

UNDERSTANDING LUPUS

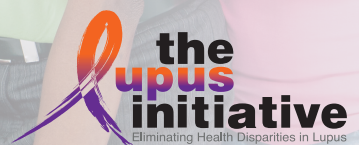
A Promotor(a) de Salud Training Program



Facilitator's
Guide



AMERICAN COLLEGE
OF RHEUMATOLOGY
EDUCATION • TREATMENT • RESEARCH



ACKNOWLEDGEMENTS

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Latinos is used throughout this guide to represent the Latinx community

American College of Rheumatology's Understanding Lupus curriculum was supported by the Grant or Cooperative Agreement Number, 6 NU58 DP006138, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

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Introduction

Welcome to *Understanding Lupus*, a training program to educate promotores about lupus, an autoimmune disease. The program aims to increase promotores' understanding of the signs and symptoms of lupus so that they can effectively raise lupus awareness in their communities.

The need for promotores to understand lupus is great because Latinas are at higher risk of getting lupus and tend to have more serious complications from lupus than White women.

Here are a few other key points about lupus:

- › Lupus is a chronic, autoimmune disease that can cause inflammation in almost every organ, caused by the autoimmune system attacking its own cells and tissues.
- › Lupus is more common in women than in men.
- › Women are often diagnosed between ages 15 and 44.
- › Although there is no cure for lupus, there are medications and lifestyle changes that can help people with lupus manage the disease so that they feel better.

Why Use Understanding Lupus?

Promotores work to educate and reduce health barriers for their communities. The *Understanding Lupus* program provides promotores with knowledge and skills to raise lupus awareness. While lupus is more common among Latinas than many other racial and ethnic groups, much of the Latino community may be unaware of lupus and its consequences. *Understanding Lupus* expands promotores' outreach skills to help them understand lupus signs and symptoms and raise lupus awareness.

After participating in the *Understanding Lupus* program, promotores will have the skills to:

- › Describe lupus signs and symptoms
- › Raise lupus awareness in their communities
- › Identify and help clients overcome barriers to diagnosis
- › Find medical providers who diagnose and treat lupus and help people living with lupus navigate the lupus care system

Who is Understanding Lupus for?

Understanding Lupus is designed to train experienced promotores de salud at Latino-serving community-based organizations. The program teaches groups of experienced promotores how to conduct lupus outreach and raise awareness.

A facilitator or promotores trainer should deliver the *Understanding Lupus* training in person to promotores. This program should not be used independently, as it is not a self-guided program. *Understanding Lupus* is a bilingual training program. All materials are available in English and Spanish. This program contains all the necessary instructions and materials needed for implementation.

How is the *Understanding Lupus* Training Implemented?

The *Understanding Lupus* training consists of a four-hour program, made up of two parts with a break in between. Each part of the training is a 2-hour session; we suggest that a break of 15 minutes occur in between Part One and Part Two. We recommend around 15 promotores participate in the training at a time. A small training class allows for promotores to ask questions and provides the opportunity for in-depth discussions.

About the Program

The *Understanding Lupus* program contains PowerPoint slides, handouts, and activities to engage the promotores. The program is designed to provide promotores with detailed knowledge on lupus, while providing them 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.

Program Documents

- › **Did You Know? Cards** engage participants with interesting facts. The cards should be read aloud and then displayed on the wall.
- › **Easel Pad Sheets** are useful for presenting information to the group and brainstorming ideas. You should write the prescribed text from the Facilitator's Guide on a blank easel pad for display.
- › **Handouts** may be fact sheets, role play scenarios, or activity worksheets. Distribute handouts to participants during the program as indicated by the Facilitator's Guide.
- › **PowerPoint Slides** display information and illustrations for all participants to see. The PowerPoint slides can be used in rooms with computers and projectors. If you don't have that technology, print copies of the slides for each participant.

Program Materials

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

- › 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 can use pens and markers to take notes and write on the easel pad sheets during the program.
- › Thick paper or card stock: Ask participants to make name plates when they arrive at the program.
- › 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.
- › Small, lightweight beach ball to complete group activity in Part One.



Understanding Lupus

Part One

In Part One of the program, promotores will learn about lupus signs and symptoms, Latinas' increased risk of lupus, and why raising lupus awareness is important in their community.

Learning Objectives

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

- ✓ Define and explain lupus to their clients
- ✓ Describe the common signs and symptoms of lupus
- ✓ Understand that Latinas are at higher risk of lupus than other racial and ethnic groups
- ✓ Explain how medical providers diagnose lupus

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

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
- ✓ Beach ball
- ✓ Transparent adhesive tape
- ✓ Refreshments (snack and/or beverage) for break (if possible)
- ✓ Music to play during break (if possible)

Teaching Materials

- ✓ 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)

Understanding Lupus

Part Two

In Part Two of the program, promotores will learn and discuss ways to raise awareness in their communities. To conclude, promotores will review all of the information that was taught throughout the program.

Learning Objectives

After completing *Understanding Lupus* Part Two, participants will be able to:

- ✓ Recognize the importance of raising awareness about lupus
- ✓ Develop strategies for raising lupus awareness
- ✓ Identify lupus resources online and in the community

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

Support Materials

- ✓ Pens and colored markers
- ✓ Easel pad sheets
- ✓ Transparent adhesive tape
- ✓ Small prizes for the loteria game, if possible

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 – Raising Lupus Awareness Role Play (make four copies)
- ✓ Handout 2.2 – How to Evaluate Online Information (make one copy for each participant)
- ✓ Handout 2.3 – Managing Lupus through Lifestyle Changes (make one copy for each participant)
- ✓ Handout 2.4 – Expanding your Network (make one copy for each participant)
- ✓ Handout 2.5 – Lupus Lotería (make one copy for each participant)
- ✓ Handout 2.6 – Certificates (make one copy for each participant)

Welcome and Introductions



20 MINUTES

Welcome

Say Hi, my name is _____. Welcome to the Understanding Lupus training program.

- Do** Give background information on yourself.
- › Your role in the community
 - › Why you became a promotor(a)/How long you've been a promotor(a)
 - › Why you are interested in educating promotores about lupus and raising lupus awareness

Say Over the next four hours we will learn about lupus and how to raise awareness about this disease that affects many Latinas. This training program will consist of two parts that will last two hours each. Between the part one and part two of the program we will take a 15-minute break. What comes to mind when you hear "lupus"?

Do Allow two or three participants to respond.

Say Lupus is an autoimmune disease that can affect anyone. However, Latinos and people of color are more at risk to develop lupus than Whites. Lupus also tends to affect Latinos and people of color more severely. Latinos and people of color with lupus are more likely to have worse health outcomes than Whites with lupus. The goal of *Understanding Lupus* is to provide you with knowledge and skills to help raise awareness in the Latino community. It is important to raise awareness around autoimmune diseases, especially lupus, because it is a disease that affects Latinos. Yet, many Latinos do not know the signs and symptoms or how lupus affects the body.

Introductions

Say First, let's take a moment to get to know each other.

Do Complete the Introduction Icebreaker Activity.

Hold a small beach ball and explain to promotores that you will gently toss the ball to a participant. The participant will 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, smart Sonia, generous Guadalupe. Then, the participant will gently toss the ball to another participant and that participant will do the same. The activity will continue until everyone has a chance to introduce themselves.

Thank everyone for their participation.

Distribute a sheet of thick paper to each participant. Ask participants to fold the card in half to make a name plate, write their name, and place it in front of them.

Why is it Important to Raise Lupus Awareness?



2-5 MINUTES



Say 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.



Do *Hang up blank easel pad sheets in four different areas of the room. Each sheet should have a number one through four. Assign participants to one of four groups and tell them to stand near the easel pad sheet with their group's number on it.*



Say In your assigned groups, make a list of why you think it's important to raise awareness around lupus.



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



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



Do *Ask one person from each group 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 of disability that may accompany lupus*



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

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!

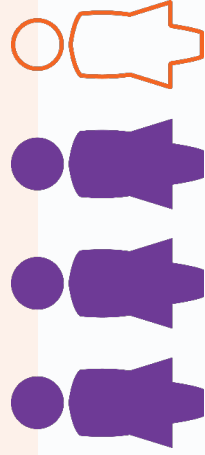
*Facilitator should transcribe the text onto a larger sheet of paper.

UNDERSTANDING LUPUS: A promotor/a de salud training program

PowerPoint Slide 1.3: Why is Lupus a Concern for Latinas?

Why is Lupus of Concern for Latinas?

Compared to White women, Latinas are two to three times more likely to have lupus



Latinas are more likely to experience kidney complications, particularly during pregnancy, compared to White women

Latinas tend to develop lupus earlier in life and have more severe disease at time of diagnosis

Latinas face socioeconomic, linguistic, and cultural barriers to health care



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Lupusinitiative.org/promotores

#PromotoresFightLupus

