RESEARCH TODAY ▶ CURE TOMORROW

2013 National Volunteer Conference

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Advocacy: Make an Impact!

BE AN ADVOCATE FOR BETTER HEALTH & QUALITY OF LIFE: LEARN HOW YOU CAN HAVE AN IMPACT

Get expert tips and proven techniques to deal with common issues faced by people with psoriasis & psoriatic arthritis.

Play a role in creating change for yourself & others at the federal, state, and local levels, including your doctor's office and with your insurance company.
Welcome

The Advocacy and Government Relations Team:

- Leah Howard, Director of Government Relations & Advocacy
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- Niva Haynes, Health Policy Manager
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- Sara Kofman, Advocacy Outreach Manager
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- Steve Bishkoff, NPF Trustee & Advocacy Committee Chair
- Terri Theisen, NPF Trustee & Advocacy Committee Past-Chair
- Kathleen Gallant, NPF Trustee & IFPA Secretary
Let’s get to know one another!

National Psoriasis Foundation: Community Divisions

- **Northeast Region**: Daryl Woolsey
- **Mid-Atlantic Region**: Christina Alexander
- **Northwest Region**: Karen Young
- **Midwest Region**: Deborah Barnard
- **Southern Region**: Jenifer Marquart
- **S. California**: Andrea Korogi
- **N. California**: Sonia Kalil

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What is advocacy?

To *advocate*:

To speak, plead, or argue in favor of.

So an *advocate* is…

1. One that pleads the cause of another; specifically: one that pleads the cause of another before a tribunal or judicial court
2. **One that defends or maintains a cause or proposal**
3. One that supports or promotes the interests of another

*From the Miriam Webster online dictionary.*
Why advocate?

You have the ability to change or champion policies and programs that may benefit you and the millions of Americans with psoriasis and psoriatic arthritis.

If you aren’t advocating on your own behalf, who will?
Am I qualified?

Your life experiences are your credentials!

Congressional staff report they are influenced by:

- Constituent letters: 90%
- Constituent emails: 88%
- Questions at town hall meetings: 87%
- In person constituent visits: 46%
- Lobbyist visits: 8%

*Data from:* 2011 Congressional Management Foundation Study
I’m game, where do I begin?

How to avoid the road blocks...

• Discomfort with the advocacy process
• Uncertainty about who to contact
• Difficulty with developing a message
• Lack of time
• Lack of energy
The Fundamentals

Whether you are urging enactment of legislation, filing an insurance appeal, or seeking out financial assistance, the advocacy process remains the same.

• Identify the issue
• Identify who is responsible for the issue
• Find resources & tools to assist you
• Polish your message
• Find partners
• Tell your story
• And tell it again and again if you have to!
The NPF is here to help!

Our mission: Working to find a cure for psoriasis and psoriatic arthritis and to eliminate their devastating effects through research, advocacy and education.

As emerging research continues to demonstrate the serious, systemic effects of these chronic autoimmune diseases, our highest priority is to find a cure.

Founded in 1968, the Psoriasis Foundation has evolved to become the leading patient advocacy group for the more than 7.5 million Americans living with psoriasis and psoriatic arthritis.

Guided by our five year-strategic plan, we’re moving towards this goal that leverages the work of members, health care providers, advocates & scientists in three critical areas: research, advocacy, and education.

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Government Relations & Advocacy

Our agenda is simple....

• Advancing a public policy agenda to secure more federal funding for psoriasis *research*.
• Improving *access* to care for patients.
But our charge is large

- 7.5 million Americans with psoriasis & approximately 2.5 million with psoriatic arthritis.
- Current federally funded research on psoriasis and psoriatic arthritis amounts to only $1.33 per patient.
- Majority of individuals with psoriasis spend more than $2,500 per year in out-of-pocket costs.
World Health Organization
Put Psoriasis on the Agenda!
NPF Advocacy Committee

Holding us to our mission...

Guide the development of the Foundation’s annual advocacy agenda, provide recommendations on advocacy strategy, advise on position statements, recommend legislative proposals, and comment on relevant state and federal regulations.
Advocacy in Action

Four real-life scenarios:

• Becoming an empowered voice
• Medicare and biologics
• Uninsured
• Insurance Denials
Becoming an empowered voice

Janice is frustrated! She is sick and tired of her high out-of-pocket costs for her psoriasis medication. She has a good income but instead of paying high copays and coinsurance, she would much rather be saving up for retirement. She has heard that the National Psoriasis Foundation is urging Congress to pass legislation that would limit copays and out-of-pocket costs. This is something Janice would like to support.

What should Janice do?
Medicare and Biologics

David just turned 65 and is now on Medicare. For the past three years, David has been successfully treating his psoriatic arthritis with a biologic. Before being on Medicare, the manufacturer patient assistance program helped him access his medication with little out-of-pocket expense. However, on Medicare, he cannot use the manufacturer patient assistance program and David can no longer afford his medication.

What should David do?
Uninsured

Chris holds a minimum wage job that does not provide health insurance to employees. Chris has psoriasis and is looking for a way to get his medical treatments and trips to the doctor covered. He has been hearing about the new health insurance marketplaces but is concerned that he will not be able to afford a plan and is worried that because he has a preexisting condition, he will not be eligible for a plan.

What should Chris do?
Insurance Denials

Jill has psoriasis and psoriatic arthritis and is currently taking Humira. Recently, Jill’s employer changed insurance carriers and she found out that Humira is not covered in the new drug formulary. Jill and her doctor both think it is important for her to continue her Humira treatment as stopping her current medication regimen could cause her disease to flare up, among other potential complications.

What should Jill do?
Group Discussions
Becoming an Empowered Voice

Suggested Advocacy Actions:

1. Visit the advocacy homepage to learn more about PATA and other advocacy initiatives;
2. Join the psoriasis action network and become an advocate;
3. Send a letter to her member of Congress on issues of importance to her;
4. Schedule a district level meeting and get acquainted with the local staff.
5. Contact the NPF by phone or email for more information.

RESOURCE: https://www.psoriasis.org/advocacy
Advocacy

Public Policy Priorities

Take Action

Tools for Advocates

Legislative Center

For Policymakers

National Psoriasis Foundation Advocacy

The National Psoriasis Foundation works to shape the laws and policies that affect people with psoriasis and psoriatic arthritis.

Harnessing the collective efforts of tens of thousands of advocates, the Psoriasis Foundation aims to:

- Make insurance fair and affordable and improve coverage for people with psoriatic disease.
- Set public health policy for psoriasis and psoriatic arthritis through the findings from data collection at the Centers for Disease Control (CDC).
- Improve the safety and affordability of psoriasis and psoriatic arthritis treatments.
- Increase federal funding for psoriasis and psoriatic arthritis research in order to find better treatments and a cure.

Get Involved

Read more about NPF’s grassroots advocacy efforts including Hill Day at Home and state advocacy. Sign up for advocacy alerts and participate in advocacy activities like Town Hall meetings, letter writing and phone-in campaigns.

NPF Legislative Center

Everything in one place for you to track the progress of critical legislative efforts relevant to the psoriasis community, speak to your lawmakers, browse key political races across the country, and contact your local media.
Medicare and Biologics

Suggested Advocacy Actions:

1. Contact the drug manufacturer as they may have a list of available resources for Medicare beneficiaries;
2. Apply for the “Extra Help” program from the Social Security Administration;
3. Apply for grants from patient assistance foundations;
4. Consider looking into changing plans during the next open enrollment period.
5. Contact the NPF by phone or email for more information.

RESOURCE: https://www.psoriasis.org/access-care
**Medicare Resources**

**Changes to Medicare through the health care law**

The Affordable Care Act made significant changes to the Medicare prescription drug coverage (Part D) program. Starting in 2010, more Medicare beneficiaries qualified for the Extra Help program with their Medicare prescription drug plan costs. Medicare beneficiaries who cannot afford their medications for psoriasis and psoriatic arthritis may see considerable savings with Extra Help. If you applied for Extra Help in the past and didn’t qualify, you might qualify now. See if you qualify and apply online or call Social Security at 800.772.1213.

**Medicare for people with psoriasis and psoriatic arthritis**

Medicare is a government-funded health insurance program for people who have reached the age of 65, or who have become disabled. The official U.S. government site for people with Medicare provides information about the program and tools for comparing prescription drug plans, hospitals, home health agencies and more, or you can call 1.800.MEDICARE (1.800.633.4227).

- You have the right to appeal any decision about your Medicare services.

A Medigap policy is health insurance sold by private insurance companies to fill the “gaps” in Original Medicare Plan coverage. Medigap policies help pay some of the health care costs that the Original Medicare Plan doesn’t cover.

Some Medicare beneficiaries are eligible for Extra Help (800.772.1213) to pay for the costs — monthly premiums, annual deductibles, and prescription co-payments — related to a Medicare prescription drug plan.

Each state has a State Health Insurance Program (SHIP) which educates and assists Medicare beneficiaries, those eligible for Medicare, and caregivers in regard to Medicare, Medicaid, Medigap insurance, prescription drug benefits, and other issues related to health insurance benefits. Contact information for your state’s SHIP can also be found by calling the Health Assistance Partnership at 202.737.6340.
Uninsured

Suggested Advocacy Actions:

1. Low-income individuals are eligible for financial support with health insurance premiums.
2. Preexisting conditions no longer exempt individuals from accessing health insurance.
3. Starting October 1 individuals can enroll in a plan through their state insurance marketplace & coverage will start Jan 1, 2014.
4. Contact the NPF by phone or email for more information.

RESOURCE: https://www.healthcare.gov/
The Health Insurance Marketplace is coming soon

A new way to get affordable coverage launches October 1.

Answer a few questions to learn if you qualify for lower costs.

SEE YOUR OPTIONS »

GET IMPORTANT NEWS & UPDATES

Email Address

SIGN UP

What is the Health Insurance Marketplace?

What is the Marketplace in my state?

What if I have job-based insurance?

How can I get coverage at lower costs?

What do small businesses need to know?
Insurance Denials

Suggested Advocacy Actions:

1. Ask your doctor to write a letter of medical necessity;
2. Write a personal letter of appeal and send an appeal letter to the state insurance commission;
3. Contact your HR department and let them know the new plan does not cover needed treatments. HR can be a strong advocate for their employees.
4. Contact the NPF. We may be able to provide a supportive letter to send to your health plan

RESOURCE: https://www.psoriasis.org/access-care
Appealing a Denied Claim from your Health Insurance

Getting started:

- Get a copy of your plan document and plan summary. Request them from your insurance company or go online if you do not have copies.
- Read the denial letter from the insurance company for information on how to appeal. Contact your health plan and request the information if it’s not included.

Filing your appeal:

- File the appeal with your health plan quickly, as many companies place limits on how long appeals may be requested after a claim is denied.
- Many health plans require you to write a letter to appeal the denied claim. Help yourself with your own letter. Here are some sample letters you can use.
- Ask your doctor for help by writing a letter of medical necessity and/or calling your health insurance provider. Your doctor and his/her staff are well qualified to explain your condition, medical history and treatment plan to your plan administrators. See our sample letters for doctors for assistance.
- Keep copies of correspondence from your doctor and from yourself to the insurance company.
- Record the names and job titles of the health insurance representatives you speak to and the time and date of your calls.

What to do when your health insurance still denies your claim:

- Talk to your employer’s Human Resources department and let the benefits manager know if the health benefits offered at work do not allow you to access the medication.