What is this booklet about and who is it for?

The Parent Guide is part of a series of educational materials for people impacted by psoriasis and psoriatic arthritis (together called psoriatic disease). This booklet is specifically for parents of children and teens with psoriatic disease, but may also be helpful for their friends and family members.

This booklet gives an overview of psoriasis and psoriatic arthritis and answers questions such as:

- What is psoriatic disease?
- What are the treatment options for my child?
- How can I best support my child emotionally?

This booklet has been reviewed for accuracy by health care providers who have experience treating psoriatic disease.

Remember, people living with psoriatic disease are all unique. That means you should work with your health care provider to identify a treatment that’s appropriate for your child’s disease severity and medical history.

If you have questions about your psoriasis or psoriatic arthritis, contact an NPF Patient Navigator.

Our navigators understand psoriatic disease and the issues that affect those living with it. Whether your child was diagnosed yesterday or 5 years ago, Patient Navigators find solutions to help you live your healthiest life.

- Phone: 800-723-9166
- Email: education@psoriasis.org
- Website: psoriasis.org/navigationcenter

What is psoriasis (sore-EYE-ah-sis)?

Psoriasis is a chronic (lifelong) disease. It is related to the immune system. This means that immune system activity plays a role in causing the disease. When you have psoriasis, your immune system becomes overactive. The overactive immune system causes inflammation (swelling and redness) of the skin and speeds up skin cell growth. This results in itchy or painful, scaly, inflamed plaques (patches) on your skin.

Psoriasis is not contagious. Your child can’t catch it from anyone. It tends to run in families, so it is linked to genes you inherit. The link between genes and psoriasis is not yet fully understood.

Psoriasis affects more than 8 million people in the U.S. Symptoms often start between ages 15 and 25. But they can start at any age. About 1 in 3 people who get psoriasis are under 20 years old when it first develops. Approximately 20,000 children under the age of 10 are diagnosed with psoriasis every year. Men, women and children of all skin colors and income levels can have psoriasis.

Psoriasis varies from person to person. It can be mild, moderate or severe, and easy or hard to treat. It affects your child’s quality of life. It can limit his or her activities, cause constant pain and itch and raise the risk for other related health conditions, like diabetes, heart disease and depression. Your child may be self-conscious about how she looks when she has a flare (sudden onset of symptoms).

While there’s currently no cure for psoriasis, there are many ways to manage symptoms. Over the last 15 years, new treatments have been approved for psoriasis and psoriatic arthritis. Today, there are more effective ways to manage psoriatic disease than ever before – and the results can be life-changing. Treatment is the best way to improve your child’s quality of life and lower the risk of related diseases.

It is important to find a health care provider who specializes in psoriasis, called a dermatologist (skin doctor). If your child does not have a dermatologist, his or her pediatrician can refer you to one in your area.

The National Psoriasis Foundation’s mission is to drive efforts to cure psoriatic disease and improve the lives of those affected.

Psoriasis
What causes psoriasis?
No one is sure what causes psoriasis. Normally, the immune system fights illnesses and infections. When you have psoriasis, your immune system overacts when you experience a trigger (discussed on page 4). This causes inflammation of the skin and speeds up skin cell growth. Normal skin cells completely grow and shed (fall off) in a month. Psoriatic skin cells do this in only 3 or 4 days. Instead of shedding, these cells pile up at the surface. This forms psoriasis lesions (abnormal changes to the skin in the form of plaques, pustules or areas of scaling, redness and swelling).

Genes also play a role. But even though psoriasis runs in families, people with no family history can develop it too. And people with a family history may never get the disease.

Is psoriasis the same for everyone?
Psoriasis differs from person to person. Psoriasis severity can be measured by how much it affects the body. How can you tell? As a rule of thumb, the entire hand (the palm, fingers and thumb) is equal to about 1% of the body surface area.

Other factors to consider when measuring severity include the areas affected and how much it impacts your child’s quality of life. Psoriasis can be severe even if it’s only on a small area of skin, like the hands, feet, face or genital area.

Psoriasis can change over time. Some people rarely have symptoms. Others have symptoms all the time. Symptoms can get better or worse, last a short or long time, and appear on different parts of the body at different times.

Odds that a child will develop psoriasis
- One parent has psoriasis
- Both parents have psoriasis

28% 65%
Psoriatic arthritis

What is psoriatic arthritis?
Psoriatic arthritis is a chronic disease. Like psoriasis, it is also related to the immune system. This means that immune system activity plays a role in causing the disease. Psoriatic arthritis causes swelling, pain and stiffness in the joints and in areas where tendons and ligaments connect to bone. It is not contagious.

Psoriatic arthritis affects adults and children differently:
- In adults, about 1 in 3 people with psoriasis develop psoriatic arthritis, which often appears between ages 30 and 50. Psoriatic arthritis can start at any time after psoriasis but often starts about 10 years after psoriasis begins.
- In children, about 1 in 10 children with psoriasis develop psoriatic arthritis, which often appears when the child or teen is still under the age of 18.

Psoriatic arthritis in children may often be referred to as juvenile idiopathic [i-dee-uh-PA-thik] arthritis (JIA). The word idiopathic means “of unknown origin.” JIA is a broad term that describes several types of inflammatory arthritis in children under 16.

To treat your child’s psoriatic arthritis, talk with a health care provider. It’s best to talk with someone who specializes in pediatric psoriatic arthritis. This can be a rheumatologist [arthritis doctor] or another medical professional who has experience treating children or teens with psoriatic arthritis.

What causes psoriatic arthritis?
As with psoriasis, no one knows for sure what causes psoriatic arthritis. Genes also play a role in psoriatic arthritis. Even though psoriatic arthritis runs in families, people with no family history can develop it too. And people with a family history may never get the disease.

What triggers a psoriasis flare?
Psoriasis triggers vary. Understanding what triggers your child’s psoriasis symptoms to flare can help you manage the disease.

The most common trigger for children is infections, especially strep (throat and anus) and viral infections. Many children start having signs of psoriasis symptoms 2 to 6 weeks after an earache, strep throat infection, bronchitis, tonsillitis or a respiratory infection.

Other psoriasis triggers include stress, starting or stopping some medicines, allergies, diet, and changes in the weather. Speak with your child’s health care provider about ways to avoid or reduce your child’s triggers.

Skin injuries may trigger flares. This is called the Koebner [KEB-ner] phenomenon. This can happen with a bug bite, sunburn, scratch or even needle puncture. Encourage your child not to scratch or pick at a psoriasis lesion.

Psoriatic arthritis

Triggers

- Stress
- Starting or stopping some medicines
- Allergies
- Changes in diet
- Changes in the weather
- Skin injuries

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How do you know your child has psoriatic arthritis?

There is no single test that can diagnose psoriatic arthritis. Sometimes, psoriatic arthritis may be incorrectly diagnosed as other types of arthritis or another condition. However, psoriatic arthritis has unique characteristics and symptoms that can help with getting the correct diagnosis.

Your child’s health care provider will evaluate symptoms:

- Stiffness, pain, swelling and tenderness in joints
- Stiffness of joints, tendons or ligaments when waking up or after being at rest
- Reduced range of motion in joints
- Tendon tenderness, pain and swelling in areas such as the bottoms of the feet, heels, hips or spine
- Fatigue (extreme tiredness or exhaustion)
- Swollen fingers and toes
- Asymmetric joint symptoms (not the same on the right and left sides of the body)
- Nail changes like separation of the nail plate from the nail bed, pitting or the appearance of a fungal infection
- Uveitis (inflammation of the eye that causes swelling, pain and redness)

Talk with your child’s health care provider about his or her symptoms, especially if there is a family history of psoriasis or psoriatic arthritis. The health care provider will look at your child’s skin, nails and joints. Your child may have X-rays, an MRI, an ultrasound and blood tests to rule out other diseases.

When should your child get treatment for psoriatic arthritis?

Untreated psoriatic arthritis can cause permanent joint damage. It is important to start treatment of psoriatic arthritis as soon as possible. Early diagnosis and treatment can help slow the disease and control symptoms. It can help keep your child’s joints healthy, improve range of movement, lessen pain and tiredness, and prevent permanent joint damage.

What are psoriatic arthritis triggers?

Psoriasis triggers may also affect psoriatic arthritis. Stress or injury, especially to the joints, can make psoriatic arthritis worse.
Treatments

How do you choose the right health care provider for your child?

Finding the right health care provider is important in managing your child’s psoriatic disease. We recommend seeing a pediatric dermatologist for psoriasis and a pediatric rheumatologist for psoriatic arthritis. It may also be helpful to find specialists that have experience treating psoriatic disease.

Effective treatment requires a trustworthy relationship between you, your child and your child’s health care providers. Treatment decisions should be discussed and made together. Understanding how treatments work and their side effects or risks are important. You want to be able to discuss these issues and concerns with your child’s health care providers.

Additionally, involving your child in the treatment decision is also important to make sure that the treatment plan will be followed.

What do you expect from your child’s treatment plan?

There are safe and effective treatment options for psoriatic disease. Treatments for psoriasis can reduce symptoms like inflammation and help your child achieve clearance or remission. For psoriatic arthritis, treatments can reduce joint pain, keep joints working well and prevent future joint damage.

Your child’s health care provider will recommend treatments based on:
- Whether your child has psoriasis or psoriatic arthritis
- Whether your child’s psoriatic disease is mild, moderate or severe
- Your child’s response to a treatment

Work with your child’s health care provider to set goals for managing your child’s psoriatic disease. Setting treatment goals can be helpful in understanding whether a treatment is working well for your child. If a treatment is not meeting your child’s treatment goals, keep working with their health care provider. Speak with your child’s health care provider about other treatment options. This might mean increasing the treatment dosage, adding another treatment or switching treatments.

Finding the treatment that gives the most relief from symptoms may take time. No one treatment works for everyone. Some treatments work for a while and then stop. Some treatments work better combined. Speak with your child’s health care provider about potential benefits, side effects or risks if you have concerns.
What treatment options are available for my child?

Treatment plans for children and teens are typically less aggressive than those for adults. The U.S. Food and Drug Administration (FDA) approves many psoriatic treatments only for adults. This is because the safety and efficacy of new treatments are often only studied in adults. However, new and ongoing studies are examining the efficacy and possible side effects in children and teens, which will hopefully lead to more FDA approvals of safe, effective treatments for younger patients.

The following discusses the 4 categories of treatment options for psoriatic disease.

Topicals

Topicals are first-line treatment options (generally the first treatments recommended according to care standards) for mild psoriasis. They come in many forms, such as ointments, creams, solutions, gels, lotions, foams, shampoos, tapes and sprays.

Topicals also range from over-the-counter (OTC) to prescription strength. It is generally safer to start with lower-strength topicals. Always use topicals as directed by your child’s health care provider.

It is important to keep in mind that how well a treatment works depends in part, on how well the treatment plan is followed.

To make following topical treatment plans easier, try to make it a fun or enjoyable activity for your child:

- Apply topicals as “dots” and then connecting the dots
- Draw pictures with topicals and then “erase” them with your hands as you rub them in
- Play games, such as making it a timed event and trying to break the record each time

Generally, children older than 6 or 7 may be able to apply topicals on their own. Having your child involved with his or her treatment at every age will help you both stick with it.

Speak with your child’s health care provider if following a topical treatment plan is not something that you and your child can do regularly.

These symbols show if a treatment is for psoriasis, psoriatic arthritis or both. To learn more, go to psoriasis.org.
**Phototherapy**

Phototherapy is the second-line treatment option for mild-to-moderate psoriasis. This treatment option uses ultraviolet (UV) light to treat psoriasis under the supervision of a health care provider. UV light penetrates the skin and slows the growth of affected skin cells.

Treatments can be given in a health care provider’s office, psoriasis clinic or at home with a prescription. Phototherapy light is different from tanning booth light. You should not use a tanning booth to treat psoriasis.

Phototherapy treatments include:

- Ultraviolet B light (UVB) can be used to treat the whole body or smaller areas, such as the hands, feet or targeted psoriasis lesions.
- The combination of a drug called psoralen and ultraviolet A light (PUVA) is usually not recommended for children or teens but may be an option if other treatments have not been successful. Oral PUVA may be an option for teens 12 and older. Topical PUVA in the form of a bath or soak may be an option for younger children.
- Exposure to natural sunlight as directed by your child’s health care provider may be used to treat psoriasis. However, it is important to follow prescribed instructions and use sunscreen or clothes to cover up unaffected areas to avoid sunburns.

As with topicals, one of the keys to success with phototherapy is following the treatment plan. Try to make phototherapy treatments as enjoyable and comfortable as possible for your child.

**Biologics**

Biologics may be considered for treating moderate-to-severe psoriasis or psoriatic arthritis. They target proteins or cells in the immune system that play a role in psoriasis and psoriatic arthritis. They are given as an injection (shot) or by intravenous (IV) infusion (a slow drip of medicine into the vein). Biologics, including biosimilars, are medicines made from living sources such as human, animal or bacterial cells.

There are currently 6 biologics that are FDA-approved for treating children and teens with psoriasis or JIA (The brand name is listed first, followed by the generic name in parenthesis):

- **Actemra (tocilizumab)** is approved for JIA in children 2 and older
- **Enbrel (etanercept)** is approved for JIA in children 2 and older and psoriasis in children 4 and older
- **Humira (adalimumab)** is approved for JIA in children 2 and older
- **Ilaris (canakinumab)** is approved for JIA in children 2 and older
- **Orencia (abatacept)** is approved for JIA in children 2 and older
- **Stelara (ustekinumab)** is approved for teens 12 and older
Oral treatments

Oral treatments are medicines taken by mouth, most often in the form of a pill. They can act throughout the body, targeting different cells involved in psoriasis and psoriatic arthritis.

- Methotrexate is currently the only FDA-approved oral treatment for JIA

Unfortunately, there are no FDA-approved oral treatments for children or teens with psoriasis. However, researchers are studying the safety and efficacy of new and currently approved treatments for adults in treating children.

Can my child use a psoriatic treatment that is approved for only adults?

Your child’s health care provider may prescribe treatments for off-label use. Using a medicine off-label means you’re using it for a disease, health condition or age group other than the one for which the FDA approved it.

It is common for health care providers to recommend off-label use of topicals, biologics and oral treatments for children and teens with psoriatic disease. We recommend speaking with your child’s health care provider about a treatment plan that is most appropriate for your child and meets treatment goals.

Are there other treatment options?

Complementary and integrative health is another approach to help manage psoriatic disease.

There are many biologics and oral treatments that are FDA-approved for treating psoriatic disease in adults that may be used off-label with children and teens. For more details about these treatments, read our booklet Systemic Treatments: Biologics and Oral Treatments.

You can help support your child in many different ways:

- Teach her about psoriasis and psoriatic arthritis
- Help him find ways to talk about his disease and feelings
- Build her confidence and help her feel comfortable about psoriatic disease
- Encourage him to ask for support when he needs it

How do you talk about psoriatic disease with your child?

It is important for you to learn about psoriatic disease so that you can talk about it with your child. What you choose to share with him about the disease and how you explain it may change over time, as he grows older and has more questions.

Teaching him about his disease will help him be more comfortable talking about it with others. You can also encourage your child to practice telling you what he has learned. He can pretend that you are a teacher or even a new friend to help him become more comfortable talking about psoriatic disease with others.

Here are some facts to share with your child:

- Psoriasis and psoriatic arthritis are not contagious. You can’t catch psoriatic disease from others or give it to others.
- Similar to your hair or eye color, psoriatic disease is something you were born with. It is not something that you caused to happen.
- When you have psoriasis, it means that your skin cells grow faster than normal.
Scientists don’t know what causes psoriasis and psoriatic arthritis yet. But they are working to better understand psoriatic disease and hope to find a cure one day.

Sometimes the symptoms get better, and sometimes they might get worse.

People may make rude comments, tease or be unkind. But that is because they don’t understand. Talking to others about your psoriasis and psoriatic arthritis will help them understand.

Psoriatic disease may be part of you. But it is not all of who you are.

Always be honest and positive in the way you talk about psoriatic disease with your child and with others. Let your child know that having psoriatic disease may be difficult. But you are there to support him.

What can you expect from the emotional impact of psoriatic disease?

Psoriatic disease impacts your child physically and emotionally. Making a treatment decision and following a treatment plan is important. But another aspect of managing the disease is helping your child to understand, communicate and cope with the emotional impact.

Your child may experience a range of emotions about the disease as symptoms change over time. Children may worry about how friends and others think of them, especially as they become teenagers. Psoriasis and psoriatic arthritis may also influence your child’s interests and social interactions.

Some common feelings may include:

- Anger
- Anxiety or stress
- Confusion
- Loneliness, isolation or rejection
- Low self-esteem or insecurity
- Sadness or depression

No one can predict how a child will act or feel. Your child’s feelings may also change as symptoms change over time. These changes may also be confusing for your child to understand and process as well. There are ways for you to help your child cope with the emotional impact of her psoriatic disease.

Consider having your child speak with a mental health professional if she is experiencing symptoms of depression. A mental health professional may be a counselor, social worker, therapist, psychologist or psychiatrist.
How do you help your child cope with the emotional impact?

Again, it is important to be positive, hopeful and supportive of your child. Keep in mind that your attitude and emotions also play a role in how psoriatic disease impacts your child. Acknowledge that psoriatic disease is not easy. But together, you can deal with it positively.

There are some common ways that you can help your child cope:

- Always acknowledge and respect your child’s feelings
- Make sure that your child knows that her feelings are valid
- Listen for statements that suggest your child is feeling sad, angry or confused about his psoriasis or psoriatic arthritis
- Help your child talk about her feelings and disease in a positive and productive way
- Pay attention to your non-verbal signs when speaking with your child

If your child says: “I don’t want to follow the treatments anymore. They are not working. And even if they do work, I will always have psoriasis or psoriatic arthritis.”

Listen and acknowledge any disappointment or anger. Let your child know that you share in his feelings as well. But remind your child that researchers are working hard to find a cure. For now, these treatments can help reduce symptoms and keep him clear for longer periods of time. Encourage him to try something new and decide on another treatment plan together.

If your child says: “It’s my fault I have psoriasis or psoriatic arthritis.”

Use this opportunity to teach your child about the disease. Helping your child to focus on the facts can comfort them. Developing psoriatic disease was out of her control. But you and your child can help to manage symptoms and prevent flares.

If your child says: “No one understands what I am going through.”

Recognize how your child is feeling and remind him that he is not alone. There are millions of people living with psoriatic disease. And let him know that you are with him each step of the way even though you may not be experiencing symptoms. Try to connect with other families affected by psoriatic disease. Or help your child find someone he can identify with, perhaps someone who has overcome other personal challenges.

How do you connect with others?

Connections that you and your child make with others can play a key role in how your child copes with her disease.

Remember that siblings and other family members are affected by psoriatic disease too. Be sure to include siblings and other family members when teaching your child about the disease. Encourage him to talk about his feelings and ask questions. Talking with family members about his disease can help your child be more comfortable when talking to others.

Make connections with other families with psoriatic disease. This can help your child to realize that she is not alone in her disease, especially if she is able to speak with children her age who have psoriatic disease. This type of connection can also be helpful to share stories and learn about different treatment journeys.

Encourage your child to create a support system. This could include friends, teachers and other people who play important roles in your child’s life such as a coach or school counselor. Having a support system of people who are positive and support your child can help him know that he is not alone.

NPF’s Psoriasis One to One, a peer support program, connects you with people who have psoriatic disease or helps you support a loved one with the disease. Learn more at npf.chronus.com.
Talk with your health care provider

Psoriasis and psoriatic arthritis are chronic diseases that need lifelong treatment. The good news is there are many treatments to help manage these conditions. Make an appointment to talk with your child’s health care provider about his or her symptoms and treatment options.

Contact our Patient Navigation Center

NPF’s Patient Navigation Center provides free and personalized assistance to anyone impacted by psoriatic disease, including families and caregivers.

It doesn’t matter if you have one question or need ongoing assistance – your Patient Navigator will help you find the information you need. We can help you:

- Understand your child’s disease
- Find a health care provider
- Learn about new treatments
- Deal with insurance issues
- Find financial help for treatments
- Connect with others who care for someone living with psoriatic disease

You can reach our navigators by phone, email, text and instant chat:

Phone: 800-723-9166  
Email: education@psoriasis.org  
Learn more or chat: psoriasis.org/navigationcenter

Visit Our Spot

Our Spot is a website for kids, teens and families living with psoriatic disease. Join our online community to learn more about psoriatic disease, how to best support your child and find stories from young people living – and thriving – with psoriasis and psoriatic arthritis.

Go to psoriasis.org/our-spot.

Want more information?

Learn about the following topics in our educational booklet series:

- Psoriasis and psoriatic arthritis, including diagnosis, symptoms, triggers and treatments
- Psoriatic arthritis, including how to manage flares and chronic pain
- Psoriatic disease in children and young adults
- Treatment options, including biologics and oral treatments, phototherapy and topicals

The National Psoriasis Foundation (NPF) is a 501(c)(3) organization governed by a Board of Directors and advised on medical issues by a Medical Board.

NPF’s educational materials are reviewed by members of our Medical Board and are not intended to replace the counsel of a physician. NPF does not endorse any medicines, products or treatments for psoriasis or psoriatic arthritis and advises you to consult a physician before initiating any treatment.