Frequently Asked Questions About Lupus

The answers to these FAQs are not intended to replace specific medical advice of your health care team. It is the LFA’s mission to educate the public about lupus, providing medically accurate and consistent information from leading experts. The FAQs should not be used to provide medical advice, nor should the LFA or chapters provide any medical advice.
# Table of Contents

Using Frequently Asked Questions About Lupus............................2

Understanding Lupus

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding Lupus</td>
<td>3</td>
</tr>
<tr>
<td>Drug-induced Lupus</td>
<td>21</td>
</tr>
</tbody>
</table>

Diagnosing Lupus

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosing Lupus</td>
<td>23</td>
</tr>
</tbody>
</table>

Treating Lupus

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medications and Lupus</td>
<td>29</td>
</tr>
<tr>
<td>Clinical Trials</td>
<td>33</td>
</tr>
</tbody>
</table>

Living with Lupus

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with Lupus</td>
<td>36</td>
</tr>
<tr>
<td>Sex, Reproduction, and Pregnancy Issues in Women with Lupus</td>
<td>46</td>
</tr>
</tbody>
</table>

Coping with Lupus

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial Assistance and Disability</td>
<td>52</td>
</tr>
<tr>
<td>Tissue and Body Donations for Lupus Research</td>
<td>54</td>
</tr>
</tbody>
</table>

Lupus and the Body

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lupus and the Cardiopulmonary System</td>
<td>57</td>
</tr>
<tr>
<td>Lupus and the Gastrointestinal (GI) System</td>
<td>58</td>
</tr>
<tr>
<td>Lupus and the Nervous System</td>
<td>61</td>
</tr>
<tr>
<td>Lupus and the Kidney (Renal) System</td>
<td>62</td>
</tr>
<tr>
<td>Lupus and the Skin</td>
<td>65</td>
</tr>
</tbody>
</table>

Special Populations

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>For Parents of Children Living with Lupus</td>
<td>74</td>
</tr>
</tbody>
</table>
Using *Frequently Asked Questions About Lupus*

The LFA is the trusted source for medically accurate information on lupus. As the number of public inquiries to the LFA National Office and chapters has increased, so have the number and type of questions asked. As a result, LFA Health Educators have compiled responses to frequently asked questions creating a “ready reference” to assist chapters when responding to similar inquiries. The content of *Frequently Asked Questions About Lupus* is based on expert advice from physicians who serve on the LFA Medical Scientific Advisory Council. These FAQs are available on the MyLFA section of the website.

The answers to these FAQs are not intended to replace specific medical advice of your health care team. It is the LFA’s mission to educate the public about lupus, providing medically accurate and consistent information from leading experts. The FAQs should not be used to provide medical advice, nor should the LFA or chapters provide any medical advice.

The FAQs are part of the LFA’s Information and Referral Guide as an appendix to the *LFA Guide to Telephone Inquiries*, but may be used independently. These FAQs can be used as a reference when responding to inquiries by mail, email or over the telephone. FAQs vary in detail and not all topics are covered. It is okay not to know the answer to a question and please use your own comfort level when responding to an inquiry. You may want to consult your local Medical-Scientific Advisory Council when unsure about how to respond to a question or refer the individual to an LFA Health Educator. If the inquiry is personal in nature, you will need to refer the inquirer to his/her physician.

*Frequently Asked Questions About Lupus* will be updated periodically on the MyLFA section of the LFA website.
Understanding Lupus

What is lupus?

Lupus is a chronic, autoimmune disease that can cause inflammation and damage in any part of the body (skin, joints, and/or organs inside the body). Chronic means that the signs and symptoms tend to last longer than six weeks and often for many years.

Normally our immune system produces proteins called antibodies that protect the body from foreign invaders like viruses, bacteria, and germs. Autoimmune means your immune system cannot tell the difference between these foreign invaders and your body’s healthy tissues (“auto” means “self”) and creates autoantibodies (meaning, “against self antibodies”) that attack and destroy healthy tissue. These autoantibodies cause inflammation, pain, and damage in various parts of the body.

Lupus is also a disease of flares (the symptoms worsen and you feel ill) and remissions (the symptoms improve and you feel better). Lupus can range from mild to life-threatening and should always be treated by a doctor. With good medical care, most people with lupus can lead a full life.

What is inflammation?

Literally, inflammation means “setting on fire.” It is a protective process the body uses. When tissues are injured by a foreign invader, such as a virus or bacteria, inflammation is a signal to the immune system to eliminate these foreign invaders in order to prevent further damage. Inflammation can occur inside the body, in cells and tissues, or outside the body, in the skin. Signs of inflammation are swelling, redness, pain, and warmth. If inflammation is long-lasting, as it can be in lupus, then the damage can impair cellular and organ function in those areas. Inflammation is the hallmark of active lupus. This is why the treatment of lupus is aimed at reducing the inflammation by suppressing the immune system and also by limiting any known causes of the inflammation.

What exactly happens in autoimmune diseases like lupus?

The immune system is designed to protect and defend the body from antigens—foreign intruders, such as bacteria and viruses. To do this, it produces many different types of cells. Some of these cells are like “security guards” and are constantly on the lookout for any foreign invaders. When they spot an antigen, they take action to disable and eliminate the intruder. In lupus, for unknown reasons, the immune system loses its ability to tell the difference between
a foreign antigen and a person's own normal tissues and cells, and the “security guards” take action. Part of the immune system response is to bring antibodies to the site that attach to these invaders. In lupus, because the antigen is not really foreign, these antibodies are called “autoantibodies” (“auto” means “against self”). The autoantibodies then form immune complexes, which help to set in motion a series of events that result in inflammation at the site. These immune complexes may travel through the circulatory system (blood) and lodge in distant tissues and cause inflammation there.

**Is lupus contagious?**

Lupus is not contagious, not even through sexual contact. You cannot “catch” lupus from someone or “give” lupus to someone.

**Is lupus like cancer?**

Lupus is not like or related to cancer. Cancer is a condition of malignant, abnormal tissues that grow rapidly and spread into surrounding tissues. Lupus is an autoimmune disease, as described in the response to the above question “what is lupus?”

**Is lupus like HIV/AIDS?**

Lupus is not like or related to HIV (Human Immune Deficiency Virus) or AIDS (Acquired Immune Deficiency Syndrome). In HIV or AIDS, the immune system is underactive; in lupus, the immune system is overactive.

**Where did the name “lupus” come from?**

Lupus is the Latin word for “wolf”. The term has been associated with the disease since the 10th century, though the reasons are unclear. Erythematous means redness. It is speculated that the name was given to describe the skin lesions (sores), which typically are red and perhaps at that time in history were thought to resemble the bite of a wolf. Today we know that not everyone with lupus has rashes or skin lesions, and those who do would not say their rashes look anything like a wolf bite.

**Who can develop lupus?**

Lupus can occur at any age, including in children and teens, and in females and males. Nine out of ten people with lupus are women, and the disease most often develops during childbearing years (ages 15-44). People of all races can have lupus; however, women of color have two - three times higher incidence (approximately 1 in 250) of lupus. Women of color tend to
- Have more severe disease overall
- Develop lupus earlier in life.
- Experience greater disease activity at the time of diagnosis (including kidney problems).
- Have a higher frequency of neurological problems such as seizures, hemorrhage (internal bleeding) and stroke.

Although lupus is not common in men, African American men in particular tend to experience severe lupus disease activity. Lupus is also more common in women of Hispanic, Asian, and Native American descent.

**What are the risks for developing lupus?**

**Sex**

More than 90 percent of people with lupus are women.

**Age**

Symptoms and diagnosis occur most often when women are in their childbearing years, between the ages of 15 and 44. Symptoms of lupus will occur before age 18 in 15 percent of the people who are later diagnosed with the disease.

**Race**

In the United States, lupus is more common in people of color—African Americans, Hispanics/Latinos, Asian Americans, Native Americans, Native Hawaiians and Pacific Islanders—than in the Caucasian population. It also appears that lupus develops at an earlier age and is more severe among members of these ethnic groups.

**Family History**

Relatives of people with lupus have an approximately 5-13 percent chance of developing lupus. However, only about 5 percent of children will develop lupus if their mother has lupus.

**Are there different forms of lupus?**

- **Systemic lupus erythematosus** (SLE)
- **Cutaneous lupus erythematosus**, which is limited to the skin. The most common subtypes of cutaneous lupus include:
  - Discoid lupus erythematosus
  - Subacute cutaneous lupus
Acute cutaneous lupus (butterfly rash)

- **Drug-induced lupus erythematosus**, which is relatively rare, may be triggered by such drugs as hydralazine and procainamide
- **Neonatal lupus erythematosus**, which occurs in infants of women with specific blood test abnormalities

**What is systemic lupus erythematosus?**

*Systemic lupus erythematosus* (SLE) refers to lupus that affects internal tissues and organs and the skin on the outside of the body. Systemic lupus is the most common form of lupus, and is what most people mean when they refer to “lupus.” Systemic lupus can be mild or severe. Some of the more serious complications involving major organ systems are:

- Inflammation of the kidneys (lupus nephritis), which can affect the body’s ability to filter waste from the blood and can be so damaging that dialysis or kidney transplant may be needed
- An increase in blood pressure in the lungs (pulmonary hypertension)
- Inflammation in the heart muscle (myocarditis), which can lead to congestive heart failure
- Inflammation of the nervous system and brain, which can cause memory problems, confusion, headaches, and strokes
- Inflammation in the brain’s blood vessels, which can cause high fevers, seizures, behavioral changes, and psychosis
- Hardening of the arteries (coronary artery disease), which is a buildup of deposits on coronary artery walls that can lead to a heart attack

**What is cutaneous lupus erythematosus?**

*Cutaneous* refers to the skin, and this form of lupus is limited to the skin. The most common subtypes of cutaneous lupus are:

- Chronic (or discoid) cutaneous lupus erythematosus
- Subacute cutaneous lupus erythematosus
- Acute cutaneous lupus erythematosus

Although there are many types of rashes and lesions (sores) caused by cutaneous lupus, the most common rash is raised, scaly and red, but not itchy. It is commonly known as a discoid rash, because the areas of the rash are shaped like disks, or circles. Another common example of cutaneous lupus is a rash over the cheeks and across the bridge of the nose, known as the “butterfly rash.” Other rashes or sores may appear on the face, neck, or scalp (areas of the skin
that are exposed to sunlight or fluorescent light), or in the mouth, nose, or vagina. Hair loss and changes in the pigment, or color, of the skin are also symptoms of cutaneous lupus.

Approximately 10 percent of people who have cutaneous lupus will develop systemic lupus. However, it is likely that these people already had systemic lupus, with the skin rash as their main symptom.

**What is drug-induced lupus erythematosus?**

*Drug-induced lupus* is a lupus-like disease caused by certain prescription drugs. The symptoms of drug-induced lupus are similar to those of systemic lupus, but only rarely will any major organs be affected. The drugs most commonly connected with drug-induced lupus are hydralazine (used to treat high blood pressure or hypertension), procainamide (used to treat irregular heart rhythms), and isoniazid (used to treat tuberculosis). Drug-induced lupus is more common in men because they are given these drugs more often; however, not everyone who takes these drugs will develop drug-induced lupus. The lupus-like symptoms usually disappear within six months after these medications are stopped.

**What is neonatal lupus?**

Neonatal lupus is a rare condition that affects infants of women who have lupus and is caused by antibodies from the mother acting upon the infant in the womb. At birth, the infant may have a skin rash, liver problems, or low blood cell counts, but these symptoms disappear completely after several months with no lasting effects. Some infants with neonatal lupus can also have a serious heart defect. With proper testing, physicians can now identify most at-risk mothers, and the infant can be treated at or before birth. Most infants of mothers with lupus are entirely healthy.

**Is lupus a fatal disease?**

Lupus is not a universally fatal disease. Today, with close follow-up and treatment, 80 to 90 percent of the people with lupus can expect to live a normal lifespan. Lupus does vary in intensity and degree. Some people have mild to moderate symptoms, which they manage with medications and lifestyle changes. Others will have more severe disease activity, which tends to be more difficult to treat and manage. Because lupus is a disease that can be active (flare) or inactive (remission), there is a greater chance that lupus may be life-threatening for people who have a severe flare.

People frequently read in the literature that 80-90 percent of people with lupus live for more than 10 years. Unfortunately, this is often misinterpreted as meaning that people with lupus live for only 10 years. We would like to clarify this.
It is important to understand that this statement was taken from a research study of people with lupus. The “10 years” in this statement does not represent the number of years the study participants survived following their lupus diagnosis, but rather the number of years that the researchers followed the participants after they were diagnosed. At the end of the 10-year study period, the researchers were able to conclude that 80-90 percent of the participants were still alive. What this study did not look at is what happened in years 11, 12, 15, 20, and so on. There are many people alive today who have been living with lupus for 15, 19, 25, 30, 40 years, or more. This is not a disease that is universally fatal to all. Some people do die from complications of this disease, but the majority of people with lupus today can expect to live a normal lifespan.

**When people die of lupus, what do they usually die of?**

Heart disease and other cardiovascular complications, overwhelming infection, and kidney failure are the most common causes of death in people with lupus.

**Are people with lupus more likely to develop cancer?**

According to Dr. David Isenberg and Dr. Susan Manzi: “The links between lupus and cancer are being re-assessed. A group of researchers recently reviewed 10,000 patients under long term follow-up with lupus looking in great detail for cases of cancer and comparing the rates of the various types of cancer in patients with lupus and matched healthy controls. While, overall, there was very little difference in the cancer risk between those with lupus and the matched healthy controls, there was a small increase in a cancer called non-Hodgkin’s lymphoma and, to a lesser extent, with lung cancer. Intriguingly, the patients who developed non-Hodgkin’s lymphoma tended to do so within the first year or two of their lupus diagnosis. The study did not find a major increase in those with lupus who had been treated with immunosuppressive drugs for a number of years (a concern that had been expressed by some prior to this study), although even longer term studies will be needed to confirm these data.”

**Are there any special considerations regarding treatment of cancer in people with lupus?**

Cancer can be treated with surgery, radiation and/or chemotherapy. Radiation and chemotherapy usually don’t cause any particular problems for people with lupus; in fact, chemotherapy is sometimes used to reduce lupus disease activity. People with lupus who have surgery for cancer should be followed closely by their oncologist and their rheumatologist to monitor lupus activity. Anyone taking corticosteroids, such as prednisone, should talk to their doctors about adjusting the steroid dosage shortly before surgery, because steroids suppress the immune system and may allow infection to take place or impair healing of the wound. The
dose may then be increased slowly over time after surgery. Anyone taking non-steroidal anti-inflammatory drugs (NSAIDs) or aspirin should talk to their doctors about stopping these medications prior to surgery, as these drugs can thin the blood and lead to excess bleeding.

Is lupus hereditary?

No gene or group of genes has been proven to cause lupus. Lupus is a “multigenic” disease, which means a number of genetic changes are necessary for someone to develop lupus. This is in contrast to sickle cell anemia or cystic fibrosis, which are caused by an abnormality in a single gene. So, lupus is hereditary in the sense that it runs in families but the risk of developing lupus, even with a family member having the disease, is small. Researchers have discovered that when one of two identical twins has lupus, there is an increased chance that the other twin will also develop the disease. These findings, as well as others, strongly suggest that genes are involved in the development of lupus. (Genetics alone are not enough; environmental triggers and hormonal factors also play a role.) Certain ethnic groups (people of African, Asian, Hispanic/Latino, Native American, Native Hawaiian, or Pacific Island descent) have a greater risk of developing lupus, which may be related to genes they have in common. Even with a family member with lupus, however, the chances of developing lupus are less than 5 percent.

We say that a person has a “genetic predisposition” to developing the disease. This means that someone who has a first-degree relative (sibling, parent, aunt, uncle, or grandparent) with lupus is more likely to develop lupus than someone who does not have a family member with lupus. When lupus develops in people with no family history of lupus, there are likely to be other autoimmune diseases in some family members. Still, the majority of the time, lupus develops sporadically, meaning that no known relative has the disease.

Routine laboratory screening of family members is not currently recommended. If there are symptoms of joint pain or swelling, unexplained rashes, chest pain, or hair loss, then they should see let their doctor and be sure to mention that a family member has lupus or any other autoimmune disease.

My wife’s mother has lupus. Are there any specific health tests that my wife should have done? Is it possible to prevent lupus in my wife or in our children?

Currently, no screening or genetic tests are available. If symptoms develop, such as joint swelling and pain, unexplained rashes, chest pain, or hair loss, we encourage family members to see their regular doctor and to be sure to mention the family history of lupus or any other autoimmune disease. Several surveys have estimated the risk of a mother with lupus having a daughter develop lupus is 10 percent and 2 percent for her son. These numbers are thought to
be somewhat lower when the father is the individual with lupus. There is no known way to prevent the development of lupus.

**Can I have my children tested for lupus?**

Testing is not currently recommended in individuals who do not have symptoms of possible lupus.

**What are some of the environmental triggers that can set off lupus or bring on a flare?**

- ultraviolet rays from the sun
- ultraviolet rays from fluorescent light bulbs
- sulfa drugs, which make a person more sensitive to the sun, such as:
  - *Bactrim*® and *Septra*® (*trimethoprim-sulfamethoxazole*)
  - sulfoxazole (*Gantrisin*®)
  - tolbutamide (*Orinase*®)
  - sulfasalazine (*Azulfidine*®)
  - diuretics
- sun-sensitizing tetracycline drugs such as minocycline (*Minocin*®)
- penicillin or other antibiotic drugs such as:
  - amoxicillin (*Amoxil*®)
  - ampicillin (*Ampicillin Sodium ADD-Vantage*®)
  - cloxacillin (*Cloxapen*®)
- an infection
- a cold or a viral illness
- exhaustion
- an injury
- emotional stress, such as a divorce, illness, death in the family, or other life complications
- anything that causes stress to the body, such as surgery, physical harm, pregnancy, or giving birth

**Can hormones trigger the development of lupus?**

Hormones are the body’s messengers and they regulate many of the body’s functions. In particular, the sex hormone estrogen plays a role in lupus. Men and women both produce
estrogen, but estrogen production is much greater in females. Many women have more lupus symptoms before menstrual periods and/or during pregnancy, when estrogen production is high. This may indicate that estrogen somehow regulates the severity of lupus. However, it does not mean that estrogen, or any other hormone for that matter, causes lupus.

**Are flares related to hormones?**

We do not know for sure. There are many anecdotal reports (personal accounts) of lupus flaring with pregnancy, the menstrual cycle, birth control pills, and hormone replacement therapy. We suspect that hormones play a role, but we don't know precisely what the role is. Lupus has a 9 to 1 female to male ratio, so it is likely that hormones play a role, perhaps by influencing the immune system. Also, we know that female hormones have a definite effect on mice with lupus that are used in research.

**Is lupus stress related?**

There are many anecdotal reports (personal accounts) of symptoms of lupus occurring or flaring during or after a stressful time. Any type of stress is considered a trigger for lupus. Definitive answers will require further scientific study, however.

**Are there any medications people with lupus should avoid?**

People with lupus should be especially careful if they are prescribed sulfa antibiotics. These medications (Bactrim®, Gantrisin®, Septra®) are often prescribed for urinary tract infections and may cause an increase in sun sensitivity and occasionally lower blood counts, which could cause a lupus flare. Sulfa diuretics (water pills) such as Dyazide®, and diabetic drugs containing sulfa, such as Aldactone®, could cause lupus to flare.

Your doctor also should watch for allergic reactions to prescribed medications, and any connection between disease flares and the use of any hormone supplements or oral contraceptives.

**Does lupus occur more often in certain geographical areas?**

There are on-going research studies looking at suspected “clusters” of lupus, possibly related to toxicities in the soil, water, or air, but no clear evidence has emerged that suggests lupus is more prevalent in specific areas.
Is lupus related to pollution or toxic chemicals?

We do not know. The causes of lupus, and many other autoimmune diseases, remain unknown. Likewise, the roles of environmental factors in triggering lupus remain to be determined. The National Institutes of Health (NIH), the principal research arm of the United States Government, established the National Institute of Environmental Health Sciences (NIEHS) to study issues related to environmental health. At an NIEHS meeting in 1998, researchers looked at autoimmunity and the environment, and specifically lupus. A review of the discussion was published in the medical journal, *Arthritis & Rheumatism* (1998 Oct; 41(10): 1714-24) in an article titled “Hormonal, Environmental, and Infectious Risk Factors for Developing Systemic Lupus Erythematosus” by Cooper GS, Dooley MA, Treadwell EL, St Clair EW, Parks CG, Gilkeson GS.

Is there a connection between multiple sclerosis and lupus?

Multiple sclerosis and lupus are both autoimmune diseases. They are diagnosed and treated in very different ways. There is no direct connection between the two; however, the symptoms of lupus can sometimes mimic or imitate the symptoms of multiple sclerosis.

Can something in your diet cause lupus?

We do not believe so. There are only a few food items that we recommend you avoid in large quantities (in particular alfalfa sprouts), and a few others that we encourage you to include in your diet (in particular omega-3 fatty acids, found in fatty fish and in fish oil supplements). Diet, nutrition, and lupus are areas that still need scientific study. We do know that certain herbs and dietary supplements can create problems when combined with certain prescribed medications, so consult your physician before adding these to your diet.

Is there any connection between silicone breast implants and lupus?

There has been a great deal of interest in this issue and to date, there have been numerous well-controlled research studies since 1992 that have looked at this question. However, none has shown a clear association between silicone breast implants and the development of lupus. At the present time, as far as we know, there is no scientific evidence to indicate a cause-effect relationship between silicone breast implants and lupus.
If I have my implants removed, will my lupus symptoms improve, will the lupus go away?

We don't know. There have been reports of women who had silicone breast implants removed and their symptoms improved. On the other hand, there have been cases where symptoms have not improved after removal. However, it is unlikely that removing implants will cause lupus to go away.

To receive the most recent information on breast implants contact:

The Food and Drug Administration (FDA)
Breast Implant Information Line
1-800-532-4440 or visit their web site at: www.fda.gov/cdrh/breastimplants

I have heard that dental fillings may trigger lupus. Is there anything to this?

At the present time, we do not have any scientific data that indicates that dental fillings may act as a trigger of lupus.

Is there a cure for lupus?

At the present time there is not a cure for lupus, but there are effective treatments. However, many people with lupus can have a full and rewarding life with the help of doctors, a good support system, and lifestyle changes.

Can the antiphospholipid syndrome (APS) seen in lupus go into remission?

The antiphospholipid syndrome is a blood-clotting disorder. Also known as Hughes Syndrome, the antiphospholipid antibody syndrome involves many different antibodies that are associated with clots in both arteries and veins. The signs and symptoms depend on where clots form or travel. A clot (embolus) that forms or travels can cause: deep vein thrombosis (DVT) in the leg, pulmonary embolism in the lung, miscarriages or stillbirths and other complications of pregnancy, such as premature delivery and high blood pressure during pregnancy (preeclampsia), and stroke.

It appears that APS can go into remission, but there is no specific test to determine that it has actually truly remitted at any given time. There are three primary classes of antibodies
associated with APS: anticardiolipin antibodies, the lupus anticoagulant, and antibodies directed against specific molecules, including a molecule known as beta-2-glycoprotein 1.

Once a person is diagnosed with APS, treatment is anticoagulation medication that thins the blood to help prevent clots. This is considered a preventive treatment that is required indefinitely. Unfortunately, long-term use of blood-thinners causes significant side effects, and there is no way to know, in individual cases, if this ongoing treatment is really necessary. Still, as it stands today, the risks of not using anticoagulation therapy outweigh the risks of using it.

Numerous laboratories around the world are working on this area of research, and we hope that tests to assess a person’s actual ongoing risk for blood clotting will be improved in the near future. We can also be cautiously optimistic that, in time, safer therapies will be developed.

Are people with lupus more prone to infections even if they are not taking immunosuppressive drugs?

There is some evidence that people with lupus are more likely to get infections than completely healthy people, even when they are not taking corticosteroids, such as prednisone. The most common infections are in the respiratory tract (colds, sore throats, sinusitis, bronchitis, and pneumonia), the urinary tract (bladder or kidney infections), and the skin (boils, cellulites, and infected cuts).

There are excellent strategies to the risk for infection:

- Keep your vaccinations up to date, including Pneumovax® to prevent pneumococcal pneumonia.
- Get a flu shot every year.
- Most women can tell accurately that a bladder infection is present, and you should inform your doctor immediately when symptoms begin.
- If you are taking high doses of immunosuppressive drugs and/or prednisone, ask your doctor about taking medications to prevent pneumocystis pneumonia.
- If you have frequent urinary tract infections, there are antibiotics taken once at bedtime and agents that change the acid in the urine that are effective at reducing urinary tract infection rates.
- If you suffer from outbreaks of herpes virus lesions/ulcers in your mouth, on your lips, or in genital areas, discuss preventive anti-viral treatment with your doctor.
- If you have been exposed to tuberculosis, have a PPD skin test (tuberculin) and consider taking six months of anti-tuberculosis antibiotics if the test is strongly positive.
• Finally, if it is possible to avoid people with bad colds or other communicable infections, you should do so. Of course, you cannot protect yourself from participating in life, so use your common sense.

**Can a person with lupus donate blood?**

You should always discuss the issue of donating blood with your doctor. You should not donate blood if you are too anemic (a low red blood cell count).

The only components in the blood that might be problematic are plasma and antibodies. Red blood cells or platelets should be safe to donate as long as you have sufficient amounts, and these are the parts of the blood most often needed by blood banks.

However, each blood donation service will have its own set of guidelines for eligibility, so be sure to know the guidelines of the donation service you intend to use. For example, a diagnosis of lupus used to be a disqualifier for the donation of blood at the American Red Cross, but now people with lupus may donate blood even while taking such medications as Plaquenil® or corticosteroids. However, the National Institutes of Health (NIH) will not accept blood donations from those with lupus. The reasoning is that, without a full understanding of the causes of lupus and the role of antibodies in the disease, the NIH cannot be sure that there is absolutely no risk of transmission of harmful elements to those receiving the blood.

**Can the lights used to treat seasonal affective disorder (SAD) trigger lupus flares?**

Two-thirds of people with lupus have increased sensitivity to ultraviolet (UV) rays, from sunlight and/or from artificial inside lights, such as fluorescent lights. Light therapy has not been approved as a seasonal affective disorder treatment by the Food and Drug Administration because of mixed evidence about its effectiveness. Furthermore, not all light therapy boxes filter out harmful ultraviolet (UV) light. UV light can cause eye and skin damage. There is a potential risk of a lupus flare when using light therapy. However, if you don’t experience photosensitivity, and your SAD symptoms are severe and no other therapies are working, it may be a consideration. Be sure to talk with your rheumatologist before beginning any therapy involving UV light.
I'm concerned about the government encouraging people to change all incandescent light bulbs to fluorescent bulbs. Don't fluorescent lights produce ultraviolet rays that are harmful for people with lupus?

The issue of lupus photosensitivity is a complex one and one of the least scientifically studied clinical aspects of cutaneous and systemic lupus. It is the opinion of some experts that if a standard fluorescent tube is covered by an acrylic plastic shield, or diffuser, there is virtually no significant risk for people with lupus. These plastic diffusers are available from a variety of companies. However, if a person with lupus is exposed to unshielded fluorescent lighting at close distances for prolonged periods of time, the cumulative exposure to UVB and UVA could be a problem.

In 1997, I was diagnosed with lupus. In the beginning my doctor sometimes said "lupus" and sometimes "connective tissue disease." Why?

Lupus is one of the several diseases that have been considered to be connective tissue diseases. This is an old-fashioned term, but it is still used in confusing cases when the diagnosis is uncertain. This frequently happens to people early in diagnosing lupus. When a definitive diagnosis of lupus cannot be made, the doctor may use the term “mixed connective tissue disease” or “undifferentiated connective tissue disease.”

How does diabetes affect my lupus and vice versa?

Diabetes and lupus are both diseases that can increase the risk for kidney damage, high blood pressure, and heart disease. Successfully managing your symptoms of lupus and keeping your blood glucose (sugar) level under control are the two most important steps to living well with these diseases. Modifying all other risk factors for heart disease, avoiding medications that are toxic to the kidneys, and being sure your blood pressure is normal are also recommended.

Is there a connection between chronic fatigue syndrome and lupus fatigue?

It is generally believed that chronic fatigue syndrome (CFS) and lupus fatigue are two distinct entities. In 1994, an international panel of CFS research experts convened to draft a definition of CFS that would be useful both to researchers studying the illness and to clinicians diagnosing it. Chronic fatigue syndrome is defined as (1) having severe chronic fatigue of six months or longer with other known medical conditions excluded by clinical diagnosis; and (2) concurrently having four or more of the following symptoms: substantial impairment in short-term memory
or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without swelling or redness; headaches of a new type, pattern or severity; un-refreshing sleep; and pain in muscle after exercising that last more than 24 hours. Lupus fatigue does not have a formal definition. Note that CFS appears in the absence of other medical conditions. Therefore, fatigue can be seen in lupus, but by definition is not related to CFS.

Can lupus cause thyroid problems? If so, what effect does removal of the thyroid have on the body?

Autoimmune thyroid problems are relatively common in people with lupus, but lupus is probably not causing the thyroid disorders. Certain genes contributing to lupus also predispose a person to thyroid problems. Also, a protein called interferon-alpha is seen in increased amounts in the blood of people with lupus, and contributes to both lupus and autoimmune thyroid disease. It may be that specific genes, together with interferon-alpha, contribute to the development of both lupus and thyroid diseases independently, rather than lupus causing the thyroid problem. Removing the thyroid will cause the usual problems associated with low thyroid hormone, but it has not been reported to affect lupus.

Can you tell me the risk a woman with lupus has when having sex with a man with genital and/or oral herpes simplex?

Lupus itself and the immunosuppressive medicines used to treat lupus increase the chance of infections, including viral infections such as herpes. Evidence suggests that people with lupus have a particular problem with herpetic viral infections. Several environmental factors, including sunlight and stress, can also set off a herpetic viral reactivation. We do not have an actual risk percentage, however.

Can lupus affect your vision?

According to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), changes in vision can be due to lupus or caused by the corticosteroids and antimalarials used to treat lupus. Complications can include inflammation of the eye, glaucoma, cataracts, general changes in vision, and blocked tear ducts. On very rare occasions, blindness can result. Warning signs include:

- development of a rash over the eyelids
- mucus discharge from the eye
- blurred vision
- sensitivity to light
- headaches
• a sore, red eye
• lack of tears, and eyes that hurt and are dry
• episodes of flashing lights and partial blindness

**Is it safe for a person with lupus to get a tattoo?**

There are no specific problems that have been associated with tattoos in those with lupus. If the person is taking immunosuppressive medications, there is an increased chance of infection and slower healing of the tattoo area. Also, there is a small risk of infection with hepatitis B and C, and people with lupus occasionally will have a reaction to the tattoo dye. As with other invasive procedures, any sort of skin treatment is best done when lupus is in remission or in a well-controlled mild disease state. It is recommended that anyone considering a tattoo consult with their doctor first.

**I just returned from a dental exam. I had six cavities, which is unusual for me. Could my dental situation and my lupus be connected?**

It is possible that these are related. An estimated 10 to 20 percent of adults with lupus also have Sjögren’s syndrome, a condition in which the immune system attacks moisture-producing glands. Because the saliva in our mouths helps neutralize acid made by certain bacteria, the risk of tooth decay dramatically increases when saliva is reduced. Also, decay-causing bacteria grow at a much higher rate in a dry mouth.

Decay can almost always be conquered with a combination of these efforts: daily fluoride applications, dietary changes, prescription mouthwash, use of gums or mints containing significant amounts of xylitol, and of course, daily use of a toothbrush and dental floss. Xylitol, which occurs naturally in certain fruits and vegetables, is gaining increasing acceptance as an alternative sweetener because of its role in reducing the development of cavities.

Dry mouth also can be caused by the medications you may be taking for lupus. You can check the labeling that comes with your medications, or ask your doctor or pharmacist for more information.

**Does lupus always eventually go into remission?**

The simple answer is no. The more complex answer is that, for the majority of people, the disease is characterized by periods of active disease (flares) and periods of inactive disease, or “quiescence,” when symptoms are relatively quiet. Quiescence is usually achieved with medication.
Remission may be harder to define. One definition is that there are no symptoms, the individual is taking no medication, and all tests results are in normal ranges. In a study published 20 years ago, fewer than 6 percent of people with lupus ever achieved that goal.

Therefore, it would be preferable to say that lupus may often become quiescent, but some medication may be required to keep it that way.

**What happens if a person decides not to treat lupus?**

Because lupus is such a heterogeneous disease (meaning different for each person), it is difficult to predict or generalize about what would happen if it were left untreated. The management and treatment of lupus should be guided by the degree and severity of clinical symptoms.

Up to 50 percent of people with lupus have non-life-threatening symptoms, such as fatigue, joint pain, and rash. Non-steroidal anti-inflammatory drugs (NSAIDs such as ibuprofen or naproxyn) and antimalarials (Plaquenil®) are frequently used for relief of these symptoms. Many rheumatologists prescribe antimalarials even in the setting of mild disease because there is good evidence that the drug may decrease the frequency and severity of flares, and also can help with joint pain and fatigue.

Because there is a risk of disease flare when a person with lupus has organ involvement (for example, in the kidneys, lungs, heart, or nervous system), it is important to have regular medical evaluations to look for any signs that inflammation may be developing.

It is especially important for those with organ involvement to receive regular treatment, such as steroids and other immunosuppressive medications that suppress the overactive immune system and reduce the inflammation.

**To access further information on this topic, please explore the following URLs:**

- LFA Web Site: Understanding Lupus
- LFA Web Site: Lupus and the Skin
- LFA Web Site: Treating Lupus
- LFA Web Site: Living with Lupus (Sensitivity to Light)
- LFA Web Site: How Lupus Affects the Body (Eyes)
- LFA Web Site: Living With Lupus (Diet and Nutrition)
- LFA Web Site: Oral Disease
LFA Web Site: Living with Lupus (Infections)
LFA Web Chat: Lupus and the Environment
LFA Web Chat: Skin Disease in Lupus
LFA Web Chat: UV Light and Lupus
Safety of Silicon Breast Implants

Choosing a Light Therapy Box: Treating Seasonal Affective Disorders
Drug-induced Lupus

What is the difference between drug-induced lupus and systemic lupus?

Drug-induced lupus is caused by certain prescription drugs. The symptoms of drug-induced lupus are similar to those of systemic lupus, but only rarely will any major organs be affected. The lupus-like symptoms usually disappear within six months after these medications are stopped. Drug-induced lupus is more common in men because they are more likely to take the drugs that most often cause drug-induced lupus; however, not everyone who takes these drugs will develop drug-induced lupus. Although some people will continue to have a positive test for antinuclear antibodies (ANA) for years after symptoms of drug-induced lupus have ended, this does not mean they have a form of lupus.

What drugs are most commonly associated with drug-induced lupus?

The drugs most commonly connected with drug-induced lupus are hydralazine (used to treat high blood pressure or hypertension), procainamide (used to treat irregular heart rhythms), and isoniazid (used to treat tuberculosis).

Are there other drugs that might cause drug-induced lupus?

The majority of drug-induced lupus cases are due to one of the three drugs mentioned above. There are at least 70 other drugs that have been implicated in causing drug-induced lupus but there is not yet definite proof of an association between these drugs and drug-induced lupus. Check with your doctor or pharmacist to find out if you are taking a drug that might be causing lupus-like symptoms.

Should people diagnosed with systemic lupus or cutaneous lupus avoid taking the drugs associated with drug-induced lupus?

Most of the drugs associated with drug-induced lupus can be safely used in people with systemic or cutaneous lupus if there are no suitable alternatives. Again, it is always best to check with your doctor or pharmacist.
How soon after taking the drug do the symptoms appear?

Generally, drug-induced lupus requires months to years of frequent use of a drug before symptoms appear. Usually symptoms disappear after six months after stopping the drug, but it could be days or weeks. The test for ANA may remain positive for years.

Is it possible that drug-induced lupus can last for years or never go away after stopping the medicine?

It would be very rare to have drug-induced lupus symptoms that last for a long time after the drug was stopped. This may happen occasionally with sulfa drugs. In these cases, it is likely that the person was already predisposed to developing lupus and the sulfa drug triggered the onset of the disease. This would not be considered drug-induced lupus. Many people with lupus have lupus flares that have been triggered by sulfa drugs.

To access further information on this topic, please explore the following URL:

LFA Website: Drug-Induced Lupus
Diagnosing Lupus

Is there a test for lupus?

There is no single diagnostic test for lupus. A variety of laboratory tests are used to detect physical changes or conditions in your body that can occur with lupus. Each test result adds more information to the picture your doctor is forming of your illness.

Why is lupus so difficult to diagnose?

It is difficult for a number of reasons:

- Lupus is a multisystem disease, and before a multisystem disease can be diagnosed, there have to be symptoms in many parts of the body and lab work that supports the presence of a multisystem disease.
- Lupus is also difficult to diagnose because it is a disease that does not typically develop rapidly, but rather develops slowly and evolves over time. Symptoms come and go and generally it takes time to gradually accumulate enough symptoms to indicate that a multisystem disease is present.
- Lupus is known as a “The Great Imitator” because it mimics so many other diseases and conditions.
- Lupus is difficult to diagnose because there is no single diagnostic test for lupus. In fact, many people may have positive lupus tests—particularly the antinuclear antibody (ANA) test—and yet NOT have the disease.

How is lupus diagnosed?

A doctor who is considering the possibility of lupus will look for signs of inflammation. The signs of inflammation are pain, heat, redness, swelling, and loss of function at a particular place in the body. Inflammation can occur on the inside of your body (your kidneys or heart, for example), on the outside (your skin), or both.

However, there are many challenges in confirming that a person has lupus and not some other disease. Lupus is known as “the great imitator,” because its symptoms mimic many other illnesses. Also, lupus symptoms can be unclear, can come and go, and can change. Therefore, a lupus diagnosis is made by a careful review of:

- your current symptoms
- your laboratory test results
● your medical history
● the medical history of your close family members such as grandparents, parents, brothers and sisters, aunts, uncles, and cousins.

All of this information may be necessary for a doctor to make a diagnosis of lupus because, for a number of reasons, laboratory tests alone cannot give a definite “yes” or “no” answer.

● No single laboratory test can determine whether a person has lupus.
● Test results that suggest lupus can be due to other illnesses, or can even be seen in healthy people.
● A test result may be positive one time and negative another time.
● Different laboratories may produce different test results.

I am afraid I might have lupus and my doctor is going to miss something and end up diagnosing me with lupus too late. If I have it, I want to be diagnosed as early as possible. How can I make sure I am diagnosed earlier rather than later?

Because lupus tends to develop slowly and evolve gradually over time, awaiting a diagnosis can be like waiting for a Polaroid picture to develop. If you are seen by a doctor at a point in time when only one or two criteria are satisfied, it is like looking at a picture that is only one-quarter or half-way developed. No one looking at that picture can accurately identify what it is nor can they predict if it will develop at all, what it will develop into, or how long it will be before it is developed to the point where it’s identifiable. Just as there is no good way to speed-up the development of a Polaroid, there is no way to hurry-up the diagnosis of lupus.

The length of time it takes before lupus can be diagnosed is highly variable; it may take weeks, months or years; three years is not an uncommon length of time for many people to have symptoms before being diagnosed. In some cases, it can take as long as 10 years before enough evidence has accumulated to indicate that it is lupus. However, the doctor usually has a pretty good idea, though s/he may not be certain, if a person does or does not have lupus.

Please remember that nothing is set in stone. If you continue to have worrisome symptoms, seek further medical evaluation so that a determination can be made as to what may be causing your health issues. The important thing is to learn the signs and symptoms of lupus and if you develop something new, let your doctor know so s/he can determine if you have yet satisfied enough criteria to be diagnosed.
My doctor suspects I have lupus, but hasn't diagnosed me with it yet. I have a lot of joint pain in my hands and knees. Can anything be prescribed to give me some relief, or do I have to wait until I have a definite diagnosis before they can treat me?

Sometimes, a trial of medications used to treat lupus may be helpful, so discuss this with your doctor.

My doctor said my lupus test came back "borderline positive." What does this mean?

The screening test for lupus is called the ANA (antinuclear antibody). All lab tests have normal values. If a test result comes back and the value is at the upper limit of normal, this is often referred to as being on the border or borderline. These results are often very difficult to interpret; and the assessment of its importance is dependent on meeting other criterion. It is likely that a borderline positive ANA assumes more importance if other criteria are also present.

How can an ANA come back positive one time and negative the next? The doctor said I do not have lupus because of this.

In general the diagnosis of lupus is based on a combination of physical symptoms and laboratory results. It is usually a diagnosis that evolves over time either towards more certainty or to the conclusion that the person does not have lupus. People can have brief periods of autoimmunity problems with an elevated ANA result. It may be reasonable to conclude that the person is unlikely to have lupus if it goes away and does not come back for awhile. Some things to know about diagnosing lupus:

- First and foremost, lupus cannot be diagnosed solely based on lab work.
- Secondly, positive lab tests for lupus can come and go over time and that is quite common. When they come and go, it is less likely that the person will end up with a diagnosis of lupus although that is still possible.
- Thirdly, it is very common to get somewhat different results at different labs. However, if a person has lupus, it is likely that the ANA test will be positive at most laboratories most of the time and that other autoantibodies will be present as well. 97% of those with lupus have a positive ANA test.

Antibodies to double-stranded DNA (anti-dsDNA) are antibodies that attack the DNA—the genetic material—inside the cell nucleus. Anti-dsDNA antibodies are found in half of the people with lupus and antibodies to the Sm antigen are found in about 30 – 40 percent of people with
lupus, but lupus can still be present even if these antibodies are not detected. Erythrocyte sedimentation rate (ESR or “sed” rate) is another test for inflammation. It measures the amount of a protein that makes the red blood cells clump together. The sed rate is usually high in people with active lupus, but it can also be high due to other reasons, such as an infection.

I was told my Antinuclear Antibody (ANA) was positive, but I don't have lupus. My doctor thinks I have a connective tissue disease. What does this mean?

Connective tissue refers to the joints, tendons, cartilage, collagen, muscles and skin. There are a number of connective tissue diseases: rheumatoid arthritis, scleroderma, Sjögren's syndrome, Raynaud's phenomenon, vasculitis, polymyositis, dermatomyositis, and lupus.

It is not uncommon for a person to have test results and symptoms that indicate inflammation of the connective tissues, but not enough criteria to clearly specify a particular disease. Sometimes doctors will instead say that a person has mixed connective tissue disease or undifferentiated connective tissue disease. In some people, disease signs and symptoms will change over time to indicate a certain disease, but other people may never receive a more specific diagnosis.

Most people who have a positive ANA do not have lupus. However, most people with lupus will have a positive ANA.

I was told my Antinuclear Antibody (ANA) was negative, and I don't have lupus. Is it possible to have lupus with a negative ANA?

It is rare to have lupus and have a negative ANA test; however, it is possible. The ANA is negative in about 3 percent of people with lupus. This is called ANA-negative lupus. These people often will have other antibodies, though, that are seen with lupus, such as the anticardiolipin, antiphospholipid, anti-Sm, anti-DNA, anti-Ro (SSA) or anti-La (SSB).

The ANA test result sometimes will change from positive to negative if the person is taking certain medications, like steroids or cytotoxic drugs, or if their body is experiencing kidney failure (uremia).

What kind of doctor can diagnose lupus?

If many signs and symptoms are present, a diagnosis of lupus may be made by a family practitioner, an internist, dermatologist, or, for children, a pediatrician. If, as is often the case, symptoms develop gradually over time, the diagnosis may not be as obvious. To be sure of a
complete and accurate diagnosis of lupus, you should see a board certified rheumatologist or immunologist. If the symptoms are on the skin—such as the scalp, sun-exposed area of the body, or in the mouth or nose—a dermatologist should be seen.

**My doctor suspects that I may be developing lupus, but I don’t have enough symptoms to be diagnosed. Is there anything I can do to slow its development or prevent it from occurring?**

If you are indeed developing lupus, there is no known way of arresting it. You can, however, be an active participant in your well-being by:

- learning as much as you can about lupus so if you develop further symptoms, you will recognize them and notify your doctor
- eating a well balanced diet
- managing stress more effectively, and
- following your doctor’s advice

**I was told my Antinuclear Antibody (ANA) was positive and I have a lot of pain, but my doctor thinks I have fibromyalgia and not lupus. What does this mean?**

People who have a positive ANA test and also have muscle and joint pain do not necessarily have lupus. Fibromyalgia, which is also common in women, sometimes explains the widespread pain. Besides pain in 18 sites or “tender points” around the neck, shoulder, chest, hip, knee and elbow regions, fibromyalgia can cause twitching and burning in the muscles, aching joints, weakness, non-restful sleep, and extreme fatigue. Approximately 20 percent of people with lupus will also have fibromyalgia.

For more information, contact:
Fibromyalgia Network
P.O. Box 31750
Tucson, AZ 85751-1750
1-800-853-2929 or (520) 290-5508
www.fmnetnews.com

**Where is the BEST place to go for diagnosis and treatment of lupus?**

Treatment centers specializing in lupus are located in various parts of the United States. Some of these have been designated as Centers of Excellence by the National Institutes of Health. The Lupus Foundation of America does not provide ratings of hospitals, medical centers, or doctors.
Doctors who are affiliated with a medical school or university hospital often are involved in lupus research and will be up-to-date on the latest advances in diagnosis and treatment of lupus.

To access further information on this topic, please explore the following URLs:

LFA Web Site: Diagnosing Lupus
LFA Web Site: Understanding Lupus
Fibromyalgia Network
Medications and Lupus

Are there medications that can have harmful affects on lupus and cause the disease to get worse?

There are very few medications that are absolutely contraindicated (considered unsafe) for people with lupus. We do know that people with lupus should avoid sulfa drugs, and that penicillin should be used with caution. Still, even some medications known to cause drug-induced lupus have been successfully used for treating symptoms of lupus. The best thing you can do is to learn about potential side effects of each medication that is prescribed for you. You also will want to consider your own personal medical history as you make decisions about medications. Your reaction to each new medication will be trial and error to some extent. It is important to have a good relationship with your medical team, so that full knowledge about you, as an individual, is factored into your treatment plan.

If I have lupus, do I need to avoid all sulfa drugs?

Although there is a high incidence of skin rash and other side effects, including lupus flares, among people with lupus who have taken sulfa-containing antibiotics (called sulfonamides), not everyone with lupus needs to avoid the sulfa medications. If you have tolerated sulfa drugs in the past, you are probably okay. If you have never tried one, it may not be worth the risk, given so many other antibiotic choices. Not all sulfa-containing drugs are implicated in causing side effects in lupus, but it is impossible to predict which medicines will cause allergic reactions or other side effects in an individual person.

If I have lupus, is it true that I should avoid medications that control blood pressure?

No. In fact, using medication to treat high blood pressure can be very important for people with lupus. Uncontrolled high blood pressure can lead to heart attacks and strokes, both of which already occur more frequently in people with lupus than in the general population. Also, high blood pressure can increase the risk of kidney failure in people with lupus nephritis (kidney involvement). There are effective medications that lower blood pressure and do not have adverse effects on lupus activity or immune function.
If I have lupus, is it safe for me to take beta blockers?

Beta blockers are on the list of medications that might induce drug-induced lupus (usually in elderly people). However, this does not mean that beta blockers are not safe for most people with lupus. Keep in mind that there are the risks and benefits when taking any medication. If you have other medical problems, such as autoimmune conditions that often co-exist with lupus, you and your doctor should always discuss new medications before adding them to your treatment plan.

Does long-term use of prednisone cause diabetes?

Long-term prednisone use can cause type 2 diabetes in a person with lupus who is predisposed to develop diabetes due to a variety of other factors. The body naturally makes a “stress hormone” called cortisol which is produced when the body is being stressed by some sort of challenge, such as a fight, or an accident, or a fear. The rise in blood glucose levels in the body is a natural byproduct of preparation for this stress, and the glucose levels build up in the tissues of the muscles, brain, and heart (for example). Thus, an increase in the stress hormone, or adding high doses to the body by taking prednisone, can result in an increase of the body's stores of glucose. This condition is known as “steroid-induced diabetes.” The higher the dose of prednisone over time, the greater the likelihood that the blood glucose level will climb. Being obese and having a family genetic history of diabetes also give a person with lupus a greater chance of developing steroid-induced diabetes.

Should I avoid drinking alcohol if I am taking Plaquenil®?

There is no known interaction between alcohol and Plaquenil®, and Plaquenil® is not known to be toxic to the liver. There is no specific contraindication to having an occasional drink.

What can you tell me about the use of Rituxan© as a treatment for lupus?

Rituxan© (the brand name for rituximab) was initially developed by Genentech as a treatment for non-Hodgkin’s lymphoma and later approved for the treatment of rheumatoid arthritis. This drug works by reducing the number of B cells. The body’s immune system makes B cells to help fight against bacteria and viruses. Increased numbers of B cells or abnormal B cell activity appear to be a factor in lupus and other autoimmune diseases. Rituxan© is currently in clinical trials to see if it could be useful for people with lupus.
What side effects can I expect from taking steroids?

Prednisone® is an anti-inflammatory medication that works quickly and effectively to suppress many symptoms of lupus. However, it has a long list of side effects that include weight gain (especially in the cheeks and over the back of the neck), acne, thin skin and easy bruising, hair thinning on the scalp, new facial hair (on the chin or above the lips), mood swings, agitation, sleeplessness, and difficulty concentrating. Your doctor may also discover that your prednisone has caused higher blood pressure, higher blood glucose levels, and higher cholesterol. Over time, the side effects of higher doses of the medication can be significant, such as weakened bones, damage to the blood supply to joints (especially in the hips) and steroid-induced diabetes.

I know that Plaquenil® helps with lupus inflammation and fatigue, but does it lower the Westergren Sed rate?

Antimalarials such as Plaquenil® (hydroxychloroquine) are effective in treating skin and joint symptoms that may occur in lupus. Plaquenil® has two known mechanisms of action that are relevant to lupus: it inhibits, or blocks, blood fragments called platelets and may help to protect against excessive blood clotting and it inhibits proteins called toll-like receptors, which may be involved in the overreactive immune response that occurs with lupus. The Westergren Erythrocyte Sedimentation Rate (ESR or SED rate) is a measure of how quickly red blood cells (erythrocytes) fall in a test tube and may indirectly indicate the presence of inflammatory proteins in the blood. However, because the ESR can be elevated from many causes, including some not related to lupus, it is not considered a particularly useful blood test or treatment target for lupus.

What is IVIG and is it helpful for people who have weak immune systems with lupus?

It is normal for the immune system to make antibodies against infections and another name for these antibodies is immune globulin. IVIG stands for intravenous immune globulin, meaning a big dose of antibodies are given in the vein as an infusion. There are several roles that these antibodies can play. First, they can protect against infections. Sometimes, people with lupus are on immune-suppressing treatments and could use some help to protect against infection. Also, people with lupus sometimes have too much of some kinds of antibodies, called auto-antibodies. This interferes with the healthy regulation of the immune system and can lead to inflammation. It seems that IVIG can actually provide some “regulating” antibodies and calm down an immune system that is causing too much inflammation under certain situations. IVIG is often used for certain types of lupus manifestations, especially when there is no response to initial treatments. IVIG might also be used where there are concerns about the need for more
immune suppression in a person who has had a great deal of immune suppression already. IVIG is generally not given as a routine, continuing treatment in lupus though it does happen in other disorders. Although this treatment can be very effective, there are issues with shortages of IVIG and expense.

To access further information on this topic, please explore the following URLs:

LFA Web Site: Treating Lupus

LFA Web Chat: What Is New for Lupus Research and Treatment

LFA Web Chat: Medication Management and Lupus
Clinical Trials

Is any research being done on lupus?

Yes, there is a good deal of interest in lupus today. Research scientists all over the world are trying to discover information on every aspect of this complex and “prototypical” autoimmune disease. Research can be divided into two types: basic and clinical. Basic lupus research is when scientists attempt to develop or refine theories of how the body works and how the immune system functions. It is conducted in the laboratory and generally does not involve studies of the human body. Instead, studies are conducted using animal models (in particular, mice that have been genetically engineered to develop lupus) so that research can be investigated more easily.

Clinical research involves the study of people and how the body behaves or reacts to outside influences or to mechanisms of disease. Clinical research includes applying or testing theories and evaluating their usefulness in solving clinical problems.

Each year the American College of Rheumatology publishes a listing of summaries, termed “abstracts,” of research projects. Hundreds of these abstracts involve some aspect of lupus. The majority of these will be basic research studies.

Where is lupus being researched?

Lupus research is conducted by both public and private organizations, companies, universities and colleges, as well as the federal government. This includes the National Institutes of Health (NIH), the Department of Veterans Affairs (VA), Centers for Disease Control and Prevention (CDC), the Food & Drug Administration (FDA), and the Military. The lead NIH institute for research on lupus is the National Institute for Arthritis, Musculoskeletal and Skin Diseases. This is commonly referred to as NIAMS, and it is here where much of the federally funded research related to lupus originates.

Lupus Family Registry and Repository

In early 1996, the NIAMS established the Lupus Family Registry and Repository to study people with lupus and their families in order to identify genes that determine susceptibility to the disease. The high prevalence of lupus among relatives of lupus patients suggests a genetic component for the disease. However, genetic studies of lupus to date have been incomplete. The Lupus Family Registry and Repository is located at the Oklahoma Medical Research Foundation in Oklahoma City, OK.
Dr. John Harley directs this extensive project. He and his associates collect and update clinical, demographic and laboratory data on all patients with lupus and their families for the Lupus Registry. Blood, cells, and DNA from these individuals are stored in the Lupus Repository for genetic testing.

They are seeking lupus patients who have two or more family members who have been diagnosed with the disease. Families who qualify for the study receive a blood sample collection kit, a consent form and a questionnaire. A blood sample is collected and completed materials are sent to Dr. Harley and his associates for evaluation. Patients or physicians interested in participating should contact:

Recruiter
lupus-recruiter@lupus.omrf.org
Lupus Genetic Studies
Oklahoma Medical Research Foundation
825 NE 13th Street, MS #5
Oklahoma City, OK 73104
1-888-655-8787 (1-888-OK-LUPUS)
or (405) 271-7479
http://lupus.omrf.org/

**Does the Lupus Foundation of America (LFA) conduct research?**

The LFA provides funding to support research. A primary focus of the LFA is to encourage research related to the causes, treatments, prevention, and cure of lupus. The LFA research program is supported exclusively through donations from the LFA’s nationwide network of chapters and support groups, private foundations or corporations, and the concerned public. It is the LFA’s hope that its investment in research will produce new information which may directly lead to much larger projects and substantially increased funding from other sources, particularly federal funding.

**How do I find out more about the LFA's National Research Grant Program?**

The LFA Research Program is constantly evolving and growing. The LFA Medical-Scientific Advisory Council annually establishes priorities and programmatic goals for lupus research. The LFA then distributes requests for proposals (RFPs) through its Web site and newsletters to teaching centers, hospitals, educational institutions, and individual researchers across the country.
Researchers interested in the LFA National Research Program should contact the LFA National Office and ask to be placed on the RFP mailing list. Information and applications may be downloaded from the ‘Research’ section of the LFA Web site at [www.lupus.org](http://www.lupus.org).

To access further information on this topic, please explore the following URLs:

- LFA Center for Clinical Trials Education
- LFA Web Chat: What Is New for Lupus Research and Treatment
- LFA Web Chat: Clinical Trials and Lupus
Living with Lupus

I was diagnosed with lupus. Are there any do's or don'ts with regards to living with lupus?

The more you understand about how lupus can affect your body, the better you will be at understanding how you can make lifestyle changes to stay as healthy as possible. Successfully managing lupus starts with awareness:

- awareness of your particular symptoms and how your illness affects you
- awareness of what you can do to prevent flares, and what to do if you do experience a flare
- awareness of any changes in symptoms or physical conditions that could suggest disease activity
- awareness of the tension and stress that often accompany chronic illness
- awareness of the best coping strategies and techniques to reduce that stress

Will eating nightshade vegetables increase my lupus flares or joint pain? It seems that every place I read about this has a different opinion about this.

The nightshade vegetables include potatoes (not sweet potatoes, or yams), tomatoes, peppers (both sweet and hot varieties), tomatillos and tamarillos, and eggplants. While there is anecdotal evidence that some of these foods can be related to inflammation, there is no solid scientific evidence to support this claim. It is not uncommon to have or develop an allergic reaction to a certain food or food group, whether or not you have lupus.

The best way to determine if something you consume is affecting you, or contributing to a disease flare, is to keep track of what you eat for a period of time, and to look for a pattern between what you consume and any active lupus symptoms. You would want to observe a link between a particular item and a flare on multiple occasions—not just once or twice. If there does seem to be a connection, then try avoiding that particular food for a period of time and keep track of whether symptoms cease.

Keep in mind that completely removing a food group from your diet might create a nutrient deficiency. Many people with lupus find that a registered dietician or nutritionist can help them create an individualized dietary plan.
How can I tell if my lupus is active?

When a lupus flare occurs, many people will notice a return of the symptoms they experienced previously. Active disease is caused by inflammation in an organ or organ system. Common symptoms that indicate a flare are:

- fever
- swollen joints
- increase in fatigue
- rashes
- sores or ulcers in the mouth or nose
- temperature over 100 degrees F, not due to an infection

When should I call the doctor?

It is very important to inform your doctor of any new symptoms you experience, as these could be related to a flare, a medication side effect, or a new complication.

You should call the doctor about any changes in or worsening of symptoms as soon as possible. For example, if the doctor has put you on a new medication and you’ve been taking it as prescribed, and your symptoms are not better or they are worse, you need to let the doctor know. You should also be aware that there are certain symptoms that may require that you see your doctor immediately. These symptoms or signs include the following:

- vomiting
- blood in your stool
- severe abdominal pain
- chest pain
- seizures
- new onset of a fever or if your fever is much higher than usual
- excess bruising or bleeding anywhere on your body
- confusion or mood changes
- a combination of symptoms such as severe headache with neck stiffness and fever

Remember: It is always better to be overcautious with a disease like lupus!

How long will a flare last? How long will a remission last?

It is frequently said that the only thing predictable about lupus is its unpredictability. At this time there is no way of predicting how long a flare may last or long a remission will last.
I've had lupus for 2 years and haven't had a remission yet. Is this possible?

Yes. Lupus affects each person differently—even twins or siblings who are in similar environments and have similar genes may find their disease courses to be different. In some people, lupus will flare, become inactive (quiescent), and go into remission—this course of the disease may or may not occur regularly throughout their life. In other people, lupus will remain in a chronic (long-lasting) state of flare and their symptoms will persist every day. Still others may have a flare once every few years, or every 10 years, and be in a quiescent state the rest of the time.

The first five years after being diagnosed with lupus often seem to be the most uncertain for both you and your doctor. During this time, your doctor is trying to find the best course of treatment for your particular symptoms, while at the same time looking out for flares or new problems. Your involvement in your care can make a huge difference! If you take your medication exactly as prescribed, avoid known lupus triggers (especially excess sun exposure, stress, and overwork), describe all new symptoms to your doctor promptly, eat a balanced diet, and get plenty of rest and exercise, you may feel better overall and the disease activity may stabilize as well.

Will I become crippled and end up in a wheelchair?

Lupus is a disease of inflammation that often begins by involving the musculoskeletal system, but most people do not become incapacitated due to lupus. Although the term “lupus arthritis” is sometimes used, this is not the same as rheumatoid arthritis, which typically causes joint deformities. In the context of lupus a better term would be inflammatory arthritis. This type of arthritis is present in 69 to 95 percent of those with lupus. Still, while the arthritis is less inflammatory than is seen with rheumatoid arthritis, deforming arthritis can occur in some people.

However, there are two important complications that affect the bones that you need to know about as you live your life with lupus: osteoporosis and avascular necrosis. Both are related to the use of corticosteroid medication, a very common treatment for lupus.

Osteoporosis is a disease in which bones become fragile and are more likely to break. The areas most often affected are the spine, hip, and wrist. Lupus itself is a risk factor for osteoporosis.

Other risk factors are:

- not enough calcium and Vitamin D in your diet, which can prevent bone from growing normally
- not enough bone-building exercise, which also can prevent bone from growing normally
• being female, with smaller, less dense bones than males
• having a small-boned and thin body type, whether you are a female or a male
• being of Caucasian or Asian heritage
• being a smoker

If you have two or more of these risk factors, talk to your doctor about having your bone mineral density tested. In many cases, osteoporosis can be prevented if proper measures are taken when warning signs first appear.

Avascular necrosis (AVN), also called aseptic necrosis or osteonecrosis, is characterized by reduced blood flow and increased pressure within a portion of the bone. Weakening of the bone occurs, causing tiny breaks, and eventually the bone surface collapses. The hips, shoulders, and knees are most commonly affected by AVN, and the initial symptom is pain in these joints, especially when you are engaged in weight-bearing activities such as walking, running, and lifting objects. When AVN develops in people with lupus, it is almost always a result of corticosteroid use. In many cases, total hip or knee replacement surgery will be necessary to repair the damage.

Is there anything I can do to alleviate the pain when medication doesn’t seem to work and I can’t get in to see the doctor for a few days?

Dealing with pain is probably the most common challenge for people with lupus. And, despite the fact that many pain relief medications exist, it can be very useful to know non-pharmacologic approaches to pain relief.

• heat and/or cold applications
• acupuncture
• acupressure
• biofeedback
• chiropractic adjustments
• progressive relaxation
• meditation
• self-hypnosis
• guided imagery
• focused breathing
• low-impact yoga
• Tai Chi


- regular exercise
- staying busy with work or volunteer activities
- including play time in your day

Before you begin complementary or alternative treatments for pain or other symptoms, we recommend that you first discuss the options with your doctor. This is especially important if you plan on adding any herbal or nutrition supplements to your diet, as these may interact with your prescribed medications.

It also is possible that persistent pain has other causes. Chronic and often severe muscle pain is the main symptom of fibromyalgia (FM), a condition that affects about 30 percent of people with lupus. Although fibromyalgia is still not well understood, its diagnosis is based on widespread and often extreme pain and sensitivity at 18 “tender points.” These points occur on both sides of the body at the same time, in the areas of the neck, shoulders, chest, hips, knees, and elbows. If you believe that your pain is occurring particularly in these areas, talk to your doctor about FM.

Is acupuncture helpful to people with lupus?

Because most alternative and complementary practices have not been through the scientific testing and clinical research that conventional medicines undergo, it can be difficult to know their effectiveness in treating lupus. The use of acupuncture for various conditions, including pain relief, has been studied by the National Center for Complementary and Alternative Medicine (NCCAM). There are promising findings in some conditions, such as chronic low-back pain and osteoarthritis of the knee; for most other conditions, however, additional research is needed. According to NCCAM researchers, acupuncture is generally considered safe when performed correctly. We recommend that you first talk to you doctor about the appropriateness of trying acupuncture for your pain, and then get recommendations for a qualified acupuncture practitioner, ideally someone who has worked with people with lupus.

Are there any restrictions on physical activity for people with lupus? Are there any exercises that have been particularly beneficial, or especially harmful?

Exercise is encouraged in people with lupus, as a regular daily routine or combination of workout options to enhance overall health, improve mood, lessen symptoms of fatigue, and promote restful night-time sleep.

The ideal aerobic activities are those that do not strain the joints or muscles, but still increase heart rate and flexibility, such as brisk walking, swimming, bicycling, and low impact movement
exercises like yoga, Pilates, and Tai Chi. Weight-bearing and resistance exercises are very important as well, especially to promote strong bones. Keep in mind that exercise should be in moderation and never to the point of exhaustion.

A DVD called *The Right Moves for Lupus: A Gentle Fitness Program* is available through the LFA’s online store [http://shop.lupus.org](http://shop.lupus.org) at a cost of $14.95 (plus S&H). It offers a low-impact exercise program with two workout levels that was designed specifically for people with lupus and is led by a licensed American Council on Exercise (A.C.E.) instructor who also has lupus.

**I have heard that hair dyes may trigger flares in lupus. Does this mean I should stop dying my hair?**

Although a study conducted some years ago did indicate an association between the use of hair dye and lupus symptoms, subsequent studies found no association. The initial study findings are of uncertain significance, and no recent evidence has been reported. Today most doctors do not feel that hair dye is risky for people with lupus.

Nevertheless, any time you introduce a new product into or onto your body, there is a chance of an allergic reaction which could potentially trigger symptoms of lupus. As when trying to determine a food allergy, the best way to find out if a product is bothering your body is to test the product on a small area of your skin, as most hair dye packages explain.

**What can I do about the weight gain brought on by Prednisone®?**

Increased appetite is a well-known side effect of corticosteroid therapy. Often, just being aware that this may occur is the first step towards managing the potential weight gain. If you have been prescribed steroids, or if you have to increase your dosage, you may want to consider planning out your meals with healthy choices, and making sure that you stick to it. During those times between meals when you're really hungry, these choices may help:

- A large glass of low sodium vegetable juice cocktail.
- Air popped or low fat microwave popcorn.
- Raw vegetables dipped in fat-free sour cream or yogurt.
- A walk (take along water so you stay hydrated).
- A cup of decaffeinated flavored coffee with low fat milk or cream.

Taking steroids can also increase water weight gain. You can help to cut down the amount of fluid retention by reducing your sodium and salt intake. Here are some suggestions:

- Avoid processed or convenience food whenever possible (such as canned soup).
- If you do eat processed or convenience foods, check the labels and make sure that no item contains more than 200 mg of sodium per serving.
If you eat frozen meals, choose those with no more than 700 mg of sodium total.

Avoid processed meats such as luncheon meats, sausages or bacon, as well as cheese—all of these are high in sodium.

If you have a choice among fresh, frozen, or canned vegetables, choose fresh or frozen, which are lower in sodium.

You may also benefit from local support groups and commercial weight loss programs can assist in weight control efforts. And remember, a regular exercise routine can help you with weight control.

Can you give me nutrition advice or advice on vitamins and foods that are good for lupus?

At this time, there is no specific “lupus diet,” and most people with lupus do not require special diets. However, if you have kidney involvement, your doctor may recommend that you reduce your sodium intake in order to minimize water retention. Sometimes a diet that is low in protein also will be recommended.

It is of course important to maintain a nutritionally sound and well-balanced diet that includes all of the necessary vitamins, minerals, fats, and protein, and carbohydrates that your body needs to function at its optimum level. Therefore, if your regular food choices include fresh fruits and vegetables, fiber-rich cereals and grains, lean cuts of meat, and adequate healthy fats (for example, from fish oil, avocado, and olives), then you may have what you need to be healthy.

Dietary supplements are not scientifically tested for safety, efficacy, or even ingredients—even products labeled as “natural” can have harmful effects on anyone taking prescribed medications. Also, there is little scientific evidence to prove that taking in extra amounts of micronutrients through supplementation can help improve lupus. Always talk to your doctor before you add anything new to your diet.

Is there anything I can add to my diet that could lower the inflammation that lupus causes?

There has been considerable interest in the influence of dietary factors on many different autoimmune diseases, including lupus. Much of this interest has focused on omega-3 fatty acids because of their potential to lessen inflammation. Fish, flaxseed and canola oils, and green, leafy vegetables are sources of omega-3 fatty acids. (Animal fats are a source of omega-6 fatty acids.) The amount of omega-6 and omega-3 fatty acids in the diet affects the types of prostaglandins and other compounds the body produces that influence the inflammatory
response. In particular, the omega-3 fatty acids have been found to increase production of more anti-inflammatory compounds.

In one large study of dietary factors in relation to lupus disease activity (conducted in Japan), there was no association found between participants’ intake of total fat, type of fat, or omega-3 fatty acids and lupus disease activity over a four-year period. However, higher intakes of antioxidants (for example, vitamins C and E) were associated with decreased disease activity.

Thus, although currently available studies suggest that diets high in antioxidants—and possibly omega-3 fatty acids—may help lupus symptoms, this is still a largely unanswered question. In general, the role of antioxidants in lupus disease activity is a relatively under-studied area of research.

It is important to discuss any major change in your diet, especially changes that include use of dietary supplements, with your doctor. There may be potential interactions with prescribed medications or with other aspects of your care that are important for your doctor to evaluate.

Is dehydration, either mild or moderate, a greater potential problem for those with lupus than for the general population? And can being dehydrated cause lupus to flare?

People with lupus can be more susceptible to the damaging effects of dehydration for the following reasons:

- Dehydration can worsen kidney function, a problem in particular for those with any kidney disease or involvement.
- Some people with lupus have autonomic nerve involvement resulting in hypotension, meaning that their blood pressure drops when they simply stand up, and dehydration could definitely lead to complications.
- Being dehydrated may increase fatigue, already a serious challenge for many people with lupus.
- Being dehydrated may have a negative impact on the body’s ability to clear medication from the system.
- In addition, prolonged dehydration can lead to an increased heart rate and could perhaps stress the body in a way that could increase the chances for, or the effects of a flare.
Is there any truth to the claims being circulated on the Internet that lupus is caused by the artificial sweetener, aspartame?

For many years—even before there was an Internet—there have been claims of a causal link between the artificial sweetener aspartame and lupus. According to Evelyn V. Hess, M.D., M.A.C.P., M.A.C.R., one of the world’s leading researchers in the area of lupus and environmental influences, there is no specific proof of aspartame being a cause or having a worsening effect on lupus. It is helpful to remember that anyone can post anything on the Internet. The preferred online sources for information should always be websites run by trusted organizations, such as the National Institutes of Health, the LFA, the Mayo Clinic, Johns Hopkins University, Medscape, and Medline Plus.

Is the use of tanning beds okay for people with lupus?

In general, those with lupus should not use tanning beds. The bulbs in tanning beds produce ultraviolet light rays. It is the ultraviolet light rays that cause the skin to tan. The majority of people with lupus tend to be unusually sensitive to ultraviolet light. That is to say, exposure to excessive ultraviolet light, especially the UVB sun burning rays, can cause lupus skin lesions to appear, or make existing lupus skin lesions worse. Ultraviolet light can also activate the internal, or systemic, manifestations of lupus in some people.

There have been many examples of lupus skin disease patients who were thought to have psoriasis instead, and were then treated for psoriasis in medical phototherapy cabinets that are similar to tanning beds. A number of these people almost died from severe activation of their systemic lupus following such mistaken treatment.

Some research suggests that very long ultraviolet light wavelengths, in what is called the "UVA-1" range, can improve certain forms of lupus skin disease and mild forms of systemic lupus. This research has been somewhat controversial, because other research has found that higher doses of the same UVA-1 wavelengths are capable of aggravating the systemic manifestations of lupus. Therefore, the biological effects that people with lupus might experience (i.e. getting worse or better) are likely to be critically dependent upon the amount of the different wavelengths of ultraviolet light energy that their skin receives.

In a routine commercial tanning bed setting, it would be quite difficult for people with lupus to know how much of the various UV wavelengths they are receiving. Thus, for people with lupus, visiting a tanning salon may be too risky.

To access further information on this topic, please explore the following URLs:

LFA Web Site: Living with Lupus
LFA Web Site: Coping with Lupus

LFA Web Site: How Lupus Affects the Body: The Musculoskeletal System

LFA Web Site: Living with Lupus (Diet)

LFA Web Chat: Diet/Nutrition and People with Lupus

LFA Web Chat: New Year's Resolutions & Lupus: What Are the Best Ways to Stay Healthy & Exercise

LFA Web Chat: Eating Health, Weight Management and Lupus

LFA Web Site: Living with Lupus (Exercise and Movement)

The Right Moves for Lupus

LFA Web Site: Living with Lupus (Pain)

NCCAM

LFA Web Site: Treating Lupus (Complementary and Alternative Medicines and Therapies)

Fall 2009 Lupus Now article: Moving Past the Pain
Sex, Reproduction, and Pregnancy Issues in Women with Lupus

Will I be able to have children if I have lupus?

Although both men and women with lupus are normally fertile, it is possible that a woman may not conceive if there is inflammation anywhere in her body. Therefore, it is best to try to conceive when lupus is not active.

Problems with fertility can arise in several areas. One of these is related to the medications being taken (discussed in the following question). Other factors include ovarian or testicular problems that can occur independent of lupus or medications. For example, polycystic ovarian syndrome, endometriosis, late onset of menses, or problems with the veins of the spermatic cord all can affect fertility. While it has been reported that fertility is not decreased in women with lupus, there are data showing a later start of menstrual periods, fewer pregnancies, and earlier menopause—all occurring before diagnosis or treatment of lupus.

Will I live long enough to see my children grow up?

Lupus does vary in intensity and degree, but with close follow-up and treatment, 80-90 percent of people with lupus today can expect to live a normal lifespan.

Which medications for lupus most affect fertility?

Cytoxan® (cyclophosphamide) is the most commonly prescribed lupus medication known to affect fertility in both women and men. The risks of infertility when taking cyclophosphamide depend on several factors.

- What is the person’s age? According to the only clinical trial to evaluate the effects of cyclophosphamide on fertility in women, virtually all women in the study lost their menstrual periods after age 30 when taking the cyclophosphamide regimen defined by the National Institutes of Health. In the single published article that studied cyclophosphamide treatment and fertility in men, the risk of infertility also was shown to rise at age 24.
- What is the dose of cyclophosphamide being taken? Studies done using Lupron® (leuprolide), which decreases the production of testosterone in men and estrogen in
women, have shown that menstrual periods can be preserved, even in women over age 30. Estrogen-containing birth control pills also have been used to stop ovarian function, but should not be taken by women with hypertension and/or antiphospholipid antibodies, or when lupus disease is active.

I am trying to find out the effects of the immunosuppressive drug Imuran® on fertility and I can't find a definitive answer. Most Internet sites discuss the drug’s effect on male fertility and during pregnancy, but not how Imuran affects female fertility.

There currently are no research results that can definitively answer the question about Imuran (azathioprine) and fertility. Many women with lupus do get pregnant after taking azathioprine, so infertility is not thought to be a major issue with this medication. Although most doctors are not enthusiastic about continuing azathioprine during pregnancy if it can be avoided, it has been used safely throughout pregnancy, so there are fewer worries if a woman taking the drug accidentally becomes pregnant.

Should people with lupus who want to eventually become parents bank their eggs or sperm before taking cyclophosphamide for treatment?

Men with lupus should bank sperm before taking cyclophosphamide. Keep in mind, however, that costs can vary from one sperm bank to another. Generally there is an initial fee for counseling, collection and testing. There are also ongoing annual fees for storage, which will be determined by the number of specimens being banked and the length of time of storage. Most sperm banks will provide an up-front list of pricing; it is advisable that you review a list of all costs before you begin the process.

For women, the question is harder to answer. The woman first must take large doses of estrogen to harvest the eggs. Also, unfertilized eggs can be frozen but they don’t preserve well and certainly aren’t as good as fertilized eggs. The cost of the procedure and medical risks are both high. And, unless the woman already has a long-term partner and freezes fertilized eggs, there is less possibility for success with in vitro fertilization down the road.

Can I try to get pregnant even though I have lupus?

Planning a pregnancy and being pregnant require special considerations for women with lupus. When women with lupus do become pregnant, 70 percent of pregnancies are successful. Even so, all lupus pregnancies are considered high-risk. This does not mean that every woman with
Lupus who is pregnant is in danger. It means that, because lupus is unpredictable, these pregnancies need to be followed closely. The woman’s team of doctors should include a rheumatologist, obstetrician, and high-risk pregnancy specialist (perinatologist), just in case any problems arise.

I have lupus and am pregnant with twins. I'm sure of the date I got pregnant but the babies’ size measures four weeks smaller. Could that be from lupus, or because they are twins, or am I just wrong on my date?

Lupus pregnancy can be complicated by intrauterine growth restriction—meaning that the placenta does not work as well as it is supposed to, so that the babies do not grow at the usual rate and are smaller as a result.

How long should I wait to get pregnant after completing the third of three Cytoxan® (cyclophosphamide) infusions?

There are two main factors a woman with lupus should consider when she decides to conceive.

First: How active is the lupus? If there has been significant lupus activity within six months of conceiving, there is higher risk for pregnancy complications, including miscarriage, premature birth, and preeclampsia (a sudden increase in the blood pressure after the 20th week of pregnancy).

Second: Are the medications needed to control lupus symptoms safe during pregnancy? Cyclophosphamide is known to cause abnormalities in babies exposed to it during the first trimester. CellCept® (mycophenolate mofetil) is also associated with poor pregnancy outcomes and fetal abnormalities. Most doctors consider Imuran® (azathioprine) a safer alternative for the fetus during pregnancy.

If you have had lupus that was active enough to require cyclophosphamide, it would be wise to avoid pregnancy for at least six months after your lupus has become quiet and you have been off this drug. It is recommended to get on a stable regimen of medication that is safe for pregnancy prior to trying to conceive. It is very important that you discuss your desire to get pregnant with your rheumatologist. This information will help guide medication choices. Your doctor is best at assessing your pregnancy risks based on your own personal lupus history.
I am taking Plaquenil® (200 mg) every day. What are the risks involved if I get pregnant while I am taking this medication? Should I stop taking it? What are my options?

Plaquenil® should be continued during pregnancy. There is no known danger to the fetus. In fact, because Plaquenil® helps to control disease activity, pregnancies do better when the mother continues taking this medication.

Can lupus affect the ovaries? In particular, can it cause ovarian cysts to form?

Results of a recent research study did show that women with lupus are more likely to have ovarian cysts.

What are the risks for women with lupus when donating their eggs, and will the child of a woman with lupus be healthy?

Retrieval of eggs requires exposure to high doses of hormones, so there may be a risk of a blood clot or a lupus flare for a woman with lupus who is undergoing hormone treatment. This type of decision should be discussed with both the woman’s rheumatologist and her gynecologist. However, the child of a woman with lupus has a very low risk—about 2 percent—of developing lupus later in life.

I am looking for alternative hormone replacement treatments. My gynecologist suggested I try soy products first before using traditional hormone replacement medications. Are there any soy products you would recommend?

The soy products that have been studied as hormone replacement therapies have not shown any benefits. Some women have had success using Neurontin® (gabapentin) to help hot flashes, and studies have shown that selective serotonin reuptake inhibitors (SSRIs) often have benefit as well. Also, estrogen cream can be used for vaginal dryness.
I have recently been diagnosed with lupus. I have more frequently noticed very light vaginal bleeding after intercourse. Is this normal for women with lupus?

This can be normal for anyone but could also signal a problem with the cervix, a complication with blood clotting factors, an infection, or related to whatever birth control method you are using. However, bleeding after intercourse is not usually associated with lupus, unless the woman is taking a medication that could affect clotting factors. It would be a good idea for you to talk to your gynecologist about this, and be sure to let her or him know about all medications you are taking.

Can you tell me the risk a woman with lupus has when having sex with a man with genital and/or oral herpes?

While an exact risk figure is not known, lupus itself and the immunosuppressive medicines used to treat lupus definitely increase the chance of infections, including viral infections such as herpes. In addition, research suggests that people with lupus have a particular problem with herpetic viral infections. Several things including sunlight exposure and stress can also set off a herpetic viral reactivation.

My lupus is in remission right now but in the past it has been really severe. If I had unprotected sex with my boyfriend, can I take the Plan B pill, or will it activate my lupus?

Plan B® One-Step (levonorgestrel) is a single dose emergency contraceptive pill to help prevent an unintended pregnancy after unprotected sex or contraceptive failure. It is allowed for people with lupus. Please keep in mind, however, that people with lupus are at increased risk for infections, including those caused by viruses, and Plan B® One-Step will not protect from herpes virus, HIV infection (the virus that causes AIDS) or any other sexually transmitted diseases.

Is it true that lupus flares occur less often after menopause?

Estrogen is an important factor in having lupus—this is why lupus is more common in women than in men—but the role of estrogen is not yet completely understood. However, lupus is not cured when estrogen levels drop in menopause, and most women continue to need medication to manage lupus even after menopause. If hormone therapy is used after menopause, there is a slight increase in mild to moderate lupus flares.
What is the best form of birth control for a woman with lupus?

There can never be one “best” method for all women with lupus, just as there is not one “best” method for women. If the family has been completed, the husband may choose vasectomy or the wife tubal ligation. Progesterone treatments (oral or Depo-Provera®) are fine but after two years, Depo-Provera® is contraindicated in women with lupus, due to the added chance of osteoporosis. Oral contraceptives can be taken by women with lupus as long as there are no antiphospholipid antibodies present (which increase the risk of blood clots) and lupus remains stable.

My lupus is in remission. I want to have a breast augmentation procedure that I have been putting off for a long time. Will this surgery cause any problems with my lupus?

It is usually okay for a woman with lupus to have a breast augmentation procedure as long as she is medically cleared for the procedure. Before you schedule the surgery, however, you should discuss the procedure, the recovery, any possible complications, and your current health status with your rheumatologist. You need to be aware of several issues in particular:

- Any surgical procedure can cause a lupus flare, so you will need appropriate ongoing monitoring from your rheumatologist.
- Lupus can cause problems with wound healing, especially if there is vasculitis in the skin.
- Prednisone® or other corticosteroids also can impair wound healing.
- If you have used prednisone® during the last 18 months, you might need to take some “stress” steroid doses prior to the procedure.

In general, all other medications you may be taking, such as immunosuppressants or blood thinners, any current infections you have, and all current test results (especially if you have a low platelet count) also should be addressed before you finalize your decision.

To access further information on this topic, please explore the following URLs:

LFA Web Site: Coping with Lupus (Pregnancy)
LFA Web Chat: Pregnancy and Lupus
LFA Web Chat: Reproductive Health and Lupus
Financial Assistance and Disability

Can the Lupus Foundation of America (LFA) provide financial assistance to individuals in need?

Unfortunately, the LFA is not set up to provide individuals with financial assistance. We may, however, be able to refer you to other agencies or organizations that can be of help. We encourage you to contact your nearest LFA Chapter as they may be able to assist you in locating local resources. You also can contact your county Department of Social Services to find out about available services in your area.

The U.S. Federal Government has three web portals to help individuals identify federal programs for which they may be eligible.

Can the LFA help me pay for my prescription medications?

The LFA does not provide financial assistance to individuals with lupus to defray the cost of medications. If you are having difficulty paying for medications to treat lupus, there may be assistance available through a variety of programs.

Most pharmaceutical companies have medication assistance programs. Check with your doctor or pharmacist to see if you may be eligible.

Does the Lupus Foundation of America have a scholarship program to help students with lupus pay for college/training?

The LFA does not have a scholarship or other forms of financial aid available to students for college. We encourage you to contact your nearest LFA Chapter as they may be able to assist you in locating local resources. For example, Lupus Foundation of America, Southeast Florida Chapter, offers an annual $5,000 scholarship to support the educational expenses of a Southeast Florida resident diagnosed with lupus. Learn more about the Michael Jon Barlin Scholarship Fund at [http://www.lupusfl.org/barlin.htm](http://www.lupusfl.org/barlin.htm)

Students are also highly encouraged to talk to their school’s financial assistance office for information on grants and scholarships.
The LFA does have a summer fellowship program for student researchers who work under the supervision of an established lupus investigator. Learn more about the Gina Finzi Memorial Student Summer Fellowship Program.

**Gina Finzi Memorial Student Summer Fellowship Program**

There is a small scholarship program for people with lupus operated by another private foundation. Learn more about the Life Scholarship Program.

[www.lifescholarship.org](http://www.lifescholarship.org)

The Patient Advocate Foundation Scholarships for Survivors: the purpose of this scholarship is to provide support to individuals, under the age of 25, that are or have been diagnosed with cancer or a critical or life threatening disease.


**Can the LFA help me with filing for disability?**

The LFA does not assist people in filing for disability. However, the Patient Advocate Foundation can help answer questions about disability and other related areas. Please contact at [www.patientadvocate.org](http://www.patientadvocate.org)

*To access further information about this topic, please explore these URLs:*

Financial aid information:

- [FinAid! The SmartStudent Guide to Financial Aid](http://www.finaid.org)
- [FinAid: Information on Financial Aid for Disabled Students](http://www.finaid.org)
- [FastWeb: Scholarship and College Searches](http://www.fastweb.com)

Individual federal programs:

- [www.govbenefits.gov](http://www.govbenefits.gov)
- [www.govloans.gov](http://www.govloans.gov)
- [www.grants.gov](http://www.grants.gov)

**Prescription Medication Assistance Programs**
Tissue and Body Donations for Lupus Research

While donation of organs for transplantation is generally well known and widely accepted, research donation is an option that people willing to donate should not overlook. Scientists need human organs and tissues for important research leading to treatment and cure for many types of diseases, including lupus. At the present time, though there are very few research programs that allow those with lupus to donate their body or organs specifically for lupus research, this information may be able to answer some questions about body donation and how you might participate.

Can I pre-register to donate my body to research?

Yes, talking about your decision, when you want to donate your body to science, with those responsible for your final arrangements, helps to ensure that whole body or organ donation to science will take place.

Is pre-registration for whole body or organ donation to science necessary?

While it is recommended, it is not mandatory that you pre-register. If your doctors and family are aware of your wishes and know of programs available, arrangements can be completed at the time of death.

How do I pre-register for donating my body to science?

Contact those programs listed below that you feel meet your wishes on body and organ donation and they will be able to help you pre-register. Each program is slightly different so it may take a little investigation by you or your family.

Who can consent?

In accordance with state and federal laws, donation programs must obtain an informed consent from the donor or legal next-of-kin for you to donate your body to science. If more than one legal next-of-kin exists (i.e. mother/father or siblings), all must be in agreement with the full body donation though only one of the legal next-of-kin are required to complete the official authorization.
What are the costs to my family to donating my body?
This depends on the program that you choose. If the program is a whole body program then there is generally no cost to the family. Following the research, the body is cremated and returned to the family (if requested) or may be laid to rest in a mausoleum. If the program is an organ only donation, then at the time of death, only the organs will be retrieved. You and your family will be responsible for the internment or cremation of the body.

Can I donate my body to a medical school?
Some medicals schools will accept body donations from people who had lupus. However, there is little to no chance that the donation will be used for lupus research or education. In fact, many medical schools will not accept individuals with chronic diseases. If your wish is to donate to a medical school, please check with the school first to see if their donation program fulfills your wishes.

The website linked below provides a list of body donation programs throughout the United States. Again, these programs may or may not utilize body donations for lupus research.

http://www.med.ufl.edu/anatbd/usprograms.html

How can I find out more information about body donation?
Listed below are two programs that you may consider for whole body or organ donations for research.

1. The National Resource Center: This is an organ only program so you and/or your family will be responsible for the burial of the body. At the time of death, organs will be retrieved and sent to research programs requesting them. You can specifically request donation for lupus research.

8 Penn Center
8th Floor
1628 JFK Boulevard
Philadelphia, PA 19103
Main - (215) 557-7361
Toll-Free - (800) 222-NDRI (6374)
Fax - (215) 557-7154

General Information
Private Donor Coordinator
Colleen Cheong
2. **MedCure Inc.**: This is a whole body donation program. Upon request, your body will be cremated and returned to your family. This program is not specific for lupus research and donations go to programs that request them.

P.O. Box 55730  
Portland, Oregon. 97238  
Telephone: 1-866-560-2525  
Fax: 503-257-9101  
Program Director  
David Urbina  
702-750-2281  
david@medcure.org  
info@medcure.org
Lupus and the Cardiopulmonary System

I've read a little about polycythemia -- does a person with lupus develop this at times?

No, it is extremely rare. Research on the occurrence of this finds only two case reports of polycythemia in lupus patients. So there is no connection between the two. Lupus is an autoimmune disorder and polycythemia is a condition in which there is increased blood volume and high hemoglobin levels (too many red cells).

There are two kinds of polycythemia: primary (inherited) and secondary (usually acquired from a medical condition that causes low oxygen in the blood such as lung conditions, smoking, etc.) Mild polycythemia is common in people who smoke.

What is lupus serositis?

Serositis is the inflammation of the serous membranes (sacs) that surround organs. Serositis is one of the symptoms of lupus listed in the criteria of the American College of Rheumatology. This symptom is known to affect up to 45 percent of people with lupus. Examples of serositis that can be affected by lupus are pleurisy, an inflammation of the membrane that surrounds both lungs, and pericarditis, an inflammation of the sac (pericardium) that surrounds the heart.

My understanding is that people with lupus are at increased risk of heart disease and strokes. If this is correct, is it reasonable to start statin therapy?

Until we better understand the reason that people with lupus are at increased risk for strokes and heart attacks, we encourage doctors to treat all traditional cardiovascular risk factors such as high blood pressure, high cholesterol, smoking, etc. It is reasonable to use statins to decrease cholesterol levels.

To access further information on these topics, please explore the following URLs:

LFA Web Site: How Lupus Affects the Body (Cardiopulmonary System)
LFA Web Chat: Heart Disease and Lupus
LFA Web Chat: Women's Heart Health
Lupus and the Gastrointestinal (GI) System

Note: GI includes the liver, pancreas, bile ducts, gallbladder, esophagus, stomach, intestines, colon, urinary tract, and rectum

How can lupus harm my GI tract?

The GI system is your body’s pathway for taking in, processing, and disposing of everything you eat and drink. Everything you swallow goes from your mouth to your esophagus in your throat, on through your stomach to your intestines, and then to your colon, ending at your urinary tract or rectum. Muscle contractions control swallowing and bowel movement. People with lupus may be affected by problems in any area of the GI system, including the surrounding organs such as the liver, the pancreas, the bile ducts, and the gallbladder. Not all of these problems will be directly related to lupus disease activity; some may be traced to side effects of medication you take or other diseases that may be present.

What can you tell me about lupus and cirrhosis of the liver? My daughter is 28 years old, and has both. Her physicians say that her cirrhosis was caused by lupus.

People with lupus often have liver blood test results that are somewhat abnormal, and results of a liver biopsy may show what is known as “fatty” liver. There is no association between lupus and cirrhosis, which refers to scarring of the liver and poor liver function.

There is however, an association between lupus and autoimmune hepatitis, which causes inflammation of the liver. There also is a disease with the name “lupoid hepatitis.” When we examine the pathophysiologic findings of a person with autoimmune hepatitis and those of a person with lupus, and when overlap conditions are considered, it is not completely surprising that a physician might early on suspect both diseases of occurring in the same person. A liver biopsy can be an important clue in determining the existence of one or both diseases.

First, let us distinguish between chronic and autoimmune hepatitis.

According to a July 2008 article on WebMD, Medscape’s clinical reference site, the development of viral serologic tests has permitted hepatologists (physicians who specialize in diseases of the liver) to differentiate chronic viral hepatitis (http://www.medscapecrm.com/article/185463-overview) from other types of chronic liver disease, including autoimmune hepatitis. Autoimmune hepatitis is now accepted as a chronic
disease of unknown cause that is characterized by continuing inflammation and necrosis (tissue death) in the liver, and tends to progress to cirrhosis. Immune serum markers frequently are present and the disease often is associated with other autoimmune diseases. Autoimmune hepatitis cannot be explained on the basis of chronic viral infection, alcohol consumption, or exposure to medications or chemicals.

A form of chronic hepatitis was first described in young women in 1950. The association of the lupus erythematosus (LE) cell, an early identifying marker of lupus, in active chronic viral hepatitis was first reported in 1955. This association led to the introduction of the term “lupoid hepatitis”; however, no direct link exists between lupus and autoimmune hepatitis, so lupoid hepatitis is not considered to be associated with lupus.

Autoimmune hepatitis now is recognized as a multisystem disorder that can occur in males and females of all ages. This condition can coexist with other liver diseases (e.g. chronic viral hepatitis) and also may be triggered by certain viral infections (e.g. hepatitis A) and chemicals (e.g. minocycline).

Just as in lupus, evidence suggests that liver injury in a person with autoimmune hepatitis is the result of a cell-mediated immunologic attack, and that some people appear to be genetically susceptible to developing the illness. Also as in lupus, diagnostic autoantibodies include antiphospholipid antibodies (APL) and antinuclear antibodies (ANA). Many of the common lupus symptoms also will be seen with autoimmune hepatitis, including fatigue, myalgias (muscle pain), arthralgias (joint pain), low-grade fever, skin rashes, edema (swelling of the extremities), pleuritis (chest pain from inflammation around the lungs), and weight loss.

Many individuals who later will be diagnosed with autoimmune hepatitis will have evidence of cirrhosis at the onset of symptoms. This is true both for those with an initial presentation of acute hepatitis and for those with chronic hepatitis.

Furthermore, disease associations—especially in those with type 2 autoimmune hepatitis—include a wide variety of other disorders. Involvement of other systems may present at disease onset or may develop during the course of active liver disease. Most of these conditions are immunologic in origin, and many are also seen in overlap with lupus:

- **Hematologic complications**
  - Hypersplenism (overactive production of white blood cells from the spleen)
  - Autoimmune hemolytic anemia
  - Coombs-positive hemolytic anemia
  - Pernicious anemia
  - Idiopathic thrombocytopenic purpura
  - Eosinophilia (high numbers of white blood cells)
For access further information on this topic, please explore the following URL:

Lupus Foundation of America Web Site: How Lupus Affects the Body (Gastrointestinal System)
Lupus and the Nervous System

My MRI from 3 years ago showed plaques. Is there anything on the MRI of people with lupus of the nervous system that is diagnostic for Central Nervous System (CNS) lupus?

Diagnosis of CNS lupus is difficult as there is not one specific diagnostic test to detect nervous system involvement in lupus. The abnormalities seen on the MRI scans are not specific for systemic lupus. In other words, they could be due to a number of things. The findings on these specialized tests and sometimes other tests such as a brain wave test (electroencephalogram, EEG) and a spinal tap have to be considered along with clinical and laboratory findings in establishing a diagnosis of CNS lupus.

Having lupus has affected my memory. Is there any medication that can help with memory retention?

Lupus very commonly affects people's memory. In fact, studies have shown that as many as 80% of people with lupus have some problem with their memory at some point in the disease process -- fortunately for many people this problem is mild. There is no medication that we know of that definitely helps with this. Actually, more research has shown a benefit with interventions that include education and tips about coping strategies as well as the importance of treating fatigue, depression and pain in helping improve memory function. Talk to your doctor about any memory problems you experience.

To access further information about this topic, please explore the following URLs:

LFA Web Site: Living With Lupus (Memory Loss and Lupus Fog)
LFA Web Site: Lupus and the Nervous System
LFA Web Chat: Lupus and the Central Nervous System
Lupus and the Kidney (Renal) System

What are the stages of lupus, and how does each stage progress into the next?

The disease of lupus does not have established “stages.” When people talk about “early stage lupus”, they generally mean lupus that is in its early development period, when symptoms are becoming apparent. When people talk about “late stage lupus”, they generally mean lupus that is causing organ damage or has caused the person to become debilitated. No one can predict how lupus will or will not progress. Just as each person with lupus is different, the course of the disease will vary from person to person, and will often change over time as well.

However, lupus nephritis—which is the overall term used when lupus affects the renal system, including the kidneys—does have six different classes and sub-classes (see below). These classes were defined by the World Health Organization (WHO) in 1974 and revised in 1982. The classifications were further defined in 2003 by the International Society of Pathology/Renal Pathology Society (ISN/RPS) to include results from light microscopy and immunofluorescence tests and electron microscopy findings from renal biopsy specimens.

Lupus nephritis does not progress from an “early” class to a “late” class, although the class of disease can change over time.

**Class I** – Minimal mesangial lupus nephritis

**Class II** – Mesangial proliferative lupus nephritis

**Class III** – Focal lupus nephritis

  - Class III (A): Active lesions - Focal proliferative lupus nephritis
  - Class III (A/C): Active and chronic lesions - Focal proliferative and sclerosing lupus nephritis
  - Class III (C): Chronic inactive lesions - Focal sclerosing lupus nephritis

**Class IV** – Diffuse lupus nephritis

  - Class IV-S (A): Active lesions - Diffuse segmental proliferative lupus nephritis
  - Class IV-G (A): Active lesions - Diffuse global proliferative lupus nephritis
Class IV-S (A/C): Active and chronic lesions - Diffuse segmental proliferative and sclerosing lupus nephritis

Class IV-G (A/C): Active and chronic lesions - Diffuse global proliferative and sclerosing lupus nephritis

Class IV-S (C): Chronic inactive lesions with scars - Diffuse segmental sclerosing lupus nephritis

Class IV-G (C): Chronic inactive lesions with scars - Diffuse global sclerosing lupus nephritis

Class V – Membranous lupus nephritis

Class VI – Advanced sclerosis lupus nephritis

**How can I be sure my kidneys are not being affected by lupus activity?**

When I go to the doctor for blood work every six months, does that blood work let the doctor know if there are any kidney problems? Is there a certain test that has to be done to check my kidneys?

Everyone with lupus should have periodic tests to check kidney function, including blood urea nitrogen (BUN) and serum creatinine tests. These blood tests show how well the kidneys are eliminating wastes from the body. The urine also should be examined to look for protein and blood cells, called urine sediment, which may be due to inflammation in the kidneys. Even if these tests are normal, they are usually repeated at intervals of about 3-6 months.

However, if there is evidence of protein or blood cells in the urine, these tests will be repeated much more frequently—usually every month. Even a small change in the blood or urine can be detected, which is very important so that proper adjustments can be made in your treatment before any damage occurs in organs, cells, or tissues. For example, a temporary increase in the prednisone dose or other medication may help suppress the inflammation that is being caused by the overactive immune system.

**Because of my lupus kidney disease, there is always a certain amount of protein in my urine. What amount of protein spillage is considered normal, and would mean that my lupus is in remission?**

Urine protein spillage, called proteinuria, that is less than 150 mg in a 24-hour period is considered normal. Lupus is considered to be in complete remission if there is less than that amount spilled in 24 hours (or an amount very close to that). In addition, serum BUN and
creatinine levels (other measures of kidney function) will return to normal in complete remission.

If you have a substantial reduction in proteinuria that does not reach this point (that is, a drop from greater than 3500 mg to between 2000 mg and 150 mg in 24 hours), your lupus activity would be considered in partial remission. People with lupus who have a complete or partial remission have a better prognosis with respect to kidney disease than those whose lupus does not improve as much.

Partial remission may mean there is still inflammation in the kidneys or renal system, and additional immunosuppressive treatments may be needed. Persistent proteinuria may be due to scarring associated with the healing process, and additional immunosuppressives will not be effective; however, use of anti-hypertensive medications that also reduce proteinuria, such as angiotensin-converting enzyme (ACE) inhibitors or angiotensin II receptor blockers (ARBs) are effective in slowing disease progression. The goal in the latter situation is to reduce protein spillage—to less than 2000 mg/day, if possible. It may be necessary for the doctor to examine tissue from a renal biopsy in order to distinguish between these alternatives.

To access further information about this topic, please explore the following URLs:

LFA Web Site: How Lupus Affects the Body (Renal System)
LFA Web Chat: Kidney Involvement and Lupus
LFA Web Chat: The Kidneys and Lupus
Lupus and the Skin

How does lupus affect the skin?
Cutaneous lupus erythematosus is caused by inflammation of the tissues that form the skin. The symptoms of cutaneous lupus include:

- skin rashes and lesions (sores)
- hair loss (either temporary or permanent when there is scarring of the skin)
- photosensitivity (when exposure to ultraviolet light triggers a rash and/or other symptoms)
- ulcers (sores) on the inside of the nose or mouth
- vascular changes (abnormal levels of blood components and/or circulation problems in capillaries, veins, and/or small arteries)

How is cutaneous lupus different from systemic lupus?
Cutaneous lupus affects only the skin, whereas systemic lupus may involve any of the organ systems in the body (including the skin).

Are there different forms of cutaneous lupus?
There are three main forms of cutaneous lupus:

- chronic cutaneous lupus erythematosus, also called discoid lupus erythematosus
- subacute cutaneous lupus erythematosus
- acute cutaneous lupus erythematosus

What type of specialist can diagnose and treat cutaneous lupus?
A dermatologist is the specialist who diagnoses and treats cutaneous lupus. To determine whether a lesion or rash is due to cutaneous lupus, your dermatologist will usually take a tiny sample of the affected tissue and examine it under a microscope. Taking the tissue sample is called a biopsy. Other laboratory tests may be necessary if your dermatologist also suspects systemic lupus.
Can cutaneous lupus turn into systemic lupus?

Approximately 10 percent of people with cutaneous lupus later develop systemic lupus, but these people probably had systemic lupus to begin with and the skin rash was the first symptom.

Can you describe chronic cutaneous (discoid) lupus?

Cutaneous lupus appears as round, disk-shaped (discoid) lesions. The sores usually appear on the scalp and face, but sometimes they will occur on other parts of your body as well. Discoid lupus lesions are often red, scaly, and thick. Usually they do not hurt or itch. Over time these lesions can produce scarring and skin discoloration (darkly colored and/or lightly colored areas). Discoid lesions that occur on your scalp may cause your hair to fall out. If the lesions form scars when they heal, your hair loss may be permanent. Cancer can develop in discoid lesions that have been present for a long time, so tell your doctor about any changes in the appearance of one of these lesions.

Are there other forms of chronic cutaneous lupus?

Some other forms of cutaneous lupus are:

- verrucous (wart-like) discoid lupus erythematous
- lupus tumidus - elevated areas of red skin with no scale or scarring
- lupus profundus - discoid skin lesions in conjunction with panniculitis
- palmar-plantar erosive discoid lupus erythematous - discoid lesions on the hands and feet

Are there any precautions I should take for my discoid lupus?

Discoid lupus lesions in particular can be very photosensitive, so preventive measures are important:

- Avoid being out in the sunlight between the hours of 10 a.m. and 4 p.m.
- Use plenty of sunscreen when you are outdoors, and reapply it often especially if you are sweating or you have been in the water
- Wear sun-protective clothing and broad-brimmed hats
- Limit the amount of time you spend indoors under fluorescent lights
What is photosensitivity and what are photosensitivity reactions?
Photosensitivity is the term used to describe sensitivity to the ultraviolet (UV) rays from sunlight and other light sources, such as indoor fluorescent light. Photosensitivity can cause rashes, fever, fatigue, joint pain, and other symptoms in people with both cutaneous and systemic lupus. UV rays are especially intense between the hours of 10 a.m. and 4 p.m., at higher altitudes, and in or around the snow and the water. Excess exposure to UV rays is a common trigger for increased disease activity (flare) of both cutaneous lupus and systemic lupus.

Can avoiding the sun affect my Vitamin D level?
The most common vitamin deficiency in lupus is vitamin D deficiency due to sun avoidance. It is important to get enough dietary vitamin D to maximize bone health and not provoke or exacerbate osteoporosis. Those with lupus should consult their doctor about supplement intake.

Can you describe subacute cutaneous lupus?
Subacute cutaneous lesions may appear as areas of red, scaly skin with distinct edges, or as red, ring-shaped lesions. These lesions occur most commonly on the sun-exposed areas of the body, such as arms, shoulders, neck, ears, and face. The lesions usually do not itch or scar, but they can cause the skin to become discolored. Subacute cutaneous lesions are photosensitive so preventive measures should be taken when spending time outdoors—especially between the hours of 10 a.m. and 4 p.m., at higher altitudes, in or around the snow and the water—or under fluorescent lights.

Can you describe acute cutaneous lupus?
Acute cutaneous lupus lesions appear when your systemic lupus is active. The most typical form of acute cutaneous lupus is a malar rash—flattened areas of red skin on your face that resemble a sunburn. When the rash appears on both cheeks and across the bridge of the nose in the shape of a butterfly, it is known as the “butterfly rash.” However, the rash can also appear on your arms, legs, and body. These lesions tend to be very photosensitive so preventive measures should be taken when spending time outdoors—especially between the hours of 10 a.m. and 4 p.m., at higher altitudes, in or around the snow and the water—or under fluorescent lights. They typically do not produce scarring, although changes in skin color may occur.
How is cutaneous lupus treated?

Preventative measures are considered the first line of defense for cutaneous lupus, including avoidance of excess exposure to sunlight and artificial ultraviolet light, and protecting exposed skin with sunblock, sun-protective clothing, broad-brimmed hats, and shade.

The medications used to treat lupus-related skin conditions will depend on the type of cutaneous lupus. The most common treatments are steroid ointments, lotions, creams, gels, and sprays. In some cases, liquid steroids may be injected directly into the lesions. There are a number of other medications that can be used.

Does lupus cause hair loss?

Both cutaneous lupus and systemic lupus may cause hair thinning and hair loss.

Discoid lupus can cause hair loss and bald spots in the areas of the lesions. Total baldness may also occur on the temples and the top of the head. Systemic lupus may cause a temporary pattern of hair loss that is then replaced by new hair growth. Active disease may cause hair to fall out in clumps when being combed or washed. A severe lupus flare can result in fragile hair that breaks easily; these broken hairs at the edge of the scalp give a characteristic ragged appearance termed “lupus hair.” Infections, chemotherapy, emotional stress, and hormonal imbalances also can cause hair loss related to lupus.

Usually people do not lose all their hair when the thinning hair or hair loss are due to active disease or medications. And, unless there is scarring, the hair typically grows back once disease activity is under control.

I have hair loss due to several scars on my scalp. All are about the size of silver dollars. Is there anything to help this kind of hair loss?

If biopsy results indicate advanced scarring on the scalp, then there is little chance of bringing back significant amounts of hair. If, on the other hand, early treatment with corticosteroid and/or antimalarial drugs can prevent scarring from occurring, there may be success in getting the hair to return. When the disease is inactive, and scarring is not present, hair usually grows back.

Will the drugs used to treat baldness help the hair loss due to lupus?

Minoxidil (Rogaine®), developed as a blood pressure medication, promotes hair growth in balding men. It has been shown to promote hair growth in women and men with lupus but it does not decrease hair loss.
Hair loss is one of the symptoms of active lupus. Therefore, suppressing disease activity with medications should also help hair to re-grow. Usually, people do not lose all their hair when the thinning hair or hair loss are due to active disease or medications. Unless there is scarring, the hair typically grows back once disease activity is under control.

**Is there anything that can be done to cover the lesions (sores) on my face?**

Yes. There are several camouflage make-up products available commercially which may be helpful in this situation. Be sure to tell your doctor you are using these products, and be aware of any skin reactions that may occur.

**Total Block** (make-up as well as sunblock), [totalblock.com](http://totalblock.com), 800-332-5536

**Covermark**, [covermarkusa.com](http://covermarkusa.com), 800-524-1120

**Dermablend**, [dermablend.com](http://dermablend.com), 800-662-8011

**Can lupus cause hives or a sensation of burning in the skin?**

Hives—red bumps that are sometimes itchy—can be associated with lupus. The sensation of itching is due to irritation of nerve fibers in the skin. If the irritation is more intense, it may cause a burning sensation. Occasionally people have a condition that looks like hives that is actually a form of vasculitis. For normal hives, which last less than 24 hours, antihistamines may be helpful.

**Can you describe chilblains and can it develop into systemic lupus?**

Chilblains is a painful inflammation of small blood vessels in the skin due to sudden warming from cold temperatures. Also known as pernio, chilblains can cause itching, red patches, swelling, and blistering on extremities such as toes, fingers, ears, and nose. Chilblains can occur in people with lupus or in otherwise healthy people, especially children and the elderly. Hormonal changes and/or poor nutrition, poor circulation and bone marrow disorders are associated with chilblains. Some reports also have associated this condition with antiphospholipid antibodies.

While it doesn't usually result in permanent injury, chilblains can lead to severe damage if left untreated. In general, chilblains responds well to treatment and clears up within two weeks. Treatments typically consist of lotions and medication. Limiting your exposure to the cold, dressing warmly, and covering exposed skin are good strategies for avoiding this condition.
Is massage therapy safe for people with cutaneous lupus?

In general, massage therapy is safe for a person with cutaneous lupus. However, there are a few specific instances where caution is advised. For example, deep vigorous massage could cause bleeding under the skin or visible bruising. This may cause “koebnerization,” the process whereby cutaneous lupus may be produced at the injured sites.

Another possible concern is the use of various oils during a massage. If the oils used were to cause an allergic reaction, lupus could be activated due to koebnerization. While these issues are uncommon, and the benefit of massage for musculoskeletal disease is positive, it is worthwhile for those with cutaneous lupus to be aware and cautious.

Is laser hair removal safe for people with lupus? If so, which kinds of lasers are best?

There is some concern about the use of lasers in a person with lupus because of the slight risk of skin redness, swelling, and pigmentary changes. These types of changes could potentially cause lupus to flare. In a recent review of studies, long-term hair removal was not obtained with any treatment, so the question is whether the risk is worthwhile when there is a chance of a disease flare. Therefore, this area of research needs more study before safety can be assessed.

Is intense pulsed light therapy safe for people with lupus?

There is some concern that the longer wavelengths of light used in intense pulsed light therapy could cause lupus to flare or cause skin lesions to form or worsen. One particular wavelength of ultraviolet light (UVA-1) has successfully been used as therapy for some people with lupus. However, this area of research needs more study before safety or potential therapeutic use can be assured.

I am an African American woman with lupus, and I have significant hair loss with scarring and itching. Will it be safe for me to use hair relaxers? What about hair braiding or weaves?

It is important to remember that hair treatments that could irritate the scalp may lead to further itching and scarring. The relaxer products may be aggravating your skin, either due to your lupus or from an allergic reaction. Braiding or hair weaves should be fine, but try not to pull the hair too tightly, as that can damage the hair. Other options are wigs, hair extensions, and hairpieces. Health insurance may cover these if the hair loss is due to a medical condition. Hats and scarves can also be a nice option.
Companies that offer alternative hair covers and pieces

**Headcovers Unlimited, Headcovers.com, 580-226-5871**

**Soul of the Rose Millinery Designs, Souloftherose.net, 240-631-8868**

**Is there a connection between lupus profundus (also called lupus panniculitis) and cutaneous lupus?**

Lupus profundus is a rare condition of inflammation in the fat tissue, which creates lumpy, sometimes painful dimpling of the skin and the tissue beneath it. While the cause is not known, it is generally not associated with cutaneous lupus.

**Is there a connection between erythema nodosum and cutaneous lupus?**

There is an increased incidence of erythema nodosum in people who have lupus. There are other diseases where the association is stronger, such as inflammatory bowel disease, Behcet’s disease (or syndrome), and sarcoidosis.

**Is there a connection between lichen planus and cutaneous lupus?**

Lichen planus is a separate skin disease from cutaneous lupus but both diseases are caused by inflammation of the tissues and cells of the skin. However, there are people who have an overlap between cutaneous lupus and lichen planus, meaning that they have both types of skin lesions. However, since cutaneous lupus lesions and lichen planus lesions frequently look very different clinically and under the microscope, it is possible to tell the difference between them.

**Are lasers, collagen, restalyne, Botox or Thermage treatments okay for people with either cutaneous or systemic lupus? What about microdermabrasion chemical peels and sclerotherapy for spider veins?**

With the recent attention on plastic surgery and other cosmetic procedures, more people -- including those with lupus -- are questioning the safety of various skin treatments. Some may be considering dermatologic interventions for disease-related reasons, including side effects from lupus treatment (such as stretch marks) or from lupus itself (such as scars from discoid lupus).

However, a distinction should be made between reconstructive or reparative treatments for damaged skin and those for purely cosmetic procedures. Lupus patients in remission who are
left with permanent scarring may be treated the same way as a person who has been in a car accident or in a fire. Certainly, we are cautious with these treatments because any technique that manipulates the skin could reactivate the lupus. There are a number of criteria we establish before considering a person with lupus for these types of skin treatments. For example, the person’s lupus must be in full remission -- and his or her rheumatologist and dermatologist must agree with the planned treatment.

**How might chemical peels affect someone with cutaneous lupus and are they contraindicated for people with lupus?**

Chemical peels may irritate the skin, and thus could potentially induce skin lesions in patients with the underlying disease. This phenomenon can occur with scratching or any skin irritation and thus could be a potential risk. This procedure should be discussed with your dermatologist before using it.

**I'm going to a three day concert this summer in TN. How can I protect myself from the sun when shade really isn't an option?**

You are correct that you need to protect yourself from excessive exposure to the sun. If possible, try to have an umbrella to shade you. You should also use sunblock lotion with a SPF of at least 30 that protects against UVA and UVB rays. Apply liberally on all areas of your skin exposed to the sun and reapply as directed. You also can wear clothing specially manufactured to resist ultraviolet rays from the sun. There are many companies today that offer sun-protective clothing and broad-brimmed hats in attractive styles and colors for women, men, and children. Finally, check with your physician just before the concert to make sure that your lupus is in remission and for any last minute advice.

*To access further information about this topic, please explore the following URLs:*

- **LFA Web Site:** How Lupus Affects the Body (Lupus and the Skin)
- **LFA Web Chat:** Skin Disease in Lupus
- **LFA Web Chat:** UV Light and Lupus
- **LFA Web Chat:** Your Skin and Lupus
- **LFA Web Site:** Living with Lupus (Sensitivity to Light)
- **LFA Web Site:** “Ask the Expert / Your Skin and Lupus”

Companies that sell sun protective clothing:
Coolibar, www.coolibar.com, 800-926-6509
Sunday Afternoons, SundayAfternoons.com, 888-874-2642
SunGrubbies, www.sungrubbies.com, 888-970-1600
Sun Precautions, www.sunprecautions.com, 800-882-7860
TripleJSportswear, www.triplejsportswear.com, 800-555-5142
For Parents of Children Living with Lupus

My child has lupus. What is the prognosis?

The prognosis for children and adolescents with lupus has improved dramatically over the past 20 years. With modern medicines, better understanding of lupus symptoms, and important lifestyle changes, lupus in children and teens are treated successfully in most instances. Special areas of concern to pediatric rheumatologists who treat children with lupus, include the high incidence and prevalence rates of lupus-related kidney disease, slow bone growth from corticosteroid use, adherence and compliance with medications and lifestyle changes, the transition to the adult health care system, and lack of adequate health insurance among young adults.

What is the best preventive treatment approach to protect the bones of children with lupus who have to take corticosteroids?

Bone health in children is extremely important. Most pediatric rheumatologists understand how the medications that treat lupus can affect the skeleton; they also know that lupus itself affects bone health. Researchers are seeking solutions to both of these problems. Calcium and vitamin D supplementation are essential for children and adolescents with lupus. Physical activity and bone-strengthening exercise four to five times a week for at least 30 minutes are also essential. This combination of calcium, vitamin D, and exercise will help the body to form new and healthy bone tissue. When lupus disease activity lessens, children often have catch-up bone growth. Still, the above-mentioned strategies are imperative to help maintain bone health.

For children on high doses of glucocorticoids and/or immunosuppressive medications, cautious use of mild anti-resorptive agents like calcitonin could be considered. Whereas adults have a variety of medication options for the prevention and treatment of bone loss caused by glucocorticoids and other medications and illnesses, studies have not been done to evaluate the benefits and risks of these medications in children. Therefore, many pediatricians are waiting until more information is available before prescribing these types of medications to children.

To access further information on this topic, please explore the following URLs:

LFA Web Site: For Parents of Children Living with Lupus
LFA Web Chat: Teens and Lupus
LFA Web Chat: Pediatric Lupus