

Help Us Solve
The Cruel Mystery

LUPUSTM

FOUNDATION OF AMERICA
GEORGIA CHAPTER

LUPUS RESOURCE TOOLKIT

For Patients, Families and Caregivers

Table of Contents

1. Health Insurance Options	4
2. Employment, Disability and Legal Issues	7
3. Work Related Issues	9
4. Financial Assistance	10
5. Prescription Assistance	12
6. Additional Financial Services	13
7. Participating in Clinical Trials	15
8. Find a Doctor	16
9. Georgia Chapter Resources	19
10. National Lupus Foundation of America Resources	20

Those living with lupus, family members and caregivers can find a wide variety of information in our resource section including work related issues, insurance, financial assistance and locating and working with your doctor.

Health Insurance Options in Georgia

Health insurance is a contract between you and your insurance company. When you purchase insurance, the company agrees to pay part of your medical costs when you get sick or hurt. There are a number of health insurance options and a new option available beginning October 1, 2013 is the Health Insurance Marketplace.

Know the following to determine your options for health insurance coverage:

- Your age
- Your state of residence
- If you can obtain insurance through your job
- If you can obtain insurance through your spouse, legal guardian or school
- If you are a US citizen
- Your income compared with the federal poverty level (FPL)
- If you have served or are serving in the US military
- If you are pregnant
- If you have a disability

In addition, if you are a person with lupus, ask the following about insurance coverage:

- Are the medications I take on the plan formulary?
- What are my out-of-pocket costs to go out of the plan's network?

Medical Assistance for Georgians

Medicaid offers many types of programs for a variety of people in Georgia, from insurance premium assistance programs to

To search through a list of programs, [click here](#).

Medicare Health Insurance is free. A person will receive Medicaid immediately (only need \$1 of SSI to get Medicaid). Many individuals who qualify for Medicaid based on disability also receive cash assistance under the Supplemental Security Income (SSI) program. In almost all states, SSI eligibility automatically qualifies an individual for Medicaid coverage. However, some states use more restrictive eligibility criteria than those used by the SSI program. This means that in those states (commonly referred to as 209(b) states) receipt of SSI does not guarantee eligibility for Medicaid. Individuals not receiving SSI but seeking coverage based on disability must demonstrate that they have an impairment that prevents them from performing “substantial gainful activity” for at least one year. Once a disability determination is made, the individual must then undergo an asset test and meet specific income requirements in order to be considered for Medicaid eligibility.

How to apply

To apply for Medicaid or to request more information about Medicaid, call your state medical assistance office. To get the local phone number, call the Centers for Medicare & Medicaid Services at 1-800-633-4227 (TTY, 1-877-486-2048).

If you make less than a certain amount of money each year or are disabled, you may be able to receive Medicaid. For more information visit www.medicaid.gov.

PeachCare for Kids

The health benefits include primary, preventive, specialist, dental care and vision care. PeachCare for Kids also covers hospitalization, emergency room services, prescription medications, and mental health care. Each child in the program has a Georgia Families Care Management Organization (CMO) who is responsible for coordinating the child's care.

In 1997, Congress created Title XXI of the Social Security Act to provide health care for the growing number of uninsured children in the United States. This legislation enabled states to create State Children's Health Insurance (S-CHIP) programs to increase access to affordable health insurance. In Georgia, PeachCare for Kids® began covering children in 1998 and provides comprehensive coverage to uninsured children. S-CHIP was reauthorized in January 2018 for an additional 10 years. CHIP offers health insurance for children. You may be able to receive CHIP if you work but cannot obtain insurance through your job or your income is too much to qualify for Medicaid. For more information visit www.insurekidsnow.gov.

Medicare

Medicare offers health insurance for people who are 65 years or older. People who have been disabled for more than two years may be able to receive Medicare. For more information visit www.medicare.gov.

Medicare is a federal insurance program that pays for medical care for people who qualify. People who have been determined to be disabled and have been receiving disability benefits for at least 24 months qualify for Medicare. People with lupus who need long term dialysis treatment for chronic kidney disease or require a kidney transplant will qualify for Medicare immediately after they are determined to be disabled. In general, Medicare pays 80 percent of reasonable charges. Remember, Medicare is not free.

What are the different plans under Medicare?

Medicare Part A (Hospital Insurance) helps cover inpatient care in hospitals, including critical access hospitals, and skilled nursing facilities (not custodial or long-term care). The taxes you paid while you were working financed this coverage, so it is free.

Medicare Part B (Medical Insurance) helps cover doctors' services and outpatient care. You will need to pay a monthly premium for this coverage if you want it.

Medicare Part C (Medicare Advantage) combines hospital and doctor coverage and is provided by private insurers. Medicare pays a fixed amount for your care every month to the companies offering Medicare Advantage Plans. These companies must follow rules set by Medicare. However, each Medicare Advantage Plan can charge different out-of-pocket costs and have different rules for how you get services (like whether you need a referral to see a specialist or if you have to go to only doctors, facilities, or suppliers that belong to the plan for non-emergency or non-urgent care).

Medicare Part D provides prescription drug insurance. Private companies also provide the coverage. Beneficiaries choose the drug plan and pay a monthly premium.

If you join a Medicare Advantage Plan, the plan will provide all of your Part A (Hospital Insurance) and Part B (Medical Insurance) coverage. Medicare Advantage Plans may offer extra coverage, such as vision, hearing, dental, and/or health and wellness programs. Most include Medicare prescription drug coverage (Part D).

How to Apply

If you are receiving Social Security Disability Insurance, you must wait 24 months from the time you are declared disabled before you can apply for Medicare, unless you have end stage renal disease which makes you eligible immediately. For non-disabled people, you become eligible for Medicare when you reach the age of retirement. Call 1-800-MEDICARE or visit www.medicare.gov for information.

However, if you want to apply for Medicare coverage only (e.g., you are working and do not intend to file for monthly retirement or spouse's benefits at this time), you should call 1-800-772-1213 (TTY 1-800-325-0778) toll-free to arrange an appointment over the phone or in person at a Social Security office.

Employer-Sponsored Insurance (ESI)

ESI may be offered through your job. Some types of ESI include:

- HMO: Health Maintenance Organizations -uses a network of doctors; requires a primary care physician.
- PPO: Preferred Provider Organizations - uses a network of doctors; if you go out-of- network, it will cost more.
- POS: Point of Service- uses a network of doctors; does not require referrals to specialists; if you go out-of-network, it will cost more.

Every company's health insurance is a little bit different. Talk to your company's human resources or benefits person for details.

Private Insurance

There are numerous private insurers offering a variety of options for health insurance coverage to include Health Maintenance Organizations (HMO), Preferred Provider Organizations (PPO) and Point of Service (POS). Contact each private insurer directly for more information on their specific plan options.

Health Insurance Marketplace

As of October 1, 2013, a new option for obtaining health insurance is available. The Marketplace is a way to learn about different insurance plans, compare plans and find out which one fits your needs. If you do not qualify for other types of insurance, the Marketplace will offer options for purchasing health insurance. Visit www.healthcare.gov for more information.

Pick up copies of these three important resources:

- Eight things I need to know about the Health Insurance Marketplace
- Things to think about when choosing a health insurance plan
- Glossary of health coverage and medical terms

Employment, Disability and Legal Issues

Because lupus can range in severity, individuals with lupus may be fully able or unable to work. Fortunately, there are programs and organizations that protect the rights of individuals within and outside the workplace. Whether the individual is seeking federal disability benefits or employment opportunities, the following resources offer services to those with lupus.

Social Security Disability

Social Security Disability is the federal program, supported by payroll taxes, that pays benefits to people who cannot work due to a medical condition. In order to qualify, you must have a medical condition that meets Social Security's definition of disability and is expected to last at least one year or result in death.

You will be considered disabled if you can provide medical evidence that are unable to do the work that you did before and you cannot adjust to other work because of your medical condition(s). No benefits are payable for partial disability or for short-term disability.

Generally, to be eligible for disability benefits, you must have worked long enough and acquired enough work credits. The number of work credits required will depend on your age when you become disabled. There are different eligibility rules for children under the age of 18.

How Social Security determines if you are disabled

There are five steps along the path to being declared disabled.

Step 1 – Are you working?

In 2013, if you make more than \$1,040 in a month, that is presumed to be engage in substantial gainful activity (SGA). This may make you ineligible for benefits. This amount changes from year to year and can be found on the SSA website.

Step 2 – Is your condition severe?

Your impairment(s) must significantly limit your ability to do basic work activities, for example walking, sitting, seeing, and remembering.

Step 3 – Is your condition found in the list of disabling condition?

Social Security maintains a Listing of Impairments for each of the major body systems that are so severe they will automatically consider you disabled.

Step 4 – Can you do the work you previously did?

If your condition is severe but not at the same or equal level of severity as a medical condition on the list, then Social Security must determine if your condition interferes with your ability to do the work you did previously.

Step 5 – Can you do any type of work?

If you cannot do the work you did in the past, Social Security will see if you are able to adjust to other work. They consider your medical conditions and your age, education, past work experience and any transferable skills you may have. If you cannot adjust to other work, your claim will be approved.

How do I Apply for Social Security Disability?

You should apply for disability benefits as soon as you become disabled. You can complete some or all of the forms online or you may call the Social Security Administration (SSA) toll-free at 1-800-772-1213 to

schedule an appointment. Staff personnel at SSA office can assist you either in person or by phone. <https://www.socialsecurity.gov/applyfordisability/>

Build your case

You must be able to prove, by furnishing medical and other evidence, that you are disabled by lupus (not just that you have lupus) and meet the Social Security definition of disability. Your doctor cannot “declare” that you are disabled. You and your doctor must provide evidence that proves lupus prevents you from engaging in any substantial gainful employment and that this condition is expected to last for a continuous period of at least twelve months or result in death.

What to expect

It can take between three and five months to obtain an initial decision. Almost two out of three applicants are denied benefits initially, and most people who file a written appeal (called “reconsideration”) also are denied. The third level appeal before an administrative law judge is most successful. More than 60 percent of denials are overturned at this stage, so you must be patient. You can improve your odds of being approved for disability by building a solid case based on appropriate medical evidence. You may also want to consult with a disability lawyer to assist you through the process.

Work Related Issues

Through the Americans with Disabilities Act, the Patient Advocate Foundation, and Hire Disability Solutions, individuals with disabilities are guaranteed equal employment opportunity. In addition, the Job Accommodation Network (JAN) and DisabilityInfo.gov offer services and advice to enhance the employment of people with disabilities.

Americans with Disabilities Act (ADA)

The Americans with Disabilities Act gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services, and telecommunications.

The Act does not guarantee you a job because you have a disability. You must be qualified, compete, and perform like all other employees. Employers are required to make reasonable accommodations to permit persons with disabilities to be employed, but they are not required to give people with disabilities special considerations that they would otherwise not provide to all employees.

Learn more about the ADA

- ADA Questions and Answers - <http://www.ada.gov/q&aeng02.htm>
- Council for Disability Rights - <http://www.disabilityrights.org/faq1.htm>

Job Accommodation Network (JAN)

The JAN is a free consulting service designed to increase the employability of people with disabilities by: 1) providing individualized worksite accommodations solutions, 2) providing technical assistance regarding the ADA and other disability related legislation, and 3) educating callers about self-employment options. Learn more about JAN. - <http://askjan.org/>

DisabilityInfo.gov

This federal government website covers a variety of topics related to employment of people with disabilities: advice for individuals with disabilities seeking work; help for employers looking for hard-working and dedicated employees; information on employment rights, laws, and regulations; resources for employment programs and job accommodations for people with disabilities. Go to disability.gov for more information.

Patient Advocate Foundation

Patient Advocate Foundation is a national non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability. Learn more about the Patient Advocate Foundation. - <http://www.patientadvocate.org/index.php>

Financial Assistance

Facing medical and financial crisis as a result of lupus can have a significant impact on you and your family's way of life. This section provides information on a variety of resources to assist you in times of need.

United Way 2-1-1

United Way 2-1-1 is an information and referral service. Every Cal is completely confidential. They gather information on community resources and refer people to the resource best suited to meet their needs. Currently, their digital platforms will give you the fastest service. <https://www.211.org/>

[NeedyMeds](#)

In addition to the vast resources found on our website, we also offers some services and programs that are uniquely NeedyMeds. From our newsletter to apps, NeedyMeds provides these services and programs to help keep you up-to-date on ways to help your clients, your patients and yourself:

- [Subscription Center](#)
All-in-one center for subscribing to PAPTracker software, Patient Advocate Newsletter (PAN), Patient Assistance Program Update Service (PAPUS), and inquiries on partnership information.
- [Vitals Newsletter](#)
Monthly informative e-newsletter dedicated to highlighting new and current NeedyMeds' resources, health-related issues, interviews and more
- [Patient Assistance Program Update Service \(PAPUS\)](#)
Sign up for daily or weekly patient assistance program email alerts and new generic approvals.
- [PAPTracker](#)
Simplify and streamline the application process for patient assistance program forms.
- [Order Print Materials](#)
Order your NeedyMeds drug discount cards, brochures and information handouts. Available in English, Spanish, Portuguese, Russian and Khmer.
- [Patient Assistance Program Administration](#)
Offering experience and assistance in program design for patient assistance programs.
- [Drug Discount Card App](#)
Show the downloaded drug discount card image to the pharmacist to save up to 80% off the cost of your prescriptions. New pharmacy finder help you locate the 63,000-plus pharmacies nationwide that accept the card.

Find Free/Low-Cost/Sliding Scale Clinics

You can find free/low-cost/sliding scale clinics for primary and preventive medical and dental care in your area. You can also search for mental health or substance use disorder clinics. In addition to the name, address, contact information and clinic website (if available), the listing will also provide information about fees, details about who is eligible to be treated at the clinic, and the services the clinic offers.

<https://www.needymeds.org/free-clinics-branch>

National Association of Free & Charitable Clinics

Volunteer staff to provide medical, dental, pharmacy, vision and/or behavioral health services to people without the funds to do so. Open to all, call or visit website for nearest location. <https://nafclinics.org/>

Patient Advocate Foundation

Patient Advocate Foundation helps patients know that they are not alone when dealing with healthcare needs. There are national and regional resources dedicated to improve access to quality care and decrease the financial burden of medical treatment, and we can help you locate them quickly and easily.

To generate a list of the potential organizations that may have programs to address your needs, select the searching criteria that is the best match as it relates to the patient. There is no limit to the number of different searches you can perform. <https://www.patientadvocate.org/explore-our-resources/national-financial-resource-directory/>

Scholarships

An individual with lupus may find that their disease impacts theirs or a loved one's ability to finance their educational goals after high school. Learn more about financial assistance available for post-secondary educational needs.

National/Federal Financial Aid Information

- U.S. Department of Education- Student Financial Assistance <http://www2.ed.gov/finaid/landing.jhtml?src=ln>
- FinAid! The SmartStudent Guide to Financial Aid - <http://www.finaid.org/>
- FinAid: Information on Financial Aid for Disabled Students - <http://www.finaid.org/otheraid/disabled.phtml>
- Scholarships.com - <http://www.scholarships.com/main.aspx>

National Non-Profit Organization Scholarship Programs

The Lupus Inspiration Foundation for Excellence (L.I.F.E). Each year the L.I.F.E Scholarship Foundation will select students to receive the L.I.F.E Scholarship who have demonstrated courage and perseverance in their struggle to overcome the limitations of lupus. <http://www.lifescholarship.org/>

Through the Looking Glass and its National Center for Parents with Disabilities and their Families are pleased to announce new scholarships specifically for high school seniors and college students who have parents with disabilities. These scholarships are part of Through the Looking Glass' new federal grant (New National Center for Parents with Disabilities and their Families). <http://www.lookingglass.org/>

The Patient Advocate Foundation's Scholarship for Survivors. The purpose of our scholarships is to provide support to individuals, under the age of 25, who have been diagnosed with or treated for cancer and/or a chronic/life threatening disease within the past 5 years <http://www.patientadvocate.org/index.php?p=69>.

Lupus Foundation of America, Georgia Chapter Emergency Financial Assistance (EFA) Fund

The Georgia Chapter has established an emergency financial assistance meant to be a resource for people living with lupus who may be experiencing financial issues. The award is limited to \$500 per year and is based on filling out an application which is sent to a committee for approval.

Prescription Assistance

It can be difficult at times to pay for your prescription medications. There are several assistance programs that are available to help those who:

- Have no medical/medication insurance.
- Need assistance with medication co-pay.
- Insurance company has denied payment of treatment medication.

Please remember that all assistance programs will need to see a valid, current prescription from a physician in order to complete your application for possible approval.

What resources are available to help locate an assistance program for my medications?

Partnership for Prescription Assistance - <http://www.pparx.org/>

The Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that is right for them. Many will get them free or nearly free.

RxAssist - Patient Assistance Center - <http://www.rxassist.org/>

RxAssist offers a comprehensive database of these patient assistance programs, as well as practical tools, news, and articles so that health care professionals and patients can find the information they need.

Healthwell Foundation Co-Pay Assistance Program - <http://www.healthwellfoundation.org/>

The HealthWell Foundation provides financial assistance to eligible individuals to cover coinsurance, copayments, health care premiums and deductibles for certain medications and therapies.

Are there other resources available?

Check with your local pharmacist (CVS, Walgreens, Wal-Mart, etc.). They will be able to provide you with information on any programs they have for discounted medications.

Talk to your doctor. They may have samples available to help cover you until you can apply for an assistance program.

If you have medication insurance and your insurer has denied coverage of prescribed treatment, you should still contact an assistance program. They may provide you with assistance once they have confirmed that you have been denied coverage.

If you have any questions about possible programs that are available, please contact the Lupus Foundation of America Health Educator Line at 1-800-558-0121.

Additional Financial Services

Resources regarding food and transportation assistance as well as other sources of help for housing concerns

Food Assistance

Find links to nutrition assistance programs for families and individuals.

Catholic Charities <http://www.catholiccharitiesusa.org/>

703-549-1390

Catholic Charities USA (CCUSA) Catholic Charities agencies provide services to people in need. Affiliating with offices nationwide, CCUSA provides counseling and assistance. CCUSA provides strong leadership and support to enhance the work of local agencies in their efforts to reduce poverty, support families, and empower communities.

Community Action Partnership

http://www.communityactionpartnership.com/?option=com_spreadsheets&view=search&spreadsheet=cap&Itemid=188

202-265-7546

Community Action changes people's lives, embodies the spirit of hope, improves communities, and makes America a better place to live. We care about the entire community, and we are dedicated to helping people help themselves and each other.

Friends of Man -

<http://www.friendsofman.org/>303-798-2342

Friends of Man helps people of all ages with a large variety of needs to include mobility equipment: (prostheses, wheelchairs, van lifts, and modifications, ramps, home modifications), medical equipment and procedures, hearing aids, dentures, and glasses. They also assist with basic needs such as clothing for children, food, short-term daycare, prescriptions, Cobra/Health Insurance and more. Applications are required to be submitted on your behalf through referral of a doctor, social worker, church, health care agencies, etc.

Supplemental Nutrition Assistance Program (SNAP) -

<http://www.usda.gov/fundinglapse.htm>703-305-2022

SNAP offers nutrition assistance to millions of eligible, low-income individuals and families and provides economic benefits to communities. The Food and Nutrition Service works with State agencies, nutrition educators, and neighborhood and faith-based organizations to ensure that those eligible for nutrition assistance can make informed decisions about applying for the program and can access benefits.

Transportation Assistance

Sometimes the best medical care is not at your back door and you or a family member may need to travel to get the treatments you need. Find information on assistance with urgent and non-urgent medical travel.

National Patient Travel Center -

<http://www.patienttravel.org/800-296-1217>

The National Patient Travel Center provides information and referrals to all forms of charitable long-distance medical transportation in your area through the national medical transportation network. This ensures that no financially needy patient is denied access to distant medical treatment.

Air Care Alliance -

<http://www.aircareall.org/888-260-9707>

This site will introduce you to us and to all the groups we list whose volunteers perform public benefit flying for health care.

Angel Flight -

[http://www.angelflight.com/918-749-](http://www.angelflight.com/918-749-8992)

8992

They will arrange free air transportation for any legitimate, charitable, medically related need. This service is available to individuals, and health care organizations. They will also arrange transportation of those people who are financially distressed, or who are in a time-critical, non-emergency situation due to their medical condition.

Free Gas USA, Inc - <http://www.freegasusa.org/>

Free Gas USA gasoline grant program provides grants for fuel purchases ranging from \$50 to \$1,200 dollars. Qualified applicants must meet the federal guidelines of living at or below the poverty level and submit an agency referral with their application.

Housing and Utility Assistance

Listed below are organizations that provide help with emergency assistance for rent, mortgage, gas, electric, phone, or water bills.

Catholic Charities -

<http://www.catholiccharitiesusa.org/703-549-1390>

Catholic Charities USA (CCUSA) Catholic Charities agencies provide services to people in need. Affiliating with offices nationwide, CCUSA provides counseling and assistance. Several of our programs are able to work with families and individuals at-risk of eviction by helping provide funds for short-term financial assistance with overdue bills. We then work with the family to strengthen themselves and avoid the same crisis in the future.

Community Action Partnership -

http://www.communityactionpartnership.com/?option=com_spreadsheets&view=search&spreadsheet=cap&Itemid=188

202-265-7546

Community Action changes people's lives, embodies the spirit of hope, improves communities, and makes America a better place to live. We care about the entire community, and we are dedicated to helping people help themselves and each other.

LIHEAP -

<http://www.liheap.ncat.org/referral.htm> 202-429-8855

The Low-Income Home Energy Assistance Program (LIHEAP) helps keep families safe and healthy through initiatives that assist families with energy costs. Provides financial assistance to pay for heating and cooling bills of low-income and elderly people.

National Energy Assistance Referral (NEAR) Project -

<http://www.liheap.ncat.org/referral.htm> 866-674-6327

By emailing us at energyassistance@ncat.org, you will access the LIHEAP Clearinghouse's National Energy Assistance Referral (NEAR) project. NEAR is a free service for persons who want information on where to apply for the Low-Income Home Energy Assistance Program (LIHEAP), which may pay a portion of the energy bills of eligible low-income persons.

United Way 2-1-1 Information Line - <http://www.211.org/>

Call 2-1-1 for help with food, housing, employment, healthcare, counseling and more.

Health Care for the Homeless Directory -

<http://www.nhchc.org/resources/grantees/national-hch-grantee-directory/>
615-226-2292

The HCH Directory is a national initiative providing state by state listings of resources, grants and information for facilities that assist those who are homeless.

National Association of Hospital Hospitality Houses, Inc -

<http://www.nahhh.org/> 800-542-9730

The Healthcare Hospitality Network, Inc. (HHN) is a nationwide professional association of nearly 200 unique, nonprofit organizations that provide lodging, transportation and support services to patients, families and their loved ones who are receiving medical treatment far from their home communities.

U.S. Department of Housing and Urban Development -

<http://portal.hud.gov/hudportal/HUD> 202-708-1112

HUDs mission is to create strong, sustainable, inclusive communities and quality affordable homes for all. HUD is working to strengthen the housing market to bolster the economy and protect consumers; meet the need for quality affordable rental homes: utilize housing as a platform for improving quality of life; build inclusive and sustainable communities free from discrimination; and transform the way HUD does business.

Participating in Clinical Trials

Clinical research is research that directly involves a particular person or group of people, or that examines humans in other ways, such as their behavior, or uses samples of their tissue. Clinical research in lupus can be broadly divided into two areas: testing new therapies and expanding our understanding of different aspects of lupus.

A clinical trial is one type of clinical research that follows a pre-defined plan or protocol. By taking part in clinical trials, participants can play a more active role in their own health care. Most importantly, participating in clinical trials helps others by contributing to medical research.

There are dozens of lupus clinical trials in progress. Patient participation in these trials is essential to learning about the possible causes of lupus, testing promising new, safe, and effective therapies, and ultimately, finding a cure for lupus.

The following resources are available to educate patients and health professionals about clinical studies in lupus.

LFA Center for Clinical Trials Education

<https://www.lupus.org/get-involved-in-research/search-for-clinical-trials>

The LFA has established the Center for Clinical Trials Education (CCTE) to provide information for anyone who may be interested in participating in a clinical trial of a potential new treatment for lupus. The website includes a search function that allows trials to be identified in specific geographic areas.

Lupus Trials Listed on ClinicalTrials.gov

<http://www.clinicaltrials.gov/ct/search;jsessionid=E08B6BAB985B53C138F6968D76EC17C6?term=lupus&submit=Search>

ClinicalTrials.gov provides regularly updated information about federally and privately supported clinical research. ClinicalTrials.gov provides information about clinical trials and their purpose, as well as information about who may participate, study locations, and contact information for more details.

The National Institutes of Health

<http://www.lupus.org/resources/the-national-institutes-of-health>

The National Institutes of Health (NIH) is one of the eight health-related agencies of the U.S. Public Health Services (PHS), which is part of the U.S. Department of Health and Human Services (HHS). The NIH mission is to uncover new knowledge that will lead to better health for everyone, as well as to reduce the burdens of illness and disability.

Find a Doctor

In many cases, the best approach to treating your lupus is with a health care team. Having the right health care team and helping the doctor develop the best understanding possible of your lupus symptoms can improve the quality of your care while decreasing the stress and confusion of your doctors' appointments.

Doctors Who Treat Lupus

The form of lupus and its symptoms determine what type of doctor you will see. Most people who have mild to moderate disease will be treated by a **rheumatologist**, who specializes in the diseases of joints and muscles. Your rheumatologist may have a healthcare team to include Nurse Practitioners, Physician Assistants, Infusion Center staff, and Health Educators that are trained to access and provide treatment and resources.

However, if your lupus causes kidney problems, you will also see a **nephrologist**, a specialist in diseases of the renal system.

If you have rashes or lesions, you will see a **dermatologist**, who specializes in diseases that affect the skin (including the scalp and the mouth).

Because lupus can cause damage to any part of the body, other specialists may be necessary, such as a cardiologist, who specializes in heart problems, or a **neurologist**, who specializes in problems that affect the brain and nervous system, or a perinatologist, who specializes in high-risk pregnancies.

Locating a Doctor in Your Area –

1. Talk to your primary care physician or referring physician. They may have the best information on doctors in your area that treat lupus and/or have a special interest and knowledge in the treatment of lupus.
2. Contact your insurance company to get a list of physicians that are covered by your insurance. This will save you a lot of time calling physician's office only to find out they do not take your insurance.
3. You may also want to contact your nearest Lupus Foundation of America chapter. They can provide a list of physicians in their service area who diagnose and treat lupus.

When making an appointment with a doctor to treat your lupus, you may want to find out how many people with lupus the doctor or clinic treats. Are there certain physicians in the office that see the majority of those with lupus?

Georgia Chapter Physician Referral List - <https://www.lupus.org/georgia/find-a-doctor-0>

Preparing for a Doctor's Appointment

In today's managed care environment, the time you spend face-to-face with your physician is limited. To get the most from your health care providers (HCPs) you will need to meet them halfway, and preparation is the key. If you come prepared with the details and history of your problem, anticipate questions, know your medications, and bring medical records you increase the likelihood of an accurate diagnosis. And if you are anxious about doctor appointments, good preparation will go a long way to alleviate that anxiety. The following tips can help you make the most of your appointment.

- Come prepared for your initial doctor's appointment. This will allow your time to focus on your unique issues more fully.

- Because you have limited time with the doctor, keep a running log symptoms or questions you have. Prior to your appointment take a look at that list. Organize the list so those symptoms or issues that have the most impact on your activity daily living are at the top while those symptoms or issues that are present but do not have a significant impact on you are toward the bottom. While you may not get through your entire list, you can target the most important issues.
- If possible, have someone accompany you. Oftentimes, it helps to have another person in the room to write down important information shared by your doctor.

Georgia Chapter Resources – www.LupusGA.org

Educational Programs

Lupus Foundation of America hosts education programs to help people with lupus and their families better understand and manage the disease. Georgia Chapter Education Programs include:

- Annual Summit
- Newly Diagnosed Seminars
- Statewide Symposiums
- Ask the Experts – <https://www.lupus.org/georgia/events/ask-the-experts-teleconference-series-0>
- Regional Teleconferences - <http://www.lupus.org/georgia/events/entry/2013-ask-the-experts>
- College Forums

Georgia Support Group Network

Our Support Network is essential to all the chapter's efforts, working tirelessly to support patients, our programs and events and advocate for awareness. On any given weekend, you can find our support group members at health fairs across the state, spreading awareness and sharing our resources.

Please contact the Support Group leader or the LFA, Georgia Chapter office (770-333-5930) prior to meetings to confirm meeting dates and times.

All of our support groups are currently meeting virtually. This is a great opportunity to connect with other people living with lupus from the comfort of your home.

Georgia Lupus Support Network: <https://www.lupus.org/georgia/Support-Groups-in-Georgia>

Printed and Digital Lupus Education Materials –

<https://www.lupus.org/georgia/lupus-fact-sheets>

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.

- [Living with Lupus](#)
- [Coping with Lupus](#)
- [Treating Lupus](#)
- [Understanding Lupus](#)
- [Lupus and Children](#)
- [Lupus and Teenagers](#)

Lupus Foundation of America – National Resources

National Resource Center on Lupus

A living collection of up-to-date resources and information on lupus. Doctors, scientists, health educators, and people with lupus work together to create our resources and programs. That means we have the trusted information you need to learn about lupus :

- [English search engine](#)
- [Spanish search engine](#)

Lupus Information Packet

Wondering if you have lupus or receiving a diagnosis of lupus can be challenging and stressful. We have put together some resources to help you find the support and information that you need. Our welcome packet can help you learn about lupus diagnosis and treatment as well as how to live well with this disease.

Inside the packet you will find:

- Information on what to do if you think you might have lupus
- Information on understanding, diagnosing, treating, coping, and living with lupus
- A worksheet to help you explain lupus to others
- Information on what to do if you are diagnosed with lupus
- A symptom checklist to help you track your symptoms and communicate with your doctor
- The packet also contains information on how to connect with others who have lupus and with health educators who can answer your questions.