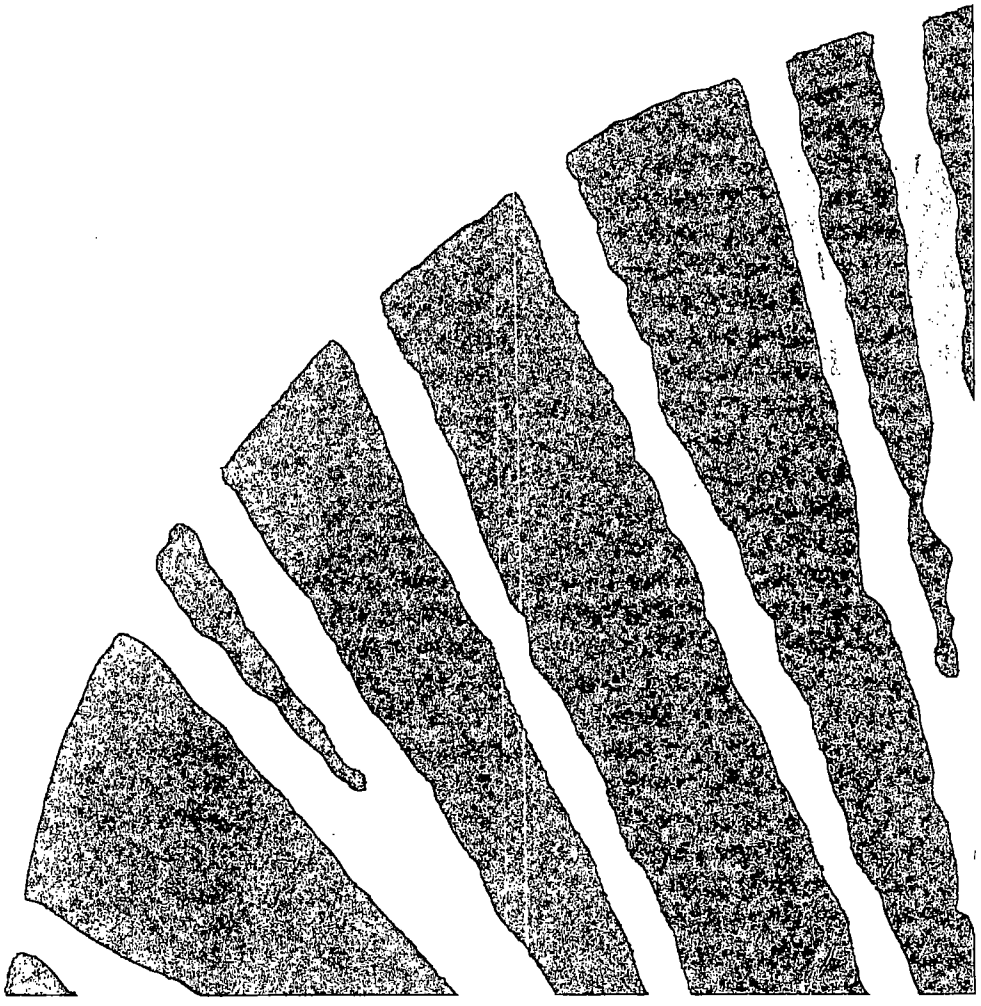
LUPUS

Foundation of America, Inc.

PHOTOCOPY
PRESERVATION



Get into the loop.™

significant deviations from a balanced diet may have a
ffect on a network as complex as the immune system.

been suggestions about various foods and the
of lupus. One example is fish oil. However, these diets
used only in animals with limited success and should
e the mainstay of a person's diet.

ıancy and Lupus

tion of concern to many families is whether or not a
ıg woman with lupus should risk becoming pregnant.
t general view is that there is no absolute reason why a
th lupus should not get pregnant, unless she has
o severe organ involvement (i.e., central nervous
lney, or heart and lungs) which would place her (the
risk. However, there is some increased risk of disease
ing or immediately after (3 to 4 weeks) pregnancy. If a
ıonitored carefully, the danger can be minimized. A
voman with lupus should be closely followed by both
ıcian and her "lupus doctor."

ıed earlier in the brochure, a condition called primary
ıolipid syndrome can be secondary to lupus and
pregnancy. Antibodies against specific auto antigens
found on coagulation factors can cause blood to clot
normal or in some cases, not at all. Antiphospholipid
can be found in many patients with lupus and pose a
ısk to pregnant women with lupus since their presence
ociated with miscarriages.

ıosis

ea that lupus is generally a fatal disease is one of the
st misconceptions about this illness. In fact, the
of lupus is much better today than ever before. It is true
al science has not yet developed a method for curing
some people do die from the disease. However, with
thods of therapy, deaths from lupus are uncommon,
percent of people with lupus live more than 10 years
osis. People with non-organ threatening disease can
rd to a normal lifespan if they follow the instructions of
ian, take their medication(s) as prescribed, and know
ek help for unexpected side effects of a medication or a
estation of their lupus. Although some people with
severe recurrent attacks and are frequently hospitalized,
le with lupus rarely require hospitalization, especially if
reful and follow their physician's instructions.

ch brings unexpected findings each year. The progress
eatment and diagnosis during the last decade has been
ın that made over the past 100 years. It is therefore a
ea to maintain control of a disease that tomorrow may

The Lupus Foundation of America

The Lupus Foundation of America (LFA) was incorporated as a nonprofit health agency in 1977. The purpose of the LFA is to assist local chapters in their efforts to provide supportive services to individuals living with lupus, to educate the public about lupus, and to support research into the cause and cure of lupus. Last year over 265,000 people received service from the LFA and its chapters.

Since its establishment the LFA has remained a grassroots, volunteer-driven organization. Volunteers, through an extensive network of over 500 constituent chapters, branches, support groups and International Associated Groups, provide the majority of services which link the LFA to the thousands of people with lupus, their families and friends. Last year LFA volunteers contributed over 525,000 hours of service at the local and national levels.

The Lupus Foundation of America is the largest lupus group in the world with nearly 45,000 members in 93 chapters throughout the US. Thousands of others are associated with the LFA through the International Associated Groups in 37 countries worldwide. The LFA and its chapters contributed more than $1,870,000 for lupus research in the past two years.

The LFA sets standards, provides direction and support to its chapters, and leads the way in operating a patient-oriented, nonprofit, voluntary health agency in an ethical and professional manner. The LFA has developed specific services and programs to assist chapters in meeting patients' needs and organizational goals. These include chapter support, volunteer leadership training, research, patient education programs, public awareness activities, professional education, advocacy, and resource development.

Contact the Lupus Foundation of America or the local chapter in your area for more information about lupus or the programs and services the LFA offers.

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What Is Lupus?

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To whom should a person go for a diagnosis of lupus? Most individuals usually seek the help of their family doctor first, and this is often sufficient. However, when unresolved questions arise or complications develop, another opinion from a specialist may be advisable. The choice of specialist depends on the problem. For example, you would see a nephrologist for a kidney problem or a dermatologist for a skin problem. Most often, a rheumatologist or clinical immunologist specializing in lupus is recommended. Referrals can be made through your family doctor, the local medical society, or the local Lupus Foundation of America chapter.

Flares (What Triggers Lupus?)

What triggers an attack of lupus in a susceptible person? In some, exposure to the sun causes sudden development of a rash and then possibly other symptoms. In others, an infection, perhaps a cold or a more serious infection does not get better, and then complications arise. These complications may be the first signs of lupus. In still other cases, a drug taken for some illness produces the signaling symptoms. In some women, the first symptoms and signs develop during pregnancy. In others, they appear soon after delivery. Many people cannot remember or identify any specific factor. Obviously, many seemingly unrelated factors can trigger the onset of the disease.

Treatment

For the vast majority of people with lupus, effective treatment can minimize symptoms, reduce inflammation, and maintain normal bodily functions.

Preventive measures can reduce the risk of flares. For people who are photosensitive, avoidance of (excessive) sun exposure and/or the regular application of sun screens will usually prevent rashes. Regular exercise helps prevent muscle weakness and fatigue. Immunization protects against specific infections. Support groups, counseling, talking to family members, friends, and physicians can help alleviate the effects of stress. Needless to say, negative habits are hazardous to people with lupus. These include smoking, excessive consumption of alcohol, too much or too little of prescribed medication, or postponing regular medical checkups.

Treatment approaches are based on the specific needs and symptoms of each person. Because the characteristics and course of lupus may vary significantly among individuals, it is important to emphasize that a thorough medical evaluation and ongoing medical supervision are essential to ensure proper diagnosis and treatment.

Medications are often prescribed for people with lupus, depending on which organ(s) are involved, and the severity of involvement. Effective patient-physician discussions regarding the selection of medication, its possible side effects, and any changes in doses are vital. Commonly prescribed medications include:

Nonsteroidal Anti-Inflammatory Drugs (NSAIDs): These medications are prescribed for a variety of rheumatic diseases including lupus. Examples of such compounds include acetylsalicylic acid (e.g., aspirin), ibuprofen (Motrin), naproxen (Naprosyn), indomethacin (Indocin), nabumetone (Relafen), tolmetin (Tolectin), and a large number of others. These drugs are usually recommended for muscle and joint pain, and arthritis. Aspirin and NSAIDs may cause stomach upsets for some people. This effect can be minimized by taking them with meals, milk, antacids, or prostaglandins such as misoprostil (Cytotec). Newer NSAIDs contain a prostaglandin in the same capsule (Arthrotec). The other NSAIDs work in the same way as aspirin, but may be more potent, and patients often require fewer pills per day to have the same effect as aspirin. Many NSAIDs are now available in "over the counter" forms. People should be cautious about taking too much aspirin or NSAID since too many of these can reduce the blood flow to the kidney and cause problems.

Acetaminophen: Acetaminophen (e.g., Tylenol) is a mild analgesic that can often be used for pain. It has the advantage of less stomach irritation than aspirin, but it is not nearly as effective at suppressing inflammation.

Corticosteroids: Corticosteroids (steroids) are hormones that have anti-inflammatory and immunoregulatory properties. They are normally produced in small quantities by the adrenal gland. This hormone controls a variety of metabolic functions in the body. Synthetically produced corticosteroids are used to reduce inflammation and suppress activity of the immune system. The most commonly prescribed drug of this type is Prednisone.

Because steroids have a variety of side effects, the dose has to be regulated to maximize the beneficial anti-immune/anti-inflammatory effects and minimize the negative side effects. Side effects occur more frequently when steroids are taken over long periods of time at high doses (for example, 60 milligrams of Prednisone taken daily for periods of more than one month). Such side effects include weight gain, a round face, acne, easy bruising, "thinning" of the bones (osteoporosis), high blood pressure, cataracts, onset of diabetes, increased risk of infection, stomach ulcers, hyperactivity, and an increase of appetite.

Antimalarials: Chloroquine (Aralen) or hydroxychloroquine (Plaquenil), commonly used in the treatment of malaria, may also be very useful in some individuals with lupus. They are most often prescribed for skin and joint symptoms of lupus. It may take months before these drugs demonstrate a beneficial effect. Side effects are rare, and consist of occasional diarrhea or rashes. Some antimalarial drugs, such as quinine and chloroquine, can affect the eyes. Therefore, it is important to see an eye doctor (ophthalmologist) regularly. The manufacturer suggests an eye exam before starting the drug and one exam every six months thereafter. However, your physician might suggest a yearly exam is sufficient.

Immunomodulating Drugs: Azathioprine (Imuran) and cyclophosphamide (Cytoxan) are in a group of agents known as cytotoxic or immunosuppressive drugs. These drugs
manner to the corticosteroid drugs in that they supp
inflammation and tend to suppress the immune syst
effects of these drugs include anemia, low white blo
and increased risk of infection. Their use may also pr
individual to developing cancer later in life.

Other agents like methotrexate and cyclosporin are u
the symptoms of lupus. Both are immunomodulatin
have their own side effects. These drugs are still in th
investigational phase for lupus. Some of these agent
conjunction with apheresis, a blood filtering treatme
has been tried by itself in an effort to remove specifi
from the blood but the results have not been promis

Newer agents are directed toward specific cells of th
system. These include agents which block the produ
specific antibodies like those against DNA, or agents
suppress the manufacture of antibodies through oth
mechanisms. Examples of this are intravenous immu
injections which are given on a regular basis to incre
(particles important to coagulation).

Anticoagulants: These drugs are employed to thi
or in actuality, to prevent blood from clotting rapidly
from aspirin at very low dose which prevents platelet
sticking, to heparin/coumadin which actually prevent
from clotting. The latter requires careful monitoring
the patient is in the "therapeutic range" or that the
excessively "thin". Generally, this type of therapy is l
people with lupus and follows an actual episode of c
(embolus or thromboses).

People with lupus should learn to recognize early syr
disease activity. In that way they can help the physici
when a change in therapy is needed. Regular monitc
disease by laboratory tests can be valuable because r
symptoms may occur only after the disease has signi
Changes in blood test results may indicate the diseas
active even before the patient develops symptoms of
seems that the earlier such flares are detected, the m
they can be controlled. Also, early treatment may de
chance of permanent tissue or organ damage and re
one must remain on high doses of drugs.

Nutrition and Diet

Although much is still not known about the nut
in many kinds of disease, no one questions the
well-balanced diet. Fad diets, an excess or an exclusi
types of foods are much more likely to be detrimenta
beneficial in any disease, including lupus. Scientists h
that both antibodies and other cells of the immune s
adversely affected by nutritional deficiencies or imbal

ition

is a chronic inflammatory disease that can affect various of the body, especially the skin, joints, blood, and ıe body's immune system normally makes proteins ɔodies to protect the body against viruses, bacteria, and gn materials. These foreign materials are called ı an autoimmune disorder such as lupus, the immune ɛs its ability to tell the difference between foreign (antigens) and its own cells and tissues. The immune n makes antibodies directed against "self " These called "auto-antibodies," react with the "self" ı form immune complexes. The immune complexes the tissues and can cause inflammation, injury to ɨ pain.

eople, lupus is a mild disease affecting only a few · others, it may cause serious and even life-threatening More than 16,000 Americans develop lupus each year. ted that 500,000 to 1.5 million Americans have been with lupus.

; of Lupus

are three types of lupus: discoid, systemic, and drug- :ed. ***Discoid*** (cutaneous) lupus is always limited to the lentified by a rash that may appear on the face, neck, Discoid lupus is diagnosed by examining a biopsy of ı discoid lupus the biopsy will show abnormalities that ınd ın skin without the rash. Discoid lupus does not ıvolve the body's ınternal organs. Therefore, the ANA ɔd test used to detect systemic lupus, may be negative vith discoid lupus. However, in a large number of th discoid lupus, the ANA test ıs positive, but at a low :er."

ıately 10 percent of patients, discoid lupus can evolve ;temic form of the disease which can affect almost any 'stem of the body. This cannot be predicted or Treatment of discoid lupus will not prevent its ı to the systemic form. Individuals who progress to the rm probably had systemic lupus at the outset with the ı as their main symptom.

ɹpus is usually more severe than discoid lupus, and can ɔst any organ or system of the body. For some people, in and joints will be involved. In others, the joints, lungs, ɔod, or other organs and/or tissues may be affected. no two people with systemic lupus will have identical Systemic lupus may include periods in which few, if oms are evident ("remission") and other times when becomes more active ("flare"). Most often when ntion "lupus," they are referring to the systemic form of

Drug-induced lupus occurs after the use of certain prescribed drugs. The symptoms of drug-ınduced lupus are similar to those of systemic lupus. The drugs most commonly connected with drug-induced lupus are hydralazine (used to treat high blood pressure or hypertension) and procainamide (used to treat irregular heart rhythms). Drug induced lupus is more common in men because they are given these drugs more often. However, only about 4 percent of the people who take these drugs will develop the antibodies suggestive of lupus. Of that 4 percent, only an extremely small number will develop overt drug-ınduced lupus. The symptoms usually fade when the medications are discontinued.

Although drug-induced lupus and discoid lupus share features of systemic lupus, the rest of this brochure primarily discusses systemic lupus.

Cause

The cause(s) of lupus is unknown. While scientists believe there is a genetic predisposition to the disease, ıt is known that environmental factors also play a critical role ın triggering lupus. Some of the environmental factors that may trigger the disease are: infections, antibıotics (especially those in the sulfa and penicillin groups), ultravıolet light, extreme stress, certain drugs, and hormones.

Although lupus is known to occur within families, there is no known gene or genes which are thought to cause the illness. There are recent discoveries of a gene on chromosome 1 which is associated with lupus in certain families. Previously, genes on chromosome 6 called "immune response genes" were also associated with the disease. Only 10 percent of lupus patients will have a close relative (parent or sibling) who already has or may develop lupus. Statistics show that only about 5% of the children born to individuals with lupus will develop the illness.

Lupus is often called a "woman's disease" despite the fact that many men are affected. Lupus can occur at any age, and in either sex, although it occurs 10-15 times more frequently among adult females than adult males after puberty or after the emergence into sexual maturity. The symptoms of the disease are the same in men and women. Women of African, American Indian, and Asian origin are thought to develop the disease more frequently than Caucasian women. The reasons for this ethnic selection are not clear.

Hormonal factors may explain why lupus occurs more frequently in females than in males. The increase of disease symptoms before menstrual periods and/or during pregnancy support the belief that hormones, particularly estrogen, may somewhat regulate the way the disease progresses. However, the exact reason for the greater prevalence of lupus in women, and the cyclic increase in symptoms, is unknown.

Symptoms

Although lupus can affect any part of the body, most people experience symptoms in only a few organs. Table 1 lists the most common symptoms of people with lupus.

TABLE 1
TABLE OF SYMPTOMS

Symptom	*Percentage*
Achy joints (arthralgia)	95%
Fever more than 100 degrees F (38 degrees C)	90%
Arthritis (swollen joints)	90%
Prolonged or extreme fatigue	81%
Skin Rashes	74%
Anemia	71%
Kidney Involvement	50%
Pain in the chest on deep breathing (pleurisy)	45%
Butterfly-shaped rash across the cheeks and nose	42%
Sun or light sensitivity (photosensitivity)	30%
Hair loss	27%
Abnormal blood clotting problems	20%
Raynaud's phenomenon (fingers turning white and/or blue in the cold)	17%
Seizures	15%
Mouth or nose ulcers	12%

Diagnosis

Because many lupus symptoms mimic other illnesses, are sometimes vague, and may come and go, lupus can be difficult to diagnose. Diagnosis is usually made by a careful review of a person's entire medical history coupled with an analysis of the results obtained in routine laboratory tests and some specialized tests related to immune status. Currently, there is no single laboratory test that can determine whether a person has lupus or not. To assist the physician in the diagnosis of lupus, the American College of Rheumatology (ACR) in 1982 issued a list of 11 symptoms or signs that help distinguish lupus from other diseases (see Table 2). This has recently been revised. A person should have four or more of these symptoms to suspect lupus. The symptoms do not all have to occur at the same time.

TABLE 2
THE ELEVEN CRITERIA USED FOR THE DIAGNOSIS OF LUPUS ERYTHEMATOSUS

Criterion	*Definition*
Malar Rash	Rash over the cheeks
Discoid Rash	Red raised patches
Photosensitivity	Reaction to sunlight, resulting in the development of or increase in skin rash
Oral Ulcers	Ulcers in the nose or mouth, usually painless
Arthritis	Nonerosive arthritis involving two or more peripheral joints (arthritis in which the bones around the joints do not become destroyed)
Serositis	Pleuritis or pericarditis (inflammation of the lining of the heart or lung)
Renal Disorder	Excessive protein in the urine (greater than 0.5 gm/day or 3+ on test sticks) and/or cellular casts (abnormal elements in the urine, derived from red and/or white cells and/or kidney tubule cells)
Neurologic Disorder	Seizures (convulsions) and/or psychosis in the absence of drugs or metabolic disturbances which are known to cause such effects
Hematologic Disorder	Hemolytic anemia or leukopenia (white blood count below 4,000 cells per cubic millimeter) or lymphopenia (less than 1,500 lymphocytes per cubic millimeter) or thrombocytopenia (less than 100,000 platelets per cubic millimeter). The leukopenia and lymphopenia must be detected on two or more occasions. The thrombocytopenia must be detected in the absence of drugs known to induce it.
Antinuclear Antibody	Positive test for antinuclear antibodies (ANA) in the absence of drugs known to induce it.
Immunologic Disorder	Positive anti-double stranded DNA test, positive anti-Sm test, positive antiphospholipid antibody such as anticardiolipin, or false positive syphilis test (VDRL).

Adapted from: Tan, E.M., et. al. The 1982 Revised Criteria for the Classification of SLE. Arth Rheum 25: 1271-1277.

Laboratory Tests Used In The Diagnosis Of Lupus

The first laboratory test ever devised was the LE (lupus Erythematosus) cell test. When the test is repeated many times, it is eventually positive in about 90 percent of the people with systemic lupus. Unfortunately, the LE cell test is not specific for systemic lupus (despite the official-sounding name) and is rarely used today. The test can also be positive in up to 20 percent of the people with rheumatoid arthritis, in some patients with other rheumatic conditions like Sjogren's syndrome or scleroderma, in patients with liver disease, and in persons taking certain drugs (such as procainamide, hydralazine, and others).

The immunofluorescent antinuclear antibody (ANA or FANA) test is more specific for lupus than the LE cell prep test. The ANA test is positive in virtually all people with systemic lupus, and is the best diagnostic test for systemic lupus currently available. If the test is negative, the person is not likely to have systemic lupus. On the other hand, a positive ANA, by itself, is not diagnostic of lupus since the test may also be positive in individuals:

1. with other connective tissue diseases;
2. without symptoms;
3. treated with certain drugs, including procainamide, hydralazine, isoniazid, and chlorpromazine;
4. with conditions other than lupus, such as scleroderma, rheumatoid arthritis, infectious mononucleosis and other chronic infectious diseases such as lepromatous leprosy, subacute bacterial endocarditis, malaria, etc., and liver disease.

Because it can be positive in conditions other than lupus, the results of the ANA test have to be interpreted in light of the patient's medical history, as well as the current clinical signs and symptoms.

ANA test reports include a titer (or strength) of the antibody. The titer indicates how many times an individual's blood must be diluted to get a sample free of anti-nuclear antibodies. Thus, a titer of 1:640 shows a greater concentration of anti-nuclear antibodies than a titer of 1:320 or 1:160. Patients with active lupus have ANA tests that are very high in titer.

Laboratory tests which measure complement levels in the blood are also of some value. Complement is a blood protein that, with antibodies, destroys bacteria. It is an "amplifier" of immune function. If the total blood complement level is low, or the C3 or C4 complement values are low, and the person also has a positive ANA, some weight is added to the diagnosis of lupus. Low C3 and C4 complement levels in individuals with positive ANA test results may also be indicative of lupus kidney disease.

Tests of individual antigen antibody reactions have been developed which are very helpful in the diagnosis of SLE. These include the anti-DNA antibody test, the anti-Sm antibody test, the anti-RNP antibody test, the anti-Ro antibody test, and tests which measure serum complement levels. These tests can be further explained by your physician.

Detection of antibodies to phospholipid, such as the anticardiolipin assay or a positive lupus anticoagulant, can be cause for concern especially if the patient has evidence of blood clots (thromboses). The most common manifestation of this is phlebitis or inflammation of the vessels in the calves of the legs. Presence of these antibodies in the absence of any abnormal clotting may require simple aspirin therapy to mildly thin the blood. Ho evidence of abnormal blood clotting may require that the take a blood thinner like heparin and later warfarin to pre blockage of small and large blood vessels. When blockage in the lung or the brain it can be very serious.

Laboratory tests are most useful when one remembers th following information. If an individual has signs and symp supporting the diagnosis of lupus (e.g., at least four of th criteria), including a positive ANA, the diagnosis is confirr no further testing is necessary. If a person has only two c of the ACR criteria, including a positive ANA, then the AI supports but does not confirm the diagnosis. In these cas unless more specific tests are positive (e.g., anti-DNA, an anti-Ro) the diagnosis of lupus is uncertain until more clir findings develop or other more specific blood tests, as cit above, become positive.

Many people may have vague symptoms and only a posit antiphospholipid (APL) antibody or a positive lupus antico A person may then be diagnosed with *primary antiphosp syndrome* instead of lupus. People with primary APL synd might still have problems with premature clotting of bloo require treatment.

Physicians will sometimes also perform skin biopsies of bc individual's rash(es) and his or her normal skin. These biop help diagnose systemic lupus in about 75 percent of patie

A kidney biopsy is sometimes required if urine or blood e show evidence of kidney disease. Kidney abnormalities va each patient. A biopsy and special preparation of the bio sample is required to give the doctor an idea of the degr type of kidney injury. Using the biopsy results the doctor therapy for each individual.

The interpretation of all these positive or negative tests, a relationship to symptoms, is frequently difficult. A test m positive one time and negative another time, reflecting th activity of the disease or other variables. When questions be resolved, consult an expert in lupus.

When someone has many symptoms and signs of lupus positive tests for lupus, physicians have little problem ma correct diagnosis and initiating treatment. However, a m common problem occurs when an individual has vague, unrelated symptoms of achy joints, fever, fatigue, or pair doctors may think the person is neurotic. Others may try drugs in the hope of suppressing the symptoms. Fortuna growing awareness of lupus, an increasing number of ph will consider the possibility of lupus in the diagnosis.

A patient can help the doctor by being open and honest healthy dialogue between the patient and doctor results medical care, not only for people with lupus, but for any seeking medical treatment.

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BASIC FACT ABOUT LUPUS

Lupus Is Wide-Spread, Devastating And Highly Discriminatory

Lupus is an acute and chronic inflammatory disease that, for unknown reasons, causes the immune system to become hyperactive and attack the body's own healthy tissue and organs. The disease is hard to diagnose, difficult to live with, incurable, and can be life threatening. Lupus is NOT infectious, rare or cancerous.

At least 1.4 million Americans have lupus, ninety percent of whom are women. Lupus attacks more people than multiple sclerosis, cystic fibrosis, sickle cell anemia, or leukemia, and can be as devastating.

The exact cause(s) of lupus is unknown, but environmental and genetic factors are involved. While scientists believe there is a genetic predisposition to the disease, it is known that environmental factors also play a critical role in triggering lupus. Some factors that may trigger the disease include infections, ultraviolet light, extreme stress and certain drugs and chemicals.

Lupus can be difficult to diagnose because symptoms mimic other diseases. Symptoms are sometimes vague and may come and go. Symptoms include achy or swollen joints, low grade fevers, extreme fatigue and skin rashes. At present there is no cure for lupus. However, with early diagnosis and current methods of therapy, 80-90% of lupus patients can look forward to a normal lifespan. However the quality of life can be severely affected.

Lupus can occur at any age, and in either sex, although it occurs 8 or 9 times more frequently among adult females than among adult males. The symptoms of the disease are the same in men and women. Hormonal factors may explain why lupus occurs more frequently in females than in males. African Americans, Native Americans, Asians and Hispanics are thought to develop lupus more frequently than Caucasians.

Treatment approaches are based on the specific needs and symptoms of each person. Anti-inflammatory medications are often prescribed for people with lupus, depending on which organ(s) are involved, and the severity of involvement. Some treatments for lupus can cause serious or life-threatening side effects from long-term use.

http://www.lupus.org/lupus

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Foundation of America, Inc.

ABOUT THE LUPUS FOUNDATION OF AMERICA

Research - Awareness - Education - Support - Advocacy

The Lupus Foundation of America is the world's largest organization exclusively dedicated to helping people with lupus and to finding a cause and cure for the disease. Incorporated as a national 501(c)(3) not-for-profit health agency in 1977, the Foundation has as its primary purposes the eradication of lupus through support of research, the early detection of undiagnosed cases through awareness promotion and the alleviation of suffering for persons with lupus through patient services, education, advocacy and support.

Last year, 200,000 people received service directly from the LFA, or from one of its nearly 100 local chapters throughout the United States. The Lupus Foundation of America has approximately 45,000 members. The LFA and its chapters provided nearly $2,000,000 for lupus research during the past two years.

The LFA is the best source of information for lupus patients. Our national information line receives between thirty and forty thousand calls each year. Many of these callers are newly diagnosed patients seeking information about lupus. Professional health educators answer questions and provide guidance and support. We encourage all callers to contact their local LFA chapter where they can join a support group or attend informational meetings. Every month, nearly 30,000 people visit the LFA's internet site for information about lupus and for confidential support from other people with lupus.

By drawing on the expertise of top medical and other professionals, the quality of information provided by the LFA is second to none. Public awareness, public education and advocacy programs serve to focus national attention on lupus, creating a heightened awareness and greater understanding of not only the disease itself, but more importantly, of the needs of the people who are affected by lupus.

The Lupus Foundation of America is a member of the National Health Council and the National Voluntary Health Agencies. The LFA submits financial information to the Better Business Bureau and to the National Charities Information Bureau.

http://www.lupus.org/lupus

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LUPUS™
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NATIONAL ORGANIZATION SERVICES

Leadership Through Service

LUPUS INFORMATION LINE - The Lupus Foundation of America receives thirty thousand calls annually from individuals requesting information. Health educators answer questions and direct patients to the local chapter serving their community. The toll-free number is 1-888-38 LUPUS. Our Internet Web site (http://www.lupus.org) receives over 60,000 visitors every month.

PUBLIC AWARENESS - The LFA creates awareness by producing and placing public service announcements on national and regional broadcast networks, on cable and satellite channels and in major newspapers and magazines. The LFA also works with producers, editors, writers and reporters to increase the exposure for lupus through the news media.

RESEARCH - The LFA Medical Council solicits research proposals from hundreds of medical centers, universities and research institutions. Each year, the Council selects several projects for funding. The Foundation seeks innovating and promising new research ideas that some day may lead to the cure for lupus.

EDUCATION AND TRAINING - The Lupus Foundation of America develops programs to train volunteers, community leaders and representatives of the medical community to provide services to people with lupus. The LFA has certified hundreds of individuals to lead local support groups for lupus patients.

GOVERNMENT RELATIONS – The federal government in an important partner with the LFA in the search for new knowledge about lupus. The LFA works in partnership with the Department of Health & Human Services and the National Institutes of Health to stimulate medical research, public awareness and services for people affected by lupus. By educating government officials about lupus and its health impact, we insure that proper resources will be made available to lead the fight against the disease.

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LOCAL CHAPTER SERVICES

Services To Patients & Their Families

PATIENT SUPPORT GROUPS - Local chapters operate one or more Lupus Support Groups for people with lupus and for members of their family. Support groups usually meet monthly under the auspices of a trained support group leader. Speakers from the medical community frequently will present a discussion about various aspects of lupus including the latest medical research findings, disease management, nutrition, stress reduction and treatment options.

EDUCATIONAL SYMPOSIUMS - Most chapters sponsor an annual symposium featuring speakers, workshops and exhibits about the management of lupus. The symposiums also provide an opportunity for lupus patients to interact with one another and to develop new friends.

SEMINARS FOR NEWLY DIAGNOSED PATIENTS - These seminars are designed to provide newly diagnosed patients with basic information about managing the disease and living well. Usually, this is the first opportunity for lupus patients to realize that there are other people available to help them cope with their illness.

INFORMATION AND REFERRALS - Chapters provide referrals for physicians, treatment centers and services, as well as answer basic questions about the disease. A free Lupus Information Packet is available that provides basic information, a list of local support groups and details about services available through the chapter.

CHAPTER NEWSLETTER & LENDING LIBRARY - The chapter newsletter provides articles about different aspects of the disease. The newsletter is especially important to patients who, for one or more reasons, cannot attend a support group meeting. Chapters have a number of books, videos and pamphlets available that can be loaned to individuals wishing to learn more about lupus.

Lupus Foundation Of America.1300 Piccard Drive.Suite 200.Rockville.MD.20850.4303
(office) 301.670.9292 (fax) 301.670.9486 (e-mail) lfanatl@aol.com
http://www.lupus.org

Info packed
on Lupus

RE: Lupus

3-22-00

thanks Anne

for taking

a look at

this let me

know what

happens but you

can call the

sender directly.

Thanks so much

LUPUS™

Foundation of America, Inc.

March 10, 2000

First Lady Hillary Rodham Clinton
Office of the First Lady
The White House
1600 Pennsylvania Avenue
Washington, DC 20500

Dear Mrs. Clinton,

The Lupus Foundation of America appreciates the high level of visibility that you have generated for women's health issues. Since becoming first lady, your efforts have increased public awareness and support for many important issues affecting women.

The Lupus Foundation of America is bringing lupus advocates from throughout the United States to Washington April 5-8 to raise the visibility of lupus on Capitol Hill, and to train volunteers in the delivery of patient services. Participants will include the leaders of our nine New York State chapters, and the co-chairman of our National Board of Directors, Mr. John Dabolt, who is from Rochester. I would like to extend an invitation for you to address our group while they are here in Washington.

At least 1.4 million Americans have lupus, 90% of whom are women. Lupus strikes women of color two to three times more often than Caucasian women and is a serious health problem among African-Americans. Based on a national survey that estimated the prevalence of lupus at 1 out of every 185 Americans, the Lupus Foundation of America estimates that as many as 90,000 New York families are touched by this chronic disease.

I am including a copy of a 27-minute documentary filmed by two young women who have lupus. The program was broadcast on PBS last October during Lupus Awareness Month. It portrays the devastating impact of this disease and the courage of those who live with it.

While in Washington, our advocates will be seeking additional support for the Lupus Research & Care Amendments Act (H.R. 762 and S. 1163). This legislation authorizes funding for lupus medical research and a grant program that provides funding for non-profit health care providers in medically under-served areas to treat uninsured or low-income lupus patients. The House bill, introduced by Congresswoman Carrie Meek, has been endorsed by the Congressional Black Caucus and has 235 cosponsors. The Senate bill has been introduced by Senator Robert Bennett, and is cosponsored by Senators Schumer, Murray, Torricelli, Cleland and Warner.

1300 Piccard Drive, Suite 200, Rockville, MD 20850-4303 (301) 670-9292 • (800) 558-0121 FAX 301-670-9486 www.lupus.org

Our members would truly enjoy hearing from you on those important health issues that affect them on a daily basis. We would be more than happy to accommodate your availability during the course of our meeting. Our functions will include a kickoff dinner on Wednesday evening, April 5, at the Holiday Day Inn Select in Old Town Alexandria; a breakfast and luncheon on Thursday, April 6, in the Hart Senate Office Building; and general conference sessions all day on Friday April 7, and Saturday April 8, at the Holiday Day Inn Select in Old Town Alexandria.

I hope you will be able to address our group while they are here in Washington. Our chapter leaders would be honored to hear from you.

Sincerely,

Duane Peters
Vice President of Advocacy
301-670-9292, ext. 17
LFAGovtRel@aol.com

Enclosures

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LUPUS™ Foundation of America, Inc.

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LUPUS NEWS™

VOLUME 20 • NUMBER 1 • WINTER 1999–2000 SCIENCE • MEDICINE • SKILL • HOPE

IN THIS ISSUE...

FEATURES

DEPARTMENTS

The Complex Genetic Basis of SLE Part 2

Kathleen E. Sullivan, M.D., Ph.D.

Defective complement genes found in every population

Genetic variations in the complement genes that direct the removal of antibody complexes have been identified in all ethnic groups examined—African-American, Asian, Hispanic, and Caucasian—although the specific genes often vary from group to group. This is not unexpected, since one of the hallmarks of SLE is antibody complexes being deposited into the kidneys and skin. Sometimes this occurs because the complement genes are not functioning to remove the antibody complexes efficiently. Therefore, defects in complement genes predispose to the depositing of antibody complexes and to SLE.

The most common type of defect is *C4A deficiency*. C4A is the name of one of the complement genes. Although C4 deficiency is found in all ethnic groups examined thus far, the exact defect leading to C4A deficiency has been different in different ethnic groups.

MHC genes

Another family of genes where many ethnic-specific differences are found are the *major histocompatibility complex (MHC)* genes. These genes mold the body's immune response to any particular foreign agent and determine our ability to recognize an infection as foreign, requiring an effective immune response. The specific autoantibodies produced by any individual with SLE are determined by their MHC genes.

Because genetic variation *(polymorphism)* is very high in MHC genes, different ethnic groups have very different MHC gene mixtures. MHC genetic risk factors have been identified in Asian, Hispanic, African-American, and Caucasian populations. In each case the specific genes are different and are associated with a different autoantibody profile. In some cases, these genes are associated with a different natural history, as well. One example is the presence of the *HLA-*

Genetics continued on page 3

LFA Honors "Stories of Lupus"

Marcia Urbin Raymond, Karin Mellberg, Dr. Daniel J. Wallace (Co-Chair, LFA Board of Directors), and Janice Wallace

Honors continued on page 4

More than 125 enthusiastic supporters of the "Stories of Lupus" documentary film and the Lupus Foundation of America gathered on October 21 at the studios of Twentieth Century Fox in Los Angeles. Use of the Little Theater and reception area was generously donated by Jim Gianopulos, President of Twentieth Century Fox International, and Lauren Shuler Donner, world-renowned film pro-

Majority in U.S. House of Representatives support Lupus Research & Care Amendments Act of 1999

Foundation of America, Inc.

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Vice President of Advocacy

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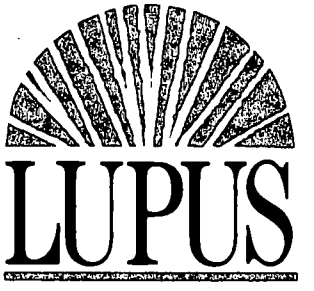

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