

Understanding Lupus & Managing Your Health with Lupus

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Answers. Advocacy. Action.

LUPUS & you™

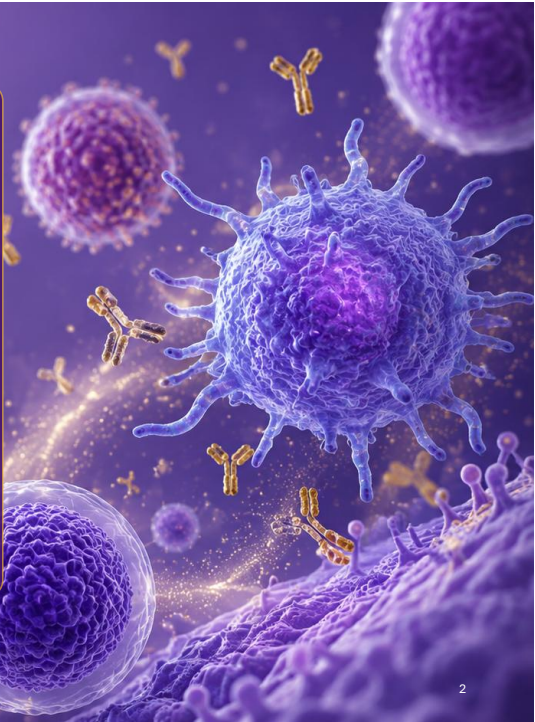
by Lupus Foundation
of America



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What Is Lupus?

The immune system, misfiring



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SYSTEMIC

Lupus can affect the whole body

Unlike diseases that stay in one place, systemic lupus can involve many organs.

- Skin, joints, blood
- Kidneys, lungs, heart
- Brain and nerves



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SYSTEMIC AUTOIMMUNE DISEASES

“Sister” diseases

Problems overlap
Often seen together

- **Rheumatoid arthritis:** mainly joints
- **Sjögren’s:** dry eyes and mouth
- **Polymyositis:** muscle inflammation weakness
- **Dermatomyositis:** skin & muscle inflammation
- **Mixed Connective Tissue Disease**
- **Undifferentiated Connective Tissue Disease**

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GENES

Close to 300 genes are linked to lupus

There is no single “lupus gene.”
Many small gene effects add up.

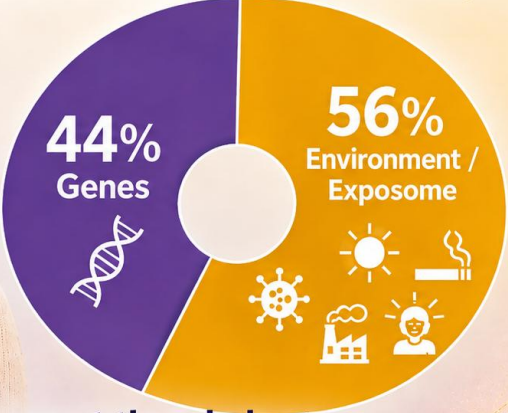
- Most nudge immunity to be more active
- Genes increase risk — they do not guarantee lupus
- Environment and habits still matter

Saadat M. Enrichment analysis of SLE susceptible loci identified by genome-wide association studies. Hum Immunol. 2024 Nov;85(6):111116

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What identical twins teach us about lupus





Factor	Percentage
Genes	44%
Environment / Exposome	56%

Genes matter, but they are not the whole story.



This study included **over 340,000** twin pairs.



This study estimated lupus susceptibility as about **44% genetic** and **56% environmental/exposomal factors**.

Kud CF. Familial aggregation of SLE and Coaggregation of Autoimmune Diseases in Affected Families. JAMA Intern Med. 2015 Sep;175(9):1518

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Genes load the gun Triggers pull it

You may inherit risk genes

Life exposures can switch those risks on and set lupus in motion

The hopeful part:
many triggers are things you can influence



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THE EXPOSOME

Triggers that can switch lupus on

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UV light

Sunlight — greatest UV source

Indoor light — small amounts over large amounts of time

Daily sun protection is one of your best defenses.

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Smoking

Smoking increases lupus gene activity (epigenetic changes)

Makes lupus more active

Blocks HCQ and Benlysta from working

Raises heart attack, stroke, cancer risk

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Paris D. Impact of tobacco smoking on disease risk, activity and therapeutic response in SLE: A systematic review and meta-analysis. Autoimmune Rev. 2019 Nov;18(11):102393

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A microscopic view of several spherical viruses with a textured, bumpy surface, set against a blue and purple background with faint cellular structures.

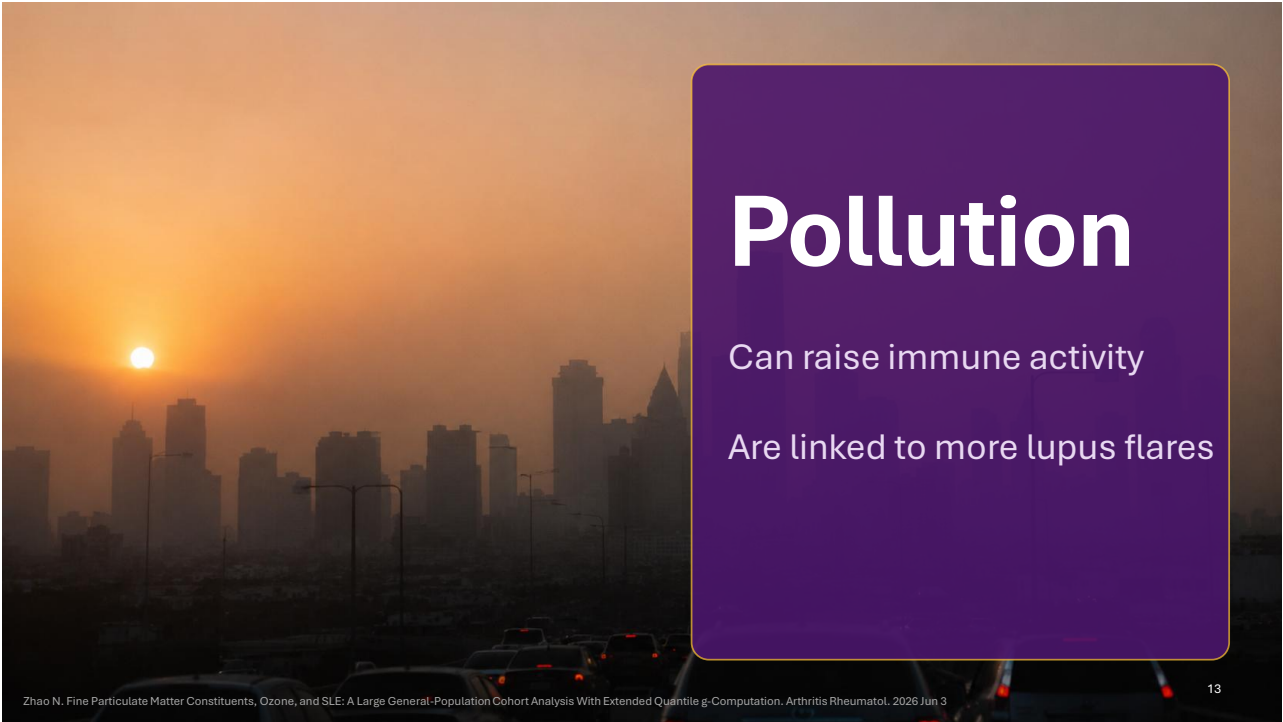
Infections

e.g. Epstein–Barr virus (the mono virus)

— may help set lupus in motion in people with risk genes

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A city skyline at sunset, with the sun low on the horizon, casting a warm orange glow over the buildings and a hazy atmosphere.

Pollution

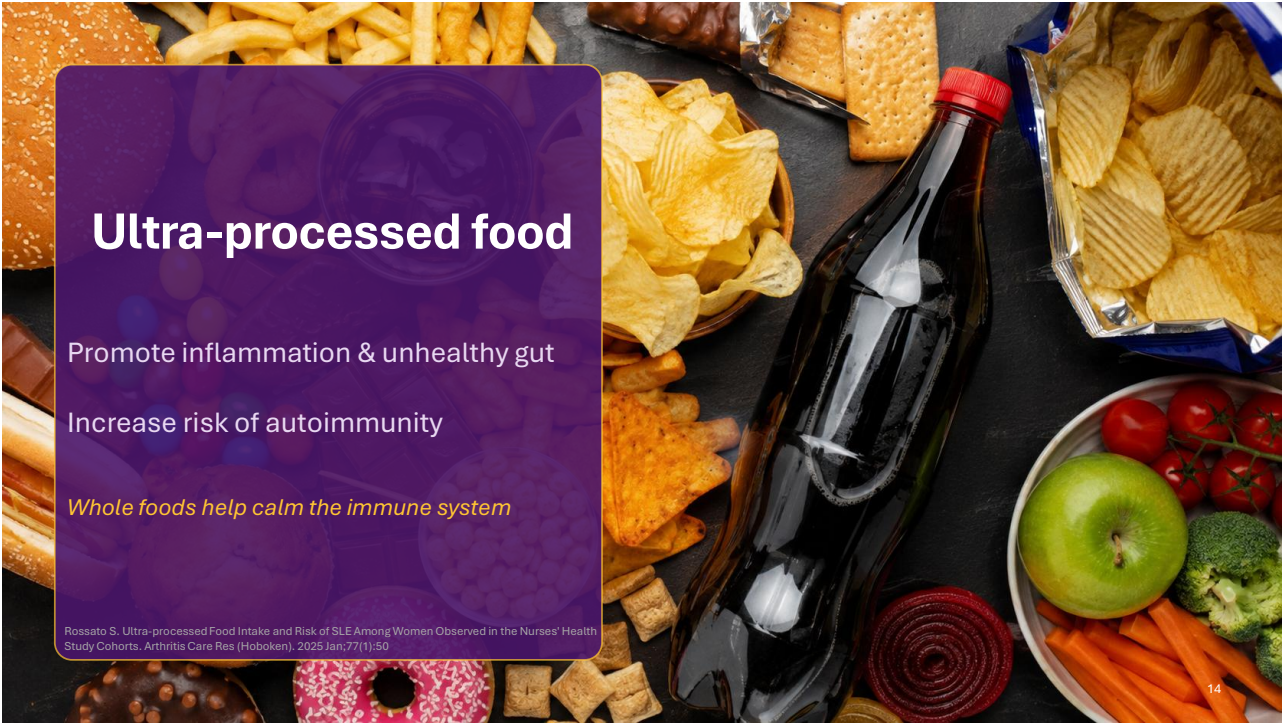
Can raise immune activity

Are linked to more lupus flares

Zhao N. Fine Particulate Matter Constituents, Ozone, and SLE: A Large General-Population Cohort Analysis With Extended Quantile g-Computation. Arthritis Rheumatol. 2026 Jun 3

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Ultra-processed food

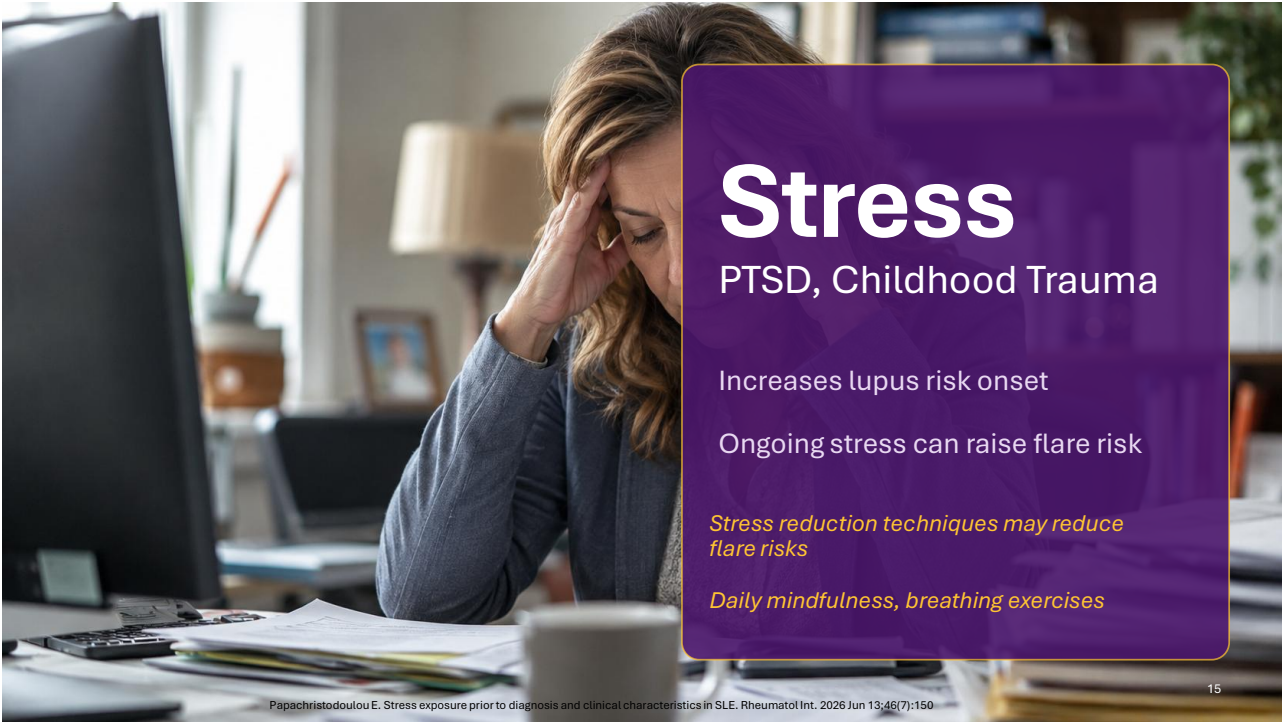
Promote inflammation & unhealthy gut

Increase risk of autoimmunity

Whole foods help calm the immune system

Rossato S. Ultra-processed Food Intake and Risk of SLE Among Women Observed in the Nurses' Health Study Cohorts. Arthritis Care Res (Hoboken). 2025 Jan;77(1):50

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Stress

PTSD, Childhood Trauma

Increases lupus risk onset

Ongoing stress can raise flare risk

Stress reduction techniques may reduce flare risks

Daily mindfulness, breathing exercises

Papachristodoulou E. Stress exposure prior to diagnosis and clinical characteristics in SLE. Rheumatol Int. 2026 Jun 13;46(7):150

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Too little sleep

Increases risk of SLE in family members

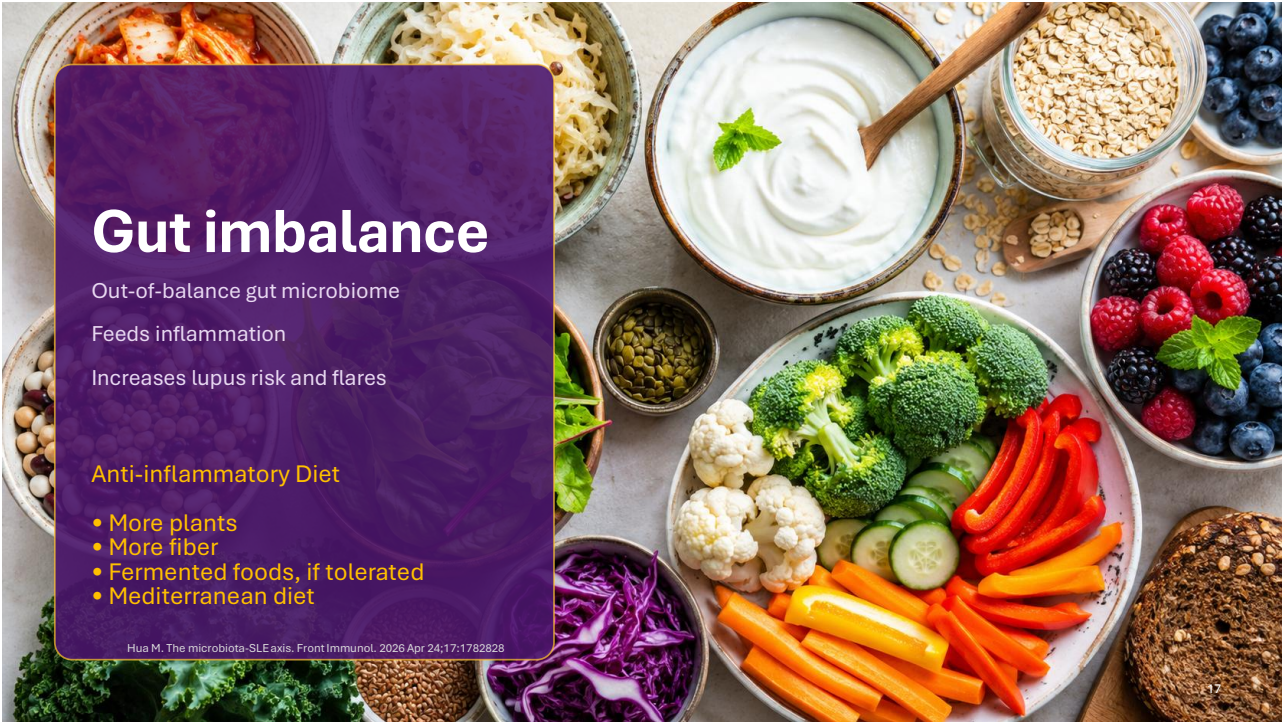
Poor or short sleep is tied to more flares

Protecting sleep helps protect your immune system

Young KA. Less than 7 hours of sleep per night is associated with transitioning to SLE. *Lupus*. 2018 Aug;27(9):1524

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Gut imbalance

Out-of-balance gut microbiome

Feeds inflammation

Increases lupus risk and flares

Anti-inflammatory Diet

- More plants
- More fiber
- Fermented foods, if tolerated
- Mediterranean diet

Hua M. The microbiota-SLE axis. *Front Immunol*. 2026 Apr 24;17:1782828

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Managing Your Health

The “Lupus Secrets” —
habits that help you live longer and better

www.lupusencyclopedia.com/lupus-secrets

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Be your own health record-keeper

Keep copies of important labs, biopsies, X-rays, scans, and doctor notes

ANA becomes negative in 30% of well-treated patients

Your own file can prevent diagnosis questioning by doctors

Wallace DJ. SLE and primary fibromyalgia can be distinguished by testing for CB-CAPS. Lupus Sci Med. 2016 Feb 1;3(1):e000127

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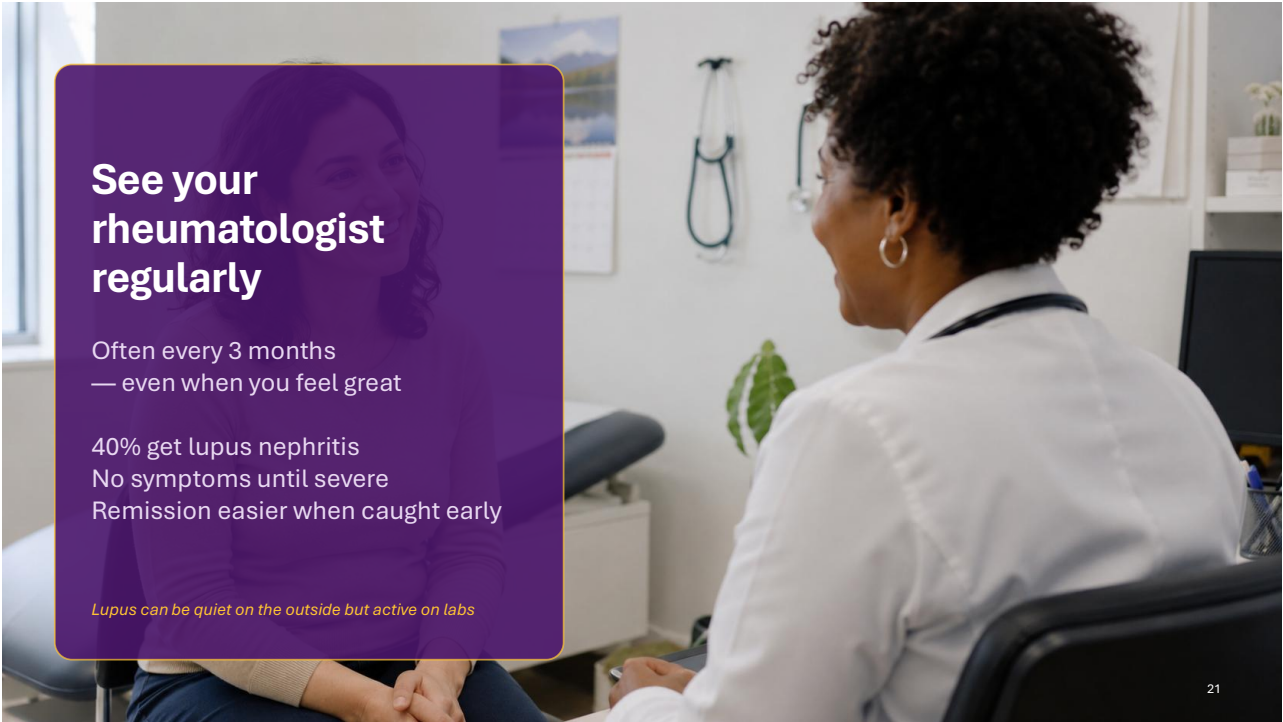


Ask doctors to communicate

Ask every specialist to copy or message your rheumatologist

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See your rheumatologist regularly

Often every 3 months
— even when you feel great

40% get lupus nephritis
No symptoms until severe
Remission easier when caught early

Lupus can be quiet on the outside but active on labs

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Carry an up-to-date medication list

or a bag of your medicines
— to every visit

Assume: ALL doctor med lists are wrong

- Every medicine and dose
- Supplements and vitamins
- Drug intolerances and allergies
- **Sulfa antibiotic allergy in everyone**

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3 MOST IMPORTANT SLE THERAPIES

Simple, **proven**, and easy to forget
— take them faithfully

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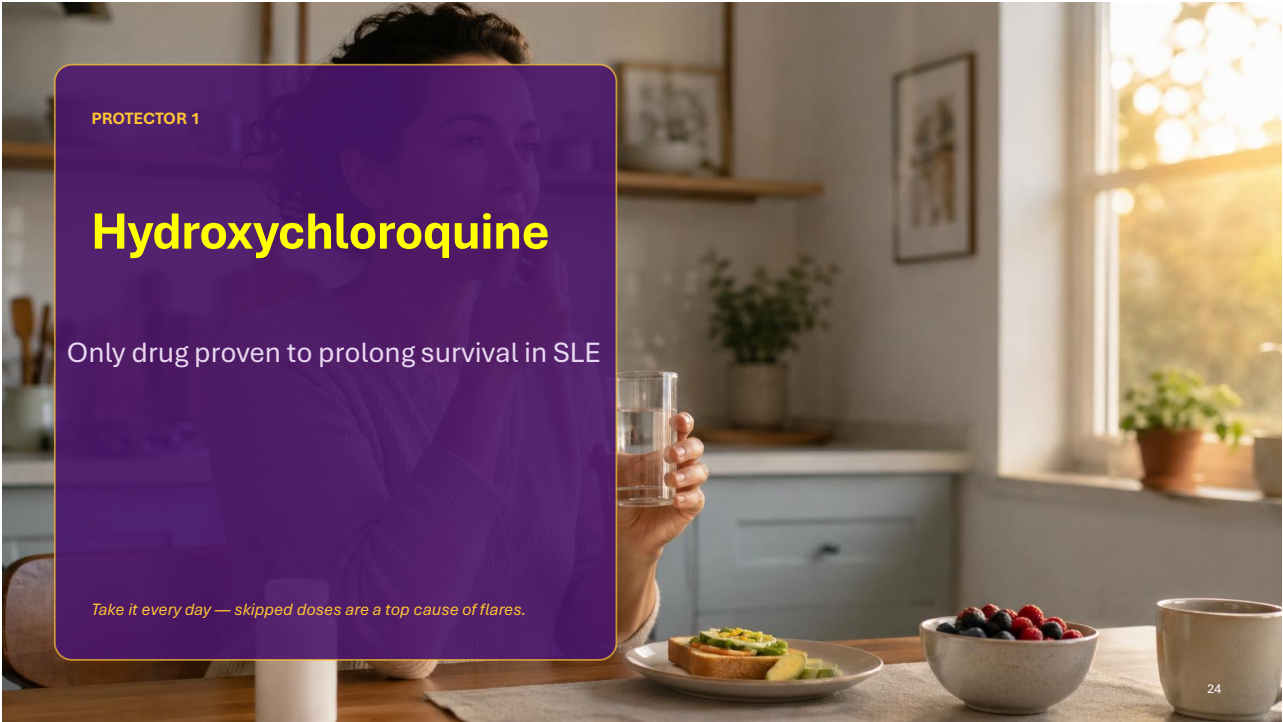
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PROTECTOR 1

Hydroxychloroquine

Only drug proven to prolong survival in SLE

Take it every day — skipped doses are a top cause of flares.

A woman with dark hair is in a kitchen, holding a glass of water. The background shows a window with sunlight, a potted plant, and a bowl of fruit on the counter. A purple semi-transparent box is overlaid on the left side of the image, containing text about Hydroxychloroquine. The number 24 is visible in the bottom right corner of the image area.

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PROTECTOR 2

Vitamin D

Low levels can raise lupus activity

- Ask your doctor to check your level
- Supplement to reach a healthy range
- Do not mega-dose without guidance

A brown glass bottle of Vitamin D supplements is on a surface, with several yellow capsules spilled out. The background is a bright, sunlit room with green plants. A purple semi-transparent box is overlaid on the left side of the image, containing text about Vitamin D. The number 25 is visible in the bottom right corner of the image area.

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A close-up photograph of a person's arm. A hand is applying a thick, white, creamy substance (sunscreen) to the forearm. The person is wearing a white, lace-trimmed sleeve. In the background, a woven basket and a small bowl are visible.

PROTECTOR 3

Sunscreen

— every day

UV light drives flares
-even through windows
-through clouds
-in winter
-from indoor lighting

Use SPF 70 or greater as a daily habit

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A still life photograph featuring various wellness and relaxation items on a wooden surface. There is a purple eye mask, a tube of cream with a sun logo, a small purple pill organizer, a purple cushion, a small vase with lavender, a lit candle in a glass holder, and a bowl of fruit. The background is softly blurred, showing greenery and a window.

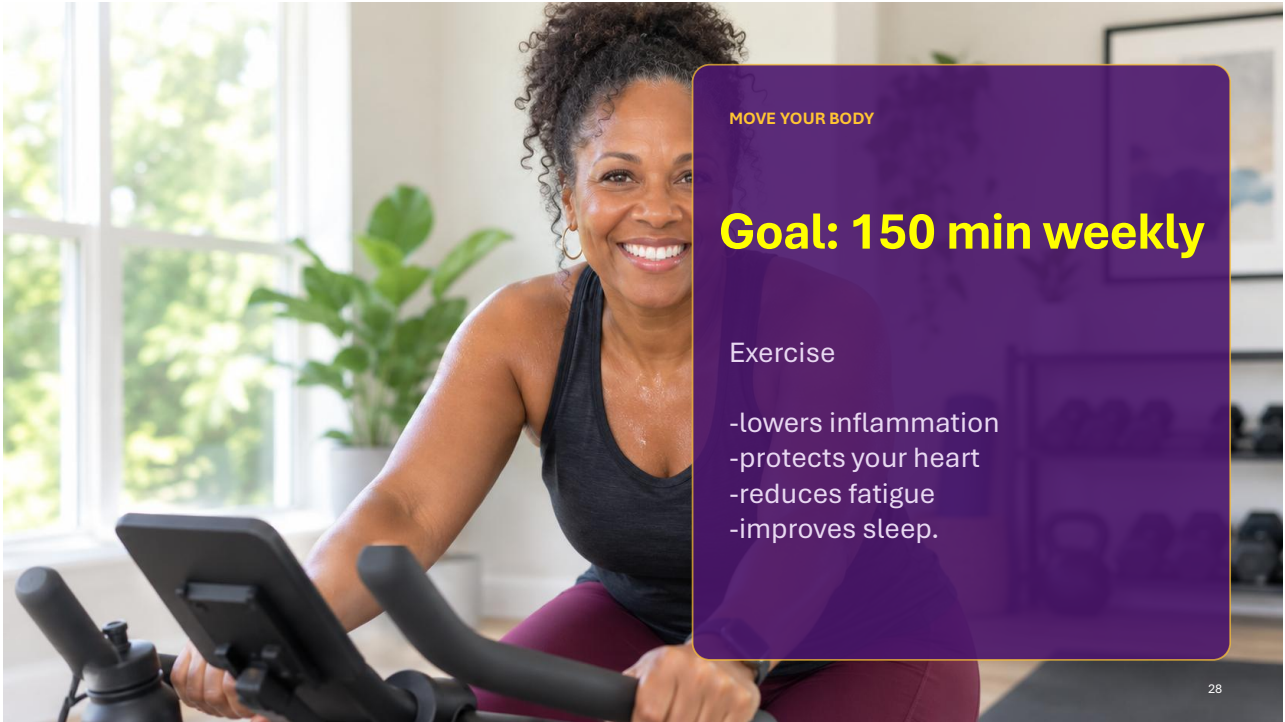
DAILY HABITS

“Free Medicine”

Choices that calm the immune system

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MOVE YOUR BODY

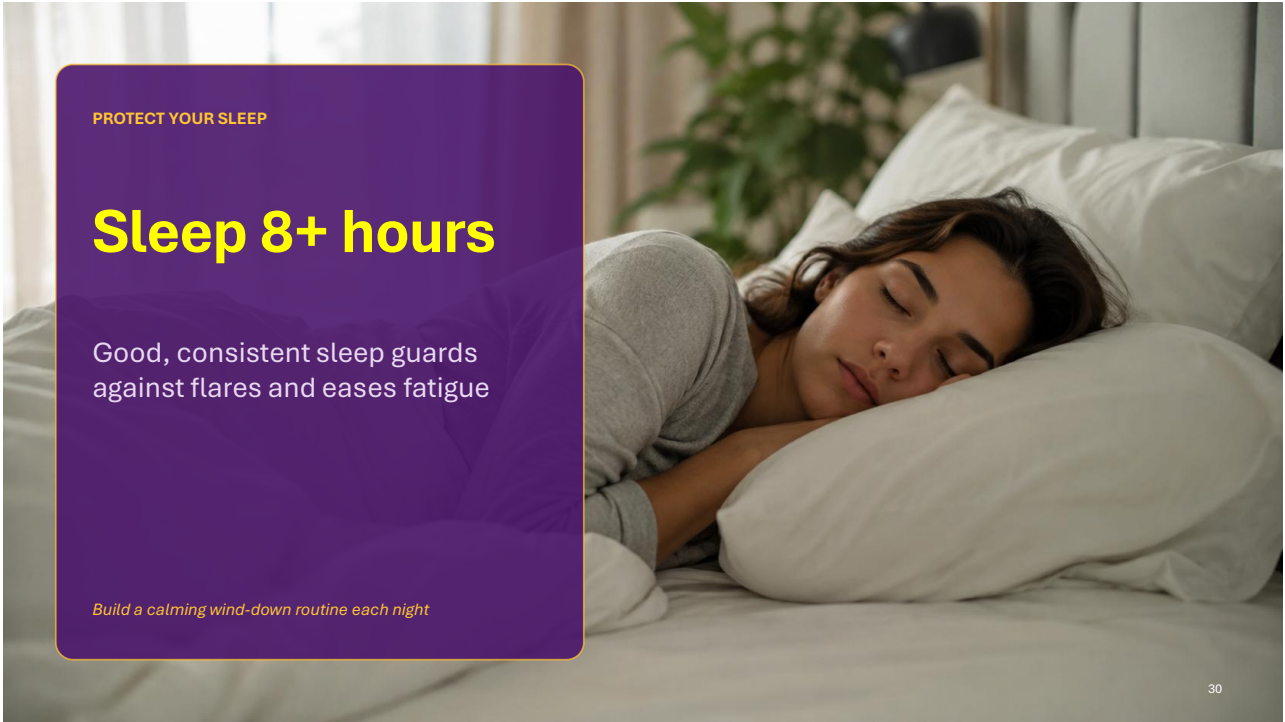
Goal: 150 min weekly

Exercise

- lowers inflammation
- protects your heart
- reduces fatigue
- improves sleep.

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PROTECT YOUR SLEEP

Sleep 8+ hours

Good, consistent sleep guards against flares and eases fatigue

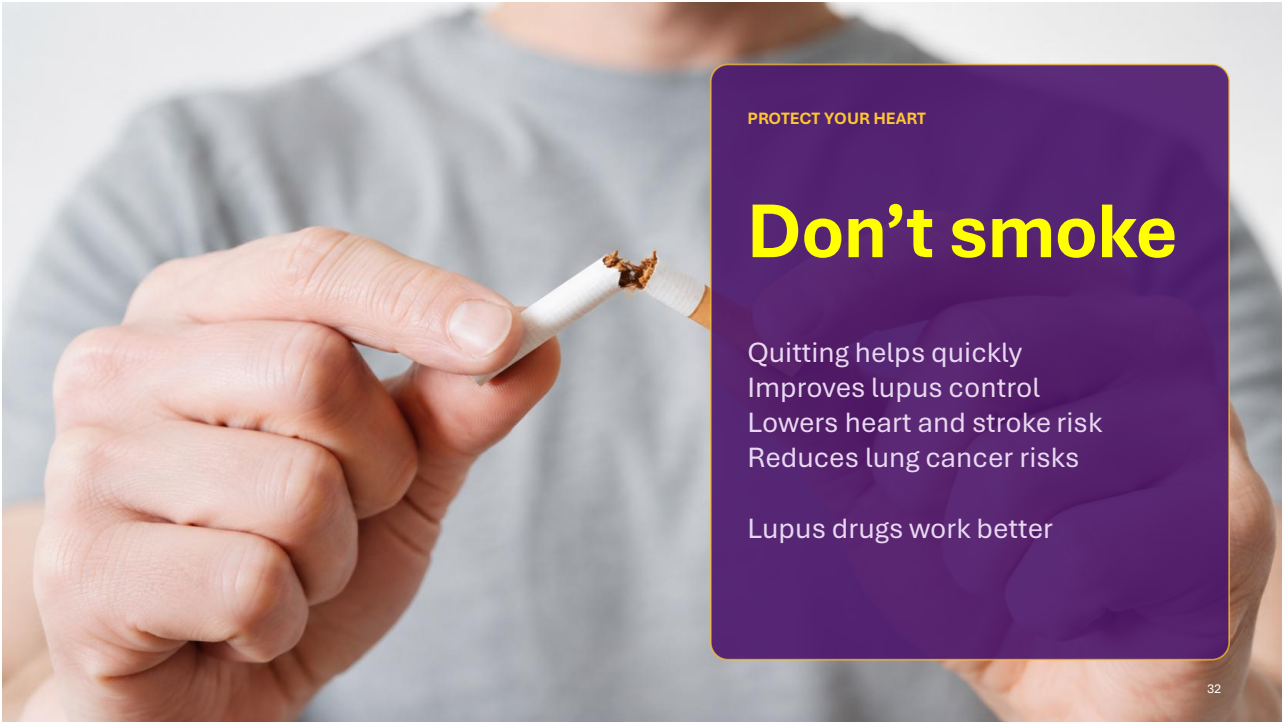
Build a calming wind-down routine each night

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Avoid immune-boosting supplements

Lupus immune system is overactive

You don't want extra immune stimulation

AVOID

- Spirulina
- Echinacea
- Elderberry
- Ashwagandha
- Alfalfa

Ask your rheumatologist before starting new supplements

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EAT ANTI-INFLAMMATORY

Mediterranean diet

Omega-3 (fish, walnuts)
olive oil
vegetables, fresh fruit
beans

probiotics (yogurt with live cultures)
prebiotics (cold oatmeal, whole grains)

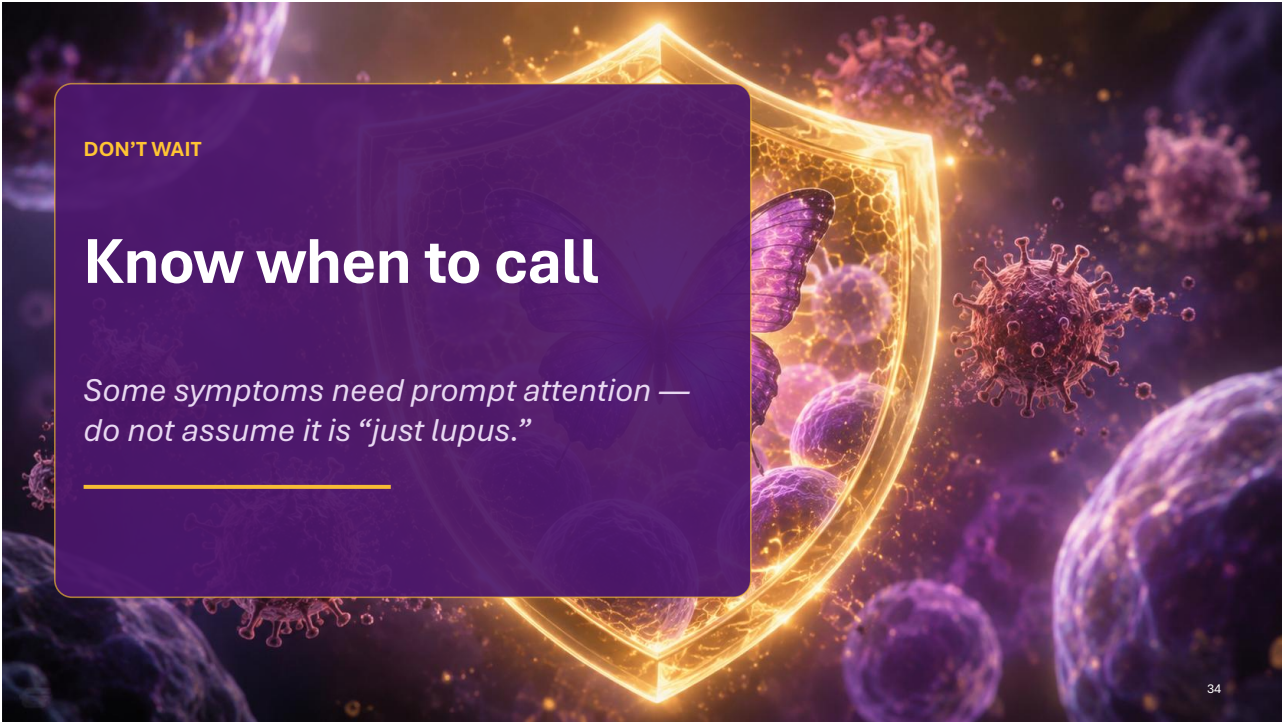
whole foods can help calm inflammation



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A woman is lying in bed, looking unwell, with her hand on her forehead. A digital thermometer is on a wooden nightstand next to her. A purple overlay box contains text about fever.

CALL PROMPTLY

Fever

Rule out infection first — especially if you take immune-suppressing medicines.

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A close-up of a person's feet on a light-colored carpet. A purple overlay box contains text about swelling or foamy urine.

CALL PROMPTLY

Swelling or foamy urine

This can signal kidney involvement, which may be silent early on.

Call before it becomes severe.

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CALL PROMPTLY

New confusion or numbness

Neurologic symptoms need quick evaluation.

- New weakness
- New numbness
- Severe new confusion

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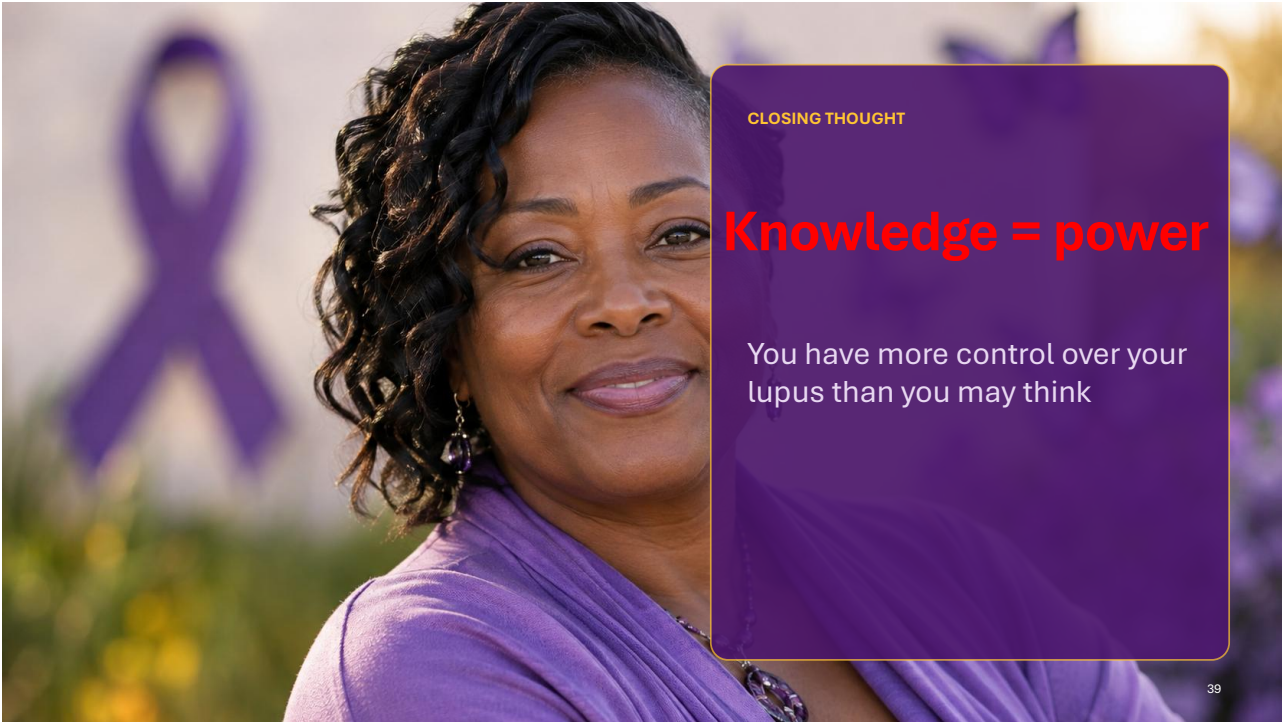
SEEK CARE NOW

Chest pain or breathlessness

Get urgent care right away
Do not wait to see if it passes

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CLOSING THOUGHT

Knowledge = power

You have more control over your lupus than you may think

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TAKE HOME 1

**Understand it
Manage it**

Genes load the gun

Triggers pull it

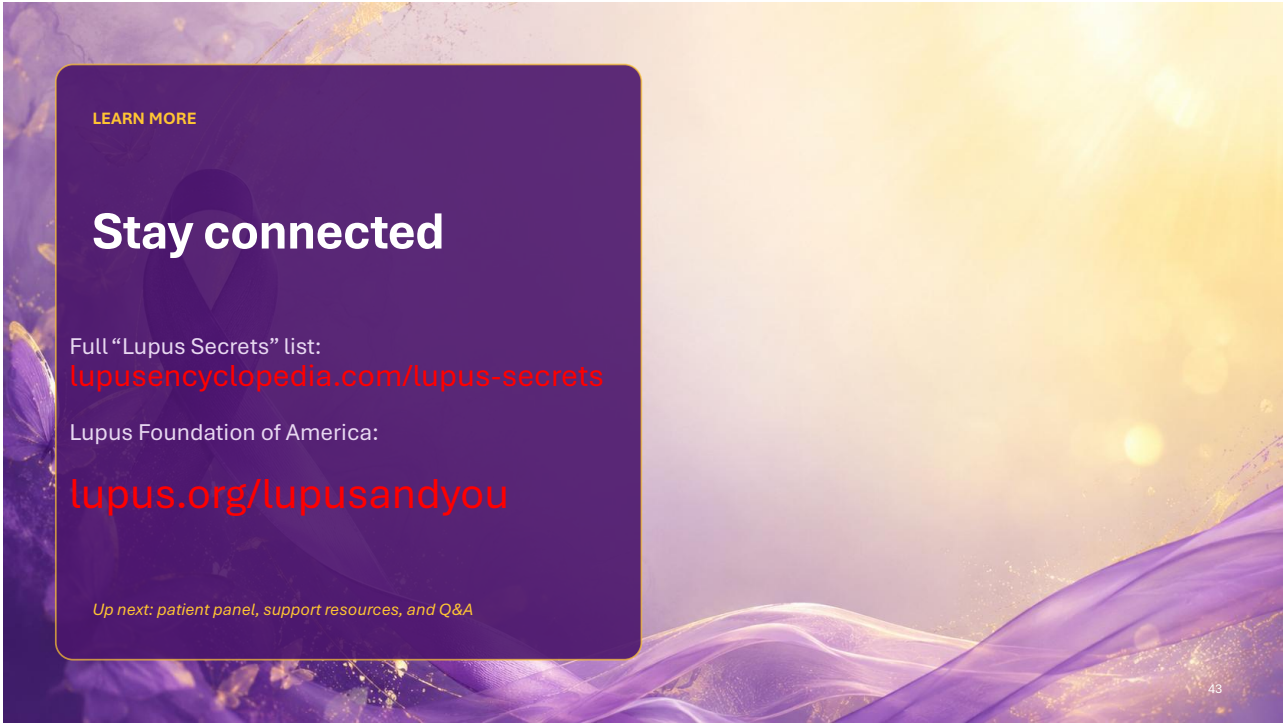
Healthy habits calm the immune system

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