Managing Your Lupus: How Can You Take a More Active Role?
What Are We Going to Talk About?

1. The **immune system** basics and systemic lupus erythematosus (SLE or just “lupus”)

2. The importance of taking an active role in **managing your lupus**

3. The **resources** that can help you monitor your symptoms and communicate with your healthcare team
Chapter 1

The Immune System and Lupus
What Is Lupus?

• Lupus:
  – Occurs when your body’s immune system—the system that fight off viruses and bacteria—attacks its own healthy tissues\(^1,2\).
    • This “autoimmune” activity can cause inflammation, pain, and damage in various parts of the body\(^1\).
  – Is called “chronic” because the signs and symptoms lasts for years\(^1\).
  – Is characterized by flares and remissions—periods during which you may feel worse, and then better\(^1,2\).
  – Lupus can be considered a “fingerprint disease”—it’s unique in every person\(^2\).

---

There Are Different Types of Lupus

- **Systemic lupus erythematosus or SLE (or just “lupus”)**
  - Can affect nearly every part of the body

- **Discoid lupus (or cutaneous lupus)**
  - Affects only the skin

- **Drug-induced lupus**
  - Certain prescription medications can cause drug-induced lupus, which usually goes away once the medication is stopped

- **Neonatal lupus**
  - The newborn of a mother who has lupus may develop a rash or other symptoms that can last for several months before disappearing

---

Immune System Basics

• Everyone has an immune system\(^1\)
  – The immune system recognizes and fights “foreign” invaders

• A general term for foreign invaders is **antigens**, which includes germs such as bacteria and viruses\(^1\)

• In your immune system\(^2\)
  – **White blood cells** talk to each other by sending **chemical messages to make antibodies**
  – **Antibodies** attach to **antigens** and “mark” them for removal

---

The Immune System in Lupus

• In lupus, the immune system cannot tell the difference between your own body and foreign invaders that are harmful

• Lupus is like an allergic reaction to some parts of your own body
  – Your body is essentially fighting itself

• This reaction leads to inflammation of organs and the signs and symptoms of SLE

Who Gets Lupus?

• The cause of lupus is not known—anyone can get lupus

• In the United States, there are approximately 171,000 individuals currently living with lupus

• Women between 15 and 44 years of age are more likely to get lupus

• Lupus is more common and severe among nonwhite populations

• Lupus may run in families, but most people with lupus do not have a close relative with lupus

Additional **Risk Factors**

- Some factors that increase the chance of someone getting lupus include:

  - Ultraviolet (UV) rays from the sun or fluorescent lightbulbs
  - Infections, colds, or other viral illnesses
  - Cigarette smoking
  - Hormonal therapy

---

How Lupus Affects Your Body

- When your immune system attacks your own body, it can cause damage to many parts of the body
  - As a result, you may have symptoms (discussed later)

- Lupus may affect 1 or more parts of the body

- Lupus can also cause serious problems that you may not see or feel

What Are Some of the Visible Symptoms of Lupus?

Although symptoms may sometimes disappear, the disease does not go away\(^1,2\)

- Symptoms may be different for everyone\(^1\)
- Some of the common visible symptoms are\(^3\):

  - Swelling of joints
  - Fever over 100°F
  - Hair loss
  - Nose or mouth sores
  - Skin rashes after sun exposure

---

Some Examples of the Invisible Effects of Lupus

- Lupus can also cause serious problems that you may not see, such as:
  - Inflamed kidneys may not work correctly
  - Inflamed linings of the heart and lungs may cause chest pain
  - Effect on the brain make it difficult to think clearly
  - Fatigue

Why Is It Important to **Monitor** Your Symptoms?

- **Active disease**
  - The presence of signs and symptoms known as “**active disease**” is associated with an increased risk of damage to your major organs.¹

- **Every symptom matters!**
  - You may not think that some symptoms are lupus related, but they may be a sign of lupus-related inflammation that could lead to organ damage.

---

Reflection: Consider Your Experiences

Take a moment for some self-reflection

- What symptoms have you experienced?
- What are the areas of the body that most concern you? Why?
- Do you worry about the silent effects, eg, inflamed kidneys of lupus?
  - Do you share these concerns with someone?
- Did you know that there are things that you can do to help manage your lupus?
Some Organs That Are Affected by Lupus

- Brain
- Eyes
- Nose and mouth
- Skin
- Lungs
- Heart
- Muscles and bones
- Kidneys
What Symptoms Should You Be Looking For?

Know the symptoms associated with active disease


**Skin**
- rashes, sensitivities to sun or light, mouth and nose sores, and hair loss

**Brain**
- seizures, headaches, dizziness, sad thoughts, memory problems, and confusion

**Eyes**
- dry eyes, eye redness, and some loss of vision
<table>
<thead>
<tr>
<th>Muscles and bones</th>
<th>• muscle weakness, stiffness in joints, and aching muscles&lt;sup&gt;1&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart and lungs</td>
<td>• chest pain and difficulty breathing&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
<tr>
<td>Kidneys</td>
<td>• swelling of legs and/or feet, and frothy and/or bloody urine&lt;sup&gt;3&lt;/sup&gt;</td>
</tr>
<tr>
<td>Daily flu-like symptoms</td>
<td>• fever, fatigue, and nausea&lt;sup&gt;3&lt;/sup&gt;</td>
</tr>
</tbody>
</table>


Routine monitoring of symptoms associated with lupus is essential\textsuperscript{1}.
Components of routine monitoring should include\textsuperscript{1,2}: 

\begin{itemize}
  \item Patient & Caregivers
  \item PCP or Rheumatologist
  \item Specialty Consultants
\end{itemize}

PCP = primary care physician.
\textsuperscript{1} American College of Rheumatology Ad Hoc Committee on Systemic Lupus Erythematosus Guidelines. \textit{Arthritis Rheum.} 1999;42(9):1785-1796.
Participating in Your Care\(^1\)

- You are a **key component** in assessing your disease activity

- **Feel empowered** to be your own advocate

- Promote **open communication** with your healthcare team

- **Educate yourself** and **ask questions**

Reflection:
Consider How **You Manage** Your Lupus

*Take a moment for some self-reflection*

- Think about how you currently manage or track your lupus:
  - What challenges do you face?
- Do you feel like you are taking an active role in disease self-management?
- Are you aware of ways that you can take an active role in disease self-management?
Chapter 2

Managing Your Lupus
You Can Take Control\(^1\)

- Eat healthy and stay active
  - Talk with your healthcare team about a heart-healthy diet
  - A healthy diet can also help keep your energy up

You Can Take Control\(^1\) (continued)

- Listen to your doctor’s instructions
  - Work with your healthcare team to develop a management plan that is right for you
  - Tell your healthcare team if a routine is not working for you or if you are having trouble sticking to a management plan
  - Together, you may be able to find a solution that works for you

---

You Can Take Control\textsuperscript{1} (continued)

- Be sun smart
  - Try to limit your exposure to UV rays when outdoors
  - Wear a hat, long sleeves, pants, and sunscreen

---

\textsuperscript{1} Lupus: A Patient Care Guide for Nurses and Other Health Professionals. 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.
• Involve friends and family
  – They are a great source of support, so let them know how they can help

• Ask for help
  – Even if you need emotional encouragement, help running errands, or a second set of eyes and ears at a doctor’s appointment
  – Don’t be afraid to lean on those closest to you

---

**Differences in Communication**¹

- In 2011, a survey* was conducted of 957 members of the lupus community, including patients, supporters, and rheumatologists.

- It revealed communication gaps about symptoms between physicians and patients.

  - 52% of patients reported that they minimized their symptoms when they talked to physicians.
  - 72% of physicians were unaware that patients tended to underreport their symptoms.

---

*Data from the 2011 National Burden of Lupus survey funded and developed by GSK. Data on file, GlaxoSmithKline, 2011.

Communication Challenges

• One of the challenges in managing lupus is the lack of communication between patients, caregivers, and families.¹

• Remember, the first step in taking control of lupus is sharing all of your symptoms with your healthcare team and with your loved ones.²

• Communication is the best way to ensure that you get the support you need.³

Why Is Communication So Important?

“I have seen these challenges reflected in my clinical practice. It is critical that patients and physicians understand the importance of clear communication because it has implications for disease management. For example, patients may not mention low-level disease symptoms as they may consider it a normal part of living with lupus. However, low-level disease activity can still cause organ damage and may represent a missed opportunity for identifying a flare and instituting early intervention.”

Anca Askanase, MD, MPH

Dr. Askanase received a fee for her participation in this program
Communication Is Key

- Work with your healthcare team
  - Monitoring of lupus should be a team effort\(^1\)

- Shared decisions and open communication are imperative\(^2\)
  - **Open and honest** communication with your healthcare team is an important part of any lupus diagnosis
  - Talk openly, even on topics that you may feel uncomfortable with
  - Your healthcare team is there to support you

---

“...over the years, I’ve learned the importance of building a strong and open relationship with my doctors. It’s so extremely important. I feel so honored to now have a doctor who not only listens to my concerns and has my best interest at heart, but also seems to genuinely care about me and my well-being.”

Rena, currently living with lupus
Rena is a paid spokesperson for GSK
Reflection: Consider **Your Interactions**
With Your Healthcare Team

*Take a moment for some self-reflection*

- What does good communication with your healthcare team look like?

- Think about whether there are symptoms you don’t talk about with your healthcare team. If so, why?

- What kind of support and interaction do you want to receive from your healthcare team?

- What ways can you assist your healthcare team in having effective communication?
Tips for Communicating

• Report all symptoms, regardless of whether you believe they are lupus related or not\(^1\)
  -- Also discuss symptoms that have disappeared

• Bring a list of all the providers you are seeing and all the medications you are taking to every medical appointment\(^2\)

• Follow the “Ask Me 3” Program\(^3\)
  -- Questions designed by the National Patient Safety Foundation

• Be informed and stay active in being educated on lupus\(^1\)

Education Is Important

• **Be informed. Be empowered!**
  – The more you know about lupus, the better you can talk to your healthcare team

• **Know how** your healthcare team monitors your disease
  – Routine blood tests to analyze how your blood is clotting
  – Urine tests, because the kidneys are often affected by SLE
  – Tests for antibodies, such as:
    • Antinuclear antibodies (ANA)
    • Anti-dsDNA

---

ANX = antinuclear antibody; anti-dsDNA = anti–double-stranded DNA.
Keeping Track and Reporting Accurately Is Important

• Keep track of all symptoms regularly so that you can report accurately\(^1\)
  – Keep a journal
  – Involve friends and family
  – Use available apps on your mobile devices
  – Have medical records available for your reference

• Share all of these important factors with your healthcare team
  – Do your symptoms change over time?
  – How are they affecting your daily life?
  – Do they prevent you from doing things that you enjoy?
  – Does lupus make you feel isolated, depressed, or frustrated?

---

Reflection: Consider How You **Track** and **Report**

*Take a moment for some self-reflection*

- How do you keep track of your symptoms?
  - Are you reporting your symptoms accurately?

- Do you forget to report symptoms?

- Are you being honest in reporting?

- Has there been a time that you have not told your healthcare team about a symptom because you thought it was not important anymore?
Where Can You Go for Help?

- Us in Lupus.com Program
- Healthcare Team
- Patient Advocacy Groups
- Family
- Friends

YOU
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
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
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.
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.
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
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 www.usinlupus.com
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:

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!

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

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