

Lupus Resource Guide

Programs and Services for People with Lupus

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About This Guide

This resource guide is a listing of organizations that provide various forms of assistance that patients with lupus may need, such as help with health insurance enrollment, payment for medical services and prescriptions, securing food, housing, legal help and general wellness. The guide includes resources that are available nationally, and includes a section for services and programs serving the New York area specifically.

This guide is broken down by category. Service organizations, websites, phone numbers if applicable, as well as any general eligibility requirements are included under each category. It's important to note that eligibility requirements, website addresses, or contact information may change over time. Information provided is up to date. You must contact the organization to verify any changes in their programs and confirm your eligibility.

While this is not a complete listing of all organizations that provide such services, it can be used to guide your search. Inclusion of any organization in this guide does not imply endorsement. For specific recommendations, speak with your doctor or the office staff.

I. National Resources

Health Insurance

Under the Affordable Care Act (ACA), insurance companies can no longer reject you or charge you more because of a pre-existing condition, like lupus. The intention of the ACA is to make health insurance coverage available to all regardless of employment, income, or health condition.

Apply for health insurance coverage at www.healthcare.gov/. When you complete the application, you may find that you qualify for coverage through your state's Medicaid program, which provides free or low cost coverage. **For Medicaid eligibility and instructions for your state, visit: www.medicaid.gov/.**

***Important note:** If you're age 65 or older, you may qualify for Medicare. Visit www.medicare.gov/ for more information. If you're a college student, your institution may require insurance and may offer a health plan. Contact your health services department for more information.*

Find Your Rheumatologist

A rheumatologist is the primary specialist caring for patients with lupus. It's important that you establish a partnership with your rheumatologist and seek a second opinion as you see fit. Here are some options in finding a rheumatologist:

Contact your insurance company. Your insurance company can give you a list of rheumatologists that are covered by your plan and in a convenient location. If your rheumatologist practices in a hospital, make sure to ask if your insurance plan covers inpatient and outpatient services.

***Important note:** When you call to schedule your appointment, make sure to ask if the rheumatologist is covered by your insurance plan.*

Use the American College of Rheumatology's Online Directory. This directory allows you to search by country, city, state, and zip code: www.rheumatology.org/Directories/Find-a-Rheumatologist.

Contact your local hospital. If you are uninsured or have limited coverage, your local hospital may have a lupus or rheumatology clinic that provides free or low cost care.

Find a Mental Health Provider

A mental health provider, like a clinical social worker, psychologist, or psychiatrist, can help you manage your lupus, and the effect having lupus may have on your daily life. To find a mental health provider:

Ask your rheumatologist or primary care provider. He/She may be able to give you specific recommendations for mental health providers that are experienced in working with patients with chronic illness.

Contact your insurance company. Your insurance company can help you find a local provider that is covered by your plan. Make sure to ask how many sessions are covered in a specific time period.

***Important note:** When you call to schedule your appointment, make sure to ask if the provider is covered by your insurance plan.*

Use an online directory or hotline service:

Substance Abuse and Mental Health Service (SAMHSA): Is a free, confidential, online-directory for behavioral health services.

Phone: (800) 662-4357

Website: <https://findtreatment.samhsa.gov/>

Lifenet: Is a free, confidential hotline staffed by trained mental health professionals to locate mental health and substance abuse services. The service is available 24 hours a day in English and Spanish

Phone: (800) 543-3638

Website: <http://www.nyc.gov/html/doh/html/mental/lifenet.shtml>

Help with Medical Expenses

If you're having trouble paying for your co-payments, deductibles, premiums or other medical expenses:

Talk with your doctor or office staff. Your doctor or hospital may be able to offer financial relief or payment plans for co-payments. Your doctor may also be able to help to reduce your co-payments by changing your office visit schedule or reviewing test results by phone instead of scheduling another office visit.

Find local help. Contact a local disease foundation to see if there are local programs or charity organizations that can suit your specific needs.

Contact a national assistance program. These programs offer financial assistance for co-payments, premiums, deductibles and certain medications and therapies. Requirements and eligibility will vary by program. Check the availability for funding certain funding may change.

Assistance Fund: Provides financial support for co-payments, deductibles, and premiums to patients who are critically or chronically ill and require medications. You must be being treated for a covered illness in the United States and have insurance coverage for prescribed medications. Income and other eligibility requirements apply.

Phone: (855) 845-3663

Website: www.theassistancefund.org/

Co-Pay Relief: Provides assistance to financially and medically qualified patients, including those insured through government programs, for co-payments, co-insurance, and deductibles required by a patient's insurer for medications. You must be being treated in the United States for a disease that they cover. Income and other eligibility requirements apply.

Phone: (866) 512-3861

Website: www.copays.org

HealthWell Foundation: Provides assistance to individuals who cannot afford their co-payments, co-insurance, or premiums for treatments. You must be treated for a disease that they cover, you must be treated in the United States, and you must have insurance that covers your medications.

Phone: (800) 675-8416

Website: www.healthwellfoundation.org/

Pan Access Network Foundation: Provides assistance to under-insured patients for out-of-pocket expenses for medications. You must have health insurance that covers your medication, the medication must directly treat the disease, and you must be treated in the United States. Income restrictions apply.

Phone: (866) 316-7263

Website: www.panfoundation.org

United Healthcare Children's Foundation: Provides financial assistance for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan.

Phone: (855) 698-4223

Website: <http://www.uhccf.org/apply/learn-more-about-medical-grants/grant-application-criteria/>

For assistance with copayments for laboratory testing only:

Quest Diagnostics Patient Assistance Program: Quest is a service provider that processes laboratory work, like blood tests. Quest offers payment plans and financial assistance for those that qualify.

Phone: (866) 697-8378

Website: www.questdiagnostics.com/home/about/corporate-citizenship/community-giving/assistance.html

Prescription Assistance Programs

It's recommended to get all of your prescriptions from the same pharmacy. By using the same pharmacist, your pharmacist can keep track and advise you on how to take all of your medications to avoid any interactions and alert your doctors of any potential interactions. However, if it is more cost effective to get your prescriptions from multiple sources, make sure you keep an up to date record of all of your medications and share that list with each of your doctors and pharmacists. If you're having trouble paying for your prescription medications:

Talk with your doctor or pharmacist. There may be generic versions of the medications you are taking or less expensive alternatives.

Contact the pharmaceutical company. The company that makes the drug may have assistance programs to help you pay for the medication you are taking.

Contact your insurance company. You may get a discount for a 3-month supply instead of 1 month. Or they may have other programs available.

Find a Prescription Assistance Program (PAP). Common requirements for PAPs are that you must be a US Citizen or legal resident, have no prescription coverage, and must meet program income guidelines, but this varies. If you have prescription coverage and don't qualify for any PAP, these sites may also offer a prescription discount cards.

NeedyMeds: Provides a list of PAPs by brand or generic names of the medication. There is also a searchable listing of free or low cost clinics.

Phone: (800) 503-6897

Website: www.needymeds.org

Partnership for Prescription Assistance: This program is for patients who do not have any form of prescription drug coverage. There is also a searchable listing of free or low cost clinics.

Phone: (888) 477-2669

Website: www.pparx.org

RxAssist: Provides a list of pharmaceutical companies that assist with medication costs and other PAPs.

Phone: (877) 537-5537

Website: www.Rxassist.org/

RxHope: Provides a list of pharmaceutical companies that assist with medication costs for brand name medications only. Your doctor will need to help complete the application.

Phone: (800) 444-4106

Website: www.rxhope.com

Together Rx: Provides a savings card for patients without prescription coverage to get discounts on their medications. Income limits apply.

Phone: (800) 444-4106

Website: <http://www.togetherrxaccess.com/>

Use a Mail Order Pharmacy. Mail order pharmacies may offer the same prescriptions at a lesser cost. Choose an online pharmacy that has been certified by the National Association of Boards of Pharmacy as a Verified Internet Pharmacy Practice Site (VIPPS). VIPPS follow all federal and state laws and regulations. Check the recent listing here:

www.nabp.net/programs/accreditation/vipps/find-a-vipps-online-pharmacy

RxOutreach: Is a VIPPS certified online pharmacy that can send certain prescriptions by mail at a lower cost. You must meet income requirements, you can be participating in a PAP and you can have insurance. You will need to send your prescription directly.

Phone: (888) 796-1234

Website: www.rxoutreach.org/

General Assistance Programs

For a national directory of organizations that can help with disaster recovery, food services, housing and utility assistance, employment help, and more, call 211 or visit www.211search.org. The service is free, confidential, and available in all languages any time.

You can also visit www.benefits.gov/ for an interactive database of government assistance programs online.

Catholic Charities: Provides a wide range of services from disaster relief, housing, meals, education, and financial counseling. Visit the website to find the local office.

Website: <https://catholiccharitiesusa.org/>

The Modest Needs Foundation: Offers grants for working individuals or families just above the poverty line that are facing financial hardship. Applicants must: be over 18 years of age, a legal resident of the United States or Canada, have at least 1 active bank account or tax return from the last 2 years, not be a homeowner, meet income restrictions, and have computer access.

Phone: (212) 463-7042

Website: www.modestneeds.org/index.asp

Patient Advocate Foundation: Provides help with arbitration and negotiations related to medical debt or job retention issues related to their illness, and has financial resource directories for uninsured and underinsured patients.

Phone: (800) 532-5274

Website: www.patientadvocate.org/resources.php

Salvation Army: Provides housing and homeless services, nutritional meals, educational counseling, and emergency utility assistance. Salvation Army programs and services vary with local needs. For information on specific programs and locations, contact your local Salvation Army Corps Community Center by using the location search.

Website: www.salvationarmyusa.org/usn/ways-we-help

Single Stop USA: Assists low income individuals and families with finding and applying for a wide range of government resources and offers free to low cost legal and tax services.

Website: <http://singlestopusa.biz/Locations.shtml>

Temporary Assistance for Needy Families (TANF): Provides grants to states to provide assistance to needy families to achieve self-sufficiency. Check the website for state contacts.

Phone: (877) 696-6775

Website: www.acf.hhs.gov/programs/ofa/programs/tanf

Workplace Accommodation

The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications and government activities. If you have lupus, it's important to know your rights under this law. The ADA requires employers to provide reasonable accommodations for people with lupus so they can continue to perform their job.

Visit the **Job Accommodation Network (JAN)** website at <https://askjan.org/> or contact them at (800) 526-7234 for workplace accommodation ideas for people with lupus. The site also includes frequently asked questions, template letters, and recommendations for discussing your lupus with your employer.

Disability Insurance

There are two kinds of disability insurance awarded through Social Security: Social Security Disability (SSD) and Supplemental Security Income (SSI). Eligibility is dependent upon the amount of time worked and how long the medical condition is expected to prevent you from working.

Disability.gov. Connects people with disabilities to resources such as how to apply for disability benefits, find employment, get health care coverage, pay for housing, and more.

Phone: 1-800-772-1213

Website: www.disability.gov/

Social Security. There are detailed instructions on how to apply for disability benefits, what information and documents you need to apply, and an overview of the process.

Phone: 1-800-772-1213

Website: www.ssa.gov/disabilityssi/

Social Security Disability Appeal. By law you have the right to appeal a denial of benefits.

Phone: 1-800-772-1213

Website: <http://ssa.gov/disabilityssi/appeal.html>

Wellness

Speak with your rheumatologist or primary care provider for free or low cost programs and services in your area that can assist with general wellness, such as exercise programs. You can also check with your local recreation center, parks department, congregation, or library.

Important note: Speak with your doctor before making any changes in your diet, including starting on any new supplement or home remedy, or starting or changing your exercise routine.

II. New York Resources

Health Insurance Enrollment Assistance

Medicaid of New York State: Provides free or low cost healthcare coverage and services. Income limits apply.

Phone: 1 (800) 541-2831

Website: https://www.health.ny.gov/health_care/medicaid/#definition

These are organizations in New York that may be able to help you enroll in health insurance coverage. Certain eligibility requirements and qualifications apply:

Community Health Advocates: They provide individuals, families, and small businesses with free information and advice on applying for health insurance.

Phone: 1 (888) 614-5400

Website: www.communityhealthadvocates.org

Community Service Society Navigator Network: The Official Health Plan Marketplace helps New Yorkers and small businesses shop for and enroll in health coverage through NY State.

Phone: 1 (888) 614-5400

Website: <http://www.cssny.org/programs/entry/community-service-society-navigator-network>

Public Health Solutions: Provides navigators in all five boroughs to help individuals, families and small businesses shop and enroll for health insurance coverage in the online marketplace.

Phone: 1 (800) 344-4306

Website: <http://www.healthsolutions.org/navigator/NewYork.html>

Lupus and Rheumatology Clinics by Borough

If you are not insured or underinsured, contact the lupus or rheumatology clinic near you, or your local hospital for free or low cost care. Make sure to verify eligibility, hours, and locations.

Bronx

Bronx Lebanon Hospital Center:

Type: Lupus

Address: 1650 Grand Concourse, 10457

Phone: (718) 518-5090

Children's Hospital at Montefiore:

Type: Lupus Nephrology
Address: 3415 Bainbridge Avenue, 10467
Phone: (718) 741-2450

Jacobi Medical Center:

Type: Lupus
Address: 1400 Pelham Pkwy South, 10461
Phone: (718) 918-5700

Lincoln Medical Center:

Type: Rheumatology
Address: 234 East 149th St., 10451
Phone: (718) 579-5000

Montefiore Medical Center:

Type: Lupus
Address: 3444 Kossuth Ave, 10467
Phone: (718) 920-5584

St. Barnabas Hospital:

Type: Rheumatology
Address: 4487 Third Avenue, 10457
Phone: (718) 960-6430/6433

Brooklyn

Brookdale University Hospital and Medical Center:

Type: Rheumatology
Address: 1 Brookdale Plaza
Phone: (718) 240-5100

Coney Island Hospital:

Type: Arthritis
Address: 2601 Ocean Parkway
Phone: (718) 616-4002

Interfaith Medical Center:

Type: Rheumatology
Address: 528 Prospect Place, 3rd Fl., 11238
Phone: (718) 613-6888

Kingsbrook Jewish Medical Center:

Type: Rheumatology
Address: 585 Schenectady Avenue, 11203
Phone: (718) 604-5700

Maimonides Medical Center:

Type: Rheumatology
Address: 4802 10th Avenue, 11219
Phone: (718) 283-8519

New York Methodist Hospital:

Type: Rheumatology
Address: 506 6th Street
Phone: (718) 246-8700

NYU Lutheran Medical Center:

Type: Rheumatology
Address: 150 55th Street, 11220
Phone: (718) 630-7942

SUNY Downstate Medical Center:

Type: Rheumatology
Address: 450 Clarkson Ave
Phone: (718) 270-1662

Woodhull Medical and Mental Health Center:

Type: Rheumatology
Address: 760 Broadway, 11206
Phone: (718) 963-8269

Wyckoff Heights Medical Center:

Type: Rheumatology
Address: 970 N Broadway Suites 312, 10701
Phone: (718) 963-7272

Manhattan

Bellevue Hospital Center:

Type: Rheumatology
Address: 462 1st Ave
Phone: (212) 562-5555

Harlem Hospital Center:

Type: Lupus
Address: 506 Lenox Avenue Brown Pavilion, 10037
Phone: (212) 939-8111

Hospital for Special Surgery:

Type: Rheumatology
Address: 535 E. 70th St., 10021
Phone: (212) 606-1000

Lenox Hill Hospital:

Type: Lupus
Address: 178 E. 85th St. 2nd Flr. 10028
Phone: (212) 434- 6776

Metropolitan Hospital Center:

Type: Rheumatology
Address: 1901 1st Avenue, 10029
Phone: (212) 423-6262

Mount Sinai Hospital:

Type: Rheumatology
Address: 5 E. 98th St, 11th Flr. 10013
Phone: (212) 241-1671

New York Presbyterian/Columbia University Medical Center:

Type: Lupus
Address: 161 Fort Washington Ave 2nd Flr. 10032
Phone: (212) 305-4308

Queens

Elmhurst Hospital Center:

Type: Rheumatology
Address: 79-01 Broadway, 11373
Phone: (718) 334-4000

Jamaica Hospital Medical Center:

Type: Rheumatology
Address: 8900 Van Wyck Expressway, 11418
Phone: (718) 206-6000

Long Island Jewish Medical Center (LIJ):

Type: Rheumatology
Address: 27005 76th Ave, 11040
Phone: (718) 470-7000

Staten Island

Staten Island University Hospital:

Type: Rheumatology
Address: 375 Seguine Ave, 10309
Phone: (718) 226-2000

General Assistance Programs

For a city wide directory of organizations that can help with disaster recovery, food services, housing and utility assistance, employment help, and more, call 311 or visit www.1.nyc.gov. The service is free, confidential, and available in all languages any time.

Health Information Tool for Empowerment (HITE) is an online directory of health and social services available to low-income, uninsured, and underinsured individuals in the Greater New York area.

Phone: (866) 370-HITE (4483)
Website: <http://www.hitesite.org>

Employment Help

These organizations offer a variety of programs such as skill-building workshops and interview coaching and general employment assistance. There are certain requirements for each program; such as being a U.S resident or of a certain age. Services and hours vary by organization.

America Works: Offers a job readiness program that lasts for 2-4 weeks that focuses on interviewing skills and job searching.

Phone: (855) 840-5627
Website: <http://www.americaworks.com/job-seekers/a-new-beginning-with-america-works>

Job Centers: The NYC Human Resources Administration's (HRA) Employment Services assist s with job search support, training, resume writing, and literacy.

Phone: Bronx- Crotona (718) 901-5274
Brooklyn- Bayridge (718) 921-2001
Manhattan- Dyckman (212) 569-9543
Queens-East River (718) 784-2922
Staten Island- Richmond (718)556-7343
Website: <http://www1.nyc.gov/site/hra/locations/job-locations.page>

Street Wise Partners: Offers a 3-month career mentoring program for low income individuals. They deliver high-impact professional development services with a career mentor in corporate settings.

Phone: (646) 705-0029
Website: <http://streetwisepartners.org/our-program/career-ventures/>

STRIVE: Offers skills training in green construction, light maintenance, office operations, and medical information technology. Participants must first complete four weeks of Attitudinal and Job Readiness training to be eligible for any of these training programs. All participants receive case management, job placement, and two years of follow-up assistance.

Phone: (212) 360-1100
Website: <http://striveinternational.org/what-we-do/>

Workforce1 Career Centers: Offers career counseling and help with resume writing, interview skills, and job searches.

Phone: Bronx- (718) 960-2458
Brooklyn-(347) 765-2250
Manhattan-(646) 358-4747
Queens-(718) 557- 6755
Staten Island- (718) 285-8388
Website: <http://www.nyc.gov/html/sbs/wf1/html/about/about.shtml>

Food Assistance

These organizations can help connect you with local food pantries or soup kitchens. Food pantries offer unprepared foods to bring home and cook, while soup kitchens offer full meals.

Food Bank of NYC: Provides a list of food pantries and soup kitchens, as well as assistance with food stamps and other referrals.

Phone: (212) 566-7855
Website: <http://www.foodbanknyc.org>

Why Hunger: Provides a hotline to connect individuals with emergency food services and supports local community based organizations.

Phone: Main: (800) 548-6479 NYC Office: (212) 629-8850

Website: <http://www.whyhunger.org>

Housing Assistance

These organizations can help with temporary or permanent housing or assistance with rent and mortgage. Hours of operations vary by location and site.

Margert Community Corporation: Provides neighborhood preservation services, housing assistance, and housing counseling to low-income tenants and homeowners, the elderly, and persons with disabilities.

Phone: (718) 471-3724

Website: <http://www.margert.org>

NYC Senior Citizen and Disability Rent Increase Exemption Programs (SCRIE & DRIE):

Is a Rent Freeze Program for Tenants with Disabilities (DRIE) can have their rent frozen and be exempt from future rent increases.

Phone: Call 311 from within the City or (212) NEW-YORK outside the five boroughs.

Website: <http://www.nycrgb.org/html/resources/seniors.html>

New York City Housing Authority NYCHA: Provides decent and affordable housing in a safe and secure living environment for low- and moderate-income residents throughout the five boroughs.

Phone: (718) 707-7771

Website: <http://www1.nyc.gov/site/nycha/eligibility/eligibility.page>

Temporary Housing Assistance: Provides temporary emergency shelter to families with children, adult families, and single adults.

Phone: (212) 361-8000

Website: <http://www1.nyc.gov/site/dhs/shelter/shelter.page>

Legal Services

The NYC Human Rights Law prohibits discrimination in New York City in areas of employment, housing, public accommodations, retaliation, discriminatory harassment, and bias based profiling by law enforcement. Those with a disability are considered protected classes.

Contact the **Commission on Human Rights** if you believe you have been a victim of discrimination in New York City.

Phone: (212) 306-7450
Website: <http://www.nyc.gov/html/cchr/html/home/home.shtml>

These legal services offer court assistance, legal education, and representation at low to no cost for seniors, victims of domestic violence, immigrants, and low income individuals facing housing, employment, disability and other legal issues. Many have a translator available.

The Family Center: Assists families with children that are affected by a chronic illness with legal services.

Phone: (800) 219-4522 ext. 113
Website: www.thefamilycenter.org/what-we-do/

Law Help NY: Provides an online tool to locate legal assistance.

Phone: Online database only
Website: www.lawhelpNY.org

Legal Services NYC: Provides low-income residents with free legal help.

Phone: (917) 661-4500
Website: www.legalservicesnyc.org

The Legal Aid Society: Provides free legal services for low-income families who cannot afford to pay for an attorney. They assist individuals in legal matters involving housing, benefits, disability, domestic violence, family issues, health, employment, immigration, HIV/AIDS, prisoners' rights and elder law.

Phone: (212) 577-3300
Website: <http://www.legal-aid.org/en/home.aspx>

NYLAG (New York Legal Assistance Group): Provides, free civil legal services to low-income New Yorkers who cannot afford an attorney. They assist individuals in legal matters involving housing, benefits, disability, and domestic violence.

Phone: (212) 613-5000
Website: <http://nylag.org/units/mobile-legal-help-center>

Transportation

These organizations offer transportation support services to those that qualify. Eligibility and hours of operation will vary.

Access-A-Ride: Provides transportation for people with disabilities who are unable to use public bus or subway service for some or all of their trips.

Phone: (877) 337-2017
Website: http://www.nyc.gov/html/mopd/html/resources/trans_aar.shtml

LogistisCare: Provides transportation services to medical appointments for people who are in NYC Medicaid fee-for-service, Family Health Plus who are 19 or 20 years old, and some NYC Medicaid Managed Care are accepted.

Phone: (877) 564-5924

Website: <http://www.nycmedicaidride.net/en-us/enrollees.aspx>

Utility Assistance

Call your service provider first and ask about a possible payment plan. If you are unable to manage your payments, these organizations offer financial assistance for rent and utilities. Eligibility requirements vary.

Home Energy Assistance Program (HEAP): HEAP is a program that assists low-income New Yorkers with the cost of heating their homes.

Phone: (800) 342-3009

Website: www.otda.ny.gov/programs/heap/

One Shot Deal Program: Is an emergency assistance program that helps people who cannot meet an expense due to an unexpected situation or event such as: dispossession/eviction, utility disconnected or pending termination, fire disaster, and homelessness.

Phone: (718) 557-1399

Website: <http://www1.nyc.gov/nyc-resources/service/1205/one-shot-deal-short-term-emergency-assistance>

Local Wellness Resources

Important note: Speak with your doctor before making any changes in your diet, including starting on any new supplement or home remedy, or starting or changing your exercise routine.

Here are some resources for local exercise programs, meditation and massage services:

American Massage Therapy Association: Provides a Massage Therapy Resource Guide. All Massage Therapists listed are licensed by the state of NY and are members of the American Massage Therapist Association (AMTA). The sliding scale fee will be determined on an individual basis and agreed to by the Therapist and client prior to the first appointment and will not change without written notice. Clients must pay in full at time of appointment.

Website: <https://www.amtamassage.org/findamassage/index.html>

Free Meditation NYC: Provides a listing of free meditation classes in New York City.

Phone: (212) 380-8153

Website: <http://www.nycmeditation.org>

NYC Parks: Provides free or low-cost physical activity programs such as Shape-Up NYC and BeFit NYC.

Phone: 311

Website: <http://www.nycgovparks.org/events/accessibility>

NYC YMCA: Offers a variety of activity programs for teens, adults, and families that are free or low cost. Financial assistance available.

Phone: (212) 630-9600

Website: <http://www.ymcanyc.org/association/membership>