LUPUS

THINGS YOU SHOULD KNOW

Social Butterflies Foundation

MAKING THESE INVISIBLE ILLNESSES VISIBLE

WWW.SOCIALBUTTERFLIESFOUNDATION.ORG

TABLE OF CONTENTS

WELCOME MESSAGE

Greetings,
We have put together some useful information for you. Whether you are wondering if you have lupus or fibromyalgia or are newly diagnosed, we want you to know that Social Butterflies Foundation is here for you. As an organization founded by a survivor, we understand your needs. Our motto is "Butterflies don't let each other fly alone."

CHASTITY CORBETT
FOUNDER & C.E.O.

ABOUT US

Social Butterflies Foundation was founded on October 5, 2018 by lupus survivor, Chastity Corbett. It is a grassroots organization dedicated to helping those battling with lupus and fibromyalgia, as well as their families and caregivers. Social Butterflies Foundation is the first and only non-profit located in Hampton Roads, Virginia devoted to providing real, direct assistance to survivors and their families living in Virginia and Maryland.

MISSION & VISION

MISSION

Social Butterflies Foundation is dedicated to empowering and uplifting individuals living with lupus and fibromyalgia, as well as their families and caregivers. Our mission is to provide direct assistance, education, support services, and encouragement to help survivors face the challenges of these debilitating illnesses.

VISION

Our vision is a world where no one suffering from lupus or fibromyalgia has to endure the challenges of these life-threatening illnesses alone. We envision a united community of survivors whose voices are heard and who receive the support they need. Together we will make these invisible illnesses visible.

OUR PROGRAMS & SERVICES

From educational resources to emotional support, we strive to empower our community members and improve their quality of life. Explore our programs and services below to see how we can assist you on your journey toward health and wellness.

SUPPORT GROUP

1

The Social Butterflies Foundation's Lupus & Fibro Support Group provides a safe and understanding environment for both youth and adult survivors, their families, and caregivers to unite. Support Group meetings are held every 4th Saturday from 11AM-1PM at Sentara Careplex Hospital inside conference room D.

E.F.A. PROGRAM

2

Living with a chronic illness can also affect survivors financially. Social Butterflies Foundation created its Emergency Financial Assistance (EFA) program to help provide assistance with medical bills, prescription costs, and utilities.

CARE OUTREACH

3

The Care Outreach Program is our way of showing that we care. We want survivors to know that they are not alone. We are there to help during the rough times as well as being there to celebrate the good times. We also adopt families during the holidays.

OUR PROGRAMS & SERVICES

WIG OUTREACH

4

Many lupus and fibromyalgia survivors suffer from alopecia due to the illness or medications taken to treat the illness. Losing your hair can be devastating and traumatic. The Wig Outreach program aids in obtaining wigs. The program also hosts workshops with guest speakers discussing hair, skin, and other beauty tips to focus on both inside and outside.

SUMMIT & HEALTH FAIR

5

Social Butterflies Foundation's Lupus and Fibromyalgia Summit and Health Fair is a step towards an awareness campaign to bring the medical community, survivors, and support services together. The summit establishes an open forum between medical professionals, patients, and their families while providing valuable resources.

SCHOLARSHIPS

6

Social Butterflies Foundation aims to provide youth battling with lupus and/or fibromyalgia, as well as children of survivors, with college scholarship opportunities to help fulfill their aspirations for higher education.

COULD IT BE LUPUS?

Lupus is a serious disease that causes your body to attack itself.

Lupus is a disease that affects the immune system, which protects the body from germs and infections. In a person with lupus, the immune system can't tell the difference between these germs and the body's healthy tissues and organs. So, the body attacks itself.

Lupus can affect nearly every part of the body. If you have lupus, you may have some symptoms that are visible and others that are not. Lupus symptoms vary from person to person, can come and go, and can change over time.

Common Lupus Symptoms:

- Feeling very tired all of the time, even when you have had enough sleep
- A butterfly-shaped red rash on your nose and cheeks
- Fingers or toes that turn white or blue in the cold or when you feel stressed
- Pain or swelling in your joints or muscles
- Feeling sick or gettinga rash after being in the sun
- A low-grade fever

DIAGNOSING LUPUS

Getting an early, accurate lupus diagnosis can reduce its long-term effects.

How do doctors diagnose lupus?

There isn't just one test doctors can use to tell if you have lupus. Doctors must consider many sources of information. Your doctor will look at:

- Your symptoms
- Your medical history
- Results from lab tests such as the ANA or AVISE® test (other tests may include anti-dsDNA or anti-Sm)

What is an ANA test and how does it work?

Doctors may use an ANA test to determine if a person has a certain type of antibody, called antinuclear antibodies (ANA), in their blood. The immune system normally creates antibodies (proteins) to fight germs and infections. Sometimes, the immune system mistakes healthy cells as foreign invaders and makes antinuclear antibodies that attack the healthy cells. Scientists have found that a majority of people with lupus (up to 98%) have antinuclear antibodies in their blood.

The ANA test is not specific for lupus and can sometimes show a positive test result when it's detecting different types of antibodies in the blood. Therefore, if you have a positive ANA test result, it doesn't necessarily mean you have lupus. It can, however, be an important clue for your doctor to look more closely for signs of lupus. After hearing more about your symptoms, your doctor may recommend more tests to help determine if you have lupus.

DIAGNOSING LUPUS

What is AVISE® testing?

New, advanced tests like the AVISE Connective Tissue Disease (CTD) test can help diagnose lupus as well as other conditions. AVISE Lupus and AVISE SLE Monitor are specialized blood tests that help doctors identify lupus disease activity in the blood. When combined with a doctor's medical assessment, AVISE tests can provide the information needed to help you get on the path to better health.

For more information on AVISE testing, visit AviseTest.com.

Talking with your doctor about all of your symptoms and getting the right lab tests are important steps to arriving at an accurate diagnosis.

UNDERSTANDING LUPUS

If you’ve been diagnosed with lupus, you probably have a lot of questions about the disease and how it may affect your life. Lupus affects different people in different ways. For some, lupus can be mild — for others, it can be life-threatening.

Right now, there’s no cure for lupus. The good news is that with the support of your doctors and loved ones, you can learn to manage it. Learning as much as you can about lupus is an important first step.

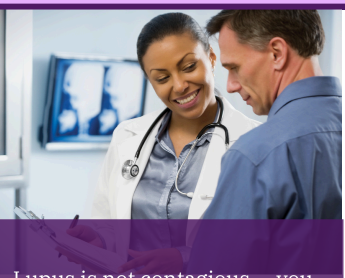
What is lupus?

Lupus is a chronic (long-term) disease that can cause inflammation (swelling) and pain in any part of your body. It’s an autoimmune disease, meaning that your immune system attacks healthy tissue (tissue is what our organs are made of). The immune system is the part of the body that fights off bacteria and viruses to help you stay healthy. Lupus most commonly affects the skin, joints, and internal organs — like your kidneys or lungs.

Who is at risk for developing lupus?

In the United States, at least 1.5 million people have lupus — and about 16,000 new cases of lupus are reported each year. People of all ages, genders, and racial or ethnic groups can develop lupus. But certain people are at higher risk than others, including:

- Women ages 15 to 44
- Certain racial or ethnic groups- including people who are African American, Hispanic/Latino, Native American, or Pacific Islander
- People who have a family member with lupus or another autoimmune disease



Lupus is not contagious — you can't "catch" lupus or give it to someone else.

What causes lupus?

No one knows what causes lupus. Lupus and other autoimmune diseases do run in families. Experts also think it may develop in response to certain hormones (including estrogen) or environmental triggers. An environmental trigger is something outside the body that can bring on symptoms of lupus — or make them worse.

Some common triggers of lupus symptoms include:

- Ultraviolet rays from the sun or fluorescent lights
- Certain antibiotic drugs
- Having an infection
- Exhaustion (feeling very tired)
- Stress to the body, like getting hurt or having surgery
- Emotional stress, like being very busy or having problems at home

What are the symptoms of lupus?

Because lupus can affect so many different parts of the body, it can cause a lot of different symptoms. Keep in mind that these symptoms may come and go.

Symptoms of lupus may include:

- Fatigue (feeling tired often)
- Painful or swollen joints
- Swelling in the hands, feet, or around the eyes
- Headaches
- Low-grade fevers
- Sensitivity to sunlight or fluorescent light
- Chest pain when breathing deeply

People with lupus may also have problems with the skin and hair, including:

- A butterfly-shaped rash on the cheeks and nose
- Hair loss
- Sores in the mouth or nose

Lupus may also cause problems with the blood and blood vessels, like:

- Blood clots
- Low numbers of red blood cells (anemia)
- Fingers and toes turn white or blue and feeling numb when a person is cold or stressed (Raynaud’s phenomenon)

What kinds of doctors treat lupus?

Most people who have lupus will see a rheumatologist. Rheumatologists are specialists who diagnose and treat diseases in the joints or muscles. But because lupus can cause problems anywhere in the body, you may also have other types of doctors on your treatment team — for example, a:

- Dermatologist (for your skin)
- Nephrologist (for your kidneys)
- Cardiologist (for your heart)
- Hematologist (for your blood)
- Neurologist (for your brain and nervous system)

Other types of lupus

When people talk about lupus, they’re usually talking about systemic lupus. But there are other types — including cutaneous lupus, drug-induced lupus, and neonatal lupus.

TREATING LUPUS

If you have been diagnosed with lupus, you're probably wondering how it is treated. One of the most important things to know about treating lupus is that it's a team effort. You and your treatment team will work together to find the combination of medicines that's right for you. Your treatment plan may depend on things like your age, lifestyle, and how healthy you are.

While there's no cure for lupus right now, having the right treatment plan can help:

- Control your symptoms — like joint pain, inflammation (swelling), and feeling tired
- Keep your immune system from attacking your body
- Protect your organs from damage

Treating lupus can be difficult. It can take months — or even years — to find the right treatment plan for you. The good news is there are medicines that can help you feel better.

What medicines can treat lupus?

Because lupus can cause a lot of different symptoms, there are many different kinds of medicines that can treat it. A doctor will need to prescribe some of them — others are available over the counter.

The most common medicines used to treat lupus include:

- Anti-inflammatories to help with inflammation and pain
- Antimalarials to protect skin from rashes and UV light
- Biologics to help your immune system work correctly
- Anticoagulants to help prevent blood clots
- Immunosuppressives to help keep your immune system from attacking your body
- Steroids to help with inflammation

What about alternative medicines?

If you're thinking of trying alternative treatments — like herbal medicines — always talk with your doctors first. Some alternative treatments might not be safe to take with certain medicines, and some could make your symptoms worse. Very few alternative medicines have been tested in people with lupus.

Keep in mind that any medicine you take for lupus can have side effects, and some medicines could put you at risk for life-threatening infections. Talk with your doctors about what changes to watch for with the medicines you're taking. And tell your treatment team right away if you have any side effects.

What do I ask the doctor?

It's normal to have a lot of questions when you and your doctors are working together to develop your treatment plan.

Here are some ideas for questions to ask about your medicines:

- What is the name of this medicine?
- How will this medicine help me?
- Is it okay to take the generic version instead of the brand name?
- How much do I need to take and when?
- What are the possible side effects?
- When will this medicine start to work?
- Is it safe to take with my other medicines?

Work with your doctors to find a treatment plan that's right for you

You may have to try many different medicines before you find a combination that works for you — and that can mean a lot of back and forth with your treatment team. Keep in mind that people with lupus usually see more than 1 doctor for treatment. That means it's especially important to keep everyone on your treatment team updated. Playing an active role in your health care can help you and your doctors find the right medicines for you faster.

Here are some things you can do to play an active role in your treatment:

- Use a journal to keep track of your medicines, the doses you're taking, and any side effects you notice
- Let your treatment team know if you're having side effects or if your symptoms change after starting a new medicine
- Share any concerns you have about your treatment with your doctors
- Write down questions about your treatment for the doctor ahead of time and take them to your appointments
- Ask a friend or family member to go with you to appointments for support — they can also help you keep track of your questions and information about your treatment

COPING WITH LUPUS

Having lupus can make everyday life challenging. When your lupus is active, symptoms like joint stiffness, pain, fatigue, confusion, or depression can make simple tasks difficult – and sometimes impossible. Since these symptoms aren't visible, the people around you may have trouble understanding how you feel.

It's important not to ignore the limitations that come with this disease. However, there are steps you can take to stay involved with work, relationships, and the activities you care about. Start by following these strategies to help you lighten the burden of your illness and maintain a fulfilling life.

Learn how to explain lupus to others

It's important for family and friends to understand lupus so they know how they can help. But since lupus has so many different symptoms that come and go – which may range from manageable to life-threatening – it can be hard to describe.

You may want to start by explaining what lupus is not:

- Lupus is not contagious – you can't "catch" it from someone or "give" it to someone
- Lupus is not like or related to cancer
- Lupus is not like or related to HIV or AIDS

Take time for yourself

While it is important to learn as much as you can about lupus, it's also important to take a break from focusing on your disease when you need to. Living well with lupus often involves making some changes within your family, your profession, and your social circle.

Even though lupus may affect many different areas of your life, it's important to remember that this disease does not define you. Taking time to do activities you enjoy will help you reconnect with yourself.

Then, you can talk about what lupus is:

- Lupus is an autoimmune disease — the immune system attacks your own healthy tissues because it mistakenly sees them as foreign invaders
- Lupus is a chronic disease — people who develop lupus will have lupus for the rest of their lives
- Lupus has many different symptoms and affects each person differently

Explain that lupus is unpredictable. Symptoms can appear, disappear, and change. Knowing this may help other people understand your ups and downs, and also the changes that you may have to make in your life.

Make adjustments as a family

Good communication is important for helping your family adjust to a lupus diagnosis. You'll want to make sure you share details of your lupus symptoms and treatment with your family — keeping them informed can lessen their concerns. It'll also help them understand why you may sometimes say "no" to activities.

These tips can also help your family adjust:

- Maintain a manageable schedule with time for breaks
- Reassign household responsibilities as needed
- Ask friends or extended family members to help around the house when possible
- If you have children, talk to them about your lupus and how it may affect life at home

Manage work with lupus

Many people with lupus can continue to work, although they may need to make changes in their work environment. Depending on what your lupus symptoms are like and what kind of job you have, you may be able to work with your employer to make adjustments so you can stick with your current career.

Use these tips:

- Make small changes to your workstation — like getting a more comfortable desk chair (sometimes called ergonomic chairs)
- Request a different or more flexible work schedule — for example, you could work from home on certain days or start your workday later
- Get help from a vocational rehabilitation counselor (job coach for people with disabilities) to find work that's more manageable

If the physical or mental demands of your job become overwhelming, you might benefit from changing jobs or switching to part-time hours. In some cases, not working at all may be the best choice for your health. You can learn about disability benefits from your company's human resources office or from the Social Security Administration (SSA).

If you're concerned about what will happen if you tell your employer you have lupus, remember that people with long-term health problems like lupus are protected by the Americans with Disabilities Act (ADA). The ADA says that employers must offer accommodations to help a person to meet the requirements for their job.

Manage school with lupus

Many people who have lupus are successful at school while pursuing their dreams. School at any level can be demanding, so you'll want to make sure you're prepared to balance tests and homework with the need to take care of your health.

To do well in the classroom while keeping your lupus in check, make sure you:

- Don't overload your schedule — try to leave time for relaxation
- Communicate with the school about your lupus — make sure you register with the school accessibility office and consider telling roommates, your academic advisor, professors, and staff at the student health center about your lupus
- Learn about financial assistance opportunities — you might be eligible for federal financial aid and a number of scholarship programs
- Think about accommodations you might need — if you expect to miss class sometimes or think you may need extra time on tests, make sure you talk to your professors or other staff members

Find the support you need

Staying connected socially can help you put lupus in perspective and build a support system. Make sure you spend time doing activities you enjoy with other people, and identify family members and friends you can turn to when you need to talk to someone.

In addition to sharing with your family and friends, there are other ways you can find support:

- Individual therapy can help you cope with issues like depression and anxiety
- Couples therapy can help you and your partner communicate as you both adjust to your diagnosis
- An online support group can help you engage with other people affected by lupus and learn tips from people dealing with similar experiences

LIVING WITH LUPUS

If you’ve been diagnosed with lupus, you may need to make some changes to your daily routine to help manage your symptoms. Living with lupus can be difficult, and it’s normal to feel overwhelmed — especially at first.

The good news is there’s a lot you can do to stay on top of your health and manage your symptoms. Start by learning some steps you can take to develop healthy habits.

Make your treatment plan work for you

One of the most important tools you have to manage lupus is yourself — your effort, your attention, and your awareness of your body.

Remember to:

- Follow instructions from your doctors
- Take your medicines as prescribed
- Keep a medical diary to record your symptoms, medicines, and side effects
- Talk with your doctor about your questions and concerns — especially if you need help with side effects
- Pay attention to how you feel, and share what you notice with your doctors
- Tell your doctor right away if your symptoms change or get worse

Eat healthy and be physically active

Healthy living is good for everyone — but for people with lupus, it's especially important. Good nutrition and physical activity can help you feel better.

Use these tips to help you eat healthy and be active:

- Eat lots of fruits, vegetables, and whole grains
- Always check with your doctors before taking any herbs, vitamins, or dietary supplements — they can affect the medicines used to treat lupus or make your condition worse.
- Choose healthy protein foods — like lean meats, poultry, and seafood
- For bone health, eat foods with lots of calcium — like spinach and dairy
- For heart health, eat foods with Omega-3 fatty acids — like salmon and walnuts
- Try walking, swimming, or biking — these low-impact activities help your bones and muscles without hurting your joints
- Try gentle yoga to relieve stress and loosen tight muscles — ask your treatment team what kind of yoga is best for you

Manage fatigue

Most people with lupus have fatigue (feel tired often).

Try these tips to beat fatigue:

- Get enough sleep — aim for at least 7 hours each night
- Take breaks during the day to rest and recover — there's no shame in needing a nap
- Make changes to your daily routine when you need to

Manage lupus fog

Many people with lupus have “lupus fog” (feelings of confusion and memory loss).

Try these ideas to clear the fog:

- Focus on 1 task at a time
- When someone tells you their name or an important piece of information, try repeating it out loud and writing it down
- Before a doctor's appointment, write down your questions — and bring your medical diary so you can tell the doctor about your symptoms and side effects
- Keep a calendar to record appointments and reminders

Manage stress

For many people with lupus, stress can trigger your symptoms — or make them worse.

Use these tips to manage everyday stress:

- Plan ahead for how you’re going to use your time — decide what’s most important and do that task first
- Ask for help when you need it
- Make time for fun, relaxing activities
- Try not to sweat it if you don’t get everything done or have to cancel plans — remember, your health comes first

Manage pain

Most people with lupus have joint pain, muscle pain, or headaches. Always check with your doctors before trying new ways to manage your pain

Smoking can trigger lupus symptoms and make them worse. If you smoke, make a plan to quit.

Protect yourself from ultraviolet (UV) light

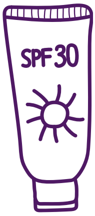
Most people with lupus are sensitive to UV light — and it can trigger lupus symptoms. Follow these tips to stay protected:

� Use sunscreen with SPF 30 or higher that blocks both UVA and UVB rays

� Wear long sleeves, pants, and wide-brimmed hats made of fabrics that protect you from the sun

� Plan outdoor activities for early in the morning or later in the evening

People with lupus can be sensitive to indoor lighting. If indoor light bothers you, try putting light shields over fluorescent bulbs. You can also buy light bulbs that send out low amounts of UV radiation, like LED lights.



Here are some ideas to try:

- Use heat or cold packs
- Talk with your treatment team about taking over-the-counter pain medicines
- Try relaxation techniques — like meditation, breathing exercises, or gentle yoga
- Consider trying healing techniques — ask your treatment team about acupuncture, acupressure, or biofeedback

Protect yourself from infections

Lupus increases your risk of infections. Use these tips to protect yourself:

- Wash your hands often
- Clean and protect any cuts or wounds
- Avoid people with colds or other illnesses you could catch
- Talk with your doctors about taking antibiotics before procedures
- Tell a doctor right away if a cut becomes red, painful, or swollen
- Tell a doctor right away if you have a fever over 100°F

If you have lupus, it's a good idea to get certain vaccines— but you may not be able to get others. Always check with your doctors before you get vaccines or allergy shots.

Get help living with lupus

Don't be afraid to get professional help if lupus interferes with your life.

Here are some types of professionals who can help with the physical symptoms of lupus:

- Cognitive therapists can help with lupus fog
- Occupational therapists can make your workspace and tasks more manageable
- Physical therapists can help with joint problems and improve your strength

You may need to make some changes in your life because of lupus. But you can learn to live with your symptoms— and keep doing the things you want to do.

Centers for Disease Control and Prevention
https://www.cdc.gov/lupus/index.htm

Mayo Clinic
https://www.mayoclinic.org/diseases-conditions/lupus

GSK
https://www.usinlupus.com/

Aurinia Pharmaceuticals
https://www.auriniapharma.com/

Lupus Research Alliance
https://www.lupusresearch.org/

United States Social Security Administration
https://www.ssa.gov/

U.S Equal Employment Opportunity Commission
https://www.eeoc.gov/

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