



COULD I HAVE LUPUS?

Information for People Who May Have Lupus

TABLE OF CONTENTS

What is lupus?	2
Take the Lupus Test	2
How do you get lupus	3
Who gets lupus	3
How can I tell if I have lupus	4
What are the symptoms of lupus	5
What if I already know I have lupus?	6
What's next	6
How can I expect to feel.....	7
What kind of medical treatment will I receive.....	8
What is a flare/signs of a flare	8
Talking and working with my doctor.....	9
What else can I do to stay healthy?.....	10
What other people with lupus want me to know.....	11
Lupus and Your Rights	13
Where can I get information on lupus	14
Educational Materials.....	16
Other Resources.....	16

ACKNOWLEDGEMENTS

WHAT IS LUPUS?

TAKE THE LUPUS TEST

- Have you ever had achy, painful or swollen joints for more than three months?
- Do your fingers and or toes become pale, numb or uncomfortable in the cold?
- Have you ever had any sores in your mouth for more than two weeks?
- Have you ever been told that you have a low blood count, anemia, or a low white cell count?
- Have you ever had a red rash or color change on your face in the shape of a butterfly across the your nose and cheeks?
- Have you ever had an unexplained fever (over 100 degrees) for more than a few days?
- Have you ever had chest pain with deep breathing for more than a few days?
- Have you ever been told you have protein in your urine?
- Have you ever had extreme fatigue or do you feel tired all the time or weak for days or even weeks at a time, even after a full night's sleep?

If you answered “yes” to three or more questions, you may have lupus. This booklet is for you.

DID YOU KNOW THAT...

- ... people of different races, ethnicities and ages, both men and women, can be **affected by lupus**?
- ... the symptoms of **lupus** are **different for each person** who has it?
- ... there is help out **there to fight lupus**?
- ... if you have lupus, chances are you have your own questions.

This booklet is designed to help try to answer them.

WHAT IS LUPUS?

Lupus is an autoimmune (aw - toe - ih - myoon) disease with many *different types of symptoms* and can affect *different parts of the body*. There is no one single test that determines whether or not you have lupus.

Your health care provider or doctor can tell if you have lupus by your history of symptoms and by testing your blood and urine.

What does “autoimmune disease” mean exactly?

Your body’s immune system is made up of millions of cells whose job it is to fight invading germs, viruses and other things that end up in your body that don’t belong there. When you have an autoimmune disease, instead of attacking germs, the immune system attacks healthy cells and tissues, or the things your body needs to keep it healthy.

Are there different types of lupus?

There are three (3) types of lupus:

1. **Systemic lupus erythematosus** (eh-rith-eh-muh-toe-sus) is the most common form. It is sometimes referred to as SLE. This form of lupus involves different parts of the body, including the kidneys, brain, heart and lungs. Symptoms of this form of lupus can be mild or serious.
2. **Discoid lupus erythematosus** comes in the form of a red rash or may cause the skin on the face, scalp or elsewhere to change color. It is usually only causes changes of the skin. People with discoid lupus can also have SLE.

HOW DO YOU GET LUPUS?

Doctors are not sure what causes lupus. Some research shows that it runs in families and can be triggered by your genes. If you have lupus, it is possible that others in your family may also have lupus. However, not all people with similar genes get lupus.

Lupus is **NOT** contagious. You can’t give or get lupus by being in close contact with someone with lupus.

Lupus is **NOT** AIDS. It has nothing to do with HIV or AIDS.

Lupus is **NOT** cancer.

Researchers are still working to understand why some people are affected by lupus and others are not.

3. **Drug-induced lupus** can occur when people take certain medications. While symptoms are similar to SLE, they are usually milder and disappear once the medication is stopped.

WHO GETS LUPUS?

Anyone can get lupus - men, women and children. But for reasons doctors don't understand, 9 out of 10 people with lupus are women.

Lupus is most common in women between the ages of 15 and 44.

African American/black women are three times more likely to get lupus than white women. Lupus is also more common among Hispanic/Latino, Asian and American Indian women. African Americans and Hispanics/Latinos tend to develop lupus at a younger age, have a greater amount of signs and more severe symptoms.

Babies born to women with lupus can also get lupus. This can sometimes cause serious problems that affect the baby's heart and liver. However, with good health care, most women with lupus have normal pregnancies and healthy babies.

HOW CAN I TELL IF I HAVE LUPUS?

If you think you might have lupus, go see

your doctor. Before your doctor visit, make a list of your symptoms. Take the list with you when you go to your doctor.

You can also use the checklist of the common symptoms of lupus (*see list, next page*).

Besides listening to your medical history and looking at your checklist, your doctor will give you a complete physical exam to look for rashes and other signs that something may be wrong. Your doctor may also test your blood and urine. Your blood and urine can provide clues about how your immune system is working.

If your doctor suspects you have lupus, one of the blood tests you will probably have is called an **Anti-Nuclear Antibody** or an **ANA** test. This test is often positive in people who have lupus. The ANA test can also be positive in people who do not have lupus. This is why a history of symptoms and a physical exam are important. The doctor may refer you to a specialist, to review the history of your symptoms and to do further tests.

Your doctor may also arrange for you to have a skin or kidney biopsy. A biopsy is a procedure that removes tiny pieces of tissue. The skin and kidney tissue is then examined through a microscope to check for signs of lupus.

No single test can prove you have lupus.

It may take some time before your doctor can determine whether lupus is the cause of the symptoms you have.

WHAT ARE THE SYMPTOMS OF LUPUS?

Check the following list of the common symptoms of lupus. If you have any or some of these symptoms, you should discuss them with your doctor.

- A red rash or color change on the face, often in the shape of a butterfly across the nose and cheeks
- Painful or swollen joints
- Unexplained fevers
- Chest pain with breathing
- Swollen glands
- Feeling tired all the time
- Unusual hair loss
- Pale or purple fingers or toes from cold or stress
- Skin reactions to the sun (skin “breaking out” after being in the sun)
- Low blood counts or anemia
- Depression, trouble thinking and/or memory problems
- Mouth sores
- Unexplained seizures (convulsions)
- More than one miscarriage
- Unexplained kidney problems

Each person’s body reacts differently to having lupus. Some people with lupus may

feel tired and have joint pain. Others may have rashes, swollen knees, kidney trouble and/or fever. More than likely, you will not have all of the possible symptoms of lupus.

If you have lupus, you may have symptoms that affect two or three parts of your body. These symptoms may not all occur at the same time. Symptoms may come and go over weeks, months, and in some cases years.

People with lupus can also have other types of autoimmune diseases. The only way to know if your symptoms are from lupus is to discuss your symptoms with your doctor and to get further tests.

WHAT IF I ALREADY KNOW I HAVE LUPUS?

NOW THAT I KNOW I HAVE LUPUS, WHAT'S NEXT?

If you have been diagnosed with lupus, you may have had the symptoms for longer than you realize. Since the symptoms of lupus differ from one person to the next, and because many of the symptoms are like other diseases, lupus is hard to diagnose. It is likely that both you and your doctor have been frustrated trying to figure things out. Now that you know you have lupus, you can begin to take better control of your health. You and your doctor can work on a plan to improve the way you feel.

There is treatment for lupus. Treatment may require that you take certain medications. You may also need to change some of the things you normally do. There are things you can do to improve the symptoms of lupus and the effects of lupus on your body.

Your doctor will suggest different types of medication depending on your lupus symptoms. These include taking aspirin or stronger medications that work on the immune cells of your body and that help fight the effects of lupus.

Other things that you may need to do include

- Getting plenty of rest so you won't feel too tired

- Avoiding too much sun so that skin rashes won't develop

- Using sunscreen to help avoid the effects of the sun on your skin

- Exercising and relaxing to help control stress

You should speak with your doctor to discuss in detail what you need to avoid and what things you can do to make your lupus better.

HOW CAN I EXPECT TO FEEL?

Lupus is different for everyone who has it. You can expect that there will be times when you look and feel good and other times when you don't.

You may feel fatigued or tired. Feeling tired or fatigued is part of the disease and is very common. How tired you feel may change over the day or week. It is good to get to know when your energy levels tend to be high or low.

You can use the energy calendar in this booklet to start keeping track of your energy levels (*see pullout at center of booklet*). Use the energy calendar and show it to your doctor. You can use it to figure out the best times of the day for you to rest, work or do things with friends or family.

Sometimes you may feel angry or sad because you have lupus. These feelings are normal. People may react to you in ways you don't like or don't understand. This may also make you angry or sad. Many people are unaware of what lupus is and what having lupus means for you. You may feel misunderstood. When you have these feelings, let your doctor know. You can talk things over.

People with lupus may feel like they are **all alone**. The changes you may need to make because you have lupus can sometimes be hard. Consider joining a local **support group** (*see support groups list on page 14*). Many people are relieved to find that they are not alone and learn new ways of coping with lupus. There is information at the end of this booklet to help you locate a support group that can help you.

You should fully discuss your feelings with your health provider and others who are available to support you. There are

Some things you can do to keep energy levels up are:

- Slow down, do things slowly
- Plan to do things during a time of the day when your energy tends to be high
- Don't do everything at once. Spread your activities over the day or week as much as possible
- Get plenty of rest and sleep. If possible, plan to take a nap during the day.
- Try to avoid stress, take time to relax. Talk with your doctor about ways to relax
- Ask and let friends and family help with whatever you have to do

people available to help you, if you let them.

WHAT KIND OF MEDICAL TREATMENT WILL I RECEIVE FOR LUPUS?

Since lupus is different for everyone who has it, your treatment will depend on your symptoms and needs. For example, if you have swollen joints or a fever, your doctor may give you aspirin. If you have a rash, he or she may prescribe a cream. For more serious symptoms, stronger medicines are needed. These may include medications that decrease inflammation or other medications that work on your immune system.

It is important to let your doctor know if you are taking any other medication, including herbal items and bottled medicine you may get from your local drug store. These other medicines may effect your lupus medication and how well they work in your body.

You may only need to take medication for a short period of time. Your doctor will only suggest medications you need for the shortest period of time to treat your lupus.

Make sure that you tell your doctor if you have any problems with the medications he or she prescribes. Working together, you and your doctor can find the best treatment plan for your symptoms and needs.

You may find that working with a team of health care workers can help you better control your symptoms. For example, many people with lupus work with a rheumatologist (room-a-tol-o-jiist). A rheumatologist is a doctor who treats diseases that affect the joints and muscles, like lupus. Other health care professionals who can help you manage your symptoms include occupational therapists, dermatologists and dietitians. You can ask your doctor for referrals to any of these professionals.

WHAT IS A LUPUS “FLARE”?

When the signs of lupus appear, it’s called a “flare.” Symptoms can come and go. You may have a rash, joint pain or swelling one week and be symptom-free the next. Even if you take medication for lupus, your symptoms can become worse at times. Sometimes a flare can occur if you have spent time in the sun or after a hard day at work.

There are ways to know when a flare is coming. Many people suddenly feel more tired or experience dizziness, a fever, rash or stomach pain just before a flare. Learning to recognize when a flare is coming can help you take steps to handle it better. You may also help prevent flares by making sure you get enough rest, eat a healthy diet, limit the time you spend in the sun and through moderate exercise.

Daily/Weekly Energy Calendars

How energetic do you feel today?

This calendar will help you keep track of your energy level over the next week.

1. Fill in the circle that reflects how you feel. Do this for a couple of weeks to track your energy patterns.
2. At the end of the week, draw a line connecting the circles to see how much you're improving over time.
3. Take this calendar to your next doctor's visit and discuss how you've been feeling.

Week: _____

DAY	Monday			Tuesday			Wednesday			Thursday			Friday			Saturday			Sunday			
	AM	N	PM	AM	N	PM	AM	N	PM	AM	N	PM	AM	N	PM	AM	N	PM	AM	N	PM	
Normal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very Tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

AM = Morning

N = Afternoon

PM = Evening

You can make copies of these calendars to use as often as you like.

Daily Energy Calendar

How energetic do you feel today? This calendar will help you keep track of your energy levels.

1. Fill in the circle that reflects how you feel.
2. At the end of the day, draw a line connecting the circles to see your energy level patterns.
3. Take this calendar to your next doctor's visit and discuss how you've been feeling.

Day: _____

	Morning					Afternoon					Evening					
Time of Day	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10
Normal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very Tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Day: _____

	Morning					Afternoon					Evening					
Time of Day	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10
Normal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very Tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Day: _____

	Morning					Afternoon					Evening					
Time of Day	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10
Normal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very Tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Day: _____

	Morning					Afternoon					Evening					
Time of Day	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10
Normal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very Tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

You can make copies of these calendars to use as often as you like.

Signs that a lupus flare may be starting:

- Fatigue (out of proportion with what you would usually expect)
- Persistent weakness
- Aching all over
- Fever
- Persistent loss of appetite
- Weight Loss
- Hair Loss
- Recurring nose bleeds
- Sores on the roof of the mouth
- Unexplained skin rashes anywhere on the body
- Hives, or raised itchy areas on the skin
- Sores on the skin
- Painful or swollen joints
- Stiffness of the joints when waking up in the morning
- Chest pain that increases with breathing
- Shortness of breath
- Coughing up blood
- Unusual headache
- Nausea or vomiting
- Recurring belly pain
- Puffy eyelids
- Blood in the urine

If you think you are having a flare contact your doctor as soon as you can. You may need to change your medication or add a new medication for a short period of time.

TALKING AND WORKING WITH YOUR DOCTOR

You and your health provider are the best things in the fight against lupus. You have an important role to play in your care. You can and should be a partner in your own health care. Lupus is a life long disease.

What can I do to partner with my health provider in my care?

Talk with your doctor; ask questions if things are not clear; bring up problems, even if your doctor doesn't ask you to.

Be ready with your questions before your doctor visits. Make a list of the questions you want to ask. Think about bringing a family member or friend to help you talk with the doctor. Let your friend or family know in advance what you want to know from the visit. If you forget this person can help remind you.

Try to update the doctor if you have had any visits with other health care providers, or if you had to go to the emergency room for any reason. Let your health provider know how you are doing on your medication and if you think you are having any side effects. Let the doctor know how you have been feeling since the last office visit.

Help your doctor work with you to manage your lupus. Discuss your difficulties and work together to create goals and an action plan to overcome the difficulties. *Take control of your lupus.*

If you have new symptoms, tell your doctor briefly what has been going on. He or she needs to know what is working and what is not from your point of view. If lupus is affecting other parts of your life, such as work or family, let the doctor know about this too. Sometimes your doctor can help you in these areas or can connect you to others who can help more.

Learn as much as you can about lupus for yourself. You can use some of the helps and information listed at the end of this booklet. This will help you to work closer with your doctor in your care.

WHAT ELSE CAN I DO TO STAY AS HEALTHY AS POSSIBLE?

It is important to think about every part of you when you think about your health. While taking your medication is important, don't forget the other things that are important for good health. Like staying connected with friends and social activities.

Exercise

Once your doctor says that it's okay, try an exercise program, exercise can help you stretch and strengthen the muscles that support and protect joints affected by lupus. You may also want to ask your doctor if you can participate in an aerobic exercise program to improve your overall fitness. Other

techniques, such as yoga or meditation, can help reduce day-to-day stress that can trigger symptoms.

Avoid sun and harmful light

Having lupus means you need to avoid exposure to the sun. People with lupus are sensitive to the sun and different types of light. Even light rays from a Xerox or copy machine and certain types of light bulbs can increase the chance of skin problems. Try to minimize sun exposure through car windows.

It is a good idea to use a sunscreen lotion regularly and clothing that fully covers the arms and legs. Sometimes you may need to wear wide brimmed hats to protect your ears, neck and face from the sun. Even on cloudy days there is still a risk for exposure to certain types of light rays that could be harmful to your skin. So protect your skin at all times.

Eat a balanced diet

People with lupus need to avoid the sun because of possible harm to the skin. The skin helps the body make Vitamin D, which is important for bone health. Talk to your doctor about vitamin supplements or a nutritionist about vitamin intake and the proper foods for good nutrition due to the risks of lupus.

Avoid stress

Stress can worsen lupus symptoms and can lead to flares. Stress can also make you feel

tired and fatigued. Try some relaxation techniques that you can learn about from your doctor (such as meditation). Try avoiding situations and people that increase your stress levels. Talk to your health team or doctor about how you are feeling and coping with your lupus. Share your feelings with family and friends who are supportive. Take advantage of support groups and counseling if needed.

Keep regular appointments

Schedule and keep regular appointments with your doctor and rheumatologist. This will keep them informed about how you are doing. This will also help the doctors check on how well your medications are working.

WHAT OTHER PEOPLE LIVING WITH LUPUS WANT YOU TO KNOW

There are people who have been living with lupus and its effects on their body for a long time. They have been involved with different doctors and clinics and hospitals. They wanted to let you know some of what they have learned to help you on your life journey with lupus.

Here are some of their suggestions:

- * Discuss your medication with your doctor and educate yourself about what they are, the side effects and interactions. Don't take medication without understanding why.
- * Understand the difference between brand name and generic medication.
- * Make sure to avoid medications that contain sulfur. Lupus makes your body sensitive to medicines that contain sulfur. Always check labels for sulfur and check with

Be prepared and expect to possibly experience and to have to cope with:

- Being misunderstood by employers
- Being misunderstood by family, friends and everyone
- Confusion
- Dental problems
- Depression
- Dry mouth
- Feelings of isolation
- Insomnia
- Loss of appetite
- Loss of energy
- Memory loss
- Mental fogs
- Mood Swings
- Nausea
- Nose bleeds
- Strange rashes
- Weight gain

your doctor before you take new medications or drug store medicines.

- * Consider getting a Medical-Alert bracelet for lupus, for the times you may be without your medical record and need emergency care.
- * Consider getting a summary of your medical history and record yearly. Carry it with you, especially when you need emergency care.
- * Try to have a family member or friend, who knows you and about your lupus, go with you when you get sick. Do not get emergency care alone, you may need an advocate.
- * Ask your doctor for information or a referral to speak to someone about your rights and resources related to what to do when you can't work because of illness related to lupus. Find this out ahead of time before you get ill and can't work.
- * Carry a list of your medications in your purse or wallet.
- * Be sure to drink plenty of water!

and that make you feel better. Take time for yourself, for family and for friends. Try to be as healthy as you can be physically, mentally and spiritually. Talk about how you feel, exercise, understand the disease and how to treat it, and you will gain better control of your life.

One of the most important things you can do to take control of lupus is to *keep a positive attitude.* Do the things you enjoy

LUPUS AND YOUR RIGHTS

There are laws that may help people with chronic illnesses such as lupus. You may need to find out more information or consult a lawyer. Here is some information that you should know.

COBRA

Employers with 20 or more employees must offer the option of continuing health insurance coverage for a period of time if you become unemployed. This is known as the COBRA requirement. You would have to pay the cost of the health insurance coverage but can get whatever health insurance continued that you had before becoming unemployed

Family Medical Leave Act

This is a federal law that allows an employee to take up to twelve (12) weeks of unpaid leave per year to recover from a serious illness. The employer must allow you to return to the same job or a similar job that was held before the illness occurred.

Americans With Disabilities Act of 1990 (ADA)

It is unlawful for an employer to discriminate against you if you are qualified for your job but have a disability. If you have a disability and are qualified for your job your employer may be required to provide

“reasonable accommodation.” This means your employer has to make changes in your place of work that will help you continue working if you have a disability. Changes must be made so long as these changes would not be an “undue hardship” on the employer. For more information, go to www.ada.gov.

More detailed information on your rights can be found on the Internet at www.eeoc.gov/facts or www.angelfire.com/ca/lupushome or through your local library. You may also be able to find out more about your rights through the information using the sources listed at the end of the booklet.

WHERE CAN I GET MORE INFORMATION ON LUPUS?

SUPPORT GROUPS

Women of Courage (WOC) Support Group

A grassroots volunteer effort and support group for women of color living with lupus. Contact: Beverly Gibson, Interim President. 111 Locust Street, No. 3C3
Woburn, MA 01801
Phone: 617-417-0836

Lupus Foundation of America, Massachusetts Chapter

Monthly support groups and programs. Check calendar at www.lupusmass.org for current locations and programs or call the toll free number.
40 Speen Street, Suite 205
Framingham, MA 01701
Toll Free: 877-NOLUPUS (877-665-8787)
Web: www.lupusmass.org

Minorities with Disabilities Advocacy Center/ Vivienne S. Thomson Independent Living Center

Now located at the ABCD Independent Living Center.
Peer support and peer counseling, skills training for independent living, social services system advocacy and self and co-advocacy skills training. Also provides information and referrals to rehabilitation agencies, other disability resource agencies and

other services for people with disabilities.
Phone: 617-288-9431

Lupus Foundation of Greater Washington
Support information, education, chat and discussion groups for people with lupus.
Web: www.lupusgw.org

Arthritis & Lupus Support Group, New England Baptist Hospital

Contact: Janice Sullivan, 617-754-5610.
125 Parker Hill Avenue
Boston, MA 02120
Phone: 617-754-5410

EDUCATIONAL MATERIALS

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

Patient education booklets NIAMS Information Clearing House:

The Many Shades of Lupus: Information for Multicultural Communities

NIH Publication No. 01-4958

Web: www.niams.nih.gov/hi/topics/lupus/shades/index.htm

Handout on Health: Systemic Lupus Erythematosus

NIH Publication No. 97-4178

Web: www.niams.nih.gov/hi/topics/lupus/slehandout/index.htm

For copies, contact:

NIAMS Information Clearinghouse

1 AMS Circle

Bethesda, MD 20892-3675

Toll-free: 877-22 NIAMS (226-4267)

TTY: 301-565-2966

Fax: 301-718-6366

Lupus: A Patient Care Guide for Nurses and Other Health Professionals

Guidebook with detailed review and information on lupus, **includes patient information sheets covering a range of topics.**

Web: www.niams.nih.gov/hi/topics/lupus/lupusguide/outline.htm

*Free copies (limited number while available) can be obtained from the Massachusetts League of Community Health Centers

Department of Clinical Health Affairs

100 Boylston Street, Suite 700

Boston, MA 02116

Phone: 617-426-2225

Fax: 617-426-9864

Web: www.massleague.org

Massachusetts LUPUS NEWS

A Publication for Members of the Lupus Foundation of Massachusetts, Individual membership starts at \$20.00.

40 Speen Street, Suite 205

Framingham, MA 01701-1898

Phone: 508-872-5200

Toll-free: 877-NO LUPUS (665-8787)

Email: info@lupousmass.org

Web: www.lupusmass.org

SPANISH LANGUAGE MATERIALS (EN ESPAÑOL)

¿Tengo Lupus? / Do I Have Lupus?

(*A free, bilingual booklet in Spanish and English)

Published by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). For copies of the booklet contact:

NIAMS Information Clearinghouse
1 AMS Circle
Bethesda, MD 20892-3675
Toll-free: 877-22 NIAMS (226-4267)
TTY: 301-565-2966
Fax: 301-718-6366
Web: www.niams.nih.gov/hi/topics/lupus/tengo/index.htm

Asociación Lupus Argentina

An Internet website with many informative and educational articles. Website is in Spanish. Titles include - What is Lupus? (Qué es el Lupus), Lupus and the Sun (El Lupus Y el Sol), Living with Lupus (Conviviendo con Lupus).

Web: www.drwebsa.com.ar/alua

OTHER RESOURCES

ORGANIZATIONS/AGENCIES

*Massachusetts Department of Public Health
Bureau of Environmental Health Assessment*

Phone: 617-624-5757

Lupus Foundation of America, Inc.

2000 L Street, N.W., Suite 710

Washington, DC 20036

Phone: 202-349-1155

Toll-free: 800-558-0121 (information request line)

Fax: 202-349-1156

E-mail: lupusinfo@lupus.org

Web: www.lupus.org

Lupus Foundation of America, Massachusetts Chapter

40 Speen Street, Suite 205

Framingham, MA 01701

Toll-free: 877-NO LUPUS (665-8787)

Web: www.lupusmass.org

Lupus Foundation of Greater Washington

Phone: 703-644-0058

Email: info@lupusgw.org

Acknowledgements

This project began in 2002 with funding through the Health Resources and Services Administration, Bureau of Primary Health Care and the Office of Minority Health and Human Services for the Lupus Awareness Project. Several people have made completion of this project possible.

Special note is made of the tremendous support received from the Women of Courage, a group of women who have found a way to provide support for themselves and who cope with lupus every day. They welcomed me with open arms and were quite frank about the medical profession and what doctors can do to improve the care for people who have lupus. This information booklet could not have been done without them.

Sadly, Bobbie Drake-Saucer, President of the Women of Courage, whose energy in the fight for better understanding and support for persons living with lupus was never ending did not live to see the completion of this project. She died suddenly before this project was completed. She will be missed, but her spirit and passion live on.

To Cynthia Parker of the Interaction Institute for Social Change and her staff, I thank you for being there and helping to get to what was needed to inform this project.

This writing also could not have been completed without the support of a group of professionals that agreed to serve as an advisory group. They included Bobbie Drake-Saucer (Women of Courage), Elisabeth E. Lanjuin, (Lupus Foundation of Massachusetts), Janice Sullivan (New England Baptist Hospital), Suzanne K. Condon (Office of Environmental Assessment, Massachusetts Department of Public Health), Patricia A. Fraser, MD (Brigham & Women's Hospital), Elmer R. Freeman (Center for Community Health, Evaluation and Service), and Judith Ann Levine (Arthritis Foundation Massachusetts Chapter).

And finally, thanks to my colleagues at the Massachusetts League of Community Health Centers for their assistance with this project.

Thank you.

Gisele Thornhill, MD, MPH



Produced by
Massachusetts League of
Community Health Centers

Funded by
Health Resources and Services Administration
Bureau of Primary Health Care
Office of Minority and Women's Health

