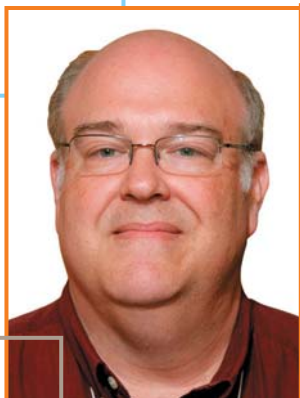




Access Action Guide: Getting the psoriasis care you need



NATIONAL
PSORIASIS
FOUNDATION®

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Section 1: WELCOME & INTRODUCTION

Welcome. *The National Psoriasis Foundation Access Action Guide will help answer your questions about obtaining medically necessary care and treatment. Living with psoriasis and psoriatic arthritis is not always easy. This guide, along with the Psoriasis Foundation, are here to support you as you pursue a high quality of life. Always keep this in mind: You have the right to advocate for and take action to improve your access to the care you need.*

Health Insurance Does Not Always Equal Access to Care



According to the Kaiser Family Foundation, an estimated 47 million Americans lack health insurance. The number of uninsured, an aging population, and the increase in chronic conditions have sent health care spending out of control.

Consumers are shouldering more of the costs of health care. Even for Americans who do have health insurance, barriers in insurance policies can make it challenging to obtain needed treatment.

High out-of-pocket costs, insurance

denials and a lack of understanding about treatment options are some of the factors that can limit access to medically necessary treatments for psoriasis and other chronic conditions.

“Even for Americans who do have health insurance, barriers in insurance policies can make it challenging to obtain needed treatment.”

This guide provides practical information to help you advocate for the care you need. Your advocacy does make a difference. We’ve seen patients and their doctors turn insurance denials into approvals countless times.

Use this guide to find out how you can be your own best advocate.

Section 2: ACTION STEPS FOR THE INSURED

Action Step 1: Be an empowered patient



Being an empowered patient is often the key to success as you advocate for yourself. Being empowered means having the confidence, the information and the know-how to handle issues and get the care you need for your psoriasis. This guide will help get you on your way.

Action Step 2: Understand your health plan



To be a successful advocate, it is important to understand the ins and outs of your current health plan—especially when communicating with your insurance company. Common health insurance plans in the United States include:

Indemnity Plans

Indemnity plan subscribers are allowed to visit the provider of their choice. Typically, subscribers must pay an annual deductible before the insurer will cover any bills. Beyond the deductible, any additional costs are split between the insurer and the patient according to the ratio your employer has negotiated. (e.g. Patient pays 20 percent, insurer pays 80 percent).

Preferred Provider Organization (PPO)

Subscribers to a PPO can visit doctors within or outside of an approved network, with a copayment for each visit. The insurer usually pays a percentage of any medical fees. If you choose to visit a provider who is outside your network, you may need to pay a deductible and your overall share of the cost of the services is often higher than for in-network services.

Health Maintenance Organization (HMO)

HMO subscribers pay a monthly fee for their benefits. Subscribers choose a primary care provider (PCP), whose referral is required for a visit to a specialist such as a dermatologist or rheumatologist. Without a referral, you may have to pay all of the charges, so be sure to read your plan carefully. Likewise, if you choose to visit a doctor who is not part of the HMO, you will be responsible for some or all of the charges.

Point of Service Plan (POS)

A POS is something like a combination of an HMO and a PPO. Like an HMO, subscribers to a POS have a primary care provider. Like a PPO, subscribers can

If you have a denial letter from your health plan, always hold onto it. This will help us help you.

visit doctors who are both in- and out-of-network. If you visit an out-of-network provider, you may be required to file additional paperwork with the insurance company. Subscribers can choose their own specialist or be referred by their primary care provider. If you refer yourself without getting clearance from your PCP, you will be responsible for a larger portion of the costs.

Medicare

Medicare is a government-funded safety net program for retired people who have reached age 65 or have become disabled. To learn more about Medicare programs, and for help with problems and questions, visit the *Centers for Medicare & Medicaid Services* at: www.cms.hhs.gov/home/medicaid.asp. You may also want to consider contacting your State Health Insurance Program (SHIP). Find your state SHIP at: www.healthassistancepartnership.org/ship-locator.

Medicaid

A federal- and state-funded safety net program, Medicaid provides health insurance for eligible individuals with disabilities, the elderly, children and families, and pregnant women. Eligibility for Medicaid depends on state-established income and resource guidelines. State Medicaid information can be found through the Centers for Medicare and Medicaid Services at: www.cms.hhs.gov/home/medicaid.asp.

Action Step 3: Understand your coverage



Here are some important points to help you determine whether your health coverage is adequate or if you will need to take extra action to obtain the care you need.

Which psoriasis treatments does your plan currently cover?

Knowing which treatments your health plan covers will help you determine what kind of care you will have access to. Consider these options when talking to your doctor about creating a treatment program.

Are you responsible for a copayment? If so, how much?

Know how much your copayment will be for prescriptions and other psoriasis treatments, such as phototherapy. Your out-of-pocket expenses may influence which treatments you and your doctor choose.

TIP: Consider speaking with someone in your human resources (HR) department. Human resources may be willing to negotiate a different health plan in the future that better suits your medical needs as a psoriasis or psoriatic arthritis patient.

Does your plan have an annual pharmacy benefit?

Many psoriasis treatments are expensive and some health plans may cover only a certain amount of drug costs each year, leaving the patient responsible for any remaining costs. Consider your financial resources when looking for a plan.

Does your plan require you to try and fail multiple treatments before moving on to others?

Known as “step therapy,” many plans require patients to try some treatments before moving on to others, which can be a lengthy process. Keep this in mind when considering treatments.

Action Step 4: Exercise your right to appeal a health plan decision 

Diane’s Access to Care Story



Like many others, Diane, 50, has endured her share of health insurance struggles. She has faced multiple problems with her health plans over the 44 years she has had psoriasis—though most of her insurance problems have surfaced since biologic drugs became available for the treatment of psoriasis and psoriatic arthritis.

“My advice is to never give up, and to always be persistent.”

It has become, “harder and harder to get approved,” she says. When Diane was battling a case of erythrodermic psoriasis—and was nearly 95 percent covered—her insurance carrier required her to try and fail methotrexate before approving a biologic drug.

With a determination to take charge of her own health care, Diane joined forces with the nursing staff at her dermatologist’s office to send numerous letters and make phone calls to appeal her health plan’s decision.

Her efforts were successful.

“I still have to fight with the insurance company whenever I change to a new medicine, but in the end I always prevail.”

When working with your insurance company, have patience. Also, know that your doctor is your best ally with your insurance company. Ask your doctor to get involved in your case.

If you have been denied coverage by your health plan for a treatment your doctor has deemed medically necessary, you can formally appeal that decision. Use the following checklist to guide you through the appeals process:

- ✓ Ask your dermatologist or rheumatologist to write a letter of medical necessity on your behalf. Sample letters can be found at our Web site www.psoriasis.org. Search for "sample appeal letter."
- ✓ Read your health plan's appeal guidelines carefully to determine its requirements.
- ✓ Notify your health plan officials in writing and let them know that you will be formally appealing their decision.

Guidelines for appealing a denial from your insurance provider are often included in the denial letter

- ✓ Record the date and time of your contact and the name of the person you spoke with. Keep copies of anything you or your doctor send to the health plan. Pay attention to all deadlines.
- ✓ Contact the National Psoriasis Foundation. If you provide us with a copy of your denial letter, we may be able to provide you with a supportive letter to send to your health plan.
- ✓ If you continue to be denied coverage, contact your state insurance commission and request an independent medical review. Contact information and specific guidelines for your state insurance commission can be found at: www.kff.org/consumerguide/7359.cfm.
- ✓ Use our sample appeal letters to write both your health plan and your insurance commission. Both you and your doctor can find sample letters by visiting www.psoriasis.org and searching for "sample appeal letter."
- ✓ Contact your human resources (HR) department. HR departments are responsible for purchasing insurance plans that meet the needs of employees and can be strong advocates for patients.

TIP: If your appeal has been denied by your health plan, you have the right to take your case to your state insurance commission. According to a 2008 Families USA report on state consumer protections for individuals, external reviewers decide in favor of patients in 40 percent of all cases.

Action Step 5: Be a proactive patient

Your doctor is a valuable resource when it comes to appealing a health plan decision, so it is important for you to establish a good relationship with him/her. Below are some tips to help you get started:

- ➔ Don't be afraid to ask questions.
- ➔ Educate yourself about psoriasis or psoriatic arthritis as much as possible. Start by visiting www.psoriasis.org.
- ➔ If your doctor seems too busy to help, ask the nurse or office manager if s/he can help.

Action Step 6: Know where to go for financial assistance

Even those with comprehensive health insurance can't always pay for the treatment they need. If you're having trouble meeting out-of-pocket expenses, explore whether you qualify for financial assistance. A list of drug manufacturers and additional patient assistance programs can be found at www.psoriasis.org. Search for "financial assistance."

Section 3: ACTION STEPS FOR THOSE IN BETWEEN JOBS

Action Step 1: Know your options and your rights

When you switch jobs, changing your health insurance can be complicated. However, the following programs may protect your health care coverage while you are in transition.

Family Medical and Leave Act (FMLA). Companies employing more than 50 employees must provide 12 weeks of leave for any employee due to an illness, birth, injury or other qualifying event. During this time, your employer must continue to pay your health care premiums. For more information on FMLA, visit www.dol.gov/esa/whd/fmla.

Consolidated Omnibus Budget Reconciliation Act (COBRA). If you are leaving your job and were insured under a group health plan, you may be able to extend your coverage for up to 36 months. In order to qualify for COBRA, you must:

- 1) Work for (or be covered by) an employer with 20 or more employees;

- 2) Be covered by a group health plan as an employee or as the spouse or child of an employee; and,
- 3) Have a qualifying event that would cause you to lose your group health coverage. Examples of qualifying events include voluntary or involuntary termination of employment or a reduction in hours worked per week.

Under COBRA, you will have to pay for your former employer's share of premium costs as well as your own share. For more information on COBRA and qualifying events see the Department of Labor Web site at www.dol.gov/dol/topic/health-plans/cobra.htm.

State Continuation Laws. If you worked for an organization with fewer than 20 employees, you may be eligible for state continuation coverage that will allow you to stay on your group health plan. Contact your state insurance department for more information on your state's health insurance continuation laws. Contact information for your state insurance department can be found at www.kff.org/consumerguide/7350.cfm.

Action Step 2: Understand insurance options and pre-existing conditions policies when shopping for individual insurance



When you no longer qualify for coverage from your employer, you have the option of buying individual health insurance. If you have psoriasis and/or psoriatic arthritis, you may be identified as having a pre-existing condition and may be denied coverage. Under the Health Insurance Portability and Accountability Act (HIPAA) of 1996, you have the right to some form of health insurance if you meet all of the following:

- You have had at least 18 months of continuous coverage with the last day being under a group health plan;
- You have exhausted COBRA or state continuation coverage;
- You are not eligible for Medicare, Medicaid or a group health plan;
- You do not have health insurance coverage;
- You apply for HIPAA-eligible health insurance within 63 days of losing your prior health insurance coverage.

Speak with your human resources department for more information on how to apply for HIPAA or contact www.hhs.gov/ocr/hipaa.

Your state may also have a high-risk insurance pool. A high-risk pool provides health insurance to those who are not able to obtain health insurance due to a pre-existing condition. Although monthly premiums tend to be much higher than with a group or individual plan, those with low incomes may qualify for a subsidy.

To find out if a high-risk pool exists in your state, visit www.healthinsuranceinfo.net; contact your State Health Insurance Program (SHIP); or read the Georgetown University Health Policy Institute guide titled, "Understanding Private Health Insurance," available at www.healthinsuranceinfo.net/nefe.

Section 4: ACTION STEPS FOR THE UNINSURED

Action Step 1: Know where to go for help



Visit the Georgetown Health Policy Institute Web site, www.healthinsuranceinfo.net, to review the consumer guide for your state on getting and keeping health insurance. These guides describe state-specific resources as well as general financial aid information.

If you are able to see a dermatologist and obtain a prescription for a medication, call the drug manufacturer to see if the company provides financial assistance. Many manufacturers offer drugs at reduced rates or for free. To view a list of these and other patient assistance programs, visit: www.psoriasis.org and search for "financial assistance."

Action Step 2: Know how to negotiate reduced or free care



It is reasonable to talk with your doctor about getting care at a reduced price. Start by asking either your doctor or an office manager for a waiver or reduction of your bill. Also, many hospitals have policies in place to offer free or reduced-price care for those who are uninsured. You can also ask about a plan to pay larger bills in multiple payments over time.

Action Step 3: Be prepared to manage medical debt

Being uninsured for extended periods of time can result in overwhelming out-of-pocket costs. Medical debt is one of the top reasons for personal bankruptcy. If your medical bills have reached unmanageable levels, review the guide, “Options for Avoiding and Managing Medical Debt” available at www.healthinsuranceinfo.net/nefe.

The Patient Advocate Foundation offers debt crisis assistance for chronic disease patients who qualify. Visit www.patientadvocate.org.

Action Step 4: Connect with your community services

Community health clinics are valuable resources for obtaining reduced-cost or free primary care. To find a listing of community health clinics in your area, visit the health center directory at www.findahealthcenter.hrsa.gov or call at 1.888.275.4772.

Finally, knowing what resources are available in your community can help if times get tough. Many states offer energy, housing, food and childcare subsidies. Contact your state department of health or human services to learn more.

Action Step 5: Learn about health care reform and programs in your community

Many states have active health care reform initiatives, as well as health care strategies to assist the uninsured. You can help yourself and others by becoming involved with the movement to provide health insurance to the uninsured. The Kaiser Family Foundation Web site has information on all current state health care reform initiatives and programs to extend access to care for the uninsured. Learn more at www.kff.org/uninsured/kcmu_statehealthreform.cfm.

The Psoriasis Foundation can help. If you need assistance with appealing your health plan’s decision, please email advocacy@psoriasis.org or call 1.800.723.9166 x550.

Section 5: ACCESS ACTION QUICK TIPS

Q: *How do I file an appeal with my health plan?*

A: Use the checklist in this booklet [p.6], and visit the Psoriasis Foundation Web site for information on the appeals process, including sample appeal letters for patients and doctors. Visit www.psoriasis.org and search for “sample appeal letter.”

Q: *How do I find health insurance?*

A: The guide “Understanding Private Health Insurance” from the Georgetown University Health Policy Institute answers many questions related to private insurance. Download it at www.healthinsuranceinfo.net/nefe.

To get the coverage you need, remember to ask:

- What medical services/treatments are included in the plan?
 - How much will I have to pay (deductible) before the plan kicks in?
 - After reaching the deductible, how much will I be responsible for paying for services/treatments?
 - Will the plan cover pre-existing conditions?
 - Will I be able to see my doctor or will I have to choose a different doctor?
 - Is there a maximum amount per year that the health plan will pay toward prescriptions?
-

Q: *Where can I find financial aid?*

A: Many drug manufacturers have patient assistance programs that offer medicine or assist with out-of-pocket costs. For a list of these, and other financial assistance programs, visit www.psoriasis.org and search for “patient assistance.”

Some state-specific consumer guides developed by the Georgetown University Health Policy Institute also include financial aid information. Download your state’s guide at www.healthinsuranceinfo.net.



Q: *What if I have questions related to Medicaid/Medicare?*

A: Your State Health Insurance Program (SHIP) and the Health Assistance Partnership can help.

SHIPs provide free counseling for Medicare-related problems and questions, including choice of Medicare plans, coverage options, and financial aid information. Find your state's SHIP at www.healthassistancepartnership.org/ship-locator.

For additional information about Medicare and Medicaid, view the guide titled, "Medicare and Medicaid: A Health Care Safety Net for People with Serious Disabilities and Chronic Conditions" at www.healthinsuranceinfo.net/nefe.

Q: *How do I find legal advice?*

A: If, after appealing your health plan's decision, you feel that you have been wrongly denied coverage, you may want to consult an attorney. Reduced cost or free legal assistance may be available. For more information, visit www.lsc.gov.

Q: *How do I connect with others with psoriasis and/or psoriatic arthritis?*

A: **Walk for Awareness.** Consider joining thousands of others with psoriasis on one of our nationwide Walks for Awareness. The walks raise both awareness about the disease and much needed funds for programs and events that help psoriasis patients. Visit www.psoriasis.org to learn more.

National Psoriasis Foundation Affiliated Support Groups. Share your story at an Affiliated Support Group meeting. With support groups spanning the nation, it's easy to meet others with psoriasis and/or psoriatic arthritis. To find a support group near you visit www.psoriasis.org.

Psoriasis Action Network. Work with other psoriasis advocates to help us move closer toward a cure. E-mail action@psoriasis.org or call 1.800.723.9166 x407.

National Psoriasis Foundation Message Boards: Connect with compassionate and supportive psoriasis patients through our “virtual” community—the message boards. It’s a great place to share a thought or a story or simply lend a helping hand. To join visit www.psoriasis.org.

Q: *How do I get involved with efforts at the Psoriasis Foundation to advocate for better access to care?*

A: If you’re ready to take your efforts to the next level, join the Psoriasis Action Network.

The Psoriasis Action Network is a grassroots movement to increase the government’s investment in psoriasis research for a cure and improve access to care.

To get involved in fun, easy ways to make a difference for the psoriasis community, e-mail action@psoriasis.org or call 1.800.723.9166 x407.

Q: *How do I learn about health care reform initiatives?*

A: There are many efforts currently underway to reform health care at both the state and national level in the U.S. To learn more about initiatives in your state, visit the Kaiser Family Foundation’s Web site, www.kff.org/uninsured/kcmu_statehealthreform.cfm.

Q: *How do I contact my members of Congress to ask them to support the psoriasis cause?*

A: We encourage anyone with a connection to psoriasis to call or write their members of Congress. The Psoriasis Action Network has several initiatives underway to promote more psoriasis research and better access to care. E-mail action@psoriasis.org and ask for your elected officials’ contact information.

Q: *What other Web sites offer helpful information related to health insurance and accessing care?*

A: Here is a selection of helpful Web sites we've found:

www.healthinsuranceinfo.net

The Georgetown Health Policy Institute has a three-part series of guides related to health insurance. Learn more about private health insurance, Medicare and Medicaid, and managing medical debt.

www.covertheuninsured.org

The Cover the Uninsured project is raising awareness about the number of Americans who are uninsured, while working toward changes in public policy. Download a state-specific guide for obtaining coverage.

www.familiesusa.org

Families USA is a nonprofit organization focused on providing high-quality and affordable health care for all Americans.

www.kff.org

The Kaiser Family Foundation provides information and statistics on major health care issues. The Foundation produces policy analysis and research, acts as a clearinghouse of information for the health policy community and runs public health campaigns in the U.S. and around the world.

www.nationalhealthcouncil.org

The National Health Council is a group of patient advocacy organizations representing the health care community. The groups work together to improve the health of those people with chronic conditions and/or disabilities.

www.cms.hss.gov

The Centers for Medicare & Medicaid Services is a comprehensive Web site for information about Medicare and Medicaid.

Eugene's Access to Care Story

In the fall of 2007, Eugene's dermatologist prescribed a home phototherapy unit for the treatment of his psoriasis. Unfortunately, he faced resistance from his health plan in covering this treatment. Not knowing what else to do, Eugene contacted the advocacy department at the National Psoriasis Foundation for help in appealing his health plan's decision.

"The National Psoriasis Foundation helped walk me through the entire health plan appeal process and made me feel that I had people on my side."

After several weeks of persistence and with the help of a supportive letter from the Psoriasis Foundation, Eugene's health plan finally approved coverage of a home phototherapy unit.

"I almost gave up after being rejected the first time. I am glad I didn't because the home UVB unit makes my life and my psoriasis more manageable."

"The National Psoriasis Foundation was instrumental in helping me obtain coverage from my insurance company for a home UVB unit after my doctor prescribed one."



Join the Psoriasis Action Network to help find a cure and improve access to care!

The National Psoriasis Foundation is here to help.

Do you have a story to share about accessing treatment? Are you in need of assistance? If so, we encourage you to contact the advocacy department at the National Psoriasis Foundation. We can assist in the following ways:

- Providing support with health insurance appeals;
- Connecting patients to financial aid resources;
- Assisting with disability claims;
- Offering assistance when discriminated against.

For more information contact us at:
advocacy@psoriasis.org
800.723.9166 x550

The National Psoriasis Foundation is the largest nonprofit organization in the U.S. dedicated to serving people with psoriasis and psoriatic arthritis.

Through education and advocacy, the Psoriasis Foundation promotes awareness and understanding, ensures access to care, and supports research that will lead to better treatments and a cure.



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