelin says. “There is a biochemical overabundance of uric acid, which is very irritating and inflammatory.” Gout is part of the crystalline family of arthritis (and the best known, according to Mandelin), which is easy to remember because the disease is caused by deposits of crystallized acid. (Gout’s lesser known cousin is calcium pyrophosphate deposition disease.)

The initial onset of gout has the unique distinction of being tied directly to diet – a characteristic not shared with rheumatoid arthritis, PsA or osteoarthritis. While the disease can occur from joint injury or chemotherapy, most cases arise from diets high in purines (commonly found in shellfish and red meat), excessive alcohol consumption and crash diets.

## Symptoms

- Swelling and pain in the joints
- Limited range of motion
- Tenderness and pain in the tendons

## Treatment options

- Steroids
- Prescription medication to block uric acid production and pain relievers
- Non-steroidal anti-inflammatory drugs
- Improvements to diet

## Symptoms

- Swelling and pain in the joints
- Limited range of motion
- Tenderness and pain in the tendons
- Morning stiffness
- Bone spurs formed at the affected joint

## Treatment options

- Physical therapy and exercise
- Weight loss for overweight patients
- Non-steroidal anti-inflammatory drugs and pain relievers
- Steroid injection into the affected joint

Listen for more on this topic  
Arthur Mandelin, M.D., keeps the arthritis conversation going  
in a special episode of Psound Bytes, an original podcast from NPF.  
Tune in at [psoriasis.org/podcast](https://psoriasis.org/podcast).



## Proof that I can see. Numbers that speak to me.

### Skin Clearance That Can Last

In clinical trials, most adults taking HUMIRA were clear or almost clear. Many saw **75% and even 90% clearance** in just 4 months. Of people who achieved 75% clearance, most maintained it a full year after starting treatment.

### 300,000 Treated Over 10 Years

For over **10 years**, dermatologists have prescribed HUMIRA,<sup>†</sup> with more than **300,000 patients** treated.<sup>‡</sup>

### Works From Within

HUMIRA targets and blocks a specific source of inflammation on the inside, contributing to clearer skin on the outside.

Your results may vary.



# What's your Body Of Proof?

**ASK YOUR DERMATOLOGIST ABOUT HUMIRA.**

#### Who is HUMIRA for?¹

HUMIRA is a prescription medicine used to treat adults with moderate to severe chronic plaque psoriasis who are ready for systemic therapy or phototherapy, and are under the care of a doctor who will decide if other systemic therapies are less appropriate.

#### Important Safety Information About HUMIRA<sup>®</sup> (adalimumab)²

What is the most important information I should know about HUMIRA?

- **Serious infections.** HUMIRA can lower your ability to fight infections. **Serious infections have happened in people taking HUMIRA. These serious infections include tuberculosis (TB) and infections caused by viruses, fungi, or bacteria that have spread throughout the body. Some people have died from these infections.** Your doctor should test you for TB before starting HUMIRA, and check you closely for signs and symptoms of TB during treatment with HUMIRA, even if your TB test was negative.

- **Cancer.** For children and adults taking TNF blockers, including HUMIRA, the chance of getting lymphoma or other cancers may increase. There have been cases of unusual cancers in children, teenagers, and young adults using TNF blockers. Some people have developed a rare type of cancer called hepatosplenic T-cell lymphoma. This type of cancer often results in death. If using TNF blockers including HUMIRA, your chance of getting two types of skin cancer (basal cell and squamous cell) may increase. These types are generally not life-threatening if treated; tell your doctor if you have a bump or open sore that doesn't heal.

Tell your doctor about all of your health conditions, including if you:

- Think you have an infection or are being treated for infection. You should not start HUMIRA if you have any kind of infection unless your doctor says it is okay.
- Have symptoms of an infection, such as: fever, sweats, chills, muscle aches, cough, shortness of breath, blood in phlegm,

weight loss, warm, red or painful skin, sores on your body, diarrhea, stomach pain, burning when you urinate, urinating more often than normal, or feeling very tired.

- Get a lot of infections or infections that keep coming back.
- Have diabetes.
- Have TB or have been in close contact with someone with TB, or were born in, lived in, or traveled where there is more risk for getting TB.
- Live or have lived in an area (such as the Ohio and Mississippi River valleys) where there is an increased risk for getting certain kinds of fungal infections, such as histoplasmosis. These infections may happen or become more severe if you use HUMIRA. Ask your doctor if you are unsure if you have lived in these areas.
- Have or have had hepatitis B.
- Are scheduled for major surgery.
- Have or have had cancer.

- Have numbness or tingling or a nervous system disease, such as multiple sclerosis or Guillain-Barré syndrome.
- Have or had heart failure.
- Have recently received or are scheduled to receive a vaccine. HUMIRA patients may receive vaccines, except for live vaccines. Children should be brought up to date on all vaccines before starting HUMIRA.
- Are allergic to rubber, latex, or any HUMIRA ingredients.
- Are pregnant, planning to become pregnant, breastfeeding, or planning to breastfeed.
- Have a baby and you were using HUMIRA during your pregnancy. Tell your baby's doctor before your baby receives any vaccines.
- Take any other medicines. You should not take HUMIRA with ORENCIA<sup>®</sup> (abatacept), KINERET<sup>®</sup> (anakinra), REMICADE<sup>®</sup> (infliximab), ENBREL<sup>®</sup> (etanercept), CIMZIA<sup>®</sup> (certolizumab pegol), or SIMPONI<sup>®</sup> (golimumab). Tell your doctor if you have ever used

RITUXAN<sup>®</sup> (rituximab), IMURAN<sup>®</sup> (azathioprine), or PURINETHOL<sup>®</sup> (mercaptopurine, 6-MP).

Call your doctor right away if you have an infection or any symptoms of an infection while on HUMIRA.

HUMIRA can cause other serious side effects, including:

- Hepatitis B infection in carriers of the virus.
- Allergic reactions.
- Nervous system problems.
- Blood problems (decreased blood cells that help fight infections or stop bleeding).
- Heart failure (new or worsening).
- Immune reactions including a lupus-like syndrome.
- Liver problems. These problems can lead to liver failure and death.
- Psoriasis (new or worsening).

Common side effects of HUMIRA include injection site reactions (pain, redness, rash, swelling, itching, or bruising), upper respiratory infections (sinus infections), headaches, rash, and nausea.

These are not all of the possible side effects with HUMIRA. For more information, talk to your health care provider.

HUMIRA is given by injection under the skin.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.

If you cannot afford your medication, contact: [www.pparx.org](http://www.pparx.org) for assistance.



HUMIRA® (Hu-MARE-ah)  
(adalimumab) injection

Patient Information	
Read the Medication Guide that comes with HUMIRA before you start taking it and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical condition or treatment.	
<b>What is the most important information I should know about HUMIRA?</b>	<ul style="list-style-type: none"><li>• People with RA, especially more serious RA, may have a higher chance for getting a kind of cancer called lymphoma.</li><li>• If you use TNF blockers including HUMIRA your chance of getting two types of skin cancer may increase (basal cell cancer and squamous cell cancer of the skin). These types of cancer are generally not life-threatening if treated. Tell your doctor if you have a bump or open sore that does not heal.</li><li>• Some people receiving TNF blockers including HUMIRA developed a rare type of cancer called hepatosplenic T-cell lymphoma. This type of cancer often results in death. Most of these people were male teenagers or young men. Also, most people were being treated for Crohn's disease or ulcerative colitis with another medicine called IMURAN® (azathioprine) or PURINETHOL® (6-mercaptopurine, 6-MP).</li></ul>
<b>HUMIRA is a medicine that affects your immune system. HUMIRA can lower the ability of your immune system to fight infections. <b>Serious infections have happened in people taking HUMIRA. These serious infections include tuberculosis (TB) and infections caused by viruses, fungi or bacteria that have spread throughout the body. Some people have died from these infections.</b></b>	<ul style="list-style-type: none"><li>• have an infection. See <b>“What is the most important information I should know about HUMIRA?”</b></li><li>• have or have had cancer.</li><li>• have any numbness or tingling or have a disease that affects your nervous system such as multiple sclerosis or Guillain-Barré syndrome.</li><li>• have or had heart failure.</li><li>• have recently received or are scheduled to receive a vaccine. You may receive vaccines, except for live vaccines while using HUMIRA. Children should be brought up to date with all vaccines before starting HUMIRA.</li><li>• are allergic to rubber or latex. Tell your doctor if you have any allergies to rubber or latex.</li><li>• The needle cover for the HUMIRA Pen 40 mg/0.8 mL, HUMIRA 40 mg/0.8 mL prefilled syringe, HUMIRA 20 mg/0.4 mL prefilled syringe, and HUMIRA 10 mg/0.2 mL prefilled syringe may contain natural rubber or latex.</li><li>• The black needle cover for the HUMIRA Pen 80 mg/0.8 mL, HUMIRA 80 mg/0.8 mL prefilled syringe, HUMIRA Pen 40 mg/0.4 mL, HUMIRA 40 mg/0.4 mL prefilled syringe, HUMIRA 20 mg/0.2 mL prefilled syringe, HUMIRA 10 mg/0.1 mL prefilled syringe and the vial stopper on the HUMIRA institutional use vial are not made with natural rubber or latex.</li><li>• are allergic to HUMIRA or to any of its ingredients. See the end of this Medication Guide for a list of ingredients in HUMIRA.</li><li>• are pregnant or plan to become pregnant, breastfeeding or plan to breastfeed. You and your doctor should decide if you should take HUMIRA while you are pregnant or breastfeeding.</li><li>• have a baby and you were using HUMIRA during your pregnancy. Tell your baby's doctor before your baby receives any vaccines.</li></ul>
<b>You should not start taking HUMIRA if you have any kind of infection unless your doctor says it is okay.</b>	
<b>Before starting HUMIRA, tell your doctor if you:</b>	
<ul style="list-style-type: none"><li>• think you have an infection or have symptoms of infection such as:<ul style="list-style-type: none"><li>• fever, sweats, or chills</li><li>• muscle aches</li><li>• cough</li><li>• shortness of breath</li><li>• blood in phlegm</li><li>• warm, red, or painful skin or sores on your body</li><li>• diarrhea or stomach pain</li><li>• burning when you urinate or urinate more often than normal</li><li>• feel very tired</li><li>• weight loss</li></ul></li><li>• are being treated for an infection</li><li>• get a lot of infections or have infections that keep coming back</li><li>• have diabetes</li><li>• have TB, or have been in close contact with someone with TB</li><li>• were born in, lived in, or traveled to countries where there is more risk for getting TB. Ask your doctor if you are not sure.</li><li>• live or have lived in certain parts of the country (such as the Ohio and Mississippi River valleys) where there is an increased risk for getting certain kinds of fungal infections (histoplasmosis, coccidioidomycosis, or blastomycosis). These infections may happen or become more severe if you use HUMIRA. Ask your doctor if you do not know if you have lived in an area where these infections are common.</li><li>• have or have had hepatitis B</li><li>• use the medicine ORENCIA® (abatacept), KINERET® (anakinra), RITUXAN® (rituximab), IMURAN® (azathioprine), or PURINETHOL® (6-mercaptopurine, 6-MP).</li><li>• are scheduled to have major surgery</li></ul>	
<b>After starting HUMIRA, call your doctor right away if you have an infection, or any sign of an infection.</b>	
<b>HUMIRA can make you more likely to get infections or make any infection that you may have worse.</b>	
<b>Cancer</b>	
<ul style="list-style-type: none"><li>• For children and adults taking TNF-blockers, including HUMIRA, the chances of getting cancer may increase.</li><li>• There have been cases of unusual cancers in children, teenagers, and young adults using TNF-blockers.</li></ul>	<ul style="list-style-type: none"><li>• moderate to severe rheumatoid arthritis (RA) in adults. HUMIRA can be used alone, with methotrexate, or with certain other medicines.</li><li>• moderate to severe polyarticular juvenile idiopathic arthritis (JIA) in children 2 years and older. HUMIRA can be used alone, with methotrexate, or with certain other medicines.</li><li>• psoriatic arthritis (PsA) in adults. HUMIRA can be used alone or with certain other medicines.</li><li>• ankylosing spondylitis (AS) in adults.</li><li>• moderate to severe Crohn's disease (CD) in adults when other treatments have not worked well enough.</li><li>• moderate to severe Crohn's disease (CD) in children 6 years and older when other treatments have not worked well enough.</li><li>• moderate to severe hidradenitis suppurativa (HS) in people 12 years and older.</li><li>• In adults, to help get moderate to severe ulcerative colitis (UC) under control (induce remission) and keep it under control (sustain remission) when certain other medicines have not worked well enough. It is not known if HUMIRA is effective in people who stopped responding to or could not tolerate TNF-blocker medicines.</li><li>• To treat moderate to severe chronic (lasting a long time) plaque psoriasis (Ps) in adults who have the condition in many areas of their body and who may benefit from taking injections or pills (systemic therapy) or phototherapy (treatment using ultraviolet light alone or with pills).</li><li>• To treat non-infectious intermediate, posterior, and panuveitis in adults and children 2 years of age and older.</li></ul>
<b>What should I tell my doctor before taking HUMIRA?</b>	
HUMIRA may not be right for you. Before starting HUMIRA, tell your doctor about all of your health conditions, including if you:	<ul style="list-style-type: none"><li>• See the <b>Instructions for Use</b> inside the carton for complete instructions for the right way to prepare and inject HUMIRA.</li></ul>

CONSUMER BRIEF SUMMARY  
CONSULT PACKAGE INSERT FOR FULL  
PRESCRIBING INFORMATION

- Make sure you have been shown how to inject HUMIRA before you do it yourself. You can call your doctor or 1-800-4HUMIRA (1-800-448-6472) if you have any questions about giving yourself an injection. Someone you know can also help you with your injection after they have been shown how to prepare and inject HUMIRA.
- **Do not** try to inject HUMIRA yourself until you have been shown the right way to give the injections. If your doctor decides that you or a caregiver may be able to give your injections of HUMIRA at home, you should receive training on the right way to prepare and inject HUMIRA.
- Do not miss any doses of HUMIRA unless your doctor says it is okay. If you forget to take HUMIRA, inject a dose as soon as you remember. Then, take your next dose at your regular scheduled time. This will put you back on schedule. In case you are not sure when to inject HUMIRA, call your doctor or pharmacist.
- If you take more HUMIRA than you were told to take, call your doctor.

What are the possible side effects of HUMIRA?

HUMIRA can cause serious side effects, including:

**See “What is the most important information I should know about HUMIRA?”**

- **Serious Infections.** Your doctor will examine you for TB and perform a test to see if you have TB. If your doctor feels that you are at risk for TB, you may be treated with medicine for TB before you begin treatment with HUMIRA and during treatment with HUMIRA. Even if your TB test is negative your doctor should carefully monitor you for TB infections while you are taking HUMIRA. People who had a negative TB skin test before receiving HUMIRA have developed active TB. Tell your doctor if you have any of the following symptoms while taking or after taking HUMIRA:
  - cough that does not go away
  - low grade fever
  - weight loss
  - loss of body fat and muscle (wasting)
- **Hepatitis B infection in people who carry the virus in their blood.** If you are a carrier of the hepatitis B virus (a virus that affects the liver), the virus can become active while you use HUMIRA. Your doctor should do blood tests before you start treatment, while you are using HUMIRA, and for several months

after you stop treatment with HUMIRA. Tell your doctor if you have any of the following symptoms of a possible hepatitis B infection:

- muscle aches
- feel very tired
- dark urine
- skin or eyes look yellow
- little or no appetite
- vomiting

- clay-colored bowel movements
- fever
- chills
- stomach discomfort
- skin rash

- **Allergic reactions.** Allergic reactions can happen in people who use HUMIRA. Call your doctor or get medical help right away if you have any of these symptoms of a serious allergic reaction:
  - hives
  - swelling of your face, eyes, lips or mouth
- trouble breathing
- **Nervous system problems.** Signs and symptoms of a nervous system problem include: numbness or tingling, problems with your vision, weakness in your arms or legs, and dizziness.
- **Blood problems.** Your body may not make enough of the blood cells that help fight infections or help to stop bleeding. Symptoms include a fever that does not go away, bruising or bleeding very easily, or looking very pale.
- **New heart failure or worsening of heart failure you already have. Call your doctor right away** if you get new worsening symptoms of heart failure while taking HUMIRA, including:
  - shortness of breath
  - swelling of your ankles or feet
- sudden weight gain
- **Immune reactions including a lupus-like syndrome.** Symptoms include chest discomfort or pain that does not go away, shortness of breath, joint pain, or a rash on your cheeks or arms that gets worse in the sun. Symptoms may improve when you stop HUMIRA.
- **Liver Problems.** Liver problems can happen in people who use TNF-blocker medicines. These problems can lead to liver failure and death. Call your doctor right away if you have any of these symptoms:
  - feel very tired
  - poor appetite or vomiting
  - skin or eyes look yellow
  - pain on the right side of your stomach (abdomen)
- **Psoriasis.** Some people using HUMIRA had new psoriasis or worsening of psoriasis they already had. Tell your doctor if you develop red scaly patches or raised bumps that are filled with pus. Your doctor may decide to stop your treatment with HUMIRA.

**Call your doctor or get medical care right away if you develop any of the above symptoms. Your treatment with HUMIRA may be stopped.**

**Common side effects with HUMIRA include:**

- injection site reactions: redness, rash, swelling, itching, or bruising. These symptoms usually will go away within a few days. Call your doctor right away if you have pain, redness or swelling around the injection site that does not go away within a few days or gets worse.
- upper respiratory infections (including sinus infections).
- headaches.
- rash.

These are not all the possible side effects with HUMIRA. Tell your doctor if you have any side effect that bothers you or that does not go away. Ask your doctor or pharmacist for more information.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

General information about the safe and effective use of HUMIRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HUMIRA for a condition for which it was not prescribed. Do not give HUMIRA to other people, even if they have the same condition. It may harm them.

This brief summary summarizes the most important information about HUMIRA. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about HUMIRA that is written for health professionals. For more information go to [www.HUMIRA.com](http://www.HUMIRA.com) or you can enroll in a patient support program by calling 1-800-4HUMIRA (1-800-448-6472).

Manufactured by:

AbbVie Inc.

North Chicago, IL 60064, U.S.A.

US License Number 1889

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LAB-1387 **MASTER**

US-HUMD-181987

abbvie





Volunteers are the heart and soul of our organization. Without them, we would have no purpose, no promise, no power. Meet some of the faces who keep us going strong.

For 50-plus years, the National Psoriasis Foundation has been powered by a river of volunteers. Patients, families, friends, scientists and health care providers have repeatedly pitched in to help our cause.

For some people, getting involved is as simple as reading our emails or *NPF Advance* and then sharing

what they've learned. Others take our quizzes, listen to our podcasts and webinars, go to our events and make donations.

And then there are the people who are propelled even further by their passion to help. Maybe they have psoriatic disease. Maybe they know someone who does. Maybe they care for patients, whether they wear a

white coat or not. Maybe they spend their day in a lab, looking for a cure. Whatever their reasons, these folks have become very active in our community, and our community is better for it.

In this story, you'll meet a crew who, in their own quiet, steady way, have been working hard to help everyone with psoriasis and psoriatic arthritis.

## MICHELLE STRANGIS

Michelle Strangis is one of those lawyers who decided early on not to practice law. She has instead used her training to reinforce her real calling: diplomacy.

Strangis worked for 26 years for the Minnesota Department of Health on state health policies. She spent five of those years writing the first licensure system for occupational therapists.

Around the time she retired in 2018, she received an email from NPF asking if any Minnesota residents had been denied insurance coverage for a physician-prescribed drug. "That's exactly what happened to me!" says Strangis, who has been coping with psoriasis since she was 35. "I had had a bad experience with step therapy. In that case, I used my skills as a lawyer, calling out the improprieties of the process, to help win my appeal."

Strangis answered the email and instantly became a volunteer. "It's always better to change policy as opposed to going to war with insurers, patient by patient," she says. "I know how effective policy is at addressing large-scale issues. A policy is like a blanket. It's for everybody."

She hit the ground running. Her first patient advocacy event was Capitol Hill Day in March 2018. She plans to participate in a future webinar on step therapy, providing the patient perspective.

Strangis' two priorities going into retirement were preparing to down-size and traveling, but now she's added volunteering with NPF as she advocates for her own cause.

*Story by Steve Bieler  
Photos by Diana Yopez*





# DEREK & ISAAC SHUJAHN

Derek Shujahn, from Franklin, Tennessee, knows all too well that psoriatic disease can impact a whole family. His youngest son, Isaac, who is about to turn 18, was diagnosed with psoriasis at age 6.

The roller coaster of treatments – finding one that works and starting the whole process over again when a drug stops working – has been physically and emotionally exhausting.

Watching his son feel isolated has been hard for Derek. There have been many nights over the past 12 years when he prayed he could take his son's place. "As a dad, you reach a point where you feel completely helpless," he says.

In order to do *something* – and get himself back into shape – Derek signed up for a triathlon. And to keep himself motivated, he dedicated his race to his son by raising money for Team NPF.

In the months leading up to the event, Derek woke up before sunrise to run, ride his bike and swim as much as possible. His training paid off, as he finished the triathlon in just over three hours and raised \$500.

When Isaac first learned about his dad's fundraising efforts, he was concerned about drawing attention to his psoriasis. But seeing his dad's hard work and perseverance changed that perspective.

"I'm really proud of him," says Isaac. "Because [training] is something he hasn't done in so long."

While Isaac isn't quite ready to join his dad at the next triathlon, he will be there to give him the emotional support (and go for the occasional early morning jog with him).

Story by Chris Paoli  
Photos by Morgan Nagle





# RONALD PRUSSICK, M.D.

Ronald Prussick, M.D., understands that education opens doors. During his residency at the University of Toronto, he had the good fortune of meeting an inspiring dermatologist who got him interested in psoriasis.

And for the past 30 years, he's empowered patients to learn more about their disease. He was happy to see that the new psoriasis treatment guidelines released in February by the American Academy of Dermatology and NPF recommend biologics as front-line therapies.

"Too many patients are still getting topicals," he says. "I can give patients the proper perspective on the risks versus the rewards of the new biologics. Their doctor may not know the data. I can help people make a decision. I can also talk to them about health and lifestyle changes."

Prussick is passionate about educating patients, but he also knows how to listen. "I get great feedback from psoriasis patients," he says. "They're my most appreciative patients, possibly because other dermatologists have disappointed them."

Among his volunteer activities, Prussick served on the NPF medical board for six years. He enjoys walking with Team NPF ("It's something I can do with my staff and patients together") and he has guest-starred on two episodes of our podcast, Psound Bytes: "Treatment side effects impacting psoriatic disease" and "If I'm clear, why do I need to continue my psoriasis treatment?"

Prussick moved to Maryland in 1991 for a dermatology fellowship at the U.S. National Institutes of Health and since 1995 has been running his own practice in Rockville, Maryland.

*Story by Steve Bieler  
Photos by Storytellez*



# CAROL L. SELBY

Growing up on an Indiana farm in the late 1960s, Carol Selby felt completely alone when it came to her psoriasis. It wasn't until she stumbled upon a black-and-white newsletter from NPF that she learned there were others just like her.

Almost 50 years later, the retired financial analyst is making sure nobody with psoriatic disease feels alone. Selby joined NPF in 2016 as a community ambassador before becoming a research ambassador. In her current volunteer position, she interacts with doctors and researchers while showing them a human face of the disease.

Selby's first outing as a volunteer was also her most memorable. She attended the U.S. Food and Drug Administration's Patient-Focused Drug Development public meeting. There, she gave her patient testimonial in front of researchers and doctors. "Speaking to the FDA was truly a once-in-a-lifetime opportunity," says Selby.

More recently, Selby attended the 2018 NPF Research Trainee Symposium in Portland, Oregon, as a guest on the patient panel. Again, she had the chance to talk about living with psoriasis to a room full of researchers. She says the symposium helps bring the two sides of the equation together and that events like these are invaluable to the development of new treatment options. "Not everyone in the labs gets a chance to speak with someone who has life experience with the disease," she says. "While we are in a lot better place than we have been when it comes to treatment, we still have so much important work to be done."

*Story by Chris Paoli  
Photos by Violet Short*





# THE KUMAR FAMILY

Anju Kumar didn't know where to turn after her oldest son, Ashwin, was diagnosed with psoriasis and PsA at age 12. Both felt isolated and powerless. Neither had heard of psoriatic disease.

The San Diego mom says it took time to process the diagnosis and she wondered what her son's future would hold. "It was hard coming to terms with the fact that there is no cure," says Anju.

At the same time, Ashwin was becoming disconnected from his peers and frustrated with a disease he felt nobody could relate to.

Anju reached out to NPF about a year into Ashwin's treatment journey in hopes of tapping into a community who would understand. The Kumars attended an intimate meeting with NPF volunteers and discovered they weren't alone. "That was a turning point in our lives. We saw others with the disease and it was strong testimony that you can live a normal life with psoriasis."

The family became heavily involved with NPF, and Ashwin became a youth ambassador. The Kumars have attended a host of local events like meet-ups and fund-raised for Team NPF walks and bike rides. They also joined the western advocacy action network, traveling to Sacramento, California, to fight for better drug options and insurance coverage for people with chronic diseases.

Ashwin, now 17, is on a treatment that has cleared his psoriasis and gotten his PsA under control. His younger brother, Neel, was recently diagnosed with psoriasis and PsA – however, the family feels more prepared to tackle it this time around thanks to their community.

*Story by Chris Paoli*

*Photos by Anna Lynch*

*Left to right: Neel, Anju and Ashwin Kumar.*





# CHARLOTTE HURABIELLE-CLAVERIE

Researchers like Charlotte Hurabielle-Claverie, M.D., support NPF's mission of finding a cure for psoriatic disease and improving the lives of those affected. The 2018 Early Career Research Grant recipient is studying the skin to learn more about the nature of microbes and their connection to psoriasis.

The Paris, France native, who works at the U.S. National Institutes of Health in Bethesda, Maryland, knew early on that research was her calling. "With my educational background, I was very interested in autoimmune diseases and inflammatory disorders," says Hurabielle-Claverie. "It really made sense that after my clinical training that I would find myself in psoriatic disease."

She acknowledges that psoriatic disease still raises many questions – from what the causes are to why results from available treatments vary – and those are the kinds of questions that excite her. She hopes that her current research, which may identify new ways of treating people based on their individual skin microbes, will answer more about the nature of the disease.

The research conducted by Hurabielle-Claverie (among others who have received NPF grants) has immense potential to positively impact anyone living with psoriasis or psoriatic arthritis through more effective treatments. "It's rewarding to know that what I do will help patients at some point to have a better life."

*Story by Chris Paoli  
Photos by Storytellez*



# LENA OSLUND

Lena Oslund of Lansing, Michigan, has spent most of her life dealing with psoriasis. She was diagnosed at age 6. Psoriasis made her self-conscious. It didn't help that some kids bullied her.

At a young age, she responded to unkind comments in a mature way. "I handled it by walking away," she says.

Today, Oslund is heading into her junior year of high school, where she takes AP classes and swims the 500 meters. She's a lot more confident; she's older and her psoriasis is "under control" thanks to a combination of a biologic and a systemic.

Her life no longer revolves around psoriasis, she says. And you can tell from her wide-ranging interests, including bicycling, drawing, karate, photography and reading.

Psoriasis is still a big influence – in a positive way. Oslund participates in Team NPF Walk and Team NPF Cycle with her parents. In 2017, she became an NPF youth ambassador for her region.

"I want [people] to know what psoriasis is and that they can't catch it and there are good treatments to try," she wrote on her application.

As a youth ambassador, Oslund spoke at the 2017 Team NPF Walk in Chicago and led Team Lena on the walk. She also attended the 2017 NPF National Volunteer Conference in Chicago.

Psoriasis has had another notable influence on Oslund: Like other patients before her, she wants to go into a medical field. Maybe someday, Lena Oslund will be the person explaining to her patient that there are good treatments to try.

*Story by Steve Bieler  
Photos by Britney Weber*







# YOU AND YOUR FRIENDS GO EVERYWHERE TOGETHER. BUT SO DO YOUR FLAKES.

**4 DOSES  
A YEAR  
AFTER  
2 INITIAL DOSES**

**6 OUT OF 10  
— PEOPLE WERE —  
CLEAR OR  
ALMOST CLEAR  
AFTER 2 DOSES  
(AT 12 WEEKS)**

**ASK YOUR DOCTOR FOR ILUMYA™ TODAY  
FOR A CLEARER TOMORROW.**

**FOR ADULTS WITH MODERATE-TO-SEVERE PLAQUE PSORIASIS**

## WHAT IS ILUMYA?

ILUMYA is a prescription medicine used to treat adults with moderate to severe plaque psoriasis who may benefit from taking injections, pills (systemic therapy), or phototherapy (treatment using ultraviolet or UV light).

## IMPORTANT SAFETY INFORMATION

**What is the most important information I should know about ILUMYA?**

**Do not use ILUMYA** if you have had a severe allergic reaction to ILUMYA or any of its ingredients.

**Get emergency medical help right away if you get any of the following symptoms of a serious allergic reaction:**

- feel faint • trouble breathing or throat tightness
- swelling of your face, eyelids, lips, mouth, tongue or throat
- chest tightness • skin rash

ILUMYA is a medicine that may lower the ability of your immune system to fight infections and may increase your risk of infections. Your healthcare provider should check you for infections and tuberculosis (TB) before starting treatment with ILUMYA and may

treat you for TB before you begin treatment with ILUMYA if you have a history of TB or have active TB. Your healthcare provider should watch you closely for signs and symptoms of TB during and after treatment with ILUMYA.

Tell your healthcare provider right away if you have an infection or have symptoms of an infection, including:

- fever, sweats, or chills • muscle aches • weight loss • cough
- warm, red, or painful skin or sores on your body different from your psoriasis • diarrhea or stomach pain • shortness of breath
- burning when you urinate or urinating more often than normal
- blood in your phlegm (mucus)

**Before receiving ILUMYA, tell your healthcare provider about all of your medical conditions, including if you:**

- have any of the conditions or symptoms listed in the section **“What is the most important information I should know about ILUMYA?”**
- have an infection that does not go away or that keeps coming back
- have TB or have been in close contact with someone with TB
- recently received or are scheduled to receive a vaccine (immunization). You should avoid receiving live vaccines during treatment with ILUMYA.

• are pregnant or plan to become pregnant. It is not known if ILUMYA can harm your unborn baby.

• are breastfeeding or plan to breastfeed. It is not known if ILUMYA passes into your breast milk.

**Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements.

It is not known if ILUMYA is safe and effective in children under 18 years of age.

**What are the possible side effects of ILUMYA?**

**ILUMYA may cause serious side effects. See “What is the most important information I should know about ILUMYA?”**

The most common side effects of ILUMYA include: upper respiratory infections, injection site reactions and diarrhea. These are not all of the possible side effects of ILUMYA. Call your doctor for medical advice about side effects.

**You are encouraged to report any negative side effects of ILUMYA to FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.** You are also encouraged to report side effects or ADEs (adverse drug events) to our Drug Safety Department at

1-800-406-7984 or [drug.safetyUSA@sunpharma.com](mailto:drug.safetyUSA@sunpharma.com) (preferred) with as much information as available.

**Please read Brief Summary of the full Prescribing Information for ILUMYA on the next page and discuss any questions with your doctor.**



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PM-US-ILY-0243 01/2019

 **ILUMYA™**  
tildrakizumab-asmn  
Injection 100 mg/mL

**LEARN MORE AT [ILUMYA.COM](http://ILUMYA.COM)**



Consumer Brief Summary	
The risk information provided here is not comprehensive. This information does not take the place of talking with your doctor about your medical condition or treatment To learn more about ILUMYA™ (tildrakizumab-asmn), talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 888-726-2299 or visit www.ilumya.com	
<b>What is the most important information I should know about ILUMYA?</b> <b>ILUMYA may cause serious side effects, including:</b> <b>Serious allergic reactions. Get emergency medical help right away if you get any of the following symptoms of a serious allergic reaction:</b> <ul style="list-style-type: none"><li>• feel faint</li><li>• trouble breathing or throat tightness</li><li>• swelling of your face, eyelids, lips, mouth, tongue or throat</li><li>• chest tightness</li><li>• skin rash</li></ul> <b>Infections.</b> ILUMYA is a medicine that may lower the ability of your immune system to fight infections and may increase your risk of infections. Your healthcare provider should check you for infections and tuberculosis (TB) before starting treatment with ILUMYA and may treat you for TB before you begin treatment with ILUMYA if you have a history of TB or have active TB. Your healthcare provider should watch you closely for signs and symptoms of TB during and after treatment with ILUMYA. Tell your healthcare provider right away if you have an infection or have symptoms of an infection, including: <ul style="list-style-type: none"><li>• fever, sweats, or chills</li><li>• muscle aches</li><li>• weight loss</li><li>• cough</li><li>• warm, red, or painful skin or sores on your body different from your psoriasis</li><li>• diarrhea or stomach pain</li><li>• shortness of breath</li><li>• burning when you urinate or urinating more often than normal</li><li>• blood in your phlegm (mucus)</li></ul> See “What are the possible side effects of ILUMYA?” for more information about side effects.	
<b>What is ILUMYA?</b> ILUMYA is a prescription medicine used to treat adults with moderate to severe plaque psoriasis who may benefit from taking injections, pills (systemic therapy) or treatment using ultraviolet or UV light (phototherapy). It is not known if ILUMYA is safe and effective in children under 18 years of age.	
<b>Do not use ILUMYA</b> if you have had a severe allergic reaction to tildrakizumab or any of the other ingredients in ILUMYA. See the end of this Medication Guide for a complete list of ingredients in ILUMYA.	
<b>Before receiving ILUMYA, tell your healthcare provider about all of your medical conditions, including if you:</b> <ul style="list-style-type: none"><li>• have any of the conditions or symptoms listed in the section “What is the most important information I should know about ILUMYA?”</li><li>• have an infection that does not go away or that keeps coming back.</li><li>• have TB or have been in close contact with someone with TB.</li><li>• recently received or are scheduled to receive a vaccine (immunization). You should avoid receiving live vaccines during treatment with ILUMYA.</li><li>• are pregnant or plan to become pregnant. It is not known if ILUMYA can harm your unborn baby.</li><li>• are breastfeeding or plan to breastfeed. It is not known if ILUMYA passes into your breast milk.</li></ul> <b>Tell your healthcare provider about all the medicines you take</b> , including prescription and over-the-counter medicines, vitamins, and herbal supplements.	
<b>How will I receive ILUMYA?</b> <ul style="list-style-type: none"><li>• ILUMYA should only be given to you by a healthcare provider.</li><li>• ILUMYA is given as an injection under your skin (subcutaneous injection) in areas of your body such as your thighs, stomach area (abdomen), or upper arm.</li><li>• If you miss a follow-up appointment and do not receive your dose of ILUMYA, schedule another appointment as soon as possible.</li></ul>	
<b>What are the possible side effects of ILUMYA?</b> <b>ILUMYA may cause serious side effects. See “What is the most important information I should know about ILUMYA?”</b> The most common side effects of ILUMYA include: <ul style="list-style-type: none"><li>• upper respiratory infections</li><li>• injection site reactions</li><li>• diarrhea</li></ul> These are not all of the possible side effects of ILUMYA. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.	
<b>General information about the safe and effective use of ILUMYA.</b> Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. You can ask your healthcare provider for information about ILUMYA that is written for health professionals.	
<b>What are the ingredients in ILUMYA?</b> <b>Active ingredient:</b> tildrakizumab-asmn <b>Inactive ingredients:</b> L-histidine, L-histidine hydrochloride monohydrate, polysorbate 80, sucrose, and Water for Injection, USP.  Manufactured by: Sun Pharma Global FZE, Inc. Sharjah, U.A.E. U.S. License No. 2092 At: MSD Ireland (Carlow), County Carlow, Ireland Tildrakizumab-asmn (active ingred.). Product of The Netherlands. Distributed by: Sun Pharmaceutical Industries, Inc. Cranbury, NJ 08512 Copyright © 2018 Sun Pharma Global FZE. All rights reserved. PLR-00019 RX ONLY  usmg-tildrakizumab-pfs-00001	

This Medication Guide has been approved by the U.S. Food and Drug Administration.

Issued: 08/2018



# A careful touch

When psoriatic disease attacks the hands and feet, it affects everyday movements and activities often taken for granted. Get a grip on what’s happening.

Story by Emily Delzell  
Photos by Aaron Coury

Our hands and feet are ultra sensitive. Sensory neurons, which trigger pain sensations in the brain, cluster at the fingertips. The complex anatomical structure of hands and feet – with many joints, tendons and ligaments packed tightly together – gives us an acute sense of touch and lets us do precision movements. Our hands, particularly when used for communication through gesture, draw attention.

That’s why psoriatic disease, when it strikes the hands and feet, has an outsize effect. The symptoms can be more intense and more upsetting. Fingernail psoriasis, for instance, is often immediately noticeable and can make something as basic as a handshake feel

*It’s hard to do anything without fingernails, and if I use my fingers too much, they bleed.*

uncomfortable. Pain and other symptoms of psoriasis and psoriatic arthritis (PsA) in the hands and feet can make other routine tasks hard to accomplish.

Gary Bixby, who lost all his fingernails and toenails to severe psoriasis (but is otherwise fit at 73), says psoriatic nail disease makes it painful to chop fuel for his wood-burning stove, a frustrating problem during winters at his home in Blair, Wisconsin.

“It’s hard to do anything without fingernails, and if I use my fingers too much, they bleed,” says Bixby, who developed psoriasis two years ago. The disease appeared first as pitting in two fingernails and a few



scales of plaque psoriasis on his left foot. His primary care provider didn't recognize it as psoriasis, and the disease went undiagnosed until it rapidly got worse.

"It was affecting more fingernails, then my toenails and large areas on my arms, legs and trunk," says Bixby. "That's when I went to a podiatrist, who thought I had psoriasis, and then then to a dermatologist, who confirmed it."

**Location matters**

To get an idea of the impact of psoriatic disease on the hands and feet, think of the pain of a hangnail on a finger or a blister on a foot, and how much these small injuries consume your attention and interfere with daily tasks, says Kristina Callis Duffin, M.D.,

and soles of the feet (called palmoplantar psoriasis) with those who have the disease elsewhere. The study, published in September 2018 *Journal of the American Academy of Dermatology*, found that those with hand and foot involvement were almost twice as likely to report problems with mobility and almost two-and-a-half times more likely to say they had trouble completing usual activities.

"Those with palmoplantar psoriasis scored much worse on multiple quality-of-life measures, even though they typically had less total affected body surface area," says Duffin, who is also an NPF medical board member.

Body surface area is one way dermatologists measure psoriasis severity and decide how aggressively to



co-chair of the department of dermatology at the University of Utah in Salt Lake City.

"Having psoriasis or psoriatic arthritis on the hands and feet is life-altering," she says. "It raises the bar for how much it affects your quality of life."

Duffin was the lead investigator for a study comparing people who have psoriasis on the palms of the hands

treat it. But it's not the best tool for making treatment decisions when the hands or feet are affected, Duffin says. "In those cases, we often start treatment with a biologic even when the total involved body surface area is relatively small."

PsA also hits especially hard when it affects hands and feet.

"If joints in the hands and feet are hurting and swollen, it can affect every aspect of their function," says Alice Gottlieb, M.D., Ph.D., clinical professor of dermatology at the Icahn School of Medicine at Mount Sinai in New York City and an NPF medical board member.

**Types, symptoms and treatment**

Like psoriasis and PsA elsewhere on the body, psoriatic disease in the hands and feet can cause itchy, scaling, reddened skin plaques and painful, swollen joints. Specific types and symptoms of hand and foot psoriasis and PsA, however, can also cause less-familiar skin and joint issues.

**Palmoplantar psoriasis**, plaque psoriasis on the feet or hands, affects about 40 percent of people with plaque psoriasis, who often don't have much skin disease elsewhere. As noted, its substantial effects on function and quality of life mean dermatologists typically use advanced medications to control symptoms. Treating certain types of palmoplantar psoriasis is still challenging, despite the rapidly expanding list of medications for psoriasis and PsA. Often, palmoplantar psoriasis doesn't respond as well to treatment as does psoriasis on other parts of the body.

Most biologics, which work by targeting specific proteins that turn up inflammation in psoriatic disease, such as tumor necrosis factor (TNF) or interleukin-17 (IL-17), have some effect on certain people with palmoplantar psoriasis.

No drug works for everyone, and people with palmoplantar psoriasis may have to try several medications or combinations of treatments to relieve symptoms. Gary Bixby, for example, didn't get better with either a TNF or an IL-17 inhibitor. The third biologic he tried blocks another interleukin protein, IL-23, and, three months after his first injection, he's getting better results.

"I'm seeing improvements in my fingernails and the plaques on my body, which I didn't get with the first two biologics. I'm cautiously hopeful," he says.

**Palmoplantar pustular disease, or pustulosis**, affects about 5 percent of people with psoriasis. It shows up as small, pus-filled blisters on reddened, tender skin. It can also cause painful cracking and fissuring.

**5 self-care tips**

*Dermatologists share simple ways to pamper your hands and feet.*

1. Moisturize hands and feet regularly with bland creams or ointments – not lotions, which are lighter weight than other formulations. Look for active ingredients such as urea that exfoliate and soften thickened, scaly skin. This helps topical medications penetrate.
2. Cover just-moisturized skin with plastic wrap or close-fitting gloves or socks for at least two hours. This technique, called occlusion, traps extra moisture and can reduce pain and help heal cracked, fissured skin.
3. Avoid excessive handwashing. It can cause irritant dermatitis on top of psoriasis.
4. Go easy on nails. Keep them trimmed short so they don't catch on objects. Explain to nail technicians that your disease isn't infectious but does require extra-gentle care. This means careful filing and pushing back (but not cutting) cuticles.
5. Use nail polishes with caution. Nail polishes and removers can dry out nails and cause irritation in the nail fold if you're allergic to acrylic. However, nail polish can mask the appearance of nail disease, and experts don't rule out its use. They advise taking off polish before appointments so your doctor can evaluate the extent of symptoms and whether treatments are working.

Not all nail polishes are the same. Research the different types and ask your health care provider for help reviewing ingredients.



Biologics can sometimes make pustular disease worse, says Duffin, so dermatologists may decide to begin treatment with a traditional disease-modifying antirheumatic drug (DMARD) such as methotrexate or cyclosporine.

“There are also new medications in development, specifically anti-IL-36 biologics, that could be a good treatment pathway for pustular psoriasis,” says Duffin.

**Psoriatic nail disease** can cause a host of symptoms in both the nail bed and the matrix, the area where fingernails and toenails start their growth. These include pitting, crumbling, thickening, discoloration, white or reddish spots, and separation of the nail from the nail bed (called onycholysis). None of these symptoms is specific to nail psoriasis, however, and some people have both nail psoriasis and nail fungus.

All this can make nail disease difficult to diagnose, says Duffin.

“If you have pitting, for example, you could have vitiligo or eczema instead of psoriasis,” she explains. (Vitiligo is a disease that causes skin, or sometimes hair, to lose its natural color.) “Sometimes, psoriasis patients are concerned about normal nail features, such as ridging or brittleness, that aren’t psoriasis.”

When the cause of nail symptoms isn’t clear, dermatologists look for signs of psoriasis elsewhere on the body. They may also look at a nail clipping under a microscope to distinguish one condition from another.

Once dermatologists understand what’s going on in the nails, they can decide how best to treat them. “All biologics have some data showing they can work better for nails than traditional DMARDs, but there is still no one slam-dunk treatment,” says Duffin, who notes that it can take months to learn whether a treatment is improving nail symptoms.

“It takes three to six months for nail to regrow entirely, so patients need to be on a drug continuously for that time for us to know whether it’s working,” she says.

Nail psoriasis is also a risk factor for PsA, and when it occurs with other symptoms, may prompt a

referral to a rheumatologist, who can evaluate you for joint disease.

**Dactylitis**, sometimes called “sausage” fingers or toes, is the painful swelling of digits that can occur with PsA. “When people have dactylitis, all the structure of the digits are inflamed, and this means every aspect of their function is impaired,” says Gottlieb.

**Enthesitis**, the swelling of the entheses, the connective tissue that joins ligaments and tendons to bone, can cause discomfort in the hands and feet of people with PsA. The sole of the foot and the back of the heel, where the Achilles tendon inserts into the heel bone, are common sites for enthesitis.

Treating PsA with appropriate medications, typically a DMARD or a biologic, should also relieve symptoms of dactylitis and enthesitis, Gottlieb says.

Researchers are now focusing more on hand and foot symptoms in clinical trials. That means physicians are getting better data about what works for specific symptoms, says

Gottlieb, who is triple board-certified in dermatology, rheumatology and internal medicine.

### TLC for hands and feet

Avoiding injuries, even small ones (often called micro-traumas), makes good sense for people with psoriasis or PsA affecting the hands and feet.

“The Koebner phenomenon is the flaring of psoriasis in response to injury. Even minor trauma can cause a flare,” says Duffin. “For example, if you use your nails to pry open a lid, you’re probably going to make your nail psoriasis worse.”

Similarly, shoving feet into shoes without enough room to wiggle toes or wearing high heels means you’re putting constant pressure on nails and joints, which can increase pain and nail problems.

“I generally recommend flats that have good cushioning and arch support that takes the weight off toe joints – which doesn’t mean wearing ballet slippers that have no padding in the bottom,” says Gottlieb.

“You don’t want a triangle profile that squeezes the toes, because that elicits pain.” She also cautions that flip-flops, a summer favorite, expose toes and feet to trauma.

A consultation with a podiatrist, who can advise on the right footwear and design an orthotic for individual foot issues, is often helpful for people with PsA that affects the feet, Gottlieb says.

### Live your healthiest life

NPF patient navigators offer personalized assistance to anyone with psoriatic disease. Reach out by email, phone or text and tap into a wealth of resources.

Visit [psoriasis.org/navcenter](https://psoriasis.org/navcenter).

## Protect your hands and feet from powerful rays

*Just in time for summer, the FDA has released new sunscreen guidelines.*

Protecting your skin from ultraviolet (UV) damage is important year-round, not just during the long days of summer. “A sunburn can worsen psoriasis, so be sure to wear your sunblock,” says Meghan Feely, M.D., a board-certified dermatologist practicing in New Jersey and New York City who serves as a clinical instructor at Mount Sinai’s department of dermatology.

Swayed by ongoing concerns about the safety of chemical ingredients, the U.S. Food and Drug Administration in early 2019 proposed major changes in sunscreen regulations. Currently, the FDA reports that only two sunscreen ingredients, zinc oxide and titanium dioxide, are “generally recognized as safe and effective.”

Mineral ingredients like zinc oxide and titanium dioxide don’t penetrate the skin to reach living tissue. These mineral ingredients also provide broad-spectrum protection, meaning they block both UVA and UVB light.

“These ingredients are also less likely to irritate the skin in a patient with psoriasis,” Feely says.

Chemical sunscreen ingredients, on the other hand, can be absorbed by the body, producing hormone-like effects that can leach into breast milk.

## 5 hot tips



Use a broad-spectrum, water-resistant, zinc oxide or titanium dioxide sunblock with an SPF of 30 or greater.



Skip products that contain fragrances, parabens (a type of preservative used in cosmetics and medications), insect repellents or other ingredients that can irritate the skin.



Apply generously to all exposed skin at least 15 minutes before going outdoors.



Reapply every two hours or after sweating, swimming or bathing.



Wear clothing and hats that provide an extra layer of protection from harmful UV rays.





week 1



week 9

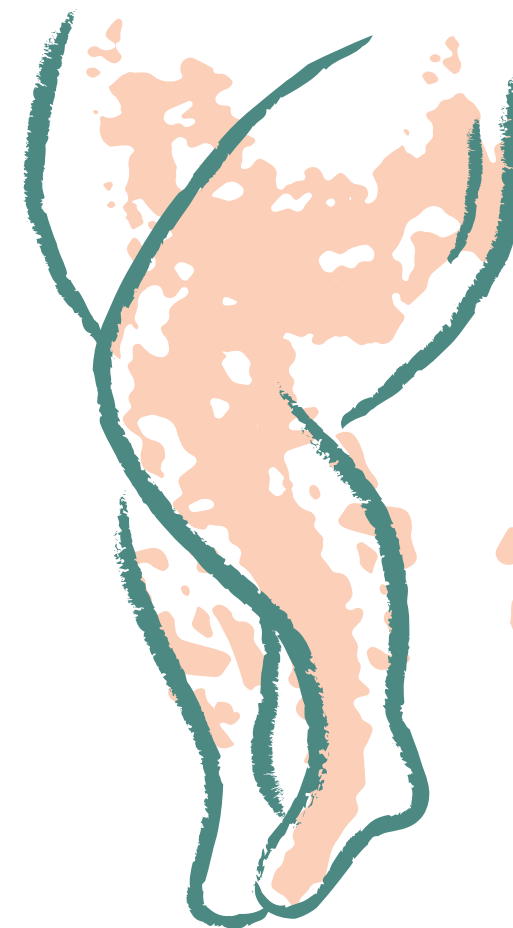
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# Baring it all

**One in four of you will experience genital psoriasis. Relief starts with having an honest conversation with your doctor.**

*By Chris Paoli*

For many of us, a doctor's visit is right up there with taking the trash out on a cold, rainy night or sitting through your child's favorite animated movie for the thousandth time. The waiting room is a drag, those paper gowns are never fun, and bringing up issues involving a sensitive area may make you feel self-conscious.

This is especially true when it comes to psoriasis in the genital area. Just as psoriasis can appear on your elbows, hands and scalp, psoriasis pops up around the genitals, pubis, buttocks and upper thighs 24 percent of the time.

Sometimes called inverse psoriasis, if it appears in the folds of the skin, the lesions characterized in genital psoriasis typically involve small, red round plaques. Genital psoriasis brings the same symptoms as non-genital psoriasis: itchiness, burning, pain and worsening lesions due to external triggers.

Treatments for genital psoriasis, like other types of psoriasis, include low-potency topical steroids for mild to moderate cases and systemics and biologics for more extreme cases. You can get genital psoriasis under control with proper treatment and careful monitoring. The biggest hurdle may be a reluctance to seek medical advice.

## *Speak up (even if you're embarrassed)*

According to an August 2017 study published in the *Journal of Drugs in Dermatology*, 45.8 percent of psoriasis patients did not discuss their genital psoriasis with a health care provider. The top reason: embarrassment.

Dermatologist Abby S. Van Voorhees, M.D., chair of the NPF medical board and a co-author of the study, says that physicians have a hard time treating something they don't know about – or can't examine – due to a patient's inability to speak up.

"I'll ask patients if they have any psoriasis on the genitalia or on the rectum and then they will look at me a little sheepishly and say, 'Actually, I do.' I then say, 'May I see it?' They then usually hesitate and ask, 'Well, do I really have to? I'm embarrassed.' "

Van Voorhees, professor and chair of dermatology at Eastern Virginia Medical School in Norfolk, says she often must convince patients that she does need to see their genital psoriasis so that she can properly diagnose it and prescribe the appropriate treatment.



The same level of hesitation in discussing the issue extends beyond face-to-face interactions with physicians. The NPF Patient Navigation Center, which provides personalized assistance to learn about treatment options and find health care providers, is no stranger to genital psoriasis inquiries – and the awkward dance around the conversation.

Mercy Rivera has been a patient navigator for two years and has noticed a pattern when it comes to calls about genital psoriasis. First, the majority of inquiries are from women – whether they are reaching out about a problem for themselves or a male partner. Second, it might take some coaxing to discuss potential genital issues.

“With some of the people that we talk to, it does take a while for them to open up to actually let us know that they have genital psoriasis,” says Rivera. “I think that for the most part, at least on the phone, people tend to shy away from saying that they have genital psoriasis.”

Rivera says that it’s usually well into the conversation, after the patient has discussed the severity of her symptoms and concerns, that she hints at possibly having genital psoriasis.

### When in doubt, consult your dermatologist

Once the subject of genital psoriasis has been broached with a health care provider or a patient navigator, that’s not the last roadblock on the path to a diagnosis.

Finding a health care specialist who won’t unintentionally steer you wrong could be an issue. Rivera comments that cases of misdiagnosis from gynecologists, while not the norm, may happen.

“There have been cases of patients, specifically women, who aren’t diagnosed [for psoriasis], going to their gynecologist when an issue in the genitals occurs,” says Rivera. “The gynecologist, especially those not familiar with psoriasis, sometimes is unsure of what is going on or might misdiagnose the issue as an STD.”

Rivera says that many of those contacting the Patient Navigation Center about genital issues are concerned that their condition may be related to a sexually transmitted disease based on conversations with their primary care provider or gynecologist. If you find yourself in a similar situation, Rivera says it might be worth asking your doctor for a skin biopsy to test for psoriasis, especially if you have an existing diagnosis for psoriasis. That will save you the headache and cost associated with bouncing from one provider to another until you receive the correct diagnosis.

As a practicing physician, Van Voorhees agrees that confusion can stem from doctors who might be working with a limited knowledge base when it comes to psoriasis.

“I think there’s a higher rate of misdiagnosis,” says Van Voorhees.

“And I believe that to be true because primary care doctors, while they’ll usually always recognize psoriasis when it is on the elbows or knees, in the genital area it can be confused with yeast infections, fungal infections and sometimes eczema. That’s why it’s important to go to a dermatologist to find out what’s going on.”

### Start treatment

You’ve spoken up about your genital issues. You’ve seen a dermatologist and have been diagnosed with psoriasis. Now it’s time to start treatment.

In mild-to-moderate cases, a typical treatment recommendation is a topical steroid used for up to a month. According to the *Journal of Drugs in Dermatology* study, if issues continue after the initial month of treatment, doctors may explore other options, including non-steroid-based topicals, emollients, tar-based products and antimicrobial therapy.

And for severe cases when other treatments are not working, systemics and biologics are options.

Watching out for triggers is also important when managing genital psoriasis. As with any other part of your skin, internal and external factors can exacerbate your psoriasis. However, genital psoriasis shares some unique considerations. “Just like all psoriasis, genital psoriasis gets triggered by harsh environments,” says Van Voorhees. “For example, some patients might get a gastroenteritis bug and they develop diarrhea, then their psoriasis might flare. The skin around the rectum might develop psoriasis.”

Along with administering treatment, Van Voorhees also educates her patients on the importance and use of barrier creams to limit the adverse effects of issues like diarrhea.

### Don’t be shy

If you’ve been diagnosed with psoriasis, there’s a good chance that your genitals will be affected at some point. Talking to your doctor and loved ones should not be a hurdle to getting the treatment you need. If you’re too embarrassed to speak with your health care provider, you could start by contacting the Patient Navigation Center.

[Visit psoriasis.org/navcenter.](https://psoriasis.org/navcenter)

## Sexual healing

A major concern for people with genital psoriasis is the intimacy factor. Sexual intercourse can trigger flares due to friction, says dermatologist Abby S. Van Voorhees, M.D., chair of the NPF medical board. To reduce the amount of friction, use lubricants or lubricated condoms and modify sexual activity to avoid prolonged friction.

Embarrassment is common when it comes to intimacy and sex, especially with a new partner who may not be familiar with your psoriasis or the disease in general. The best policy is honesty. Having a straightforward conversation with your partner about your psoriasis will help you ease any embarrassment and avoid flares due to intercourse.

Get tips on how to talk to your partner about genital psoriasis by requesting a free guide.

[Visit psoriasis.org/genital-psoriasis-guide.](https://psoriasis.org/genital-psoriasis-guide)

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# Patient advocates pave the way to success in 2019

Step therapy reform passed in five states, with many just one “step” away.

By Amy Prentice

NPF’s advocacy team had a great start in 2019. In under four months, step therapy reform has passed in Georgia, Ohio, Oklahoma, Virginia and Washington, improving access to care for an estimated 1,045,894 psoriatic disease patients.

Bills in New Jersey and North Carolina have already passed through one legislative chamber. Twenty-two states have now taken action to implement patient protections against burdensome insurance protocols.

This is no small feat, since advocacy groups banded together around the issue less than five years ago.

## Why the success?

A key to our successful step therapy reform campaigns was strong patient

and provider advocates. Educating lawmakers and ensuring that they understand the real-life impact of living with a chronic illness, and the critical need for proper treatment, makes the difference between success and failure.

In Ohio, NPF board of directors member Jason Lichten, M.D., and his wife, Rachel, supported our efforts throughout the multi-year campaign; Rachel appeared in local media. In Minnesota, Michelle Strangis shared her story and used her expertise in health policy to advocate for change. Virginia resident and dedicated patient advocate Stephen Keat was diligent in his efforts to pass step therapy reform by sending regular emails, building relationships and attending town halls.

## How else are patients getting involved?

You can influence the political process in different ways and through different levels of commitment. Advocating for policies that help patients better treat their disease is just one click away. NPF regularly posts updates on our state and federal efforts and asks for feedback on a host of issues. Sharing our updates and building your online presence will raise awareness, bolster our campaigns and grow our network of patient advocates.

You may prefer to share your story and get involved via email or handwritten notes. Sharing your written story is extremely valuable. NPF can use your story, with your permission, for blog posts or media campaigns. They can be assembled with similar stories and shared with lawmakers to emphasize the importance of patient-friendly policies.

Maybe you’d prefer to jump into action in person. Lawmakers and

their staffs will hold one-on-one conversations with you about legislation, a general awareness of psoriatic disease or the importance of supporting patients. In each state and federal campaign, we host annual advocacy days where you join patients and providers from various disease communities to meet lawmakers and discuss the issues that impact your daily life.

Many volunteers have a strong passion for advocacy. For those interested in doing more on a regional level, you can join one of our advocacy action networks. These are networks of patients and providers that meet monthly for legislative updates, special training and information sharing.

Whatever your skill or interest, NPF staff will work with you to help you advocate in ways that are convenient and comfortable for you.

## Are opportunities still available?

Yes. We are targeting more than 10 states on step therapy reform. We’re in many other states working on other patient issues, such as high out-of-pocket costs or Medicaid access. Even if there isn’t a specific piece of legislation to support, it is always the right time to begin cultivating a relationship with your lawmaker.

To learn more about our advocacy work, visit [psoriasis.org/advocacy](https://psoriasis.org/advocacy). You can also follow us on social media and retweet our #NPFAdvocacy posts. We look forward to hearing from you.

*Amy Prentice is the associate director of state government relations at the National Psoriasis Foundation.*

## my story

by Jocelyn O’Neil



## Alcohol was blowing up Jocelyn O’Neil’s psoriasis and her life. Then her boyfriend gave her an ultimatum.

It wasn’t until I was sitting in the infusion room reclining chair that it hit me: This was going to *really* hurt. I remember my psoriasis was burning and my veins were flat from my hangover.

Between 2012 and 2014, my biologic infusions were usually done while I was hungover. Anyone who has had an IV or had blood drawn while hungover knows that dehydration flattens veins, making it harder to find a good one.

Drinking made my infusions more painful, my psoriasis symptoms worse and my flare-ups more frequent. Yet I wouldn’t stop drinking. My drinking was more important than self-care. Frankly, because I didn’t care.

I’ve had severe psoriasis since I was 4 years old. Anyone who has the disease knows the psychosocial

burdens that come along with it: isolation, anxiety, depression, embarrassment, shame. The fact that a flare-up could happen at any time caused a paranoia that I was desperate to numb.

I started drinking at 14. I used alcohol like you would use the reset button on a video game. Hit the button, no matter where you are in the game, and boom. Blackness. Clean slate. Anxiety wiped. I drank to numb my anxiety or lift the depression for even a little while.

But when I woke up the next day my skin burned, my anxiety was heightened and my sadness kicked in. I needed to feel better, so I would start the drinking cycle all over again.

Most studies conclude that people who have psoriasis drink more. The severity of the disease correlates

Illustration by Pat Fennessy



# I would use alcohol to numb out and then use alcohol again to numb the hangover.

with the amount of alcohol consumed. At age 20, my body was 90 percent covered. After years of using only topicals, I began taking a systemic. I was told that I could not drink alcohol at all as it carried some serious side effects.

Despite my doctor's warnings, I couldn't stop drinking. While on the medication, alcohol seemed to hit me a lot harder and faster. Blacking out became my new normal. I lasted six months on the systemic. After that I maintained some semblance of skin clarity from biologic samples my doctor would ship me when I moved to California from Rhode Island. I couldn't afford to see a dermatologist and it would be years before I even met a rheumatologist.

My drinking developed into alcohol-use disorder. I would use alcohol to numb out and then use alcohol again to numb the hangover. It became a vicious cycle, just like the psoriasis cycle.

Then around 2012 my drinking became dangerous. It was affecting my family and friends because of the person I became when I drank. I was incoherent. My actions and thoughts were dangerous and disoriented. It was the cliché Dr. Jekyll and Mr. Hyde.

I quit drinking on Sept. 10, 2014, the morning after a two-day binge. My boyfriend (now husband) was fed up with my behavior and had given me one last chance. I knew I wouldn't get another.

That day I finally asked for help. I called my doctor's office complaining of flu-like symptoms. What I really had was the booze flu. Once the examination door

closed, my eyes filled with tears and the real reason came out.

"I'm here because I can't stop drinking and it's ruining my life," I told the nurse practitioner.

She gave me a referral to a center that focused on both addiction and mental health. There, my new psychiatrist put me on a different antidepressant and suggested I try a drug that could help curb my drinking cravings.

That drug changed my life. I don't even think about alcohol anymore.

After I quit drinking, my skin lesions did not come back as quickly. I began to stretch the time between biologic infusions by months. I had been diagnosed with psoriatic arthritis in 2014, and I realized that some of my PsA symptoms were either amplified or were due to my alcohol use. Injuries to my body had been drastically reduced, making it less likely to have a flare-up.

I'm 33 now and have been sober for more than four years. I feel more stable, mentally and physically, than I have in my entire life. I recently went off my current biologic in an attempt to start a family. Pregnancy is another unknown journey my psoriasis and I are about to go on. I can't wait for the day when there is a cure for psoriasis and PsA, and my life can be even better.

Although psoriasis and PsA are still mysteries, what is certain is that booze never made me feel better or heal. I'm better without it.

*Jocelyn O'Neil is a journalist living in Portsmouth, Rhode Island, with her husband and their dog. When she's not working as a newspaper copy editor, you can find her making art for her Etsy shop, trying to make her dog Instagram-famous or riding her motorcycle into the sunset. Follow her adventures at JocieOneil.com.*

## Share your story

Everyone has a story to tell. We want to hear yours. Email [editor@psoriasis.org](mailto:editor@psoriasis.org) and you may appear in a future issue.

When it comes to treating psoriasis, you've got options.  
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# 2019 *event calendar*

For a full list of events, visit [teamnpf.org](http://teamnpf.org).

- |   |  |   |
|---|--|---|
| 06/15 <b>Team NPF Cycle</b><br>Tulsa, Oklahoma            | 07/21 <b>Team NPF Run</b><br>Napa to Sonoma Half Marathon                | 09/22 <b>Team NPF Walk</b><br>New York City, New York           |
| 06/18 <b>Pstamp Out</b><br>Sacramento, California         | 08/03 <b>Regional volunteer conference</b><br>San Francisco, California  | 09/28 <b>Team NPF Cycle</b><br>Culpeper, Virginia               |
| 06/19 <b>Pstamp Out</b><br>Louisville, Kentucky           | 08/10 <b>Regional volunteer conference</b><br>Dallas, Texas              | 10/13 <b>Team NPF Run</b><br>Chicago Marathon                   |
| 06/20 <b>Pstamp Out</b><br>Houston, Texas                 | 08/24 <b>Regional volunteer conference</b><br>Philadelphia, Pennsylvania | 10/19 <b>Team NPF Walk</b><br>Houston, Texas                    |
| 06/20 <b>Pstamp Out</b><br>San Gabriel Valley, California | 09/08 <b>Team NPF Cycle</b><br>Tour de Tahoe                             | 10/26 <b>Team NPF Walk</b><br>San Diego, California             |
| 06/22 <b>Team NPF Cycle</b><br>Raleigh, North Carolina    | 09/08 <b>Team NPF Walk</b><br>Chicago, Illinois                          | 10/27 <b>Team NPF Run</b><br>Marine Corps. Marathon, 5K and 10K |
| 06/25 <b>Pstamp Out</b><br>Orange County, California      | 09/14 <b>Team NPF Walk</b><br>Philadelphia, Pennsylvania                 | 11/02 <b>Team NPF Walk</b><br>San Francisco, California         |
| 06/26 <b>Pstamp Out</b><br>Austin, Texas                  | 09/15 <b>Team NPF Run</b><br>Philadelphia Rock and Roll                  | 11/03 <b>Team NPF Run</b><br>New York City Marathon             |
| 06/27 <b>Pstamp Out</b><br>San Diego, California          |  | 11/16 <b>Team NPF Walk</b><br>Arlington, Texas                  |