PARENT GUIDE

For primary caregivers of young people who have psoriasis
THE NATIONAL PSORIASIS FOUNDATION (NPF) wrote this booklet for people who care for children with psoriasis.

This guide provides essential information to help parents or caregivers understand and cope with their child’s disease. It is to be used as a reference. It is not intended to replace the advice of physicians or other health care professionals.

NPF is committed to improving the lives of people who have psoriasis and psoriatic arthritis and to supporting research to find a cure for the millions of people who live with these chronic diseases.

AN OVERVIEW OF PSORIASIS

PSORIASIS is a complex disease that involves a person’s genes, their immune system and the environment. The immune system becomes overactive, sometimes due to a trigger from the environment (like injury or infection), and causes skin cells to reproduce too quickly, leading to thick, scaly skin.

A normal skin cell matures and falls off the body’s surface in 28 to 30 days. However, skin affected by psoriasis takes only three to four days to mature and move to the surface. Instead of falling off (shedding), the cells pile up and form lesions.

The skin also becomes very red due to increased blood flow to bring immune cells to the skin (inflammation).

The severity of psoriasis is based on several factors: How much of the skin surface is covered by psoriasis, where the psoriasis is on the body and how much it affects a person’s quality of life. Psoriasis can be a physical and emotional
challenge for children, and depending on the child, can affect day-to-day activities and social interactions. Psoriasis can have a serious impact even if it involves a small area, such as the face or the palms of the hands or soles of the feet.

Who gets psoriasis?

The disease affects as many as 7.5 million people in the U.S.

Psoriasis affects an estimated 2 to 4 percent of the world’s population, about 300 million people worldwide. It affects almost 1 percent of kids between 0 and 18 years old in the U.S. It occurs in all races, though Caucasians are slightly more affected.

Approximately one-third of those who get psoriasis are under 20 years old when the disease first surfaces. Every year, roughly 20,000 children under 10 years old are diagnosed with psoriasis. Psoriasis can appear at any age, even in infancy.

Sometimes psoriasis is misdiagnosed because it is confused with other skin diseases. Signs of psoriasis in babies and children include diaper rash that is not responding to diaper creams; severe scalp, face and body scaling; or individual red, scaly plaques on the elbows, knees or torso.

Nails may be discolored with a rough texture and pits. Psoriasis in kids can look exactly like adult psoriasis. It can take time and close observation to determine if a rash in an infant or young child is psoriasis.

What causes psoriasis?

No one knows exactly what causes psoriasis, but it has a genetic component. If one parent has the disease, there is about a 25 percent chance of a child developing it. If both parents have psoriasis, the chance increases to 65 percent. No one can predict who will get psoriasis. Scientists now believe that at least 10 percent of the general population inherits one or more of the genes that
create a predisposition to psoriasis.

There are a number of factors that can trigger psoriasis, but scientists don’t fully understand these triggers yet. In children, the most common triggers are infections, especially strep infections of the throat or anus and viral infections. One-third to one-half of all young people with psoriasis may experience a flare-up two to six weeks after the occurrence of an earache, strep throat, bronchitis, tonsillitis or a respiratory infection.

Trauma to the skin, certain medications, and even stress can also trigger psoriasis in children. Areas of the skin that have been injured or traumatized are occasionally the sites of psoriasis; this is known as the “Koebner [keb-ner] phenomenon.” However, not everyone who has psoriasis develops it at the site of an injury.

Certain medications are also associated with triggering psoriasis, including lithium, antimalarials and systemic steroids.

**Is psoriasis linked to other diseases?**

Recent studies show that people with psoriasis are at an elevated risk of developing other chronic health conditions, like cardiovascular disease and metabolic syndrome. Because of this increased risk, it’s important to regularly schedule routine health exams with a general health care professional.

Psoriatic arthritis is a condition that is closely linked to psoriasis. If your child experiences persistent joint stiffness or pain, ask your child’s physician about the condition and contact NPF for more information.

**Is psoriasis contagious?**

No. People do not “catch” psoriasis from other people, nor can they transmit the disease to others.
Currently, there is no cure for psoriasis. However, researchers around the world are seeking better, more effective treatments with fewer side effects. Many people with psoriasis can manage their disease with treatments available now.

Psoriasis treatments work by controlling the skin inflammation and thereby slowing skin cell reproduction. Some help remove scale. Others help soothe the itchy or uncomfortable skin. Most psoriasis medications are effective in clearing lesions, but not all people with psoriasis react the same way to medications. Your health care provider will need to work closely with your child to determine which regimen is best, and this may change over time. A medication that works for one patient may not work for another. Finding the right mix of medications to treat psoriasis for an individual can be challenging and may require experimentation to see which treatments work best.

Although psoriasis in children is similar to that in adults, there are some real differences, especially regarding treatments. Many treatments used for adults may not be appropriate for children due to possible long-term or delayed side effects. Physicians decide which treatments to use according to the type and severity of the psoriasis, the areas of the skin affected and the patient’s age and past medical history.

Many psoriasis treatments are not specifically approved by the U.S. Food and Drug Administration for children younger than 12. This does not mean that these medicines are not safe or effective in young children; it means there hasn’t been enough research for this patient population. When your child’s doctor prescribes these medicines, it is referred to as an “off-label” use of the medication. This is very common and acceptable, and the doctor should explain this to you.
There are three basic categories of psoriasis treatments:

01. Topical treatments like creams and ointments are used on the psoriasis plaques.

02. Light therapies (ultraviolet light A or UVA and ultraviolet light B or UVB) expose the skin to light waves that reduce inflammation.

03. Systemic medications are taken by mouth or injected into the body.

**TOPICAL MEDICATIONS**

Most people with psoriasis begin treatment with topical medications because they have the lowest risk of long-term side effects. Some treatments are available by prescription and some can be purchased over the counter. Moisturizers, including bath oils and products like mineral oil and petroleum jelly, provide hydration to the skin.

**Steroids**

Topical steroids are the best topical medicine available to treat psoriasis and doctors commonly prescribe them. Topical steroids range from mild to superpotent, and are selected based on the type and location of the psoriasis and the age of the child. Topical steroids come in a variety of forms, such as creams, ointments, oils and foams. Because side effects can occur from using strong topical steroids over a long period or from misusing them, it is important to follow the directions provided by your doctor.

Steroid medication also can be injected into a limited number of psoriasis lesions. Doctors rarely use this treatment in children because it can be painful.
Calcipotriene and calcitriol

Calcipotriene is a derivative of vitamin D3, sometimes sold under the brand name Dovonex. Calcitriol (brand name Vectical) is a naturally occurring active form of vitamin D3. This type of prescription medicine has few side effects when used as directed. The advantage of topical vitamin D creams and ointments is that they can be used on the face and sensitive skin folds where topical steroids are most likely to cause side effects. Calcipotriene and calcitriol are not approved for children under 12, but a physician may prescribe one of these medications off-label. Studies are underway that examine the use of this type of medication in children with psoriasis.

The vitamin D prescription medication for psoriasis is not the same thing as vitamin D sold as a dietary supplement. Vitamin D supplements are not effective in treating psoriasis and taking them in large doses can have serious consequences.

Calcineurin Inhibitors

Calcineurin inhibitors are a type of non-steroidal topical treatment that block the inflammation process, which is part of the body’s immune response. While they are approved to treat other skin conditions like eczema, they have also been found to be helpful in treating psoriasis in sensitive areas, such as the face, genitals and skin folds. Protopic (tacrolimus) and Elidel (pimecrolimus) are two such topical treatments.

Tazarotene

Tazarotene is a topical retinoid that is a derivative of vitamin A prescribed for mild to moderate psoriasis. The brand name is Tazorac and it is available in a gel or cream. Do not take over-the-counter vitamin A supplements for the treatment of psoriasis.
Coal tar

Coal tar for psoriasis treatment comes both over the counter and by prescription. Apply tar to the skin, mix it with bath water or apply to the scalp in a tar shampoo. It works best for people with psoriasis lesions limited to areas such as the knees, elbows, scalp and shins. It is often combined with ultraviolet light therapy. Few side effects are associated with coal tar, though it does have an odor and can stain clothing and bedding.

Anthralin

Anthralin is a synthetic derivative of an ingredient found in Goa powder from the bark of the araroba tree of South America.

This substance has been used to treat plaque psoriasis for more than 100 years. Anthralin has no known long-term side effects, but can be messy to use and can stain hair or unaffected skin.

Salicylic acid

Salicylic acid removes built-up scale so medications can penetrate the lesions and slow the excessive skin cell production. It is available in many over-the-counter products and is often used with tars and steroid medications to increase their effectiveness. This should not be used on infants or small children.

Moisturizers

Apply moisturizers on a daily basis to keep the skin lubricated and reduce the discomfort of itching, scaling and dryness. Skin experts say the greasiest products (creams and ointments) work best for locking water into the skin. Cooking oils and even shortening can be effective and economical substitutes for commercial moisturizers.
LIGHT THERAPIES

Light therapy involves exposing the skin to wavelengths of ultraviolet light. This is done in a doctor’s office, a light therapy clinic or sometimes at home with cautious use of natural sun or with a home light unit. Various light therapies may be prescribed based on the age, type of psoriasis and skin color of your child.

Sunlight

Ultraviolet light occurs in natural sunlight. This may be recommended for your child. You must follow the doctor’s instructions carefully to avoid overexposure and burns.

Long-term exposure to sunlight carries a risk of early signs of aging and skin cancer. It is essential to use sunscreen on unaffected skin, avoid sunburn and have your child’s skin checked frequently by a doctor.

UVB

UVB treatments are administered in a physician’s office, clinic or at home with a home phototherapy device. There are two types of UVB treatments: broad band and narrow band. The major difference between broad-band and narrow-band UVB is that narrow-band UVB units emit a more specific range of UV wavelengths.

Once the skin clears, the treatments can be stopped. If lesions reappear, resume treatment. Sometimes people continue UVB on a maintenance basis. The main potential side effect of UVB is a burn resembling sunburn.

PUVA

PUVA combines a psoralen drug with exposure to ultraviolet light A (UVA). Psoralen makes the body
very sensitive to UVA rays and comes in oral or topical form. It may be used on a short-term basis to bring a severe or disabling case of psoriasis under control. The main long-term side effect of PUVA is the increased risk of skin cancer.

Oral PUVA is typically used for children aged 12 and older. For younger children, topical psoralen in the form of a bath or soak may be used. Never use psoralen drugs with sunbathing or tanning salons because of the risk of severe, even life-threatening, burns.

Lasers

There are two kinds of lasers approved to treat psoriasis: excimer lasers and pulsed dye lasers. Both lasers treat chronic, localized plaque lesions.

The excimer laser emits a very small, high-intensity beam of UV light. It is very similar to the light delivered by narrow-band UVB units.

Although no longer commonly used, pulsed dye lasers destroy the tiny blood vessels that contribute to and support the formation of psoriasis lesions.

Systemic Medications

Systemic and biologic medications are used only for children with severe or disabling psoriasis that did not respond to other types of treatment, or those who also have psoriatic arthritis. The traditional systemic medications are methotrexate, acitretin and cyclosporine. Topical medications and sometimes UVB light are used with these potent drugs to help speed clearing and limit the dosage needed to clear the psoriasis.

Biologic agents are given by infusion or injection and may be appropriate for your child. Your doctor will discuss these powerful medications and the risks and benefits of their use.
COMPLEMENTARY MEDICINE

Complementary and alternative medicine (CAM) treatments are popular with many people. However, it is difficult to assess their effectiveness because they have not been studied adequately in adults or in children.

Acupuncture, balneotherapy and climatotherapy (natural water and sun exposure), chiropractic adjustments, diets and dietary supplements have all been reported to help treat the symptoms of psoriasis in some individuals. Like conventional approaches, not all CAM approaches work for everyone. Results may vary from person to person. It’s important to talk to your child’s primary care provider before starting any CAM treatment.

If you are interested in trying a CAM treatment with your child, you can look for a licensed CAM provider. Your child’s primary care provider may be able to give you a referral or recommendation.

STICKING WITH A TREATMENT PLAN

Once you, your child and your physician settle on a treatment plan, follow through with it. Half of all patients do not adhere to the treatment plan prescribed by their doctors. This makes it seem like the treatment isn’t working, when the reality is that the individual didn’t use it in the correct way or give it enough time to be effective.

PSORIASIS AND EMOTIONS

When young people develop psoriasis, it affects
them not only physically but emotionally as well. It may influence how they view and interact with the world, the activities they take part in, the people they seek out as friends and the interests they develop.

Some children may show little emotional reaction; others may be embarrassed, angry or sad. Children may worry about their psoriasis getting worse or recurring over time. Anxiety over peer rejection is very common and is hard to keep in check, especially as the child moves toward the teenage years.

Psoriasis can bring on a range of emotional responses. Coming to terms with having the disease may take some time. No one can predict how a child with the disease will act or feel. Because psoriasis tends to ebb and flow, the child’s feelings may shift and change as well. The swing in feelings alone can cause confusion. Helping your child to communicate effectively about the disease and his or her feelings is as important as developing ways to help your child manage the physical symptoms of psoriasis.

It is common for children who have psoriasis to experience strong feelings about their skin. Older children and teenagers should find someone they feel safe talking to about these feelings. It could be a family member, friend, physician or counselor. What’s important is that they find someone who is willing to recognize the feelings that accompany psoriasis. These feelings are real. Do not dismiss them as trivial or as vanity.

**SUPPORTING YOUR CHILD**

A child with psoriasis needs support from family and friends. Support can take many forms, from being able to listen to the child’s feelings to simple, common acts of friendship. You may need to remind your child periodically to ask for support or others won’t know that it’s needed.
Education

Explain to your child that the more people know about psoriasis, the better. Allow the child to practice telling you about his or her disease as if you were a teacher, a new friend or a stranger. Help your child find ways to communicate that psoriasis is not contagious, self-inflicted or mystical. Remind them that it is a medical condition in which the skin cells grow too rapidly and build up on the surface of the skin.

Connecting to others

Connecting to other children with psoriasis will help your child realize he or she is not alone. It can be helpful to share stories and treatment tips with someone who knows what it’s like to live with psoriasis. Encourage your child to create a support system. This could include teachers, coaches, friends, youth group leaders and other people who care about your child.

Selecting a doctor

Finding the right physician and other health care providers and developing a good relationship with them is critical. Managing your child’s psoriasis is a long-term team effort. Treatment decisions will grow increasingly important as your child gets older. Involving your child in those decisions is essential in carrying out an effective treatment plan.

Treatment plans

Actively involving children in their treatments gives them a certain amount of control over their disease. However, treatment can create frustration and stress. It requires a time commitment by the young person and causes varying degrees of discomfort. Repeated treatments that produce minimal results can cause anger and a feeling that there is too
much focus on the disease at the expense of other things. Over time, treatment can become a difficult, resented task, particularly if a treatment becomes ineffective and the disease reasserts itself.

To make treatment easier, experts advise setting up a “treatment center” in the home where all medicines and creams are kept. Generally, children over 6 or 7 years old may be able to apply moisturizing lotions and topical creams on their own. Children under 6 may not want creams applied. Play games with a young child’s treatments. Try applying creams as “dots” and then connecting the dots, or drawing pictures with the ointments and then “erasing” them with your hands. As children age, make treatment a timed event and try to break the last record for “least time needed” to apply a treatment.

**Handling emotions**

While emotional reactions to psoriasis are to be expected, some common techniques can help young people cope with these emotions. Listen for statements that suggest depression, apathy or anger about the disease.

Always acknowledge the feelings and avoid downplaying the effects of psoriasis. If a child’s feelings are out of control, or if you cannot cope with the feelings your child expresses, do not hesitate to seek the guidance of a mental health professional. Remember, as a parent or caregiver, your attitude affects your child. Stay positive and hopeful. If you use embarrassed or negative tones, your child will hear the message that the disease is something to be ashamed of. It isn’t.

Here are some ways to handle common emotional reactions in children and teens with psoriasis:
Distortion

“I must have done something to bring this on.”

Technique
Ask the child to base his or her feelings on the facts. While emotional states can worsen psoriasis, it does not cause the disease.

Disappointment

“I’ve done everything the doctor said, applied the treatments faithfully, and it’s back, worse than ever.”

Technique
Remind your child that it is normal for psoriasis to come and go. However, it is equally important to simply listen and accept your child’s disappointment and frustration. Just as they have to accept the realities of the disease, you have to accept that you can’t always make them feel better.

Hopelessness

“There is no point in continuing treatments. I still have the disease.”

Technique
Restate that psoriasis is treatable and that there are many treatment options. Although one type of treatment may not work, another might. Remember, sometimes all you can do is listen. With teenagers, you can delve further when you hear negative thoughts.
Challenge the negative thoughts by asking the teenager to:

- Identify the negative thought. Write it down. Test the thought. Are you jumping to conclusions? Are you making psoriasis the scapegoat?

- Dispute the thought. Offer arguments that illustrate psoriasis is not the cause of all negative events in a person’s life.

- Review options. Develop contingency plans. What will you do if . . . ?

- Carry out an action that indicates the negative thought can be overcome.

As the child’s primary caregiver, you will need to know as much as you can about the disease to help your child manage it throughout the course of childhood. Decide what to tell your child about the disease and its management based on his or her age, maturity and emotional state. You will probably need to reinforce the basic messages you want to get across many times in different ways.

Be truthful about the course of psoriasis while fostering hope. As the child gets older, you can explain more about research and findings. Medical information about the disease is very important. However, it is crucial that your child learns to recognize his or her feelings about psoriasis and to express those feelings as part of managing them. Tell your child often that it’s OK to feel angry, sad and frustrated, and it’s OK to show that pain to others.

**COMMUNICATION**

Psoriasis is a reality, but it need not take control of a young person’s emotions. Honest, straightforward information delivered with compassion and sensitivity works best. Your openness and directness with your child will serve as a good example for handling social situations.
Here are some basic points to communicate to your child:

• When you have psoriasis, it means that your skin is producing skin cells faster than normal.

• Scientists haven’t totally figured out what causes psoriasis, but things like a poor diet, bad hygiene or a certain personality type do not cause it. People do not bring psoriasis on themselves.

• It is not a contagious disease. You can’t spread it to others or catch it from someone who has it.

• Psoriasis is something you were born with, just as you were born with your eye color.

• It is a chronic disease, which means that it is ongoing. It usually goes through cycles: Sometimes it seems better, sometimes it may get worse.

• Researchers are working to determine the exact cause of psoriasis and develop better methods to treat it. Researchers don’t know yet why some people get the disease and others don’t.

• Some people who see your skin won’t know or understand what you have. They may make rude comments or tease you, or they may even avoid you altogether. The more you can explain about your skin condition to others, the less you’ll have to worry about their reactions.

• Ask your doctor questions and tell him or her if there is anything you’re worried about.

• Write down your questions before you see the doctor so you don’t forget them during your appointment.

• Ask your family members and friends for support when you need it. Other people want to help, but they don’t always know how.
Psoriasis may be part of you, but it is not all of who you are.

Of course, no single approach or technique will be appropriate for every situation or every child who has psoriasis.

These are some other tips that may be beneficial:

- Once you, your physician and your child have settled on a treatment plan, be sure you follow through with it as directed. Changing the amount of medication, the frequency of treatments or any other part of the plan can make a significant difference in the results.

- Your attitude affects your child. Stay positive and hopeful.

- Acknowledge that having psoriasis is not easy, but it can be dealt with positively.

- If a treatment fails, you probably won’t be able to ease the disappointment. Let your child know that you, too, are disappointed. Encourage them to try something new.

- Listen for objections and problems and show that you are sympathetic, but do not let the child use psoriasis to manipulate others.

- Create games to play during treatment sessions.

- While it is important to recognize the impact psoriasis can have on the whole family, don’t let the child’s psoriasis run your life or your family’s life. Your other children and significant relationships require your time, too.

- Help your child find someone they can identify
with, perhaps someone who has overcome a personal challenge.

- Be a good example when dealing with others’ questions and reactions.

- Psoriasis can worsen or become harder to treat with weight gain or obesity. For this reason a healthy diet and daily physical activity should be encouraged. If your child is overweight, a consultation with a dietitian may be helpful.

**BILL OF RIGHTS**

There is a “Bill of Rights” for people who have psoriasis, including children and teenagers. Keep these concepts in mind and help your child implement them.

**Your child has the right to:**

- A full explanation of psoriasis and the treatments or medications prescribed.

- The most potent treatment with the best result and the mildest side effects.

- Sympathetic, courteous management by physicians and other health care providers.

- The privilege of changing doctors or treatment centers.

- The freedom to experience emotional reactions from having psoriasis.

- The encouragement and support of family members and friends.
• Access to information about psoriasis, psoriatic arthritis and treatments.

• The public’s attention when describing psoriasis from a medical and scientific point of view.

• Deal with psoriasis in his or her own way and not as other people think they should cope.

• See himself or herself as a person of great worth who has a diagnosed medical condition called psoriasis.

ADDITIONAL RESOURCES AND TREATMENT INFORMATION

The National Psoriasis Foundation (NPF) maintains an extensive library of information on psoriasis and related topics. To learn more, visit www.psoriasis.org or email education@psoriasis.org.

Thanks to diligent scientific research, today’s treatments are providing a wide range of safe and effective options for people with psoriasis and psoriatic arthritis. The search continues to find safer and even more effective treatments.

NPF tracks the movement of drugs for psoriasis and psoriatic arthritis from preliminary studies through the three phases of clinical trials as required by the U.S. Food and Drug Administration. This information is compiled, along with that from other sources, and entered into our drug research pipeline.

To learn more about research and upcoming treatments visit www.psoriasis.org/pipeline.
We’re here for you.

At NPF, our priority is giving you the information and services you need to take control of your psoriasis and/or psoriatic arthritis, while funding research to find a cure.

RESEARCH

Finding a cure for psoriasis and psoriatic arthritis is our highest priority. We’re working for you by:

- Funding promising new studies through our Discovery and Translational grants programs
- Increasing the number of scientists doing research through our Medical Fellowship program
- Hosting the world’s largest collection of psoriasis DNA for genetic research

ADVOCACY

We’re ensuring that people with psoriasis and psoriatic arthritis have a say in the policies that affect their lives. Join us as we:

- Work to increase federal funding for psoriasis and psoriatic arthritis research
- Improve access to health care for patients

HEALTH EDUCATION

NPF is your one-stop shop for news and information about psoriasis and psoriatic arthritis. Visit www.psoriasis.org to learn more about:

- The latest treatment information and research updates
- Health events in your area

CONNECTION

Sometimes the best resource to manage psoriasis and psoriatic arthritis is another person with your condition. Share information and get support from:

- TalkPsoriasis.org, the largest online community for people affected by psoriasis and psoriatic arthritis
- Psoriasis One to One mentor program: www.psoriasis.org/one-to-one
- Team NPF Walk, Run, Ride and DIY events: www.teamnpf.org
LEARN MORE

Find more information and resources at www.psoriasis.org.

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Become a member of the National Psoriasis Foundation and get the tools and information you need to manage your psoriasis and/or psoriatic arthritis. As a member, you’ll receive a full year of Psoriasis Advance magazine and other benefits and services designed to help you live well with psoriatic disease.

☐ Yes, I want to join the National Psoriasis Foundation. Please send me a bill for $35. For faster service, join online at www.psoriasis.org or call 800-723-9166.

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