



Resources for the Lupus Community
Presented by

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Today



- About Lupus
- About the Lupus Society of Illinois (LSI)
- Resources Available to the Lupus Community in Illinois



About Lupus

- 4 types
- Most common is SLE
 - *Lupus can affect many body parts, including the joints, skin, kidneys, heart, lungs, blood vessels, or brain.*
 - *You will have periods of illness (flares) and wellness. Painful & Pain-free days.*
 - *Anyone can get lupus, 9 times out of 10 it affects women. Lupus is also more common among African American, Hispanic, Asian, and Native American women.*



About Lupus

- Cutaneous lupus – affects the skin
 - Worsens when exposed to UV light
 - Steroid ointments prescribed
 - Low dose meds that help reduce pain & swelling
 - Protect skin with broad-spectrum sunscreen, protective clothing, hats
 - Avoid sunlight between 10a – 4p
 - Fluorescent lights in offices & classrooms also can cause flare ups



About Lupus

- Cutaneous lupus – cont.
 - Photosensitivity – causes exhaustion, migraines, rashes, pains, and flare ups
 - Apply sunscreen at least a shot glass full 15 mins before going out into the sun
 - Constantly apply when in water (pool)



About Lupus

■ Drug-induced lupus

while lupus may damage your kidneys or lungs, drug-induced lupus rarely affects your organs

It's also temporary. Once you stop taking the certain meds, symptoms usually clear up within a few weeks or months

About Lupus

■ Neonatal lupus (NL)

an autoimmune disease in which antibodies pass from the mother to the fetus

- skin rashes
- liver problems
- low blood cell count

Typically disappears about 6 months later

Lupus Society of Illinois



- LSI promotes lupus awareness and complements the work of health care professionals by providing personalized resources for the lupus community while supporting research.
- LSI is the OLDEST organization in Illinois helping the lupus community TODAY.
- The LSI is an incorporated 501 (c) 3 nonprofit health agency that was founded in 1973.

Lupus Resources



- Practical Resources
- Emotional Resources
- Financial Resources
- Government Resources

Practical Resources



- How to talk to your doctor
 - *Lupus Symptom Tracker*
 - *Articles*

Practical Resources



- Learning about lupus
 - *Educational events*
 - *LSI Website*
 - *Reputable Websites*

Practical Resources



- Problems getting covered for procedures or medication
 - *Social media*
 - *Pharmaceutical companies*
- Medicaid
- Medicare
- SSI
- Prescription Assistance

Emotional Resources



- Navigator
- Support Groups
- Individual Peer Support
- Share Your Story

Emotional Resources



- Networking with others in the lupus community
 - *Educational events*
 - *Illinois Lupus Walks*
 - *Volunteer Opportunities*
 - *Support Groups*
 - *Webinars*

Financial Resources



■ Living with Lupus Grant

- *Up to \$400 for a medical related expense.*
- *Eligible once every 12 months*
- *Applications include a physician portion*
- *Funds paid to vendor, not to individual*
- *For Illinois residents*

Financial Assistance



■ Catholic Charities

- *Financial assistance for basic needs can be paid for. Of course, funding needs to be available, and applicants need to meet conditions before Catholic Charities will provide them with emergency financial assistance. Cash assistance can be provided to pay for some or all of the following:*
- **Utilities** - *Money to pay to prevent a disconnection of electric or water bills. Or if you have run out of heating fuel or oil then Catholic Charities may help.*
- **Clothing** - *Including work and/or school uniforms for children attending school.*
- **Prescriptions** - *Only a select few locations can pay for medications, and aid is very limited.*
- **Rental assistance** - *Get help in an emergency to pay rent if you are faced with imminent eviction, so funds can be paid for security deposits.*
- *Call 311 for Short Term Help*
- *Call 312-655-7700 in Chicago*
- *Call 877-426-6515 outside of Chicago*

Financial Assistance



■ Prescription Assistance

- *Partnership for Prescription Assistance* (www.pparx.org)
- *Needy Meds* (www.needymeds.org)
- *Good RX* (www.goodrx.com)
- *RxAssist* (www.rxassist.org)
- *Always ask your pharmacists too. They have coupons to help their patients.*

Financial Assistance



- CEDA

www.cedaorg.net

- LIHEAP (Low Income Home Energy Assistance Program)

<https://liheapassistance>

- Salvation Army

<http://www.salvationarmy.org>

- Healthcare.gov

Government Resources



- Social Security Disability
 - *SSDI*
 - *SSI*

Government Resources



■ Medicare

- *Federal program attached to Social Security*
- *All US citizens 65 years and older*
- *Also disability*
- *4 parts*
 - Part A – Hospitalization coverage
 - Part B – Medical Insurance
 - Part C – privately purchased supplemental insurance that provides additional services and through which all medicare services offered by Part A and Part B can be accessed
 - Part D- Prescription Drug Coverage

Government Resources



■ Medicaid

- *Expanded in Illinois due to ACA*
- *Joint state and federal program*
- *Strict requirements*
- *Needs based*
- *Must live in Illinois, US citizen (or qualified immigrant)*
 - Children don't have to be qualified immigrants

Government Resources



- IDPH – Illinois Dept. of Public Health
 - *Temporary Assistance for Needy Families (TANF)*
 - *Aid to the Aged, Blind, and Disabled (AABD)*
 - *Earnfare*
 - *Earned Income Tax Credit (EITC)*
 - *Illinois Welcoming Centers – Illinois Department of Human Services*

Government Resources



- Department of Human Services (US)
<https://www.dhs.state.il.us/>
 - *Cash*
 - *Food*
 - *Child Care*
 - *Housing*
 - *Disability & Rehabilitation*
 - *Mental Health*

- Personal assistance for anyone with a lupus related question or problem.
 - *Facts sheets*
 - *Legal issues*
 - *Insurance*
 - *Disability*
 - *Men & Lupus*
 - *Mental Health*

For more information



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