

Recognizing
The National
Bone and Joint Decade
2002–2011

*Questions
& Answers*
about . . .

Vitiligo

*National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
National Institutes of Health
Public Health Service • U.S. Department of Health and Human Services*

For Your Information

This publication contains information about medications used to treat the health condition discussed in this booklet. When this booklet was printed, we included the most up-to-date (accurate) information available. Occasionally, new information on medication is released.

For updates and for any questions about any medications you are taking, please contact the U.S. Food and Drug Administration at 1-888-INFO-FDA (1-888-463-6332, a toll-free call) or visit its Web site at www.fda.gov.

For updates and questions about statistics, please contact the Centers for Disease Control and Prevention's National Center for Health Statistics toll free at 1-800-232-4636 or visit its Web site at www.cdc.gov/nchs.

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What Is Vitiligo?

Vitiligo (pronounced vit-ill-EYE-go) is a pigmentation disorder in which melanocytes (the cells that make pigment) in the skin are destroyed. As a result, white patches appear on the skin in different parts of the body. Similar patches also appear on both the mucous membranes (tissues that line the inside of the mouth and nose) and the retina (inner layer of the eyeball). The hair that grows on areas affected by vitiligo sometimes turns white.

The cause of vitiligo is not known, but doctors and researchers have several different theories. There is strong evidence that people with vitiligo inherit a group of three genes that make them susceptible to depigmentation. The most widely accepted view is that the depigmentation occurs because vitiligo is an autoimmune disease – a disease in which a person’s immune system reacts against the body’s own organs or tissues. People’s bodies produce proteins called cytokines that, in vitiligo, alter their pigment-producing cells and cause these cells to die. Another theory is that melanocytes destroy themselves. Finally, some people have reported that a single event, such as sunburn or emotional distress, triggered vitiligo; however, these events have not been scientifically proven as causes of vitiligo.

Who Is Affected by Vitiligo?

About 0.5 to 1 percent of the world's population, or as many as 65 million people, have vitiligo. In the United States, 1 to 2 million people have the disorder. Half the people who have vitiligo develop it before age 20; most develop it before their 40th birthday. The disorder affects both sexes and all races equally; however, it is more noticeable in people with dark skin.

Vitiligo seems to be somewhat more common in people with certain autoimmune diseases, including hyperthyroidism (an overactive thyroid gland), adrenocortical insufficiency (the adrenal gland does not produce enough of the hormone called corticosteroid), alopecia areata (patches of baldness), and pernicious anemia (a low level of red blood cells caused by the failure of the body to absorb vitamin B₁₂). Scientists do not know the reason for the association between vitiligo and these autoimmune diseases. However, most people with vitiligo have no other autoimmune disease.

Vitiligo may also be hereditary; that is, it can run in families. Children whose parents have the disorder are more likely to develop vitiligo. In fact, 30 percent of people with vitiligo have a family member with the disease. However, only 5 to 7 percent of children will get vitiligo even if a parent has it, and most people with vitiligo do not have a family history of the disorder.

What Are the Symptoms of Vitiligo?

People who develop vitiligo usually first notice white patches (depigmentation) on their skin. These patches are more commonly found on sun-exposed areas of the body, including the hands, feet, arms, face, and lips. Other common areas for white patches to appear are the armpits and groin and around the mouth, eyes, nostrils, navel, genitals, and rectum.

Vitiligo generally appears in one of three patterns:

- **focal pattern** – depigmentation limited to one or only a few areas
- **segmental pattern** – depigmented patches that develop on one side of the body only
- **generalized pattern** – the most common pattern. Depigmentation occurs symmetrically on both sides of the body.

In addition to white patches on the skin, people with vitiligo may have premature graying of the scalp hair, eyelashes, eyebrows, and beard. People with dark skin may notice a loss of color inside their mouths.

Will the Depigmented Patches Spread?

Focal pattern vitiligo and segmental vitiligo remain localized to one part of the body and do not spread. There is no way to predict if generalized vitiligo will spread. For some people, the depigmented patches do not spread. The disorder is usually progressive, however, and over time the white patches will spread to other areas of the body. For some people, vitiligo spreads slowly, over many years. For other people, spreading occurs rapidly. Some people have reported additional depigmentation following periods of physical or emotional stress.

How Is Vitiligo Diagnosed?

The diagnosis of vitiligo is made based on a physical examination, medical history, and laboratory tests.

A doctor will likely suspect vitiligo if you report (or the physical examination reveals) white patches of skin on the body – particularly on sun-exposed areas, including the hands, feet, arms, face, and lips. If vitiligo is suspected, the doctor will ask about your medical history. Important factors in the diagnosis include a family history of vitiligo; a rash, sunburn, or other skin trauma that occurred at the site of vitiligo 2 to 3 months before depigmentation started; stress or physical illness; and premature graying of the hair (before age 35). In addition, the doctor will ask whether you or anyone in your family has had any autoimmune diseases and whether you are very sensitive to the sun.

To help confirm the diagnosis, the doctor may take a small sample (biopsy) of the affected skin to examine under a microscope. In vitiligo, the skin sample will usually show a complete absence of pigment-producing melanocytes. On the other hand, the presence of inflamed cells in the sample may suggest that another condition is responsible for the loss of pigmentation.

Because vitiligo may be associated with pernicious anemia (a condition in which an insufficient amount of vitamin B₁₂ is absorbed from the gastrointestinal tract) or hyperthyroidism (an overactive thyroid gland), the doctor may also take a blood sample to check the blood cell count and thyroid function. For some patients, the doctor may recommend an eye examination to check for uveitis (inflammation of part of the eye), which sometimes occurs with vitiligo. A blood test to look for the presence of antinuclear antibodies (a type of autoantibody) may also be done. This test helps determine if the patient has another autoimmune disease.

How Can People Cope With the Emotional and Psychological Aspects of Vitiligo?

Although vitiligo is usually not harmful medically, its emotional and psychological effects can be devastating. In fact, in India, women with the disease are sometimes discriminated against in marriage. Developing vitiligo after marriage can be grounds for divorce.

Regardless of a person's race and culture, white patches of vitiligo can affect emotional and psychological well-being and self-esteem. People with vitiligo can experience emotional stress, particularly if the condition develops on visible areas of the body (such as the face, hands, arms, and feet) or on the genitals. Adolescents, who are often particularly concerned about their appearance, can be devastated by widespread vitiligo. Some people who have vitiligo feel embarrassed, ashamed, depressed, or worried about how others will react.

Fortunately, there are several strategies to help people cope with vitiligo. Also, various treatments – discussed in the next section – can minimize, camouflage, or, in some cases, even eliminate white patches. First, it is important to find a doctor who is knowledgeable about the disorder and takes it seriously. The doctor should also be a good listener and be able to provide emotional support. You must let your doctor know if you are feeling depressed, because doctors and other mental health professionals can help people deal with depression. You should also learn as much as possible about the disorder and treatment choices so that you can participate in making important decisions about your medical care.

Talking with other people who have vitiligo may also help. The National Vitiligo Foundation can provide information about vitiligo and refer you to local chapters that have support groups of patients, families, and doctors. Contact information for the foundation is listed at the end of this booklet. Family and friends are another source of support.

Some people with vitiligo have found that cosmetics that cover the white patches improve their appearance and help them feel better about themselves. You may need to experiment with several brands of concealing cosmetics before finding the product that works best.

What Treatment Options Are Available?

The main goal of treating vitiligo is to improve appearance. Therapy for vitiligo takes a long time – it usually must be continued for 6 to 18 months. The choice of therapy depends on the number of white patches; their location, sizes, and how widespread they are; and what you prefer in terms of treatment. Each patient responds differently to therapy, and a particular treatment may not work for everyone. Current treatment options for vitiligo include medication, surgery, and adjunctive therapies (used along with surgical or medical treatments).

Medical Therapies

A number of medical therapies, most of which are applied topically, can reduce the appearance of vitiligo. These are some of the most commonly used:

- **Topical steroid therapy** – Steroid creams may be helpful in repigmenting (returning the color to) white patches, particularly if they are applied in the initial stages of the disease. Corticosteroids are a group of

drugs similar to hormones such as cortisone, which are produced by the adrenal glands. Doctors often prescribe a mild topical corticosteroid cream for children under 10 years old and a stronger one for adults. You must apply the cream to the white patches on the skin for at least 3 months before seeing any results. Corticosteroid creams are the simplest and safest treatment for vitiligo, but are not as effective as psoralen photochemotherapy (see below). Yet, as with any medication, these creams can cause side effects. For this reason, the doctor will monitor you closely for skin shrinkage and skin striae (streaks or lines on the skin). These side effects are more likely to occur in areas where the skin is thin, such as on the face and armpits, or in the genital region. They can be minimized by using weaker formulations of steroid creams in these areas.

- **Psoralen photochemotherapy** – Also known as psoralen and ultraviolet A (PUVA) therapy, this is probably the most effective treatment for vitiligo available in the United States. The goal of PUVA therapy is to repigment the white patches. However, it is time-consuming, and care must be taken to avoid side effects, which can sometimes be severe. Psoralen is a drug that contains chemicals that react with ultraviolet light to cause darkening of the skin. The treatment involves taking psoralen by mouth (orally) or applying it to the skin (topically). This is followed by carefully timed exposure to sunlight or to

ultraviolet A (UVA) light that comes from a special lamp. Typically, you will receive treatments in your doctor's office so you can be carefully watched for any side effects. You must minimize exposure to sunlight at other times. Both oral and topical psoralen photochemotherapy are described below.

- Topical psoralen photochemotherapy – often used for people with a small number of depigmented patches affecting a limited part of the body and for children age 2 and older who have localized patches of vitiligo. Treatments are done in a doctor's office under artificial UVA light once or twice a week. The doctor or nurse applies a thin coat of psoralen to your white patches about 30 minutes before exposing you to enough UVA light to turn the affected area pink. The doctor usually increases the dose of UVA light slowly over many weeks. Eventually, the pink areas fade and a more normal skin color appears. After each treatment, you wash your skin with soap and water and apply a sunscreen before leaving the doctor's office.

There are two major potential side effects of topical PUVA therapy: (1) severe sunburn and blistering and (2) too much repigmentation or darkening (hyperpigmentation) of the treated patches or the normal skin surrounding the vitiligo. You can minimize your chances of sunburn if you avoid exposure to direct sunlight after each treatment.

Usually, hyperpigmentation is a temporary problem that eventually disappears when treatment is stopped.

- Oral psoralen photochemotherapy – used for people with extensive vitiligo (affecting more than 20 percent of the body) or for people who do not respond to topical PUVA therapy. Oral psoralen is not recommended for children under 10 years of age because it increases the risk of damage to the eyes caused by conditions such as cataracts. For oral PUVA therapy, you take a prescribed dose of psoralen by mouth about 2 hours before exposure to artificial UVA light or sunlight. If artificial light is used, the doctor adjusts the dose of light until the skin in the areas being treated becomes pink. Treatments are usually given two or three times a week, but never 2 days in a row.

For patients who cannot go to a facility to receive PUVA therapy, the doctor may prescribe psoralen that can be used with natural sunlight exposure. The doctor will give you careful instructions on carrying out treatment at home and monitor you during scheduled checkups.

Known side effects of oral psoralen include sunburn, nausea and vomiting, itching, abnormal hair growth, and hyperpigmentation. Oral psoralen photochemotherapy may also increase the risk of skin cancer, although the risk is minimal at

doses used for vitiligo. If you are undergoing oral PUVA therapy, you should apply sunscreen and avoid direct sunlight for 24 to 48 hours after each treatment to avoid sunburn and reduce the risk of skin cancer. To avoid eye damage, particularly cataracts, you should also wear protective UVA sunglasses for 18 to 24 hours after each treatment.

- **Depigmentation** – involves fading the rest of the skin on the body to match the areas that are already white. For people who have vitiligo on more than 50 percent of their bodies, depigmentation may be the best treatment option. Patients apply the drug monobenzyl ether of hydroquinone (monobenzone or Benoquin*) twice a day to pigmented areas until they match the already-depigmented areas. You must avoid direct skin-to-skin contact with other people for at least 2 hours after applying the drug, as transfer of the drug may cause depigmentation of the other person's skin. The major side effect of depigmentation therapy is inflammation (redness and swelling) of the skin. You may experience itching or dry skin. Depigmentation tends to be permanent and is not easily reversed. In addition, a person who undergoes depigmentation will always be unusually sensitive to sunlight.

* Brand names included in this booklet are provided as examples only, and their inclusion does not mean that these products are endorsed by the National Institutes of Health or any other Government agency. Also, if a particular brand name is not mentioned, this does not mean or imply that the product is unsatisfactory.

Surgical Therapies

All surgical therapies must be considered only after proper medical therapy is provided. Surgical techniques are time-consuming and expensive and usually not paid for by insurance carriers. They are appropriate only for carefully selected patients who have vitiligo that has been stable for at least 3 years:

- **Autologous skin grafts** – The doctor removes skin from one area of your body and attaches it to another area. This type of skin grafting is sometimes used for patients with small patches of vitiligo. The doctor removes sections of the normal, pigmented skin (donor sites) and places them on the depigmented areas (recipient sites). There are several possible complications of autologous skin grafting. Infections may occur at the donor or recipient sites. The recipient and donor sites may develop scarring, a cobblestone appearance, or a spotty pigmentation, or may fail to repigment at all. Treatment with grafting takes time and is costly, and many people find it neither acceptable nor affordable.
- **Skin grafts using blisters** – In this procedure, the doctor creates blisters on your pigmented skin by using heat, suction, or freezing cold. The tops of the blisters are then cut out and transplanted to a depigmented skin area. The risks of blister grafting include scarring and lack of repigmentation.

However, there is less risk of scarring with this procedure than with other types of grafting.

- **Micropigmentation (tattooing)** – This procedure involves implanting pigment into the skin with a special surgical instrument. It works best for the lip area, particularly in people with dark skin. However, it is difficult for the doctor to match perfectly the color of the skin of the surrounding area.

The tattooed area will not change in color when exposed to sun, although the surrounding normal skin will. So even if the tattooed area matches the surrounding skin perfectly at first, it may not later on. Tattooing tends to fade over time. In addition, tattooing of the lips may lead to episodes of blister outbreaks caused by the herpes simplex virus.

- **Autologous melanocyte transplants** – In this procedure, the doctor takes a sample of your normal pigmented skin and places it in a laboratory dish containing a special cell-culture solution to grow melanocytes. When the melanocytes in the culture solution have multiplied, the doctor transplants them to your depigmented skin patches. This procedure is currently experimental and is impractical for the routine care of people with vitiligo. It is also very expensive, and its side effects are not known.

Additional Therapies

In addition to medical and surgical therapies, there are many things you can do on your own to protect your skin, minimize the appearance of white patches, and cope with the emotional aspects of vitiligo:

- **Sunscreens** – People who have vitiligo, particularly those with fair skin, should minimize sun exposure and use a sunscreen that provides protection from both UVA and ultraviolet B light. Tanning makes the contrast between normal and depigmented skin more noticeable. Sunscreen helps protect the skin from sunburn and long-term damage.
- **Cosmetics** – Some patients with vitiligo cover depigmented patches with stains, makeup, or self-tanning lotions. These cosmetic products can be particularly effective for people whose vitiligo is limited to exposed areas of the body. Dermablend, Lydia O’Leary, Clinique, Fashion Flair, Vitadye, and Chromelin offer makeup or dyes that you may find helpful for covering up depigmented patches. Self-tanning lotions have an advantage over makeup in that the color will last for several days and will not come off with washing.
- **Counseling and support groups** – Many people with vitiligo find it helpful to get counseling from a mental health professional. People often find they can talk to

their counselor about issues that are difficult to discuss with anyone else. A mental health counselor can also offer support and help in coping with vitiligo. In addition, it may be helpful to attend a vitiligo support group.

What Research Is Being Done on Vitiligo?

In the past two decades, research on the role that melanocytes play in vitiligo has greatly increased. A variety of technical advances, such as gene mapping and cloning, have permitted relatively rapid advances in knowledge of melanocytes at the cellular and molecular levels.

Much of the research that holds promise for understanding, treating, and possibly preventing vitiligo is supported by NIAMS. Current NIAMS-supported research includes the following:

- examination of the mechanism by which trauma or stress to the skin can trigger vitiligo or the development of new lesions
- development of a mouse model of vitiligo that not only would help scientists better understand the disease but also would allow them to test treatments for it
- identification of genes that play a role in and predispose people to vitiligo.

At the University of Colorado, NIAMS supports a large collaborative project involving families with vitiligo in the United States and the United Kingdom. Researchers have found evidence of a link between vitiligo and variants of a gene called FOXD3. It is hoped that further genetic analyses of these and other families will enable them to identify one or more additional vitiligo susceptibility genes. This work may lead to development of specific approaches to disease therapy and prevention for patients at high genetic risk.

Where Can People Find More Information About Vitiligo?

- **National Institute of Arthritis and Musculoskeletal and Skin Diseases**

National Institutes of Health

1 AMS Circle

Bethesda, MD 20892–3675

Phone: 301–495–4484 or

877–22–NIAMS (226–4267) (free of charge)

TTY: 301–565–2966

Fax: 301–718–6366

E-mail: NIAMSinfo@mail.nih.gov

www.niams.nih.gov

NIAMS provides information about various forms of arthritis and other rheumatic diseases as well as other bone, muscle, joint, and skin diseases. It distributes patient and professional education materials and refers people to other sources of information. Additional

information and updates can also be found on the NIAMS Web site.

- **American Academy of Dermatology**

P.O. Box 4014

Schaumburg, IL 60618-4014

Phone: 847-330-0230 or

888-462-3376 (free of charge)

Fax: 847-240-1859

E-mail: PIC@aad.org

www.aad.org

The academy is the national organization for dermatology. It is dedicated to achieving the highest quality of dermatologic care for everyone. The academy produces patient information on vitiligo. It can also provide referrals to dermatologists.

- **American Vitiligo Research Foundation**

P.O. Box 7540

Clearwater, FL 33758

Phone: 727-461-3899

Fax: 727-461-4796

E-mail: vitiligo@avrf.org

www.avrf.org

The foundation strives to raise awareness, educate, and help patients live with a greater understanding and acceptance of vitiligo.

- **National Vitiligo Foundation, Inc.**

76 Garden Road

Columbus, OH 43214

Phone: 614–261–8145

Fax: 614–261–8245

E-mail: info@nvfi.org

www.nvfi.org

The foundation strives to locate, inform, and counsel vitiligo patients and their families; to increase public awareness and concern for the vitiligo patient; to broaden the concern for the patient within the medical community; and to encourage, promote, and fund increased scientific and clinical research on the cause, treatment, and ultimate cure.

- **Vitiligo Support International**

P.O. Box 4008

Valley Village, CA 91617–0008

Phone: 818–752–9002

www.vitiligosupport.org

This organization, with more than 30,000 active members, promotes awareness and education about vitiligo, provides information and interaction to people living with vitiligo, and works to encourage and support medical research to find better treatments and a cure for vitiligo.

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