LUPUS
RESEARCH
ALLIANCE

What you need to know about LUPUS

Dear Community Educator,

As you may know only too well, lupus is under-recognized, under-diagnosed and under-researched. As a result, many people may learn they have this challenging autoimmune disease after months or even years of frustrating doctors' visits and when their prognosis is not as positive as it would have been with early diagnosis. Which makes education about lupus vitally important. And which makes your leadership in offering a presentation about lupus a true service to your community that you can be proud of. Thank you for taking this initiative!

The Lupus Research Alliance, in collaboration with the National Minority Quality Forum, created this *What You Need to Know About Lupus* program to provide all the tools needed to give an informative presentation in your community that educates attendees about what lupus is, what symptoms to look for and what to do if lupus is suspected.

Components of the Toolkit

The materials provided in this toolkit are designed to help you educate attendees to recognize the signs and symptoms of lupus, connect with the right health care providers, and support people with lupus and/or those who care about them. The presentation also provides a call to action for those interested in getting involved in lupus advocacy or for people with lupus interested in participating in a clinical trial. As a presenter, you are the facilitator in achieving these goals, and you might be the reason why even one person in the audience gets the care they need.

This toolkit provides the following materials to help you get started:

- Slides with notes to refer to in giving the presentation
- Promotional flyer to drive attendance
- Tips for conducting successful presentations
- Handout on lupus for attendees

As a member of our global lupus community as well as your own – whether it's your town, school, library, hospital, workplace or place of worship - you are in the best position to help people learn about lupus and receive the right care. If you have any questions, feel free to contact us at advocacy@lupusresearch.org. Thank you for your commitment and please let us know if there is anything we can do to help!

Sincerely,

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What you need to know about LUPUS

PRESENTER GUIDE

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What you need to know about LUPUS

Overview

What is this initiative?

The *What You Need to Know About Lupus* initiative was created to provide resources for people to educate their community about lupus. The toolkit includes all you need to educate and empower people with lupus, people who suspect they may have lupus, and people who may be at high risk for being diagnosed with lupus.

Why is this initiative important for underserved communities?

Approximately 161,000 to 322,000 adults in the U.S. are living with this complex autoimmune disease. People who are Black or African American, and of Asian, Hispanic, and Native American descent are at high risk of being diagnosed with lupus, particularly women.

Being aware of the signs and symptoms of lupus and knowing what to do if you suspect you or someone you know may have lupus, is the first step to getting diagnosed and treated. If you have symptoms, it is important to seek treatment to slow disease progression and minimize potential damage.

Why is this initiative important for women?

- Women make up nine out of ten adults with the disease
- Women's expressions of concern about their health are often dismissed
- Women of color are underrepresented in clinical research

Who developed this initiative and why?

The Lupus Research Alliance developed this initiative to provide tools and resources for anyone interested in educating their community about lupus. The National Minority Quality Forum reviewed and provided input to the materials.

Finding accurate and reliable information in an easy to use and share format can be daunting. This toolkit provides all the resources you need to lead education sessions.

What are the benefits of presenting this initiative in my community?

- Supporting individuals to know the signs of lupus and to seek care for themselves or a loved one
- Making an impact within your community
- Becoming a leader in building awareness about lupus
- Developing ties to the lupus community

What is the Lupus Research Alliance?

The Lupus Research Alliance is the largest nongovernmental, nonprofit funder of lupus research worldwide. The organization aims to transform treatment while advancing toward a cure by funding the most innovative lupus research; fostering diverse scientific talent; stimulating collaborations; and driving discovery toward better diagnostics, improved treatments and, ultimately, a cure for lupus. Because the Lupus Research Alliance Board of Directors funds all administrative and fundraising costs, 100% of all donations goes to support lupus research programs. To learn more, visit LupusResearch.org.

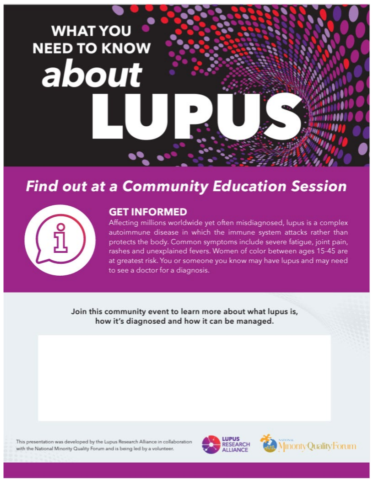
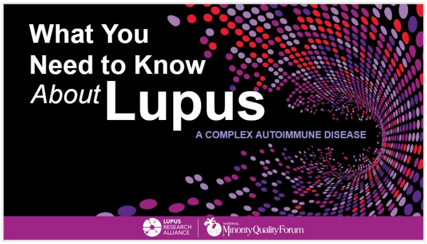
What is the National Minority Quality Forum?

The National Minority Quality Forum is a research and educational organization dedicated to ensuring that high-risk racial and ethnic populations and communities receive optimal health care. This nonprofit, nonpartisan organization integrates data and expertise in support of initiatives to eliminate health disparities. To learn more, visit NMQF.org.

What if I have other questions?

If you have any questions, feel free to contact the Lupus Research Alliance by emailing advocacy@lupusresearch.org or calling us at (646)-884-6000. Make sure to say you are reaching out about the *What You Need to Know About Lupus* program.

Materials Included and How to Use

Material	Description	How to Use It
Presentation Invitation/ Flyer  WHAT YOU NEED TO KNOW *about* LUPUS *Find out at a Community Education Session* GET INFORMED Affecting millions worldwide yet often misdiagnosed, lupus is a complex autoimmune disease in which the immune system attacks rather than protects the body. Common symptoms include severe fatigue, joint pain, rashes and unexplained fevers. Women of color between ages 15-45 are at greatest risk. You or someone you know may have lupus and may need to see a doctor for a diagnosis. Join this community event to learn more about what lupus is, how it's diagnosed and how it can be managed. This presentation was developed by the Lupus Research Alliance in collaboration with the National Minority Quality Forum and is being led by a volunteer. LUPUS RESEARCH ALLIANCE NATIONAL Minority Quality Forum	Use this invitation/flyer to promote your event. Fill out the session details on the flyer and distribute it to the audience you would like to attend.	Print it and post on bulletin boards or distribute in your community. Email it to a mailing list. For example, if presenting at your church or library, ask if it can be emailed to members. Post it on social media. For example, if presenting for your sorority chapter, share it on their social media page.
What You Need to Know About Lupus **Slide Presentation**  What You Need to Know *About* Lupus A COMPLEX AUTOIMMUNE DISEASE LUPUS RESEARCH ALLIANCE NATIONAL Minority Quality Forum	This is the main material you will use to present information on lupus. It is a PDF file that includes speaker notes. Topics covered include basic facts on lupus – what it is, who is at highest risk for developing lupus, types of lupus, how it is diagnosed and treated, how to get involved in spreading lupus awareness, and why participating in lupus research is so important.	This is the file that should be presented. Speaker notes are provided in the presentation. A separate version with each slide and corresponding speaker notes on one page is provided for you to use while presenting.

Presentation with Speaker Notes  What You Need to Know About Lupus A COMPLEX AUTOIMMUNE DISEASE LUPUS RESEARCH ALLIANCE Minority Quality Forum *Take a minute to introduce yourself and why lupus awareness is important to you* My name is ________ and I am a volunteer for the Lupus Research Alliance. It is important to me to spread awareness about lupus because ____________ *Note: This slide deck is part of an education program. If you have obtained a copy of this slide deck and are interested in learning more, please contact Advocacy@lupusresearch.org and ask about the Community Education Toolkit.*	This is the same slide deck with the slide and notes on one page.	A printable version of the presentation to easily view the slides and the corresponding speaker notes to refer to while presenting. This version is not intended to be shared with the audience.
***What You Need to Know About Lupus* Fact Sheet**  LUPUS RESEARCH ALLIANCE What you need to know about LUPUS **Lupus is a chronic disease of the immune system.** Lupus is a chronic and complex autoimmune disease that may cause widespread inflammation and tissue damage, especially in the brain, lungs, heart, and kidneys. The cause of lupus is unknown, but genetics, environment and hormones are believed to play a role. Lupus is not contagious. **Lupus can be misdiagnosed.** Other conditions that may look like lupus include infections, cancers, or inflammatory diseases. There is no single test to diagnose lupus. Diagnosis is confirmed by a combination of physical exams, lab tests, and medical history. **Symptoms of lupus vary.** Symptoms vary, but the most common symptoms of lupus include: *Fatigue* *Malar (Butterfly) Rash* *Joint Pain & Swelling* *Unexplained Fever* *Symptoms may:* • Be mild, moderate or severe • Persist or resolve • Come on suddenly or over time **Anyone can get lupus** However, some are at greater risk: Women between ages 15-44 Black/African American, Hispanic/Latino, Asian, or Native American individuals Family history of lupus or autoimmune disease **Two most common complications of lupus:** 1 Neuropsychiatric SLE (NPSLE) Describes feelings of depression, headaches, and lupus fog 2 Lupus Nephritis (LN) When the kidneys become affected by lupus, it is called lupus nephritis	Handout that reinforces information covered during the *What You Need to Know About Lupus* presentation.	When presenting in person, print copies and distribute to attendees as they leave the session. When presenting online, email to attendees.

Can I change any of the materials?

It is important that you use the materials as developed and not change or alter the look or content. The materials were designed and written by a group of medical and advocacy professionals with the community audience in mind. The facts about lupus are supported by medical literature. Your feedback is valuable to us so let us know if you have comments or suggestions.

What do I do after I finish a community awareness presentation?

Let us know that you presented the material. Email advocacy@lupusresearch.org and tell us about yourself, why you were interested in doing this, where you presented, and how it went. It is helpful for us to know how the materials are being used and how they are being received by the community to consider potential future revisions. We appreciate your dedication to presenting the materials and sharing your experience.

What if I need extra help to participate in the initiative?

We appreciate your desire to participate. This is a volunteer-based initiative—if you need extra help participating as an education leader, please email us at advocacy@lupusresearch.org and let us know.

Preparing for your Presentation: Tips for Successful Meeting Planning

1. Find a location

Now that you know all about this initiative and are ready to present, you may have ideas of groups that you belong to which may be interested such as a church health ministry, sorority or civic group chapter. Or you may want to reach out to the broader community.

Here are some ideas of places to reach out to:

- Local health department, hospitals, schools, and clinics
    - They can help identify existing programs, seminars, and workshops that educate community members on health issues. You may be able to work with these organizations to add this lupus awareness presentation to an existing seminar or class.
- Community centers and libraries
    - Look into arranging a presentation at community venues such as community centers, public libraries, and civic clubs. They may be willing to cosponsor and help you promote your educational session.
- Faith-based organizations
    - Many faith-based organizations have active health education programs. Reach out to leaders of your local churches, mosques, synagogues, and other places of religious worship to see if they would be able to cohost and/or help promote a community lupus awareness presentation.

2. Set the date and time

One you have the location secured, set a date and time. Check with the location to determine if there is an attendee limit. If space is limited, consider noting that in the meeting announcement and requesting an RSVP to reserve a spot.

3. Publicize the event to stimulate attendance

Ask the venue how they can help share an announcement. Fill in the presentation flyer with the relevant information and ask the venue to email it to their mailing list and/or post on a bulletin board.

Explore other opportunities to publicize the event such as in a community newsletter, local paper, radio, or local public TV station. Many media outlets will offer this service free for community programs.

4. **Arrange for equipment and materials needed**

When presenting in person

- Save the presentation on the computer you will be using or to a flash drive
- Check with the venue about what equipment they will provide. You will need:
    - A computer to run the slides
    - Projector and a blank wall or screen to show the presentation
    - Depending on the room size, you may need a microphone
- Print copies of the About Lupus fact sheet provided in the *What You Need to Know About Lupu'* toolkit to give attendees at the end of your presentation

When presenting online

- Make sure all attendees have the link to the platform you will be using such as Zoom, Microsoft Teams, or Google Meet
- Save the presentation on the computer you will be using
- Use a headset with a microphone to block out any background noise
- After the presentation, email the *What You Need to Know About Lupus* fact sheet to attendees and thank them for attending

5. **Have fun!**

Preparing for the Presentation: Tips for an Effective *What You Need to Know About Lupus* Presentation

If you are not used to doing presentations, here are a few tips to help you prepare.

- Familiarize yourself with the materials. Read through all the materials so you are familiar with the content and the intended use of each piece.
- The presentation speaker notes are your guide and are designed to be read throughout your presentation. Practice giving the presentation, so you feel comfortable with the material. You may also want to time yourself to make sure you can finish the presentation in the time available.
- If a participant asks a question, repeat the question and paraphrase if necessary to make sure you and the audience members heard it correctly. If you don’t know the answer to a question, offer to look it up later or direct them to resources for more information, such as the Lupus Research Alliance website (lupusresearch.org).

If you want more information on the presentation or about lupus, feel free to contact us at advocacy@lupusresearch.org. We are happy to do what we can to help you have a successful presentation! And don’t forget to email us to let us know how it went!

We thank the sponsors of the Lupus Research Alliance Multi-Cultural Outreach Task Force for their generous support

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