

Lupus: Learning and Living™

SAN FRANCISCO

Saturday, September 21, 2019

9:30 AM – 11:30 AM

UCSF Institute for Global Health Sciences

Mission Hall 1400

550 – 16th Street, 1st Floor

San Francisco, CA 94158

Entrance is on 4th Street, near the corner of 16th and 4th Street

9:00 AM	Registration Opens
9:30 – 9:40	Welcome Zachary Feuerherd
9:40 – 10:05	Advances in our Understanding of Lupus: Treatment Christine Anastasiou, MD
10:05 – 10:15	Q+A with Dr. Anastasiou
10:15 – 10:25	Networking + Break
10:25 – 10:55	Advances in our Understanding of Lupus Panel: Living and Coping Managing your Lupus Leticia Ocaña, MPH, CHES Communication and Lupus Mariel de la Paz, MSW Us in Lupus Arnita Roberts-Christie, RN, BSN, MS
10:55 – 11:05	Q+A with Leticia, Mariel, and Arnita
11:05 – 11:15	Get Connected: LFA Services and Support Leticia Ocaña, MPH, CHES
11:15 – 11:25	Get involved: LFA Walk and Advocacy Zachary Feuerherd
11:25 – 11:30	Evaluation Raffle + Closing Zachary Feuerherd

Help Us Solve
The Cruel Mystery

LUPUSTM

FOUNDATION OF AMERICA

Advancing our Understanding: Lupus Treatment

Dr. Christine Anastasiou

Topics of Discussion

- What is lupus?
- How does it affect the body?
- Diagnosis
- Lupus Treatment



What is lupus?

What is Lupus?

Lupus is a **chronic autoimmune** disease that can damage any part of the body such as skin, joints and/or organs.

Is...	Is not ...
chronic long-lasting, not curable	related to cancer
heterogeneous different for each person	contagious, not even through sexual contact
unpredictable ranging in symptoms and characterized by increases in disease activity and inflammation (flares) and/or inactivity (remission)	like or related to HIV (human immunodeficiency virus)

What are the Different Forms of Lupus?

- **Systemic Lupus Erythematosus (SLE)**
 - Commonly referred to as “Lupus”
 - 70% of lupus cases are SLE
- **Cutaneous Lupus Erythematosus (CLE)**
 - Referred to as, “Skin lupus”
 - 10% of lupus cases are CLE
- **Drug-Induced Lupus Erythematosus (DILE)**
 - Makes up 10% of all lupus cases
- **Neonatal Lupus**
 - Neonatal lupus is not *true* lupus. It is a rare condition associated with anti-SSA/Ro and/or anti-SSB/La antibodies from the mother that affect the fetus.

How common is lupus and who does it affect?

- An estimated 1.5 million Americans, and at least five million people worldwide, have a form of lupus.
- Estimated incidence is 16,000 new cases per year.
- Ninety percent (90%) of people living with lupus are women.
- Most develop the disease between the ages of 15-44.



**How does lupus
affect the body?**

Common Signs and Symptoms of Lupus

- Painful or swollen joints and muscle pain
- Unexplained fever
- Red rashes, commonly on the face
- Chest pain upon deep breathing
- Unusual loss of hair
- Raynaud's phenomenon
- Sensitivity to the sun
- Edema in legs or around eyes
- Mouth ulcers
- Swollen glands
- Extreme fatigue

Lupus and the Body

Central and Peripheral Nervous System

Seizures, Psychosis, Headaches,
Cognitive Dysfunction,
Neuropathies, Depression,
Low Grade Fever

Eyes and Mucous Membranes

Ulcers in the Eyes, Nose,
Mouth or Vagina,
Sjögren's Syndrome

Heart, Lungs

Pericarditis, Myocarditis,
Endocarditis, Pleuritis,
Pneumonitis

Kidneys

Edema, Hypertension,
Proteinuria, Cell Casts,
Renal Failure

Gastrointestinal

Nausea, Vomiting, Diarrhea,
Weight Changes

Reproductive System

Pregnancy Complications,
Miscarriages,
Menstrual Cycle Irregularities

Musculoskeletal

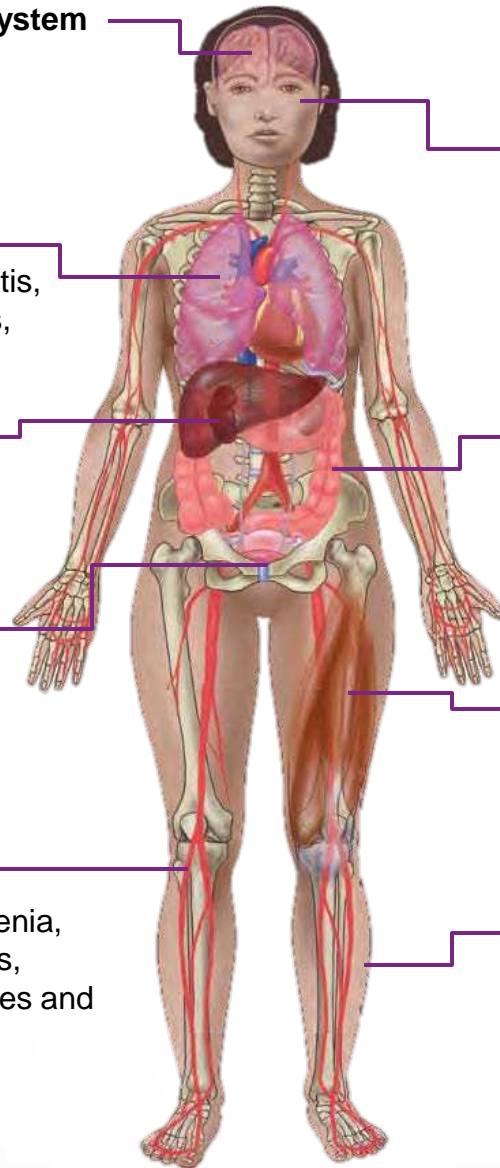
Extreme Fatigue, Arthralgia,
Myalgia, Arthritis, Myositis

Blood

Anemia, Thrombocytopenia,
Leukopenia, Thrombosis,
Circulating Autoantibodies and
Immune Complexes

Skin

Butterfly Rash, Cutaneous
Lesions, Photosensitivity,
Alopecia, Vasculitis,
Raynaud's Phenomenon



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Diagnosis

How is Lupus Diagnosed?

- Review of current symptoms and medical history and family history:
 - May require multiple specialists such as: Rheumatologist, Cardiologist, Dermatologist
- Laboratory tests:
 - ANA is positive in 97% of lupus cases.
 - No single test is used to diagnose lupus.
 - An array of different laboratory tests can help arrive at a diagnosis. These tests may include:
 - Urine tests
 - Blood Tests including autoantibodies
- Tissue biopsies
 - Skin or kidney

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Lupus Treatment

Treatment Goals

- The goals of any lupus treatment plan are to:
 - Reduce inflammation caused by lupus
 - Suppress your overactive immune system
 - Prevent flares, and treat them when they occur
 - Control symptoms like joint pain and fatigue
 - Minimize damage to organs

How is Lupus Treated:

FDA Approved Therapies

- Treatment of lupus will vary depending on the organ systems involved in the disease
- FDA Approved therapies for Lupus:
 - Aspirin (approved by FDA, 1948)
 - Corticosteroids (approved by FDA, 1948): prednisone, prednisolone, methylprednisolone, and hydrocortisone
 - Anti-malarials Plaquenil® (approved in 1955), Chloroquine (Aralen®), Quinacrine
 - Monoclonal antibodies: Benlysta® (Belimumab) (approved by FDA in 2011 as first lupus-specific treatment)

How is Lupus Treated:

Effective, Common Therapies

- Other commonly prescribed therapies for Lupus:
 - NSAIDs
 - Acetaminophen (an analgesic, antipyretic)
 - Immunosuppressive (Immune Modulators): cyclophosphamide (Cytosan®), methotrexate, azathioprine (Imuran®), rituximab (Rituxan®)
 - Anticoagulants: heparin (Calciparine®, Liqueamin®) and warfarin (Coumadin®)

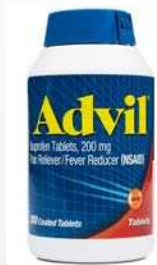
Proactive and Preventive Strategies in Lupus

- Prompt evaluation of all fevers
- Aggressive vigilance for hypertension, hyperglycemia, hyperlipidemia, obesity, smoking cessation
- Bone densitometry and use of bisphosphonates as needed
- EKG, chest X-ray, duplex scanning, stress tests, 2-D echo for pulmonary pressures in high-risk patients
- Antiphospholipid antibody screening and prophylaxis

Using NSAIDs for SLE

- Fevers
- Headache
- Arthralgias, myalgias, arthritis
- Pleurisy, pericarditis

Should Not Use with Kidney Disease



Antimalarials for lupus:

- Particularly effective for skin, arthritis, and fatigue.
- Decreases number of flares and lowers disease activity
- Antiplatelet effects
- Lipid lowering effects
- Improve survival
- Eighty percent of patients with non-organ-threatening SLE achieve disease remission with use of antimalarial drugs.
- Serious toxicity rare, can be avoided with monitoring eye exams
- Can be used during pregnancy and lactation

Corticosteroids

- Highly effective
- High dose pulse vs. daily low dose
- Goal: Use lowest cumulative dose necessary
- Immune suppression which can increase risk of infections
- Decreased bone mass, higher risk of hyperglycemia and cataracts

Cyclophosphamide (Cytoxan)

- Potent immunosuppressant drug that decreases the immune response by blocking the production of DNA in immune cells
- Treat organ or life threatening disease
- Commonly used for some types of lupus nephritis
- IV infusions for 3-6 months for remission followed by other long-term maintenance meds
- Increased risk of infections, low blood counts, nausea

Mycophenolate Mofetil (CellCept) & Mycophenolate Sodium (Myfortic)

- Immunosuppressant drug
- Taken by mouth
- Treat organ threatening disease
- Commonly used for some types of Lupus Nephritis
- Increased risk of infections, low blood counts, nausea/diarrhea

Azathioprine (Imuran)

- Immunosuppressant drug
- Taken by mouth
- Treat organ threatening disease
- If necessary can be used during pregnancy
- Increased risk of infections, low blood counts, nausea/diarrhea

Methotrexate

- Once weekly injection under the skin or once weekly pills
- Very effective for inflammatory arthritis. Can also help other SLE symptoms.
- Can lower blood counts or cause liver inflammation, nausea

Belimumab

- IV infusion approved 2011. Subcutaneous injection approved 2017.
- First FDA approved drug for SLE since 1957.
- Antibody that targets B cells of the immune system
- Useful for treating fatigue, arthritis, and skin disease
- Increases risk of infection

Other Agents Used to Manage Lupus

- Specific agents for skin: retinoids, antileprosy drugs, topical pimecrolimus or tacrolimus
- ITP: danazol, IVIg, splenectomy, rituximab
- APS: coumadin, heparin, platelet antagonists
- Raynaud's: calcium channel blockers, phosphodiesterase inhibitors
- Pulmonary hypertension: prostagrandins, phosphodiesterase inhibitors, endothelin blockers

A Bright Future

Over 200 clinical trials are
underway to improve Lupus
diagnosis and treatment around
the world

Learn more at lupus.org or clinicaltrials.org



Help Us Solve
The Cruel Mystery
LUPUS
FOUNDATION OF AMERICA



A large, stylized purple question mark serves as the background for the slide. The question mark is positioned on the left side, with its stem extending towards the bottom left corner. The word "Questions?" is written in white, bold, sans-serif font, centered horizontally and partially overlapping the question mark's stem.

Questions?

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Thank you
Dr. Christine
Anastasiou

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Managing your Lupus

Leticia Ocaña, MPH, CHES

Saturday, September 21,
2019

Central and Peripheral Nervous System

Seizures, Psychosis, Headaches,
Cognitive Dysfunction,
Neuropathies, Depression,
Low Grade Fever

Eyes and Mucous Membranes

Ulcers in the Eyes, Nose,
Mouth or Vagina,
Sjögren's Syndrome

Heart, Lungs

Pericarditis, Myocarditis,
Endocarditis, Pleuritis,
Pneumonitis

Kidneys

Edema, Hypertension,
Proteinuria, Cell Casts,
Renal Failure

Gastrointestinal

Nausea, Vomiting, Diarrhea,
Weight Changes

Reproductive System

Pregnancy Complications,
Miscarriages,
Menstrual Cycle Irregularities

Musculoskeletal

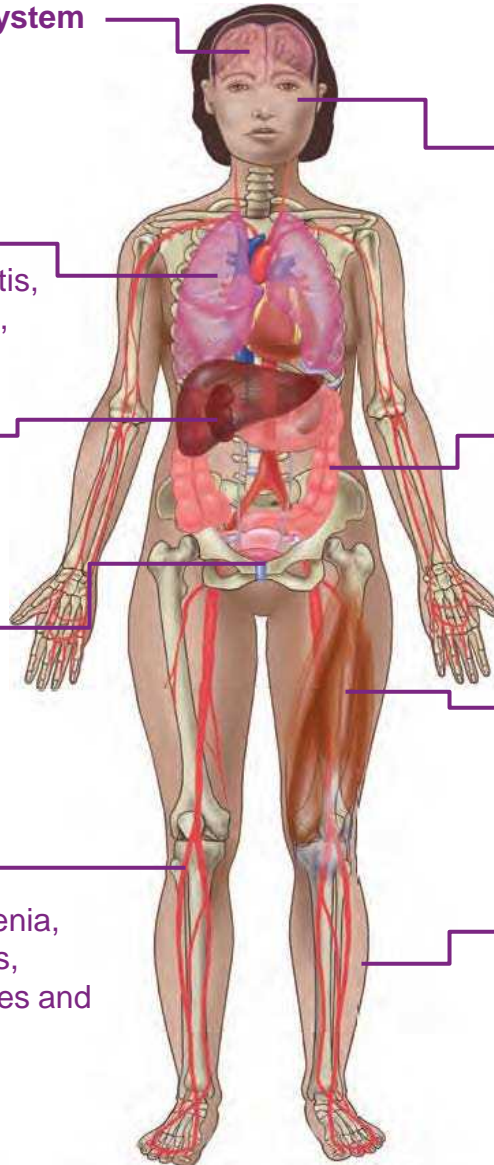
Extreme Fatigue, Arthralgia,
Myalgia, Arthritis, Myositis

Blood

Anemia, Thrombocytopenia,
Leukopenia, Thrombosis,
Circulating Autoantibodies and
Immune Complexes

Skin

Butterfly Rash, Cutaneous
Lesions, Photosensitivity,
Alopecia, Vasculitis,
Raynaud's Phenomenon



Maintain Treatment

- Keep up with medical appointments, even when feeling well.
- Understand your insurance coverage and referrals, specialists, etc. to get the care you need.
- Take your medication as prescribed.
- Remain knowledgeable of treatment options.
- Monitor lupus regularly.

Avoid Triggers

- Avoid **TRIGGERS**:
 - Ultraviolet rays from sun
 - Fluorescent bulbs
 - Sulfa drugs
 - Infections
 - Stress
 - Smoking
- Eat a balanced diet
- Get plenty of rest and exercise.

Educate and Self-advocate

- Make note of symptoms that are new or changing. Speak up about them!
- Understand your emotional and behavioral health needs and ask for help when you need it.
- Develop your support team!
- Reflect on what's important.

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Thank You

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Communication and Lupus

Mariel dela Paz MSW
Lupus Liaison

9/21/2019

Why is communication important?

Communication and Lupus

- Creates support and fosters helpfulness.
- When done ineffectively, poor communication can create:
 - Anger
 - Frustration
 - Helplessness
 - Sadness
- These feelings can negatively impact our physical, emotional, and mental health.

When does communicating about lupus become a challenge?

Health Care Professionals

- Shared decision-making
- Plan ahead when possible
- Open, honest communication
- Utilize available communication tools
- Learn the lingo

Friends / Family

- Address any feelings of changed roles and openly discuss necessary adjustments
- Find middle ground, what's too much, what's too little?
- Do not make assumptions of what your loved one “should know”

Schools/Employers

- Know your rights at school and at work
- Be proactive
- Consider “reasonable accommodations”
- Not obligated to disclose the specifics of your diagnosis

Other considerations

- Self-Reflection
- Intention
- Communication Fatigue
- Listen
- Find ways to express yourself

Elevator Pitch

- When were you diagnosed?
- What is lupus?
- How does lupus impact you personally?
- Why do you want the person to know?
- Adjust according to audience
- Practice



Contact Info:

UCSF Childhood and Adolescent Lupus Program

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415-502-2019

Chapter 3

Resources for You



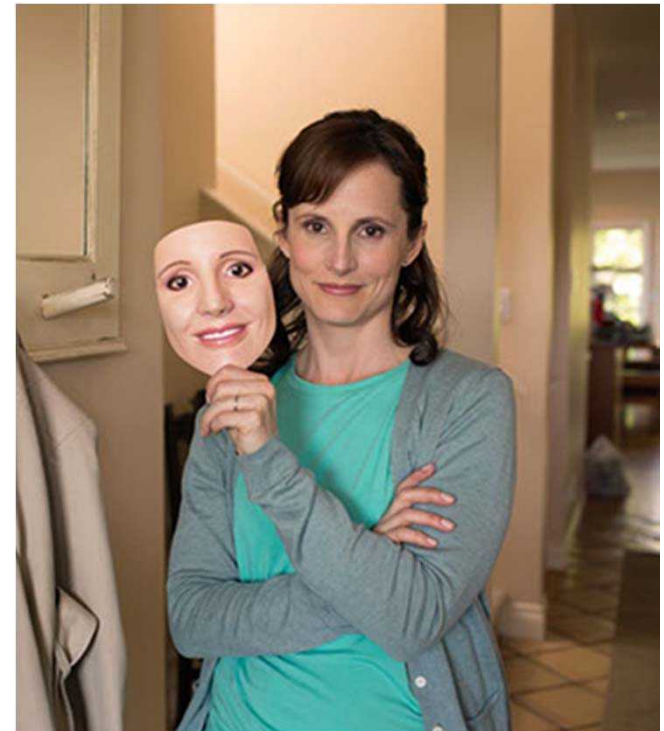
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Power against lupus

Where Can You Go for Help?



Us in Lupus.com Is Here to Help

- **Us in Lupus** gives you more than just the facts about lupus
- Designed by GSK, it offers people like you, living with lupus, the skills, tools, and confidence you need to help you face your lupus



Us in Lupus.com Provides Tools

- **Us in Lupus** provides important tools to help you prepare for your appointments and learn more about your lupus
 - Lupus Checklist
 - Lupus Impact Tracker™
 - My Lupus Log
 - Lupus Journal
 - Appointment Prep Guide
 - Lupus Dictionary

Us in Lupus
Power against lupus

Take advantage
of these tools to
help you prepare
for your
appointments
and learn more
about lupus




Lupus Checklist

This checklist helps you to recognize the symptoms and risk factors for lupus

- ✓ Print and record symptoms and other changes to your health
- ✓ Bring the completed checklist to your next medical appointment to spark discussions with your healthcare team
- ✓ To download, simply visit www.usinlupus.com

LUPUS CHECKLIST			
If you have systemic lupus erythematosus (lupus), every symptom matters.		With lupus, it is important to discuss all of your symptoms — even the ones you might not associate with lupus. Please complete the Lupus Checklist below and discuss these symptoms with your rheumatologist at each appointment.	
SYMPTOMS	I have had this symptom since my last doctor visit	I have had this symptom for _____ hr./days/weeks	This is the first time I have had this symptom
Example Skin rash	✓	3 weeks	<input type="checkbox"/>
Heart			
Chest pain	<input type="checkbox"/>		<input type="checkbox"/>
Difficulty breathing	<input type="checkbox"/>		<input type="checkbox"/>
Rapid and/or irregular heartbeat	<input type="checkbox"/>		<input type="checkbox"/>
Lung			
Pain in the chest when deep breathing	<input type="checkbox"/>		<input type="checkbox"/>
Eye			
Dry eyes	<input type="checkbox"/>		<input type="checkbox"/>
Eye redness	<input type="checkbox"/>		<input type="checkbox"/>
Some loss of vision	<input type="checkbox"/>		<input type="checkbox"/>
Blood			
Bleeding and/or bruising easily	<input type="checkbox"/>		<input type="checkbox"/>
Infections	<input type="checkbox"/>		<input type="checkbox"/>
Muscles & Bones			
Muscle weakness	<input type="checkbox"/>		<input type="checkbox"/>
Stiffness in joints	<input type="checkbox"/>		<input type="checkbox"/>
Aching muscles	<input type="checkbox"/>		<input type="checkbox"/>
Skin			
Skin rashes	<input type="checkbox"/>		<input type="checkbox"/>
Sensitivity to sun or light	<input type="checkbox"/>		<input type="checkbox"/>
Mouth or nose sores	<input type="checkbox"/>		<input type="checkbox"/>
Hair loss	<input type="checkbox"/>		<input type="checkbox"/>
Brain			
Seizures	<input type="checkbox"/>		<input type="checkbox"/>
Headache and/or dizziness	<input type="checkbox"/>		<input type="checkbox"/>
Memory problems or confusion	<input type="checkbox"/>		<input type="checkbox"/>
Sad thoughts	<input type="checkbox"/>		<input type="checkbox"/>
Weakness/numbness on one side (for example, one arm weak or numb)	<input type="checkbox"/>		<input type="checkbox"/>
Kidney			
Swelling of legs and/or feet	<input type="checkbox"/>		<input type="checkbox"/>
Frothy and/or bloody urine	<input type="checkbox"/>		<input type="checkbox"/>
General			
Fatigue	<input type="checkbox"/>		<input type="checkbox"/>
Fevers	<input type="checkbox"/>		<input type="checkbox"/>
Weight change	<input type="checkbox"/>		<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>		<input type="checkbox"/>
Other			
Other 1: _____	<input type="checkbox"/>		<input type="checkbox"/>
Other 2: _____	<input type="checkbox"/>		<input type="checkbox"/>

 This checklist is neither a diagnostic tool nor a complete list of all possible lupus symptoms. Be sure to talk to your doctor about all of your symptoms.



Lupus Impact Tracker™

The Lupus Impact Tracker™ is a simple worksheet that can help you determine a rating for how lupus is affecting your life

- ✓ Complete it once every 4 weeks, and share the results with your healthcare team
- ✓ Be sure to bring a completed version of the form for each month since your last appointment
- ✓ To download, simply visit www.usinlupus.com



Lupus Impact Tracker™

The **Lupus Impact Tracker** was developed to help you communicate effectively with your doctor about your lupus symptoms and how they may be impacting your life. Name: _____ Date: _____

To complete the form, read each statement and circle the number in the response box that best describes your experience. Select only one response for each statement. **Be sure to answer the questions in the context of your lupus.**

Complete the **Lupus Impact Tracker** once every 4 weeks, and share the results with your doctor. Be sure to bring one completed form for each month since your last appointment.

During the past 4 weeks, how often did you experience the following due to your lupus?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. I woke up feeling worn out	0	1	2	3	4
2. I felt pain and aching in my body	0	1	2	3	4
3. I was unable to perform my usual activities for long periods of time because of pain or fatigue	0	1	2	3	4
4. I was limited in fulfilling family responsibilities because of my physical health	0	1	2	3	4
5. My lupus interfered with my ability to plan activities and schedule events	0	1	2	3	4
6. I was anxious	0	1	2	3	4
7. I was depressed	0	1	2	3	4
8. I experienced difficulty concentrating	0	1	2	3	4
9. I was self-conscious about my appearance	0	1	2	3	4
10. My lupus medication(s) caused bothersome side effects	0	1	2	3	4
COLUMN SUBTOTALS	+	+	+	+	= TOTAL

How to score:

- Add your responses in each column and write the number in the space at the bottom of each column.
- Add the column subtotals along the bottom row to achieve your total. Place that number in the box to the right.
- To determine your Lupus Impact score, refer to the chart below.

If your total is...

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40

Your Lupus Impact score is...

How to use the score:
The lower your Lupus Impact score, the less impact lupus is having on your life. Share the score with your doctor to help discuss the impact lupus may be having on your life.

Lupus Impact Score is: _____

Us in Lupus

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My Lupus Log

Available **free** from the Play Store on any Android device, My Lupus Log lets you:

- Conveniently track lupus symptoms
- Record and monitor how they are affecting you
- Customize your profile
- Learn more about lupus
- Stay focused with alerts and reminders
- Customize functions with step-by-step instructions

Keeping a close eye on your symptoms is part of managing your lupus

The screenshot displays the 'My Lupus Log' app interface on an Android device. At the top, there's a status bar with icons for USB, Wi-Fi, and battery (30%), along with the time 5:22 PM. Below the status bar is a dark red header with a 'Cancel' button and the title 'My Lupus Log'. The main content area lists several symptoms, each with a scale from 0 to 5 (0 being the best, 5 being the worst):

- Headache**: Scale 0 to 5. The value '0' is selected and highlighted in green.
- Joint Pain**: Scale 0 to 5. The value '1' is selected and highlighted in yellow.
- Joint Swelling**: Scale 0 to 5. The value '2' is selected and highlighted in yellow.
- Rash**: Scale 0 to 5. The value '2' is selected and highlighted in yellow.
- Issues**: Scale 0 to 5. The value '3' is selected and highlighted in orange.
- Symptoms**: Scale 0 to 5. The value '4' is selected and highlighted in orange.

At the bottom of the screen, there are two red buttons: 'Symptoms' and 'Submit'.



Lupus Journal

When you're living with lupus, journaling can be a good way to document your thoughts, feelings, symptoms, and any questions you may want to discuss with your healthcare team

- ✓ Simply sign up at www.usinlupus.com and request your free lupus journal



Appointment Prep Guide

This handy checklist can help you make the most of medical visits

✓ Read it carefully, and bring it to all of your medical appointments

✓ To download, simply visit www.usinlupus.com

Appointment Prep Guide

You live with lupus every day, but you probably see your rheumatologist only once every 3 months or so. With most appointments lasting less than 15 minutes, it's important to make the most of the valuable time you spend with your doctor.

The steps that follow are designed to help you have the power to face your lupus. **Check each one off** as you prepare for your next appointment and you'll be ready to make your time together productive.

- ☐ **Step 1: Take note of all your symptoms.** Use the **Lupus Checklist** before your appointment to record all your symptoms, even the ones that may not feel like lupus. If you have an Android™ smartphone, you may want to download our free app, **My Lupus Log**. It can help you monitor and track your symptoms. Simply go to the Google Play™ Store and search "My Lupus Log."
- ☐ **Step 2: Document how lupus is affecting your life.** The **Lupus Impact Tracker™** can be especially helpful in understanding how lupus may be interfering with your day-to-day life. Complete the tracker now, and then plan to complete another one every 4 weeks, so you can begin to see how lupus is affecting you over time.
- ☐ **Step 3: Get ready.** One of the most important things to remember is to get ready well ahead of time. How exactly should you do that? Start by finding the date of your next appointment on your calendar. Then, find the date that is **3 weeks before your appointment**. Circle that date as your get-ready starting point.
- ☐ **Step 4: Choose your appointment buddy.** Take a trusted friend or family member to help you with important tasks during your appointment so you can be free to talk to your doctor. Ask them to serve as your **advocate, extra pair of eyes and ears, and note-taker**.

No matter what you need from your buddy, make sure you are clear about it. Your doctor will want you to do most of the talking. But it's okay to ask your advocate to "butt in" if you're having trouble expressing yourself.
- ☐ **Step 5: Gather your medical records.** If you've been to another doctor or specialist **since your last visit** to this doctor, find copies of any appointment notes you may have received at checkout. If you've had any visits to an emergency room or urgent care center since your last visit, be sure to take copies of those records, as well.

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Us in Lupus

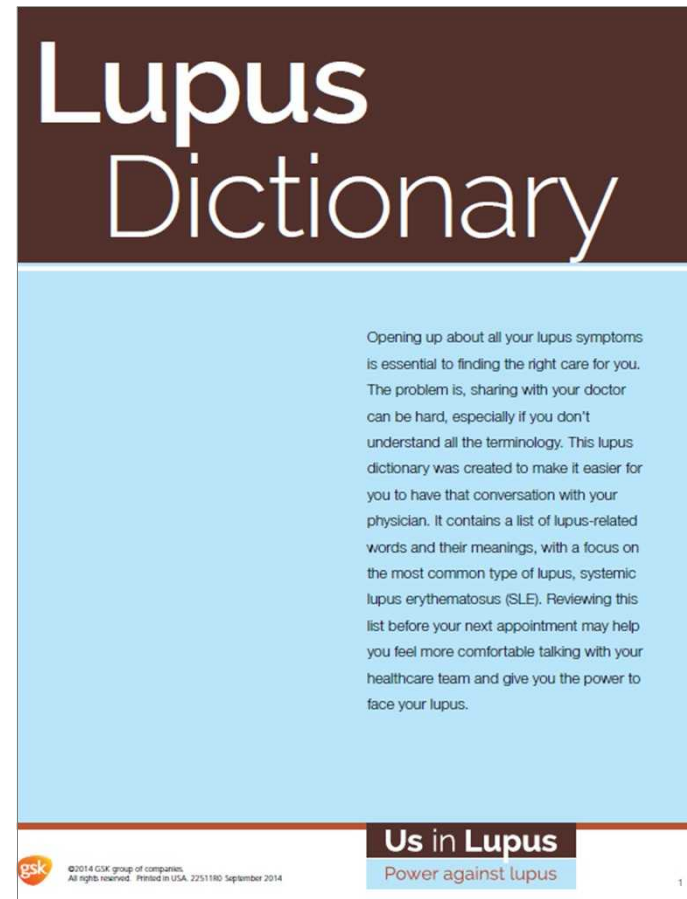
Power against lupus



Lupus Dictionary

This free list of lupus-related terms can help you prepare for medical appointments and better understand the conversations you have with your healthcare team

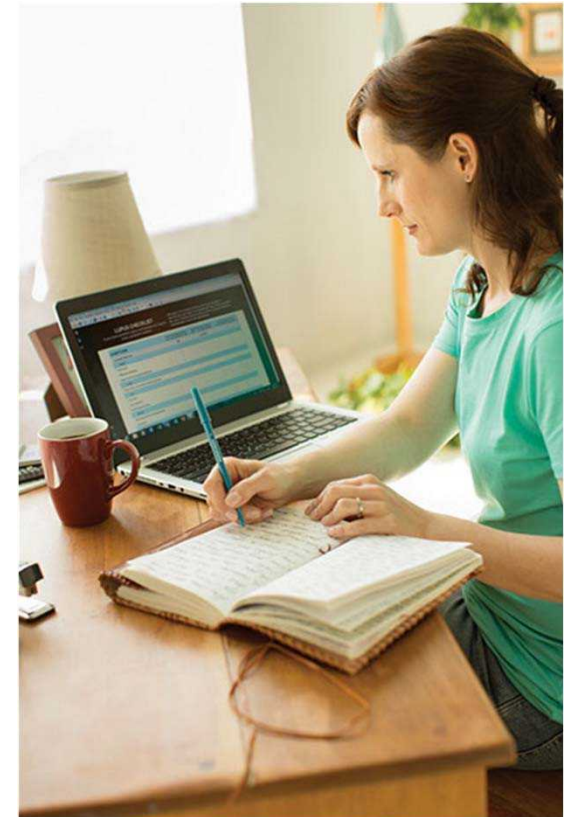
✓ To download, simply visit
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Reflection: Consider Using These Tools

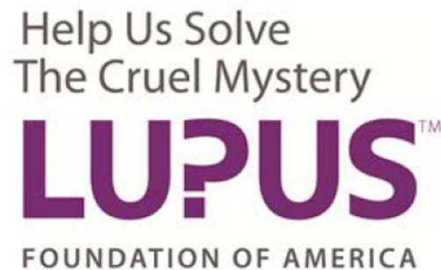
Take a moment for some self-reflection

- What are your challenges in living with lupus?
- How can these tools help?
- How can you use each of these tools?
- Pick one tool, and visualize yourself using it. Do you think you can implement it into your management plan?



Seek Patient Support

- Find a local advocacy group
- Reach out to lupus organizations and educational programs
- The following resources can help:



www.lupus.org



www.thelupusinitiative.org

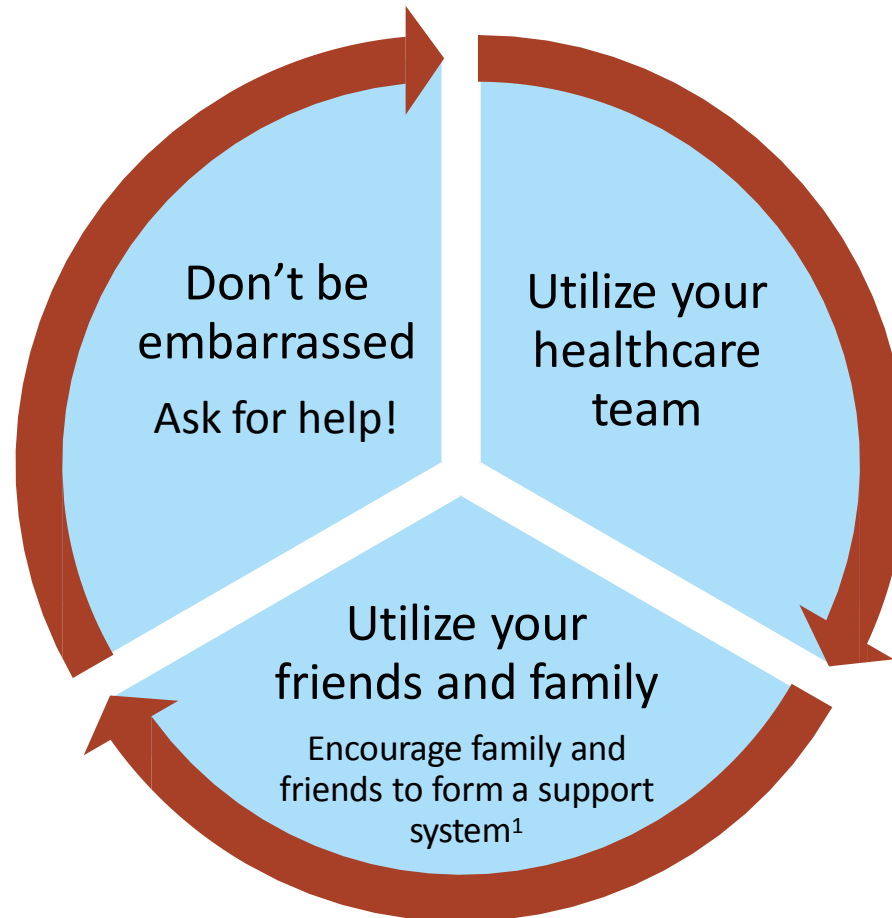


www.lupusresearchinstitute.org

Please Note: These resources are external to GSK. GSK does not have control over the content or information provided through these resources, and accordingly does not warrant their accuracy or completeness.




You Are **Not** Alone!



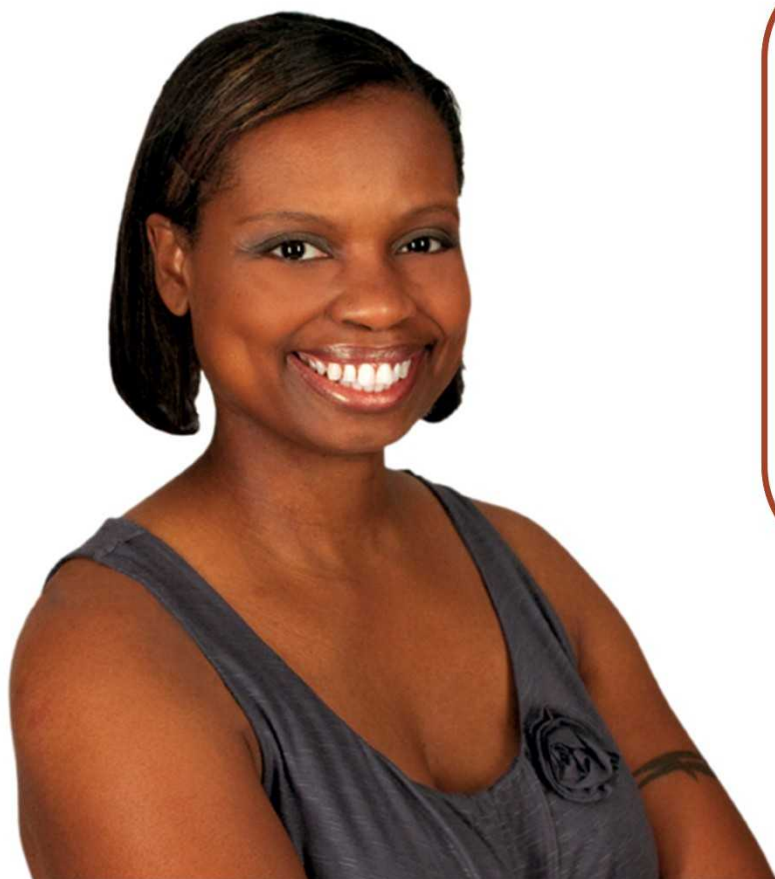
1. Isherwood DE. In: Carter SC, et al, eds. *Core Curriculum for Rheumatology Nursing*. 1st ed. Greenville, SC: Lyons Den Solutions, LLC; 2015:213-228.

Summary: **You** Are a **Key Component** in Assessing Your Disease Activity

- 
- Know that **you** play an important role in managing your lupus
 - Promote **open** and **honest** communication
 - Take advantage of **tools** and **resources** available to you
 - Stay active in being **educated** on your lupus

You Are **Empowered.**

You Can Be Your Own **Advocate.**



“For those of you who are living with lupus, I encourage you to listen to your body. Learn your body, and build a strong and open relationship with your doctors. It’s extremely important. Life is just way too short and precious to take it for granted.”

Rena, currently living with lupus
Rena is a paid spokesperson for GSK



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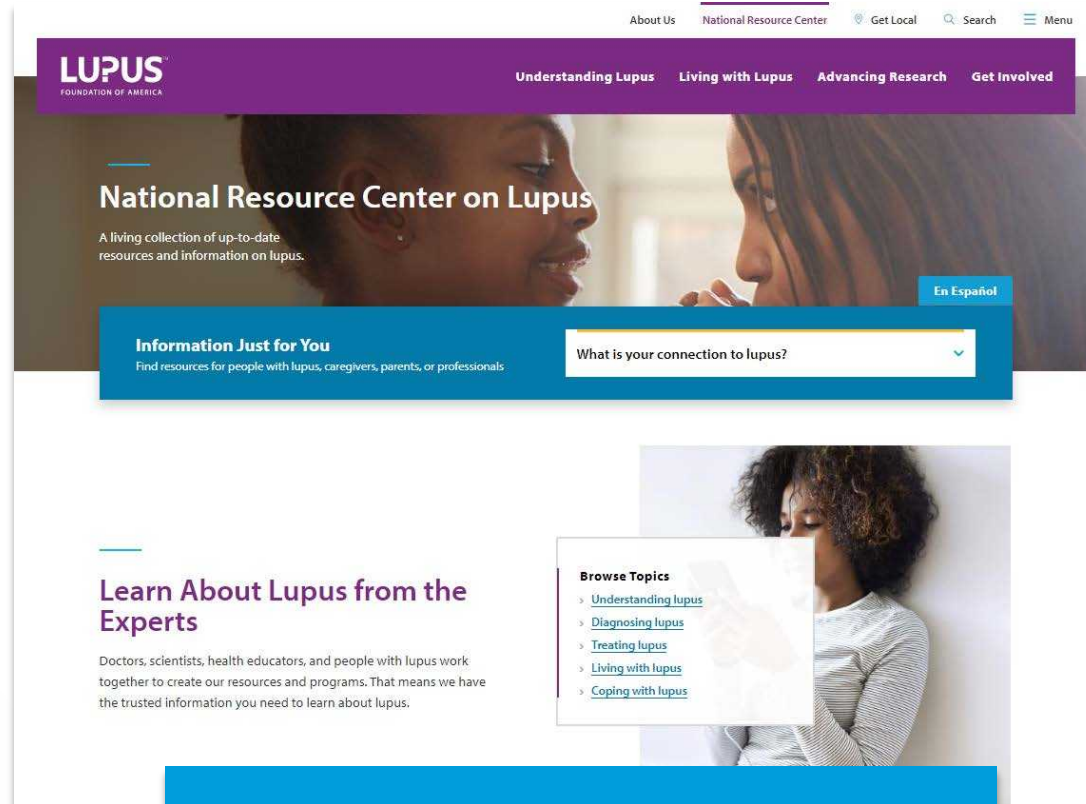
Get Connected: LFA Resources

Leticia Ocaña, MPH, CHES

Saturday, September 21, 2019

National Resource Center on Lupus

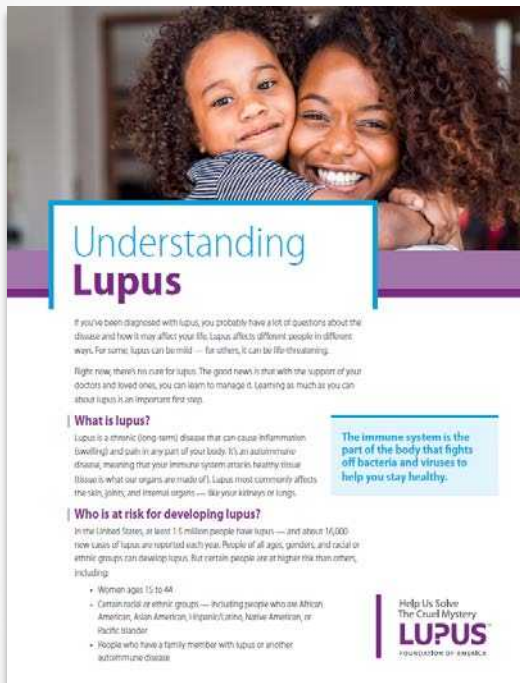
A collection of up-to-date resources and information on lupus



lupus.org/resources

National Resource Center on Lupus

Downloadable Multi-language Guides



Understanding Lupus

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.

What is lupus?

Lupus is a chronic (long-term) disease that can cause inflammation (swelling) and pain in any part of your body. It's an autoimmune disease, meaning that your immune system attacks healthy tissue (tissue is what our organs are made of). Lupus most commonly affects the skin, joints, and internal organs — like your kidneys or lungs.

The immune system is the part of the body that fights off bacteria and viruses to help you stay healthy.

Who is at risk for developing lupus?

In the United States, at least 1.5 million people have lupus — and about 14,000 new cases of lupus are reported each year. People of all ages, genders, and racial or ethnic groups can develop lupus. But certain people are at higher risk than others, including:

- Women ages 15 to 44
- Certain racial or ethnic groups — including people who are African American, Asian American, Hispanic/Latino, Native American, or Pacific Islander
- People who have a family member with lupus or another autoimmune disease

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Entendiendo el lupus

Si ha sido diagnosticado con lupus, probablemente tenga muchas preguntas acerca de la enfermedad y cómo puede afectar su vida. El lupus afecta a cada persona de manera diferente. Para algunas, puede ser moderada, para otras puede presentar un riesgo de vida.

Actualmente, no hay cura para el lupus. La buena noticia es que con el apoyo de sus médicos y seres queridos, puede aprender a vivir con él. El primer paso más importante es aprender tanto como pueda acerca del lupus.

¿Qué es el lupus?

El lupus es una enfermedad crónica (a largo plazo) que puede provocar inflamación (hinchazón) y dolor en cualquier parte del cuerpo. Es una enfermedad autoinmune, lo cual significa que su sistema inmunológico ataca el tejido sano (el tejido es con lo que están hechos nuestros órganos). El lupus ataca con mayor frecuencia la piel, articulaciones y órganos internos, como por ejemplo, los riñones o pulmones.

El sistema inmunológico es la parte del cuerpo que lucha contra las bacterias y los virus para mantenerlo sano.

¿Quién está en riesgo de padecer lupus?

En los Estados Unidos, alrededor de 1.5 millones de personas padecen de lupus, y anualmente se reportan alrededor de 14,000 nuevos casos. Personas de todas las edades, géneros, razas o grupos étnicos pueden padecer de lupus. Sin embargo, algunas personas presentan un riesgo mayor que otras, incluyendo:

- Mujeres entre 15 y 44 años
- Ciertos grupos raciales o étnicos, incluyendo gente afroamericana, asiática americana, hispano/latina, indígena americana o isleña del pacífico
- Personas con familiares con lupus u otra enfermedad autoinmune

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了解狼疮

如果你已经被诊断狼疮，你可能有很多关于这种疾病的问题，以及它会如何影响你的生活。狼疮对不同的人有不同的影响。对某些人来说，狼疮可能是轻微的 - 对其他人来说，它可能会危及生命的。

目前，狼疮并无完全治愈。不过，好消息是，在你的医生和亲人的支持下，你可以学习管理它。学习如何管理你的狼疮是很重要的第一步。

什么是狼疮？

狼疮是一种慢性（长期）疾病，可引起身体任何部位的发炎（肿胀）和疼痛。这是一种自身免疫性疾病，意味着你的免疫系统攻击健康的组织（组织是我们器官组成的部分）。狼疮最常影响的是皮肤、关节和内脏 - 就像你的肾脏或肝脏。免疫系统是身体的一部分，它们抵抗细菌和病毒，以帮助你保持健康。

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谁可能有狼疮的风险？

在美国，至少有150万人患有狼疮，每年大约有16000件新狼疮病例。所有年龄、性别、种族或族裔的人都可能患有狼疮。

但某些人患有狼疮的风险比其他人更高，包括：

- 15至44岁的女性
- 某些种族或族裔群体 - 包括非裔美国人、亚裔美国人、拉美裔人、美洲原住民或太平洋岛民
- 有家庭成员患有狼疮或其他自身免疫性疾病的人，也有得到狼疮的风险

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

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Online Symptoms Questionnaire

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Understanding LupusLiving with LupusAdvancing ResearchGet InvolvedDonate

COULD IT BE LUPUS?

Could your symptoms be related to lupus?
Use this questionnaire to learn more.

[Get Started](#)

This questionnaire cannot diagnose lupus and should not be used as a substitute for medical advice and diagnosis. The Lupus Foundation of America will not collect or share your health information with third parties.

Medically reviewed on June 8, 2017

Don't miss the next research breakthrough.

[Sign Up](#)

National Resource Center on Lupus

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NATIONAL
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on Lupus

En Español

Home / National Resource Center on Lupus / Search Resources

Search within results

Resource Library List Grid

Filters

By Topic

- Understanding lupus
- Diagnosing lupus
- Coping with lupus
- Living with lupus
- Treating lupus

By Audience

- I have lupus
- I might have lupus
- I'm newly diagnosed
- I care for someone with lupus
- I am a health care professional

Wondering if it is lupus? (brochure)

In partnership with Exagen, our downloadable brochure describes several common lupus symptoms and ta...

Downloadable PDF

Understanding lupus: a guide

If you've been diagnosed with lupus, learning about it is an important first step. Start your journe...

Downloadable PDF

Patient-Physician Dialogue Tool

This checklist can help you prepare for a discussion with your doctor.

Downloadable PDF

Videos

The Expert Series



National Network of Support



lupus.org/care-support/ask-a-health-educator | 1-800-558-0121

National Chapters and Regional Offices

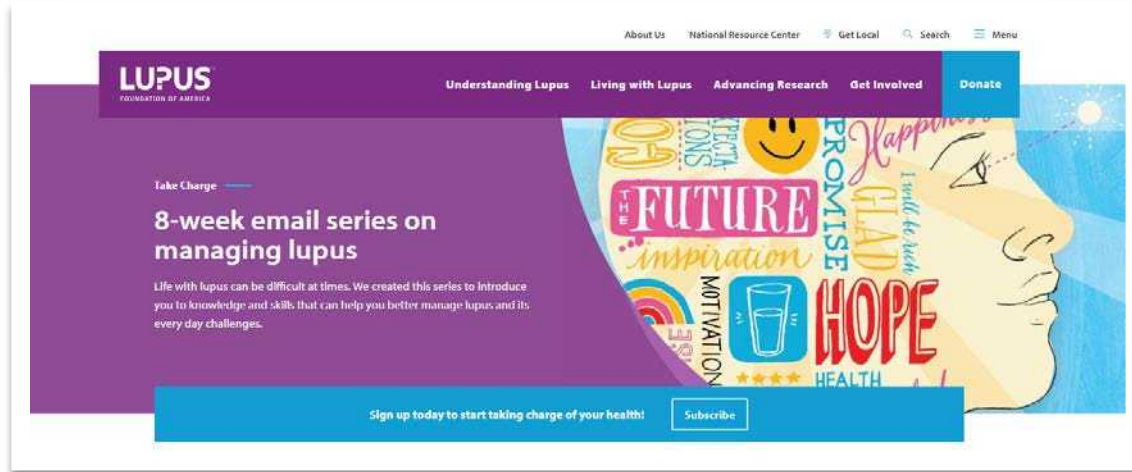


Lupus Connect™

- LupusConnect™ An online community where members engage with others like them to share experiences and find emotional support.
 - Launched in 2017
 - Today over 9,700 members from 90+ countries!



Emails



- Take Charge
- E-newsletter
 - Monthly e-newsletter includes the latest research news and articles about living with lupus.

Social Media

For daily updates on news and information on lupus,
follow us here

- Facebook : **LupusFoundationofAmerica**
- Twitter: **@LupusOrg**
- Instagram: **@LupusOrg**
- Youtube: **LupusFoundationofAmerica**

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Thank you

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Walk to End Lupus Now



World's **LARGEST** Lupus Walk

Conducted by the Lupus Foundation of America and its national network to raise money for lupus research, increase awareness of lupus, and rally public support for those who suffer from its brutal impact.

Nearly 60 Major Markets

More Than 70k Walkers

AL - Birmingham
AL - Huntsville
*AZ - **Scottsdale**
*CA - **Los Angeles**
*CA - **San Diego**
*CA - **San Francisco**
*CA - **Orange County**

IL - Bartlett
IL - Chicago
IL - Naperville
IL - Olympic Fields
IL - Vernon Hills
IN - Central Indiana
IN - Northwest Indiana

*CO - **Denver**
CT - Trumbull
CT - West Hartford
CT - West Haven
DE - Wilmington
DC - Washington, DC
FL - Broward County
FL - Miami
FL - Naples
*FL - **Tampa**
*FL - **Orlando**
GA - Atlanta
IA - Des Moines

KY - Lexington
KY - Louisville
*MA - **Boston**
MD - Baltimore
NC - Asheville
NC - Charlotte
NC - Fayetteville
NC - Raleigh
NJ - Cranford
NJ - Ocean City
*NY - **New York City**

OH - Columbus
OK - Oklahoma City
*OR - **Portland**
PA - Philadelphia
TN - Nashville
TX - Beaumont
TX - Dallas - Fort Worth
TX - Houston
TX - Killeen
TX - Lubbock
TX - Weatherford

UT - Salt Lake City
UT - St. George
VA - Richmond
VT - Burlington
WA - Lakewood/Pierce County
*WA - **Seattle**
WI - Wauwatosa

*Headquarter Walks

Walk to End Lupus Now® is our signature grassroots program that engages people with lupus, their families, and friends





SF Walk

- Sunday October 20, 2019
- Golden Gate Park
- Registration opens at 8:30 AM
- 2 mile Walk
- Goal of \$160,000!

Club 100



LUPUS FOUNDATION OF AMERICA

WALK TO END LUPUS NOW™

2019 RECOGNITION PROGRAM



\$100

T-shirt*

*Distributed on Walk Day



\$250

Insulated
Bottle



\$500

Inversion Umbrella



\$1,000

French Terry Crew Neck*
OR French Terry Pullover Hoodie*
& Lupus Trailblazer Medal*

*Available in Unisex Adult Sizes

*Medal Distributed on Walk Day



\$2,500

Cloud Vest

Available in Men's and Ladies Sizes



\$5,000

North Face Rain Jacket

Available in Men's and Ladies Sizes

CHOOSE
3
ITEMS

\$10,000

Choose any
3 items!

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To earn a certificate for a recognition gift, register at www.walktoendlupus.org.
Incentive items are not cumulative. One item per participant.
Certificates will be distributed approximately 6 weeks post event via email.
Please add WalkToEndLupusNow@lupus.org to your address book for easy delivery.
Recognition program brought to you by Turnkey Promotions.
Call 800.405.7829 or visit www.turnkey2p.com

Trailblazer for Lupus

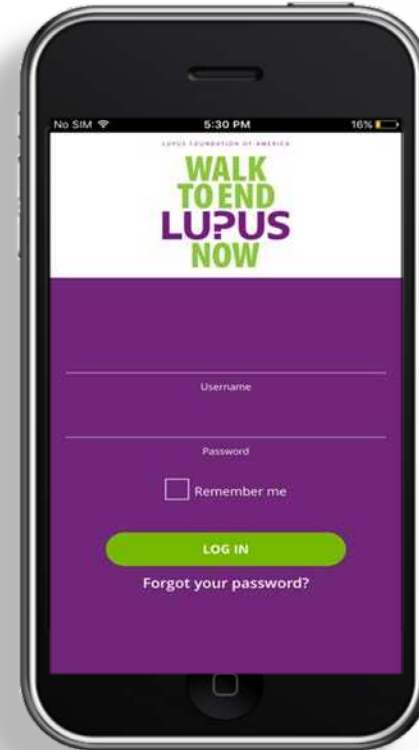


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Fundraising Tips

- **Don't be afraid to ask.** You're not asking for yourself, you're asking on behalf of the Lupus Foundation and people with lupus.
- **Start by making a donation to yourself.** Lead by example. Make a self contribution of \$10.
- **Ask 10 people for \$10.** When you raise \$100, you get a Walk to End Lupus Now t-shirt the day of the walk.
- **The earlier you ask, the better.** It can take up to 6 reminders before some will donate.
- **Does your employer match gifts?** Many companies will match 2 to 1 for employee donations.
- **Remember to say Thank You.** Thank your supporters for their time and gift – best practice is as soon as they donate.

Facebook Integration & Mobile Fundraising App

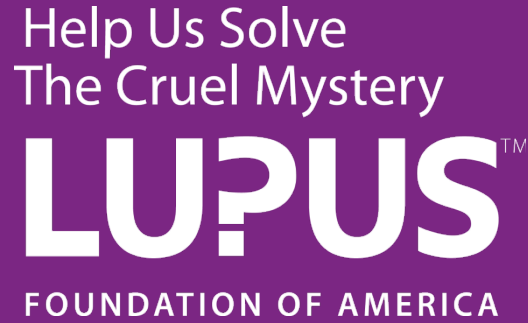


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**WALK
TO END
LUPUS
NOW™**

**Walk to End Lupus Now
San Francisco
Sunday, October 20, 2019
Golden Gate Park**

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The Importance of Advocacy

September 21, 2019

Storytelling is the
most effective way to
merge meaning and
emotions.



National Lupus Advocacy Summit: March 16 & 17 2020

At the 2019 National Lupus Advocacy Summit, including the newly established Kids' Congress, we empowered nearly 350 advocates of all ages to fight back against this disease and raise the profile of lupus on Capitol Hill and around the world.

Elevating Lupus on the National Healthcare Agenda

FEDERAL WORKING GROUP ON LUPUS AT NIH



Forum convened by the National Institutes of Health aimed at producing a comprehensive look at lupus in the federal government; *2016 Action Plan for Lupus Research*.

NATIONAL LUPUS PATIENT REGISTRY AT CDC



Generated \$63.8 million in total funding to date; Developed the National Public Health Agenda for Lupus.

LUPUS RESEARCH PROGRAM AT THE DEPARTMENT OF DEFENSE



Total project funding to date is \$36 million.

THE LUPUS INITIATIVE WITH THE OFFICE OF MINORITY HEALTH



Generated \$16.6 million in funding to date. Focus on primary care provider education and new focus is clinical trial education.

CONGRESSIONAL LUPUS CAUCUS



Established in 2012; Co-chaired by Representatives Keating (D-MA), and Johnson (D-TX), King (R-NY)



Capitol Hill

Our advocacy has generated more than half a billion dollars in federal funding over the last 5 years, and we are maximizing the impact of every dollar to reduce time to diagnosis and accelerate the search for new treatments.

Advocacy Year Round

- August district meetings with Congress
- Become an advocate and recruit more advocates
 - Take action on alerts to contact Congress
- Media
 - Interviews and quotes
 - Letter to the editor, Op-eds
- Walks & Support Groups
- Participate in the ¡Adios Lupus! Program

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¡Adios Lupus!

The first and only official charity partner of Minor League Baseball's Copa de la Diversión Hispanic outreach program, which gives LFA a platform to reach the Hispanic audience, provide resources to better serve the community, increase participation in research and reduce time to diagnosis.

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Thank You!