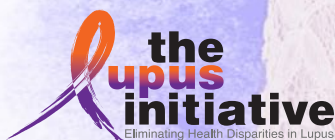


# ***Illuminating Lupus***

Facilitator's Guide  
for Community Health  
Representatives Working  
with American Indian  
and Alaskan Native  
Populations



AMERICAN COLLEGE  
of RHEUMATOLOGY  
*Empowering Rheumatology Professionals*



# ACKNOWLEDGEMENTS

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The *Illuminating Lupus* project was supported by Grant Number 6 NU58DP007138; CFDA Number 93.078, *Developing and Disseminating Programs to Build Sustainable Lupus Awareness, Knowledge, Skills and Partnerships*. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the HHS and CDC.

*Illuminating Lupus* was developed by the American College of Rheumatology. The ACR would like to thank the following individuals for their contributions to the curriculum:

## SUBJECT MATTER EXPERTS

Name

Title

Please Note\*\*\*

\*AI and American Indian is used throughout to represent communities and persons of American Indian descent and tribal communities. AN is used to represent communities and persons of Alaskan Native descent and tribal communities.

\*\*CHR/CHW is used throughout this guide as an umbrella term describing public health and/or social service workers who are close to and serve members of the community by helping them to adopt healthy behaviors.

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# A Note to Health Leaders

Dear Health Leader,

As a leader and trusted advisor in your community, we at the American College of Rheumatology (ACR) recognize the important role you play in health promotion. As a Community Health Representative (CHR), Community Health Aide (CHA) or Community Health Worker (CHW), you play a critical role in American Indian (AI) and/or Alaskan Native (AN) communities in creating connections between vulnerable populations and healthcare systems; facilitating healthcare system navigation; as well as managing care and care transitions for your community. In addition to the services you provide to your community, you also assist healthcare providers and systems by ensuring cultural competence among healthcare professionals in serving the AI/AN populations; educating providers and stakeholders about community health needs; and the important role of providing culturally appropriate health education. We are excited to have your experience and expertise brought to the *Illuminating Lupus* project.

## About *Illuminating Lupus*

*Illuminating Lupus* is a targeted project for AI/AN communities focused on providing Community Health Representatives (CHRs) with the knowledge and skills to raise lupus awareness. This project is designed to be implemented by CHRs, which we will use as an umbrella term describing public health and/or social service workers who are close to and serve members of the community by helping them to adopt healthy behaviors.

The AI/AN community is faced with higher rates of lupus than other racial/ethnic groups and tend to face an earlier onset of the disease.<sup>1</sup> Despite these disparities, much of the community may be unaware of lupus and its consequences. *Illuminating Lupus* is designed to expand your knowledge and outreach skills to aide AI/AN community members understand the signs and symptoms of lupus, raise lupus awareness and inform communities on what steps to take for their health if lupus is suspected.

After participating in the *Illuminating Lupus* program, CHRs will have the skills to:

- ▶ Describe lupus signs and symptoms;
- ▶ Raise lupus awareness in their communities;
- ▶ Understand the impact of lupus on a person's life; and
- ▶ Know how to support a person with lupus in the AI/AN community.

ACR wants leaders like you to use this facilitator's guide to educate your community about lupus. This guide will help you learn about lupus, spread the word through multiple methods to educate others CHRs and your community, and host a hands-on event. These efforts will increase the number of CHRs who know the signs and symptoms of lupus and what to do if someone they know shows signs of the disease.

If you have any questions about how to use the facilitator's guide, about lupus or the ACR, please contact us via email at [lupus@rheumatology.org](mailto:lupus@rheumatology.org) or via phone at 404.633.3777.

Thank you for assisting us in increase the awareness of lupus in the AI/AN communities.



# ***Illuminating Lupus***

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Welcome to *Illuminating Lupus*, a training program designed to train CHRs about lupus. The training program will increase CHRs' understanding of the signs and symptoms of lupus, so that they can effectively raise lupus awareness in their communities.

The need for CHRs working in the AI/AN communities to understand lupus is great, because:

- › Lupus is an inflammatory disease caused by the autoimmune system attacking its own cells and tissues.
- › For AI/AN persons, lupus has a prevalence of 178 cases per 100,000 person years. AI/AN persons develop lupus at 10 times the rate of Caucasians.
- › Among AI/AN women, the prevalence of lupus is significantly higher among women than men at 271 cases per 100,000.
- › Prevalence of lupus was found to be highest among women from 50-59 years old.<sup>2</sup>
- › There is no cure for lupus, but doctors and patients can manage lupus with medication and lifestyle changes.



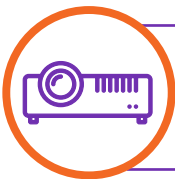
## How Is the *Illuminating Lupus* Training Implemented?

The *Illuminating Lupus* training consists of an approximately two-and-a-half-hour program, comprised of two parts with a break in between. Part One of the training is an approximately 60-minute session; we suggest that a break of 15 minutes occur between Part One and Part Two. Part Two of the program consists of a 45-minute session and 15 minutes for the completion of evaluation tools. We recommend that around 15 CHRs participate in the training at a time. A small training class allows for participants to ask questions and provides the opportunity for in-depth discussions. Upon completion of the training, each CHR will receive a certificate of completion and a PowerPoint presentation, which may be used to assist community education.

## Program Materials

The *Illuminating Lupus* program contains PowerPoint slides, handouts and activities to engage CHRs. The program is designed to provide CHRs with detailed knowledge on lupus, while providing them with the opportunity to practice outreach techniques and skills through activities. Each program part begins with a brief overview of the learning objectives, the necessary support materials and teaching materials including the session script.

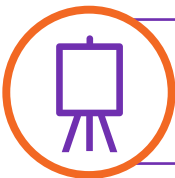
The *Illuminating Lupus* program does not require any special materials to implement. You will need the following supplies:



LCD projector for PowerPoint slides: Set up the projector before beginning the program. Use the projector to display the PowerPoint slides in Part One. If you don't have that technology, print copies of the slides for each participant.



Thick paper or card stock: Ask participants to make name plates when they arrive at the program.



Poster-sized paper to make easel pad sheets: You can buy self-adhesive pads at office supply stores or simply hang poster board with tape.



Pens and markers: Participants may use pens and markers to take notes and write on the easel pad sheets during the program.

# It All Starts With You

It all starts with you. As the driving force in your community, we want to empower you with the knowledge and resources you need. Educating yourself and your fellow health leaders about lupus sets the stage for you to engage your fellow health advocates and increase lupus awareness in your communities. As we mentioned earlier, lupus is a complicated health problem. Even health professionals can have difficulty recognizing and diagnosing lupus. However, it is critical that you learn as much about lupus as possible before launching a CHR education event. The following handouts provide information on lupus and its impact on the AI/AN community. More information on lupus can also be found at the American College of Rheumatology's Lupus Initiative website, which is located at [www.TheLupusInitiative.org](http://www.TheLupusInitiative.org).

## What Is Lupus?

Lupus is a chronic disease, meaning it is a long-term disease that should be managed. Lupus affects the immune system and is called an autoimmune disease. The immune system's job is to fight foreign invaders, like germs and viruses. But in autoimmune diseases, the immune system is out of control and mistakenly attacks healthy tissue. Lupus, also known as systemic lupus erythematosus (SLE), is a chronic, autoimmune disease that causes systemic inflammation. Lupus can affect many parts of the body including joints, skin, kidneys, lungs and the brain. It can vary from mild to severe, and usually alternates between periods of activity and periods of reduced activity, or even remission.



## How Does Lupus Affect my Community?

While anyone can develop lupus, women are affected more than men. AI/AN women have the second highest prevalence of lupus among women of color.

- ▶ For AI/AN persons, lupus has a prevalence of 178 cases per 100,000 person years. AI/AN persons develop lupus at 10 times the rate of Caucasians.
- ▶ Among AI/AN women, the prevalence of lupus is significantly higher among women than men at 271 cases per 100,000.
- ▶ Prevalence of lupus was found to be highest among women from 50-59 years old.<sup>2</sup>

<sup>2</sup>American College of Rheumatology. 2017. Lupus Patient Fact Sheet. <https://www.rheumatology.org/Portals/0/Files/Lupus-Fact-Sheet.pdf>. Accessed December 17, 2018.



# Getting Started

The *Illuminating Lupus* presentation is designed to be utilized to educate your fellow community health leaders and CHRs about lupus and provide them with tools to discuss lupus in their communities.



## Objectives of This Presentation Include:



Recognize the signs and symptoms of lupus



Understand impact of lupus on a person's life and the AI/AN community



Raise lupus awareness among CHRs and individuals working in AI/AN communities



Know how to support a person with lupus



## Length of the Activity

The presentation and discussion should last between 60-75 minutes.



## What You Need:

- › Computer and audio/visual equipment for projection of the PowerPoint presentation to the audience
- › Location that can host all of your leaders
- › *Illuminating Lupus* PowerPoint presentation
- › Presentation script
- › Lupus Facts infographic



## PART ONE:

# *Illuminating Lupus*

In Part One of the program, CHRs will learn about lupus signs and symptoms, AI/AN communities' increased risk of lupus, and why raising lupus awareness is important in the AI/AN communities. The first part of the program is designed to be presented as a PowerPoint presentation with key discussion points provided for each slide as well as activity reminders for the program facilitator.



## Learning Objectives

After completing *Illuminating Lupus* Part One, participants will be able to:

- › Describe the common signs and symptoms of lupus
- › Understand that the AI/AN community is at a higher risk of lupus than other racial and ethnic groups



## Support Materials

To prepare for Part One of the presentation, prepare the following support materials:

- › Thick paper or card stock for name plate (one per participant)
- › PowerPoint projector and laptop if using PowerPoint slides OR copies of the slides to distribute in hard copy
- › Pens and colored markers
- › Easel pad sheets
- › Transparent adhesive tape
- › Refreshments (snack and/or beverage) for break (if possible)
- › Music to play during break (if possible)



## Teaching Materials

To prepare for the education in Part One, prepare the following teaching materials:

- › Program Pre-Test Assessment (make one copy per participant)
- › Easel Pad 1.1 – Our Guidelines for Learning
- › Together (write content on poster-size paper and post in room)
- › Did You Know? Cards 1.1, 1.2 and 1.3
- › PowerPoint Slides
- › Handout 1.1 – Lupus Signs and Symptoms (make one copy per participant)
- › Handout 1.2 – Facts on Lupus (make one copy per participant)
- › Handout 1.3 – Lupus Symptom Role Play (make five copies)



## Activity 1.1:

### Welcome and Pre-Test



Hi, my name is \_\_\_\_\_. Welcome to the *Illuminating Lupus* training program.



*Give background information on yourself*

- ✓ *Your role in the community*
- ✓ *Why you became a community health representative/ community health worker/How long you've been a health advocate*
- ✓ *Why you are interested in lupus*



Over the next two hours and a half, we will learn about lupus, how it affects many AI/AN women, how to help clients who have lupus, and lastly, how to raise awareness in our community. To help us better understand your level of knowledge related to lupus, please take a moment to complete this pre-test example. Do not worry if there are items that you do not understand, as the items on this pre-test will be discussed today.



Disseminate the Pre-Test Assessments. Allow 10 minutes for the pretest to be completed and collect assessments.



Thank you for completing this assessment. Now let's get started. What comes to mind when you hear "lupus"?



*Allow two or three participants to respond.*



Lupus is an autoimmune disease that can occur in anyone. The goal of *Illuminating Lupus* is to provide you with the knowledge and skills to help raise awareness in our community.

### Introductions



Let's take a moment to get to know each other.



*Complete the Introduction Icebreaker Activity.*

*Go around the group and ask each participant to state his/her name and attach an adjective that not only describes a characteristic, but also starts with the same letter of his/her name. For example, kind Kimimela, compassionate Cheyenne.*





## Activity 1.2:

### Program Guidelines



Hi, Before we continue, let's discuss some guidelines to help us support each other and learn.



Hang up Easel Pad Sheet 1.1- Our Guidelines for Learning Together

Ask for volunteers to read each guideline aloud, then provide additional context.

Participants read	Facilitator explains
Arrive on time.	We want to begin and end the session on time. Please arrive on time.
Silence your phones.	Please set your cellphones to silent or vibrate. We will have a 10-minute break in the middle of the session when you will have time to check your phone.
Participate actively.	You are experts on your own community, its needs and strengths. Please share from your experience, so we can all learn from each other.
Ask questions.	Don't be shy. If you need more information, please ask. Someone may have the same question.
Listen respectfully to other participants.	Give everyone a chance to speak, and do not interrupt your classmates.
Keep the information shared in the session confidential.	If you share any examples from your experience, please don't provide any names of clients or other health workers.
Take breaks when you need them.	There is a scheduled break in the middle of the session, but if you need to stretch or go to the bathroom, please do so.
Have fun!	We learn better when we enjoy what we are doing.



Are there other guidelines you would add to this list?



Record additions and ask participants to agree to follow these guidelines throughout the training.



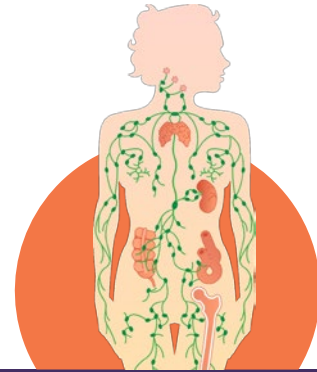
## Activity 1.3:

### What Is the Immune System and Autoimmune Disease?

#### The Immune System & Autoimmune Diseases

The immune system protects the body from disease and infection by attacking germs and other foreign cells.

Autoimmune diseases cause the immune system to attack healthy cells in the body.



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#### Key Points to



To understand lupus, we must first understand the body's immune system. The immune system is a network of cells and organs that defend the body against viruses, bacteria and other foreign invaders.

The body's immune system can usually tell the difference between your healthy cells and foreign cells. But sometimes, the cells that work to keep your immune system healthy begin to fail and instead attack your bodies' healthy cells. This causes damage we know as autoimmune disease. Autoimmune diseases attack healthy cells in the body by mistake. Lupus is an autoimmune disease.

#### Key Actions to



Display PowerPoint Slide – The Immune System and Autoimmune Diseases



## Activity 1.4:

### What Is Lupus?

#### What Is Lupus?



Lupus is an autoimmune disease that can damage any part of the body, including the skin, joints, and internal organs.



With lupus, something goes wrong with your immune system, which is the part of the body that fights off viruses, bacteria and other germs. The flu is caused by one of these “foreign invaders.”



In lupus, the immune system can attack and destroy a wide variety of healthy tissues through inflammation.

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MATERNITY

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#### Key Points to



As previously mentioned, lupus is an autoimmune disease. In lupus, the immune system attacks the body's own tissues, causing inflammation and damage in many parts of the body, including the skin, joints and internal organs. The type of lupus a person is affected by depends on the tissues or organs that are attacked by the immune system. People with lupus are affected differently. The most common type of lupus is systemic lupus erythematosus (SLE).

The body's immune system can usually tell the difference between your healthy cells and foreign cells. However, sometimes the cells that work to keep your immune system healthy begin to fail and instead attack your bodies' healthy cells. This causes damage we know as autoimmune disease. Autoimmune diseases attack healthy cells in the body by mistake. Lupus is an autoimmune disease.

#### Key Actions to



Display PowerPoint Slide – What Is Lupus?

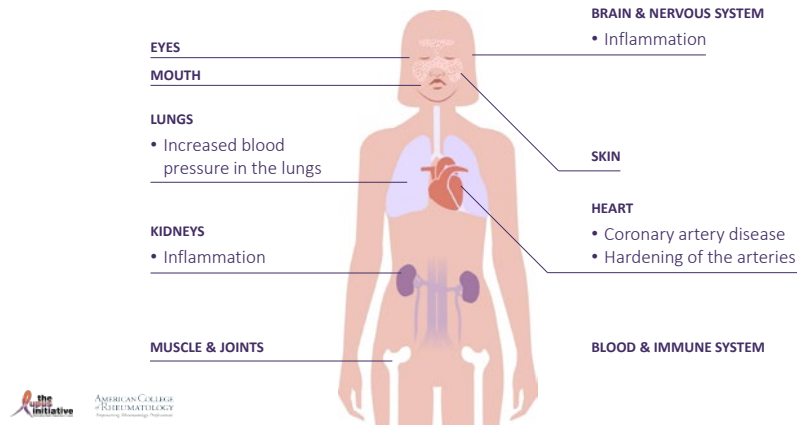




## Activity 1.5:

### How Does Lupus Impact the Body?

#### Lupus can impact many organs of the body



#### Key Points to



**SAY**

When people use the term “lupus,” they’re usually referring to systemic lupus erythematosus, or “SLE.” Systemic lupus is so-named because it affects many different organ systems in the body. It is marked by chronic inflammation, especially of the kidneys, joints and skin. The cardiovascular and nervous systems may also be affected.

SLE can cause inflammation throughout the body, including in the:

- › Kidneys, affecting the body’s ability to filter waste from the blood
- › Nervous system and brain, affecting your ability to think and may cause seizures
- › Blood vessels, causing symptoms that vary according to the location of the inflammation
- › Heart, leading to an increased risk of heart attack
- › Lungs, which may make it painful when you take a deep breath
- › Skin, causing rashes, hair loss and skin changes

Lupus can impact many organs of the body. It is important to remember that the internal impact of lupus may not always be seen.

#### Key Actions to



**DO**

Display PowerPoint Slide  
– Lupus can impact many organs of the body

**Handout 1.1 Lupus Signs and Symptoms**

**Instructions:** Match the sign(s) and/or symptom(s) that affects the body parts indicated on the diagram.

**List of signs and symptoms:**

- Swelling and joint pain
- Muscle aches
- Butterfly rash and other types of rashes
- Sores that may or may not be painful
- Low count of blood cells: red blood cells, white blood cells, and platelets
- Hair loss
- Confusion, seizures and dizziness
- Headaches
- Chest pain when taking a deep breath
- Blood in the urine

Answers on next page →

ILLUMINATING LUPUS: Facilitator's Guide  
<https://thelupusinitiative.org>  
 The Community Health Representatives Working with American Indian and Alaska Native Populations  
 American College of Rheumatology  
 Lupus Research Alliance

Distribute Handout 1.1



## Activity 1.6:

### What Are the Signs and Symptoms of Lupus You Can See?

#### Signs and symptoms of lupus **you can see**

Keep in mind that the appearance of a skin condition can vary depending on skin tone.



Butterfly rash



Painless oral ulcer



Poor circulation in fingers and toes



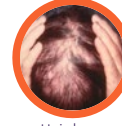
Rashes and Discoloration



Swelling and joint pain



Inflammation of the blood vessels



Hair loss



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#### Key Points to



Lupus is difficult to diagnose. However, there are common signs and symptoms. A person's symptoms vary during periods of flares and remissions. Let's go over the common signs and symptoms of lupus.

#### Key Actions to



Display PowerPoint Slide – Signs and Symptoms of lupus you can see



## Activity 1.7:

### What Are the Signs and Symptoms of Lupus You Can't See?

#### Signs and symptoms of lupus you can't see

Here are some lupus symptoms that make diagnosis difficult, because they can be indicators of so many conditions.



Achiness, headache



Fatigue



Memory lapse /  
brain fog



Depression

#### Key Points to



It is important to remember that not all of the impacts of lupus can be seen. Other symptoms include achiness, headaches, fatigue, brain fog and depression.

It is important to keep in mind that anyone who experiences at least two of the signs or symptoms should schedule a doctor's visit. You can share this with your clients, but remember that your role as a CHR is to provide information, but never to diagnose or treat an illness.

#### Key Actions to



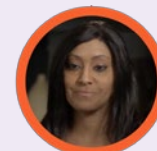
Display PowerPoint Slide – Signs and Symptoms of lupus you can't see



IVANA

Mostly external symptoms

Michelle and Ivana are sisters, They both have lupus, but they have **different symptoms**, with Ivana's being more external and Michelle's more internal.



MICHELLE

Mostly internal symptoms

#### Key Points to



The signs and symptoms of lupus can vary from person to person. Let's watch a quick video of two sisters describing their lupus symptoms.

#### Key Actions to



Display slide – Michelle and Ivana

Select video on slide "Ivana and Michelle describe symptoms" and play for the group

Allow time for discussion of the clip and the group's thoughts on the variation of symptoms.





## Activity 1.8:

### Who is a Rheumatologist?

#### Who is a Rheumatologist?



A rheumatologist is an internist or pediatrician who received further training in the diagnosis (detection) and treatment of musculoskeletal disease and systemic autoimmune conditions commonly referred to as rheumatic diseases. These diseases can affect the joints, muscles and bones causing pain, swelling, stiffness and deformity.

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#### Key Points to



A rheumatologist is a specialist who focuses on autoimmune conditions and musculoskeletal diseases.

Common diseases treated by rheumatologists include osteoarthritis, gout, rheumatoid arthritis, chronic back pain, tendinitis and lupus.

#### Key Actions to



Display slide – Who Is a Rheumatologist?



## Activity 1.9:

### What Causes Lupus?

#### What causes lupus? We don't know for sure

Researchers and rheumatologists believe many factors trigger the disease, including:



##### GENETICS

Race and ethnicity



##### ENVIRONMENTAL FACTORS

Sun exposure, taking certain medications



##### DEMOGRAPHIC RISKS

Poverty, no insurance, immigration status



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#### Key Points to



While we do not know the cause of lupus, we do know that genetics, including race and ethnicity, such as being of American Indian or Alaskan Native descent, is a factor.

It is important to remember that lupus is not contagious. Also, while it is an autoimmune disease, lupus is not related to cancer or HIV/AIDS.

#### Key Actions to



Display slide – What Causes Lupus?



## Activity 1.10:

### Lupus Is Difficult to Diagnose.

#### Lupus is difficult to diagnose

There is no single test to accurately diagnose lupus.  
The tests conducted include:



Blood tests, specifically, the antinuclear antibody (ANA) test



Skin biopsies



Urine tests, specifically a test for protein in the urine



Scans to find fluid around the lungs and heart

People who experience signs and symptoms of lupus should see a rheumatologist **as soon as possible**.



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#### Key Points to



As we have discussed, the symptoms of lupus vary from person to person, and can change at different points in people's lives. These changes in symptoms can make lupus difficult to diagnose. Many of the symptoms in lupus are present in other illnesses. In addition, because there is no one test to confirm if a person has lupus, it may take years to receive the correct diagnosis. Late diagnosis and delay in receiving proper treatment often lead to poorer outcomes.

A person with lupus may go to many doctors, including rheumatologists, dermatologists, cardiologists, pulmonologists and nephrologists, before someone puts all the pieces together and makes the diagnosis of lupus that links a person's multiple symptoms. Lupus does not look the same in everyone who has it. Medical providers may consider the results of numerous tests before diagnosing a person with lupus.

#### Key Actions to



Display slide – What Causes Lupus?

Review items on the slide, including their meanings:

- › Conducting a physical examination
- › Sending patients for laboratory tests, including blood tests: the most common blood test used to help diagnose lupus is the antinuclear antibody or "ANA" test
- › Doing a skin biopsy
- › Testing urine for protein, and X-rays or imaging scans to see if there is fluid around the lungs and heart



## Activity 1.10:

### Lupus Is Difficult to Diagnose, cont.

As the symptoms of lupus can be difficult for providers to diagnose.



A lupus diagnosis can take as long as **two or more years** and include visits to three or more healthcare providers.



This delay in diagnosis can be **devastating** for a person with lupus.



## Key Points to



With an early diagnosis, the chances of a person with lupus living a full life with a manageable, chronic disease are increased.

Unfortunately, there is no cure for lupus, but symptoms can often be managed through medications and lifestyle changes. It is important for people living with lupus to take their medications, because it can help control the disease and prevent flares. It is not safe to use alternative cures to treat lupus or to stop taking medication prescribed by medical providers when symptoms seem to go away.

## Key Actions to



Display slide – Lupus Symptoms

Remind group: We will discuss some ways you can support a person with lupus in a later activity.

Distribute handout 1.2

**Handout 1.2 Facts on Lupus**

<p><b>1 Who is at Risk for Lupus?</b></p> <ul style="list-style-type: none"> <li>Anyone can get lupus, regardless of age, gender, race or ethnicity.</li> <li>But lupus is most likely in women between the ages of 15 and 44.</li> <li>Compared to men, women are nine times more likely to have lupus.</li> <li>Lupus is also more common among women of ethnic and racial minority women, including American Indians/Alaskan Natives, African Americans, Latinas and Asians.</li> </ul>	<p><b>2 Flares and Remission</b></p> <ul style="list-style-type: none"> <li>The signs and symptoms of lupus vary widely among people living with lupus and may come and go during flares and remission.</li> <li>A flare is a time when a person with lupus is having an autoimmune attack and experiences active signs and symptoms.</li> <li>Remission is when there is little or no disease activity. A person may not experience any symptoms while in remission or may experience fewer.</li> <li>It is still important for people to take their medications as prescribed by their medical providers even if they feel better and are experiencing fewer or no symptoms.</li> </ul>
<p><b>3 Consequences of Lupus</b></p> <p>People living with lupus may experience inflammation in the:</p> <ul style="list-style-type: none"> <li>Nervous system and brain, causing memory problems, confusion, headaches, and strokes, high fevers, seizures and behavioral changes.</li> <li>Kidneys, which may affect the body's ability to filter waste from the blood.</li> <li>Lungs, causing pleurisy, coughing and chest pain while breathing deeply.</li> <li>Heart and circulatory system.</li> <li>Skin, causing rashes such as the butterfly rash across the nose and cheeks.</li> </ul>	<p><b>4 What Causes Lupus?</b></p> <ul style="list-style-type: none"> <li>Researchers are still unsure about the specific causes of lupus.</li> <li>Although more research is needed, lupus may be triggered by things in the environment and genetics. These include viruses, sunlight and drug allergies. Lupus is not contagious from one person to another.</li> <li>Lupus is not related HIV/AIDS.</li> </ul>

ILLUMINATING LUPUS: Facilitator's Guide  
<https://thelupusinitiative.org>

The Illuminating Lupus Initiative is a collaborative effort between the American College of Rheumatology and the Lupus Initiative.





## Activity 1.11:

### How Does Lupus Impact the American Indian and Alaskan Native Community?

## Did You Know?

There are **50 million** Americans with an autoimmune disease and **seventy-five percent** of them are **women**.

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### Key Points to



There are 50 million Americans with an autoimmune disease and 75 percent of them are women.

90 percent of the people with lupus are women of childbearing age.

### Key Actions to



Display slide – Did you know?

Ask group for their thoughts on this statistic.





## Activity 1.11:

### How Does Lupus Impact the American Indian and Alaskan Native Community? cont.

#### AI/AN women have the second highest prevalence of lupus among women of color.

For AI/AN persons, lupus has a prevalence of 178 cases per 100,000 person years. AI/AN persons develop lupus at 10 times the rate of Caucasians.

Among AI/AN women, the prevalence of lupus is significantly higher among women than men at 271 cases per 100,000.

Prevalence of lupus was found to be highest among AI/AN women from 50-59 years old.<sup>2</sup>

Many AI/AN persons living in rural and remote areas don't have easy access to a rheumatologist for full diagnosis and treatment, even if their primary doctor suspects lupus.



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#### Key Points to



Based on your experience, what do you think are common barriers and challenges faced by people in our communities living with lupus? Think specifically about possible barriers in their social life, work and healthcare access.

90 percent of the people with lupus are women of childbearing age.

#### Key Actions to



Display slide – AI/AN Prevalence

Allow two or three participants to respond, and ask them to explain their responses. Acknowledge participants' responses and correct any misinformation.

Answers may include:

- › Lupus has a significant effect on the body making it difficult to work or go to school.
- › AI/AN communities living with lupus may not have health insurance or have insufficient insurance.
- › A patient's socioeconomic status may make it difficult to seek care or more likely to miss work.
- › AI/AN communities may have a lack of access to providers, such as a rheumatologist.
- › A patient may get a late diagnosis due to the barriers we discussed.



## Activity 1.12:

### Lupus Role Play



So far, we've learned much about lupus. But, how do we use this information to help our clients? Let's do a role-playing activity to practice the ways that you can identify common signs and symptoms of lupus and understand how medical providers diagnose lupus.



*Ask for four participants to volunteers for a role-playing activity. Assign a role of Elizabeth, Turner, Amanda and the Doctor to each of the volunteers.*

*Distribute a copy of the Handout 1.3 – Role Play Activity to the volunteers. Allow volunteers two minutes to read and familiarize themselves with their characters. Ask participants to come to the front of the room and set the scene.*



Elizabeth is sitting at home and her husband, Turner, arrives...



*Direct volunteers to continue with role play.*



Great job, thank you for your participation. Let us reflect on the activity. What symptoms did Elizabeth have that suggested that she might have lupus?



*Allow one to two participants to answer. Answer: Elizabeth was experiencing aches throughout her body. For example, her muscles and head hurt. She also had high blood pressure. Amanda and Turner also pointed out that Elizabeth's face was red, that she might have a fever and that she had little energy.*

*Thank participants for their participation.*



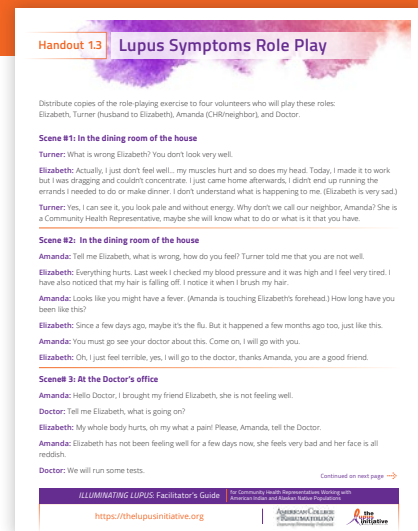
Are there any questions or comments about the activity?

We have learned so much about lupus in a short time. Let's take a quick break and come back together in 10 minutes to continue.

## BREAK

**Provide a 10-minute break for participants.**

Play music during the break period, if possible. If you can provide refreshments, invite participants to enjoy.







## PART TWO:

# Raising Awareness

In Part Two of the program, CHR's will learn and discuss way to raise awareness in their communities. To conclude, CHR's will complete assessments on the information that was taught to them throughout the program.



## Learning Objectives

After completing Part Two, participants will be able to:

- › Recognize the importance of raising awareness about lupus
- › Develop strategies for raising lupus awareness in the AI/AN communities
- › Identify lupus resources online and in their community

Prepare for Part Two by gathering and preparing the following support materials and teaching materials.



## Support Materials

To prepare for Part Two of the presentation, prepare the following support materials:

- › PowerPoint projector and laptop if using PowerPoint slides OR copies of the slides to distribute in hard copy
- › Pens and colored markers
- › Index cards
- › Transparent adhesive tape



## Teaching Materials

To prepare for the education in Part Two, prepare the following teaching materials:

- › Easel Pad 2.1 – Is It a Myth or a Fact? (write content on poster-size paper and post in room)
- › Handout 2.1 – Managing Lupus Through Lifestyle Changes (make one copy for each participant)
- › Handout 2.2 – How to Evaluate Online Information (make one copy for each participant)
- › Handout 2.3 – Certificates (make one copy for each participant)





## Activity 2.1: (Group)

### Importance of Raising Lupus Awareness



Welcome back from break. In the second half of this program, we are going to discuss the importance of raising lupus awareness in your community and practice outreach methods.



*Hand out index cards to participants. Ask them to work with a partner sitting near them.*



With your partner, make a list of why you think it's important to raise awareness around lupus.



*Allow the groups five minutes to discuss and make a list.*



Times up! Let's discuss the reasons you think raising awareness is important.



*Ask three pairs to share and explain their reasons.*

*Answers may include:*

- ✓ *Many people may be unaware that lupus exists.*
- ✓ *Patients with lupus may feel isolated and uncertain about speaking to their employers, colleagues, friends and neighbors.*
- ✓ *Lupus impacts employment because disability may accompany lupus.*



Thank you all for participating! Those were all great answers.



## Activity 2.2:

### Helping Someone With Lupus

#### Helping someone with lupus



Listen



Understand  
Medicines and  
Treatment



Support Healthy  
Lifestyles



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EDUCATION

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#### Key Points to



Based on your experience and what you now know about lupus, it is important that you are able to provide the help and support a person living with lupus may face.

Key steps to helping someone diagnosed with lupus are being willing to listen, helping him or her understand their treatment plan, and helping them make healthy lifestyle choices.

#### Key Actions to



Display slide – Helping Someone With Lupus



## Activity 2.3:

### Be a Healthcare Partner Who Listens

#### Be a healthcare partner who listens

- ✓ Understand that chronic pain may lead to depression and suicidal thoughts.
- ✓ Know the signs of depression, and help the client understand them, too.
- ✓ Encourage the client to build a social support network, exercise, eat a balanced and nutritious diet, and get enough sleep.

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#### Key Points to



As many of you know, social support is key in the proper management of a chronic disease such as lupus. It is important for the client to establish a social support network.

Provide resources such as information on depression and how to speak to their families about their illness.

#### Key Actions to



Display slide – Be a Healthcare Partner Who Listens



## Activity 2.4:

### Help With Lifestyle Changes

#### Help with Lifestyle Changes

- 1 Visit your medical providers as needed. Be open and honest with your providers about your symptoms and ask any questions that you may think of between appointments.
- 2 Take medications as prescribed and make sure you talk with your doctor about possible side effects and how the medicines affect you.
- 3 Eat a well-balanced diet.
- 4 Get plenty of rest. Avoid overworking and stressful environments.
- 5 Be active! Exercise at least three times a week for 30 minutes or more.
- 6 Stop or do not use tobacco products.
- 7 Avoid sun exposure. Use sunblock and wear protective clothing. Exposure to the sun can trigger flares.



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#### Key Points to



In your work, it is possible that you will have a client who has lupus. In addition to helping them navigate their healthcare needs, you may also support him or her to manage lupus symptoms through healthy lifestyle changes.

Symptoms for lupus vary depending on age and lifestyle. There are also small lifestyle changes that you can share to help lupus patients with their symptoms

- › Help the client understand that they play a big part in their health.
- › Sleep and a healthy diet are important.
- › Help the client reach out to family and friends when needed and learn to say no when necessary.

#### Key Actions to



Display slide – Help With Lifestyle changes

Encourage participants to seek out resources.

See [thelupusinitiative.org](http://thelupusinitiative.org)  
Distribute Handout 2.1

**Handout 2.1 Managing Lupus through Lifestyle Changes**

Visit your medical providers as needed. Be open and honest with your providers about your symptoms and ask any questions that you may think of between appointments.

Take medications as prescribed and make sure you talk with your doctor about possible side effects and how the medicines affect you.

Eat a well-balanced diet.

Get plenty of rest. Avoid overworking and stressful environments.

Be active! Exercise at least three times a week for 30 minutes or more.

Stop or do not use tobacco products.

Avoid sun exposure. Use sunblock and wear protective clothing. Exposure to the sun can trigger flares.

Prescription medications that a doctor may prescribe include:

- › Anti-inflammatory drugs, which are prescribed for patients experiencing pain or swelling of the joints.
- › Antimalarial drugs, which are often used to treat joint swelling, skin rashes, sores and to prevent flares.
- › Corticosteroids may be prescribed by a specialist for more severe lupus symptoms, such as difficulties with the kidneys, lungs or heart.
- › Immunosuppressive medications are used to reduce the hyperactivity of the immune system.

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<https://thelupusinitiative.org>

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the lupus initiative



## Activity 2.5:

### Understanding Treatment Plans

For clients diagnosed with Lupus, it is **key** that they understand their **treatment plan**!

Staying the course can be the difference between **life and death**.

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Advancing the Science of Rheumatology



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#### Key Points to



There is no cure for lupus, but it can be managed by taking medications and making lifestyle changes.

Treatment varies depending on the clients' signs, symptoms and age. Treatment options include

- › Nonsteroidal anti-inflammatory drugs (NSAIDs)
- › Antimalarial drugs
- › Corticosteroids

#### Key Actions to



Display slide – Understanding Treatment Plans





## Activity 2.6:

### Connect a Client With a Medical Home

#### Connect a client with a medical home

- ✓ Connect the client with a primary care provider.
- ✓ Give the client tools to help them keep track of appointments.
- ✓ Help the client keep track of symptoms and any questions that arise between appointments to make the most of doctor's appointments.
- ✓ Encourage the client to feel like a valued member of the healthcare team, so they feel comfortable speaking up at their appointments.

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#### Key Points to



The client is the expert when it comes to how he or she is feeling. It is important to support them in speaking with their doctor about their signs and symptoms.

With lupus, it is important to discuss all of your symptoms, even the ones you might not associate with lupus.

The ACR has developed tools to assist patients in speaking with their doctor, and we encourage you to share these resources with your patients.

#### Key Actions to



Display slide –  
Understanding Treatment  
Plans

Provide links to ACR The  
Lupus Initiative website:  
[www.thelupusinitiative.org/  
selfcare](http://www.thelupusinitiative.org/selfcare)



## Activity 2.7:

### Help a Lupus Client Take Medicines as Prescribed

#### Help a lupus clients take medicines as prescribed

- ✔ Accompany the client to their appointment so you can become familiar with what each medicine does and how it should be taken.
- ✔ Treatment varies depending on the clients, sign and symptoms and age. Treatment options include
  - » Nonsteroidal anti-inflammatory drugs (NSAIDS)
  - » Antimalarial drugs
  - » Corticosteroids
- ✔ Give the client tools to help them keep track of medicines.
- ✔ Encourage the client to talk to their doctor if they experience side effects or are having difficulty taking medicine as prescribed.



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#### Key Points to



Medications used to treat lupus range in strength from mild to extremely strong. Often, several drugs are used in combination to control the disease. However, all medications have side effects that require monitoring.

It can be difficult to remember all side effects and questions. Having a CHR or family member attend appointments can be helpful.

An effective way to keep track of a complex disease like lupus is with a daily medical diary or journal. This can be kept by you, or by a trusted family member or friend who can go with you to your doctor's appointments. Details about medications, such as dosage and possible side effects, can be recorded, as well as questions to ask at your next appointment.

#### Key Actions to



Display slide – Help a lupus client take medicine

Provide links to ACR The Lupus Initiative website:  
[www.thelupusinitiative.org/selfcare](http://www.thelupusinitiative.org/selfcare)



## Activity 2.8: (Group)

### Motivating People in Your Community



As we discussed, lupus is a difficult disease to diagnose. For this reason, it is essential that patients are open and honest about their symptoms.

You can motivate people in your community to understand lupus and seek a prompt diagnosis if they experience lupus signs or symptoms. If you talk to your family, friends and neighbors about lupus, you can spread accurate information and raise awareness about lupus. In turn, increased lupus awareness may lead to more people being accurately diagnosed more quickly. Once a person is diagnosed with lupus, it is important for him/her to take their medications and continue seeing his/her medical providers. We will discuss how you can support your clients with lupus later in the training.

Let's do a quick activity on the myths and facts about lupus.



*Read each statement aloud. Ask participants to raise their hand if they think the statement is a myth. Next, ask participants to raise their hand if they think the statement is a fact. You can write the number of people giving each response on the easel pad sheet if you like. Then, provide the correct answer. Repeat for each of the statements on the easel pad sheet.*

- ✓ *You can get lupus from shaking someone's hand. – MYTH*
- ✓ *If a person no longer feels sick, or if his/her symptoms seem to go away, it is OK to stop taking the medicine prescribed by his/her medical provider. – MYTH*
- ✓ *Lupus cannot be sexually transmitted. – FACT*
- ✓ *Lupus is related to HIV/AIDS. – MYTH*
- ✓ *There is no cure for lupus. – FACT*
- ✓ *Lupus only affects the joints. – MYTH*
- ✓ *Men do not get lupus. – MYTH*
- ✓ *Lupus can cause inflammation. – FACT*
- ✓ *Women who have lupus can still have healthy pregnancies. – FACT*
- ✓ *It is OK to follow information you find on the internet without talking to your healthcare providers first. – MYTH*

*Thank participants for their participation.*



## Activity 2.9:

### Increase Awareness About Lupus in Your Community

#### Increase awareness about lupus in your community

- Share lupus information with community centers, health ministries, and the local media.
- Reach out to your state health department, social service agencies, and hospitals to request evidence based lupus information.
- Share information from trustworthy sites that use scientific information such as lupus.org and cdc.gov
- Participate in health fairs.
- Invite an expert rheumatologist to your community organization to speak about lupus.
- Creating a list of services and resources in your community to give to clients.
- Refer clients to appropriate health care services.
- Use social media platforms such as Facebook, Instagram, Twitter, and Snapchat.



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#### Key Points to



- › Provide community members with resources on lupus.
- › Be available to answer questions.
- › Encourage community members to discuss their fears, so you can dispel myths and rumors with facts.

I want to remind you to be sure to share scientific facts when conducting outreach. As we learned in our “myth and fact” activity, there are many misperceptions about lupus and a great deal of anecdotal information about how to treat the disease. Be cautious when sharing information with your clients.

#### Key Actions to



Display slide – Increase Awareness About Lupus in Your Community

Ask about other ways the participants could share information on lupus with their communities.



## Activity 2.10:

### Resources and Information

#### Resources and Information



Ongoing care for people with lupus is a team effort, and each member of the team has a role to play.

We appreciate your time and the work you do in your community.

For more information on lupus including presentations, videos, self-management resources and other trainings visit The Lupus Initiative at <http://thelupusinitiative.org/>

We appreciate your participation in a post assessment and a four-to six-week follow-up assessment.



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#### Key Points to



- › Provide community members with resources on lupus.
- › Be available to answer questions.
- › Encourage community members to discuss their fears, so you can dispel myths and rumors with facts.

#### Key Actions to



Display slide – Resources and Information

Distribute Handout 2.2

**Handout 2.2 How to Evaluate Online Information**

When evaluating the quality of online information, consider the following:

**1. What is the source?**  
Overall, websites from government agencies, professional organizations, universities, hospitals, and academic journals contain information based on research. Examples include:

- › The American College of Rheumatology ([www.rheumatology.org](http://www.rheumatology.org))
- › The Lupus Initiative ([www.thelupusinitiative.org](http://www.thelupusinitiative.org))
- › The Centers for Disease Control and Prevention ([www.cdc.gov/lupus](http://www.cdc.gov/lupus))

**2. Who is the author?**  
The source should be written by someone with credentials, such as professional experience or a degree appropriate to the topic. For example, if you want to direct patients to additional information about how to manage a lupus flare, an appropriate author may be a rheumatologist. (Note: Websites for professional organizations, such as the American College of Rheumatology, usually do not list specific authors, but the information is vetted and reviewed by the organization.)

**3. Is the source current?**  
Scientific information, including medical information, may change as new research is published. Ensure that you have the latest available information. Websites sometimes have a copyright date or a "last updated" or "last modified" date. These dates are often located at the bottom of the home page.

**4. Does the source contain citations?**  
In general, sources with citations suggest that the information is based on research. A citation in text can be in parentheses (Fairweather and Ross, 2004) or superscripted number<sup>1</sup> and a corresponding full citation at the bottom of the page or the end of the document.

<sup>1</sup>Fairweather, D. and Ross, N.R. (2004). Women and Autoimmune Diseases. Emerging Infectious Diseases, 10(11).

Continued on next page →

ILLUMINATING LUPUS: Facilitator's Guide | All Community Health Representatives Working with Research and Education on Lupus

<https://thelupusinitiative.org> | American College of Rheumatology | The Lupus Initiative





## Activity 2.11:

### Conclusion



Before we end the program, let's share some of the key takeaway lessons we learned from the *ILLuminating Lupus* training program. These key takeaways lessons could be information that you did not know before completing the program, a resource that you think will be useful during outreach or a favorite handout that you plan on sharing with your community.



*Ask all participants to share one takeaway lesson from the ILLuminating Lupus program.*



These are all great lessons. Thank you for sharing!



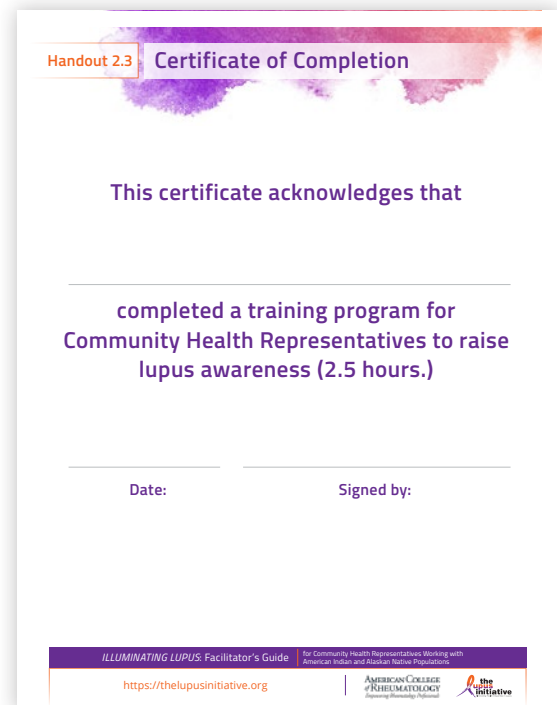
*Disseminate the post-test Assessments. Allow 10 minutes for the post-test to be completed and collect assessments.*



Thank you for participating in the *ILLuminating Lupus* training program. I hope you learned a lot and enjoyed your time. I look forward to seeing how you raise lupus awareness and the unique ways you share the hashtag #FightLupus. I am pleased to present each of you with a certificate showing that you have completed the *ILLuminating Lupus* program.



*One at a time, call each CHR to the front of the room and present him/her with a certificate of completion. Lead a round of applause for each participant. Thank participants again and dismiss the group.*



# HANDOUTS & MATERIALS

Handout 1.1 Lupus Signs and Symptoms

Handout 1.2 Facts on Lupus

Handout 1.3 Lupus Symptoms Role Play

Handout 2.1 Managing Lupus through Lifestyle Changes

Handout 2.2 How to Evaluate Online Information

Handout 2.3 Certificate of Completion

Did you know card 1.1

Did you know card 1.2

Did you know card 1.3

Easel Pad 1.1 Our Guidelines for Learning Together

Easel Pad 2.1 Is it a Myth or a Fact?

Index Card Activity Raising Lupus Awareness Role Play



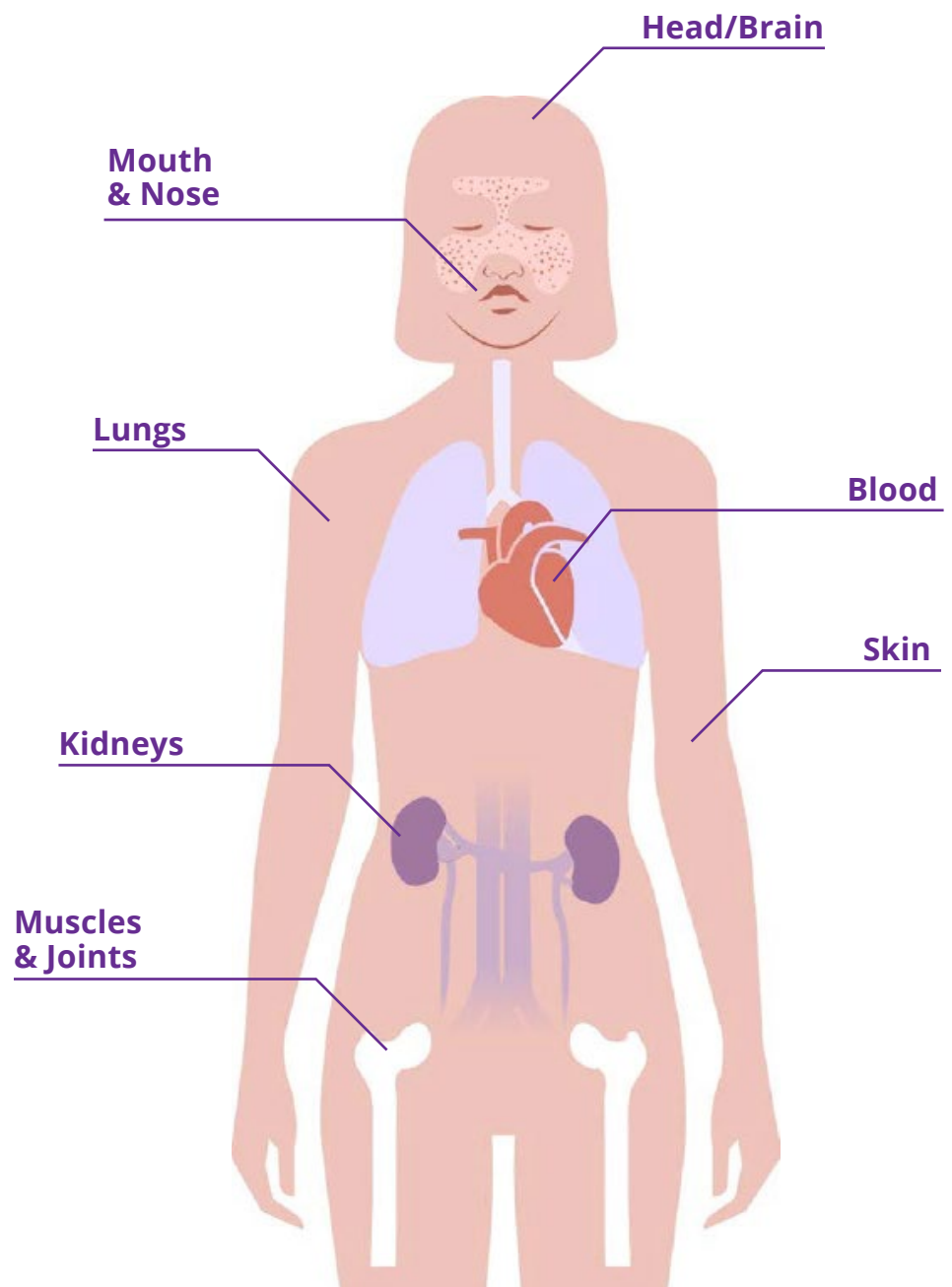
## Handout 1.1

# Lupus Signs and Symptoms

**Instructions:** Match the sign(s) and/or symptom(s) that affects the body parts indicated on the diagram.

### List of signs and symptoms:

- a. Swelling and joint pain
- b. Muscle aches
- c. Butterfly rash and other types of rashes
- d. Sores that may or may not be painful
- e. Low count of blood cells: red blood cells, white blood cells, and platelets.
- f. Hair loss
- g. Confusion, seizures and dizziness
- h. Headaches
- i. Chest pain when taking a deep breath
- j. Blood in the urine



Answers on next page

## Answer Key:

### Skin

c. Butterfly rash and other types of rashes

### Muscles & Joints

b. Muscle aches

a. Swelling and joint pain

### Kidneys

j. Blood in urine

### Head/Brain

f. Hair loss

h. headaches

g. Confusion, seizures and dizziness

### Mouth and nose

d. Sores

### Lungs

i. Chest pain when taking a deep breath

### Blood

e. low count of blood cells: red blood cells,  
white blood cells and platelets

## 1 Who is at Risk for Lupus?

- Anyone can get lupus, regardless of age, gender, race or ethnicity.
- But lupus is most likely in women between the ages of 15 and 44.
- Compared to men, women are nine times more likely to have lupus.
- Lupus is also more common among women of ethnic and racial minority women, including American Indians/Alaskan Natives, African Americans, Latinas and Asians

## 3 Consequences of Lupus

People living with lupus may experience inflammation in the:

- Nervous system and brain, causing memory problems, confusion, headaches, and strokes, high fevers, seizures and behavioral changes.
- Kidneys, which may affect the body's ability to filter waste from the blood.
- Lungs, causing pleurisy, coughing and chest pain while breathing deeply.
- Heart and circulatory system.
- Skin, causing rashes such as the butterfly rash across the nose and cheeks.

## 2 Flares and Remission

- The signs and symptoms of lupus vary widely among people living with lupus and may come and go during flares and remission.
- A flare is a time when a person with lupus is having an autoimmune attack and experiences active signs and symptoms.
- Remission is when there is little or no disease activity. A person may not experience any symptoms while in remission or may experience fewer.
- It is still important for people to take their medications as prescribed by their medical providers even if they feel better and are experiencing fewer or no symptoms.

## 4 What Causes Lupus?

- Researchers are still unsure about the specific causes of lupus.
- Although more research is needed, lupus may be triggered by things in the environment and genetics. These include viruses, sunlight and drug allergies. Lupus is not contagious from one person to another.
- Lupus is not related HIV/AIDS.



# Lupus Symptoms Role Play

Distribute copies of the role-playing exercise to four volunteers who will play these roles: Elizabeth, Turner (husband to Elizabeth), Amanda (CHR/neighbor), and Doctor.

### Scene #1: In the dining room of the house

**Turner:** What is wrong Elizabeth? You don't look very well.

**Elizabeth:** Actually, I just don't feel well... my muscles hurt and so does my head. Today, I made it to work but I was dragging and couldn't concentrate. I just came home afterwards, I didn't end up running the errands I needed to do or make dinner. I don't understand what is happening to me. (Elizabeth is very sad.)

**Turner:** Yes, I can see it, you look pale and without energy. Why don't we call our neighbor, Amanda? She is a Community Health Representative, maybe she will know what to do or what is it that you have.

### Scene #2: In the dining room of the house

**Amanda:** Tell me Elizabeth, what is wrong, how do you feel? Turner told me that you are not well.

**Elizabeth:** Everything hurts. Last week I checked my blood pressure and it was high and I feel very tired. I have also noticed that my hair is falling off. I notice it when I brush my hair.

**Amanda:** Looks like you might have a fever. (Amanda is touching Elizabeth's forehead.) How long have you been like this?

**Elizabeth:** Since a few days ago, maybe it's the flu. But it happened a few months ago too, just like this.

**Amanda:** You must go see your doctor about this. Come on, I will go with you.

**Elizabeth:** Oh, I just feel terrible, yes, I will go to the doctor, thanks Amanda, you are a good friend.

### Scene# 3: At the Doctor's office

**Amanda:** Hello Doctor, I brought my friend Elizabeth, she is not feeling well.

**Doctor:** Tell me Elizabeth, what is going on?

**Elizabeth:** My whole body hurts, oh my what a pain! Please, Amanda, tell the Doctor.

**Amanda:** Elizabeth has not been feeling well for a few days now, she feels very bad and her face is all reddish.

**Doctor:** We will run some tests.

Continued on next page ➡

## One week later: Amanda and Elizabeth return to the doctor's office

**Doctor:** Elizabeth, according to the test results it seems that you have lupus.

**Elizabeth:** Lupus, what is that?

**Doctor:** Everyone has an immune system that protects us from the common cold, the flu, bacteria and viruses that surround us trying to make us sick. In people with lupus something goes wrong, we are not sure how it happens. But, this immune system, instead of attacking everything it is supposed to be attacking, this system starts to attack the lupus patient's own body. This means that they start to have inflammation in parts of their body like their skin, their lungs and their kidneys.

**Elizabeth:** What does that mean for me?

**Doctor:** So, in you, that redness of the skin you had, that rash, that was from your lupus attacking your skin. The joint pain and swelling, that is from the lupus affecting your joints. The changes that we see on your urine and blood tests, that is from the lupus affecting your kidneys. I'm going to run more tests and have you see a few other doctors, but I'm also going to give you some more information about your lupus. It'll describe the disease a little more and help you and your family understand why you are feeling the way you are.

**Elizabeth:** Do you have any information that I can take home with me?

**Doctor:** I am going to give you a flyer with more information, and I am also going to send you for more exams. It's a good thing that you came to see me, because there are a lot of people who suffer from this disease and they don't know how serious it is when they are not under a doctor's care.

**Elizabeth:** Thank you, doctor.

## Handout 2.1

# Managing Lupus through Lifestyle Changes



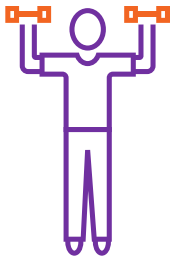
Visit your medical providers as needed. Be open and honest with your providers about your symptoms and ask any questions that you may think of between appointments

Take medications as prescribed and make sure you talk with your doctor about possible side effects and how the medicines affect you



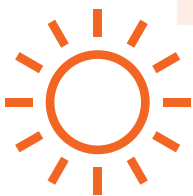
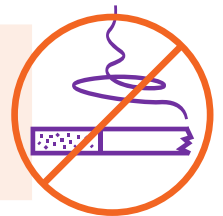
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When evaluating the quality of online information, consider the following:

## 1. What is the source?

Overall, websites from government agencies, professional organizations, universities, hospitals, and academic journals contain information based on research. Examples include:

- › The American College of Rheumatology ([www.rheumatology.org](http://www.rheumatology.org))
- › The Lupus Initiative ([www.thelupusinitiative.org](http://www.thelupusinitiative.org))
- › The Centers for Disease Control and Prevention ([www.cdc.gov/lupus](http://www.cdc.gov/lupus))

## 2. Who is the author?

The source should be written by someone with credentials, such as professional experience or a degree appropriate to the topic. For example, if you want to direct patients to additional information about how to manage a lupus flare, an appropriate author may be a rheumatologist. (Note: Websites for professional organizations, such as the American College of Rheumatology, usually do not list specific authors, but the information is vetted and reviewed by the organization.)

## 3. Is the source current?

Scientific information, including medical information, may change as new research is published. Ensure that you have the latest available information. Websites sometimes have a copyright date or a “last updated” or “last modified” date. These dates are often located at the bottom of the home page.

## 4. Does the source contain citations?

In general, sources with citations suggest that the information is based on research. A citation in text can be in parentheses (Fairweather and Rose, 2004) or superscripted number<sup>1</sup> and a corresponding full citation at the bottom of the page or the end of the document.

<sup>1</sup>Fairweather, D. and Rose, N.R. (2004). Women and Autoimmune Diseases. *Emerging Infectious Diseases*, 10(11).

Continued on next page ➤

## 5. Is the source objective?

Sources that are emotionally or financially connected to the subject may not be reliable. For example, a patients' blog devoted to how to manage lupus symptoms will feature personal experiences rather than reliable, current information based on research. Such "anecdotal" information may not apply to most people, so should be shared with great caution.

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### Keep in mind

Sometimes it is difficult to distinguish between reliable (based on science) and unreliable (not based on science) sources. Unreliable sources frequently:

- Argue that there is a conspiracy in the scientific community to silence views that contradict established knowledge
- Rely on fake experts who do not have a credible track record
- Present only information that supports their opinion, not multiple viewpoints

## Certificate of Completion

This certificate acknowledges that

---

completed a training program for  
Community Health Representatives to raise  
lupus awareness (2.5 hours.)

---

Date:

Signed by:



## Did you know card 1.1

There are about  
**50 million**  
Americans with an  
**autoimmune  
disease.**



**75%**  
of them are  
**women.**

\*Facilitator should transcribe the text onto a larger sheet of paper.

*ILLUMINATING LUPUS: Facilitator's Guide*

for Community Health Representatives Working with  
American Indian and Alaskan Native Populations

[lupusinitiative.org](http://lupusinitiative.org)

AMERICAN COLLEGE  
of RHEUMATOLOGY  
*Empowering Rheumatology Professionals*

 **the  
lupus  
initiative**  
Eliminating Health Disparities in Lupus

Did you know card 1.2

Lupus is  
**10x**  
more likely to affect  
**AI/AN**  
**persons**  
than Caucasians.



\*Facilitator should transcribe the text onto a larger sheet of paper.

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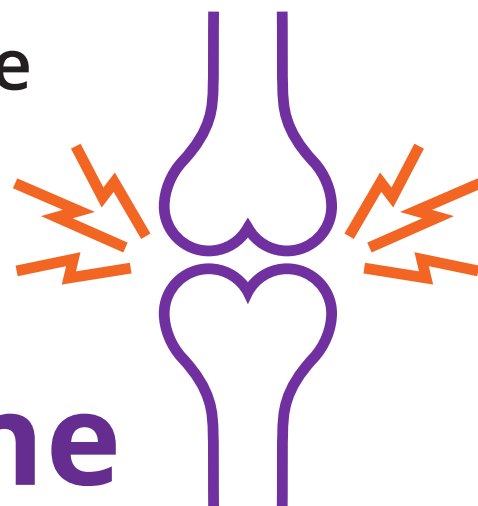


# Rheumatologists

are doctors who specialize  
in disorders in the

**joints, bones**

and **autoimmune  
diseases.**



\*Facilitator should transcribe the text onto a larger sheet of paper.

# Our Guidelines for Learning Together



Arrive on time



Silence your phones



Participate actively



Ask questions



Listen respectfully to other participants



Keep the information shared in the session confidential







Take breaks when you need them

# Have fun!

\*Facilitator should transcribe the text onto a larger sheet of paper.



## Is It a Myth or a Fact?

		MYTH	FACT
	You can get lupus from shaking someone's hand.	<input type="checkbox"/>	<input type="checkbox"/>
	If a person no longer feels sick or if his/her symptoms seem to go away it is ok to stop taking the medicine prescribed by his/her medical provider.	<input type="checkbox"/>	<input type="checkbox"/>
	Lupus cannot be sexually transmitted.	<input type="checkbox"/>	<input type="checkbox"/>
	Lupus is related to HIV/AIDS.	<input type="checkbox"/>	<input type="checkbox"/>
	There is no cure for lupus.	<input type="checkbox"/>	<input type="checkbox"/>
	Lupus only affects the joints.	<input type="checkbox"/>	<input type="checkbox"/>
	Men do not get lupus.	<input type="checkbox"/>	<input type="checkbox"/>
	Lupus can cause inflammation.	<input type="checkbox"/>	<input type="checkbox"/>
	Women with lupus cannot get pregnant.	<input type="checkbox"/>	<input type="checkbox"/>
	There is a lot of information on the internet about how to cure lupus. It is OK to follow that information without talking to your healthcare providers first.	<input type="checkbox"/>	<input type="checkbox"/>

\*Facilitator should transcribe the text onto a larger sheet of paper.

# Raising Lupus Awareness Role Play

Split the CHRs into five groups and give each group a copy of this script. Each group should prepare a role play showing the scenario and how it unfolds.

## Scenario 1: Home Visit

**Characters:** Aiyana (lady of the house), Kaya and Nita (friends), and Esther (CHR)

Aiyana is home and is surprised by the visit from her two good friends, Kaya and Nita, who stopped by for a cup of coffee. Aiyana is getting ready for a visit from a person who is scheduled to come for a home visit from the local Health Center. Aiyana is not sure why the person is coming or for what, but she got a call from the Health Center asking her if it was OK to visit her and she had said yes.

**Scene: In the living room – three friends having coffee and chatting**

Esther is a CHR at the local Health Center. She is an Educator about chronic diseases such as lupus. Esther arrives at Aiyana's house to inform/educate about lupus and its common signs and symptoms.

## Scenario 2: Health Fair Part 1

**Characters:** Margaret and Oneida (CHRs) Ana (visitor to health fair)

Margaret and Oneida are CHRs at the Community Clinic and they are participating in a health fair to motivate, inform and educate about lupus.

**Scene: CHRs at a Health Fair**

Ana visits the health fair to learn about resources in the community. Ana is a very healthy young woman, and she loves to take walks and learn about programs and resources in her community. Ana stops by the lupus table at the fair.

## Scenario 3: Health Fair Part 2

**Characters:** Margaret and Oneida (CHRs) Martha (visitor to health fair)

Margaret and Oneida are CHRs at the Community Clinic, and they are participating in a health fair to motivate, inform and educate about Lupus.

**Scene: CHRs at a Health Fair**

Martha has not been feeling well for the last few months. Most of the time she doesn't even go out of the house because she has constant and intense headaches. Today, she felt better and decided to go out and visit a local health fair. Martha stops by the lupus table at the fair.