Dear Presenter,

*Are you ready to make an impact in your community?*

By taking part in the ‘Lupus: Get the Facts’ initiative, you can make a difference for those affected by lupus. You are also developing ties within the lupus community and establishing yourself as a leader in building awareness about lupus.

*What’s included in this toolkit?*

The materials provided in this toolkit are designed to help individuals recognize the signs and symptoms of lupus, encourage individuals to connect with health care providers who are knowledgeable about lupus, and support individuals to care for themselves or a loved one. Additionally, this toolkit provides a call to action for those interested in getting involved in lupus advocacy or for lupus patients interested in participating in a clinical trial. As a presenter, you are the driving force behind these aims and you may be the reason why someone seeks out the care they need.

*What is this packet for?*

This packet will provide information to help you get started with your community awareness presentations. It includes:

- A list of materials provided in this toolkit
- Tips for getting started and conducting successful presentations
- Frequently asked questions

If you have any questions, feel free to contact us at LRAadvocacy@lupusresearch.org. You are on the front lines educating communities about lupus and ensuring those impacted by lupus have the tools they need. You may be the reason someone seeks the care they need. Thank you for your commitment and let us know if there is anything we can do to help you!

Sincerely,

The Lupus Research Alliance
What is this initiative?
- Approximately 161,000 to 322,000 US. adults are living with lupus. The ‘Lupus: Get the Facts’ initiative, sponsored by Mallinckrodt Pharmaceuticals, was created to increase community awareness of lupus and provide resources for community members to learn more. This toolkit also aims to educate and empower those with lupus or those who suspect they may have lupus.

Why is this initiative important for underserved communities?
- African Americans, when compared to Caucasians are three times as likely to have lupus.
- Women of Asian, Hispanic, and Native American descent are more prone to lupus than Caucasian women.

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.

What materials are included for me to prepare for the ‘Lupus: Get the Facts’ presentations?
- Education Tools:
  - Presentation Invitation/Flyer
  - Presentation Pre-test
  - ‘Lupus: Get the Facts’ Presentation
  - Presentation Post-Test and Feedback Sheet
  - ‘Get the Facts on Lupus’ take home sheet
- Refer to List of Materials for more details on the use of each tool
- Visit lupusresearch.org for more information on lupus

Can I change any of the materials?
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. It is important that you use the materials as developed and not change or alter the look or content. Your feedback is valuable to us so if a piece is missing information, is not clear, or you feel it should be changed, let us know. We welcome all suggestions so we can improve the materials and program.

If specific changes are needed/suggested, please email: LRAadvocacy@lupusresearch.org
How do I obtain toolkit materials?
Using the electronic files provided, you may print out as many copies of the materials as necessary for your presentation. Please contact LRAadvocacy@lupusresearch.org if you need help determining how many copies of each material you should print for your ‘Lupus: Get the Facts’ presentation.

What do I do after I finish a community awareness presentation?
- Email LRAadvocacy@lupusresearch.org with the names and email addresses of any participants who signed up for the Lupus Research Alliance mailing list on the Feedback Sheet.
- Keep up the great work!

What are the benefits of presenting this initiative in my community?
- Supporting individuals to 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 if I have other questions?
If you have any questions, feel free to contact us by emailing LRAadvocacy@lupusresearch.org or calling us at (646)-884-6000.

What if I need extra help participating in the initiative?
We appreciate your participation and understand that things do arise that can make it difficult to participate. This is a volunteer-based initiative—if you need extra help participating as an education leader, please email us at LRAadvocacy@lupusresearch.org and let us know.
Below is a list of all the materials enclosed in this kit.

If you are missing any materials, send us an email at LRAadvocacy@lupusresearch.org.

<table>
<thead>
<tr>
<th>Material</th>
<th>Description</th>
<th>Screenshot</th>
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</thead>
<tbody>
<tr>
<td><strong>Presentation Invitation/Flyer</strong></td>
<td>Use this invitation/flyer to promote your event. Fill out the session details on the flyer and post on bulletin boards or distribute in your community.</td>
<td><img src="image" alt="Screenshot" /></td>
</tr>
<tr>
<td><strong>Presentation Pre-Test</strong></td>
<td>Use the pre-test handout to gauge attendee knowledge prior to the presentation. Before starting the presentation, distribute and ask participants to complete the pre-test. Collect the completed handouts and review your participants’ answers prior to your presentation. This may help you get a sense of your audience before you begin.</td>
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<tr>
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<tr>
<td>‘Lupus: Get the Facts’ Presentation</td>
<td>This is the main material you will use to present information on lupus. Speaker notes are provided in this document (pages 9-18), as well as in the presentation file itself.</td>
<td><img src="image" alt="Lupus: Get the Facts" /></td>
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<tr>
<td>Topics covered:</td>
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<tr>
<td>• Facts on Lupus</td>
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<td>o What is it?</td>
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<td>o Who gets it?</td>
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<td>o What you should know about it.</td>
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<td>• Getting involved in Lupus Research</td>
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<tr>
<td>Presentation Post-Test and Feedback Sheet</td>
<td>Double-sided handout with a post-test and a feedback form.</td>
<td><img src="image" alt="Post-Test and Feedback" /></td>
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<tr>
<td>After the presentation, distribute and ask participants to complete this handout. Collect the completed handout before participants leave. You can use this handout to evaluate the effectiveness of the presentation. Please send email information for any participants that signed-up for the Lupus Research Alliance mailing list to: <a href="mailto:LRAadvocacy@lupusresearch.org">LRAadvocacy@lupusresearch.org</a></td>
<td></td>
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<tr>
<td>‘Lupus: Get the Facts’ Fact Sheet</td>
<td>Handout that reinforces information covered during the ‘Lupus: Get the Facts’ presentation.</td>
<td><img src="image" alt="Fact Sheet" /></td>
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<tr>
<td>Distribute to participants as they leave the session.</td>
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Preparing for your Presentation
Tips and Tools for Successful Meeting Planning

- **Identification of Potential Opportunities for Community Lupus Awareness**
  - 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 the community lupus awareness presentation to a seminar or class.
  - Shopping malls and community centers
    - Look into the possibility of arranging a presentation at popular community venues, like shopping malls, 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.
  - **Set a date, time, and location for the event**
    - Check the location to determine if there is an attendee limit. If space is limited, consider noting that in the meeting announcement.
  - **Publicize the Event**
    - Look for opportunities to have the event publicized in a community newsletter, local paper, radio, or local public TV station. Many groups will offer this service free to community programs.
    - If you can obtain a mailing/email list from a host organization, consider sending one of the following:
      - Personal invitation from the host organization, you, or both of you
      - Announcement with flyer attached
    - Post the ‘Lupus: Get the Facts’ Invitation/Flyers included in this packet on bulletin boards that advertise upcoming events in your community (e.g., faith-based organizations, community centers, local health department, etc.)
• Arrange for equipment and materials needed beforehand:
  o ‘Lupus: Get the Facts’ Presentation (utilizing PowerPoint)
    • Check the presentation 3 weeks prior to the event. If there are any problems, you can contact us at LRAadvocacy@lupusresearch.org for troubleshooting.
    • Save the presentation on a computer desktop/hard drive.
    • You will need:
      o A computer to show the presentation
      o Projector and a blank wall or screen to show the presentation
  o Make sure you have an adequate number of supplies (print what you need):
    • Presentation Pre-Test
    • Presentation Post-Test and Feedback Sheet
    • ‘Get the Facts on Lupus’ take home sheet

• Determine if you will need a microphone. Consider room size, number of attendees, how your voice will carry. Make sure someone is available to help set up the equipment or check in advance so you are familiar with how the equipment works. Do your final checks before the presentation.
  o Make sure the room and equipment are set up to your needs.
  o Connect the computer, projector, and sound equipment. Set up the screen (if needed) before the participants begin to arrive.
  o Test the following:
    • All of the equipment is set up and functioning properly
    • All of the guests are able to see and hear the presentation
    • Table is set up for distribution of:
      o Presentation Pre-Test
      o Presentation Post-Test and Feedback Sheet
      o ‘Get the Facts on Lupus’ take home sheet
Preparing for the Presentation
Tips for an Effective ‘Lupus: Get the Facts’ Presentation

- Familiarize yourself with the materials. Read through all the materials so you are familiar with the content and the intended use of the piece.
- Review the content on lupus. The presentation speaker notes have additional facts and information for your reference throughout your presentation. These speaker notes may also be useful should the attendees ask questions. If the material is new to you, consider practicing giving the presentation. Consider practicing in front of a mirror or tape yourself on a hand-held device, computer, or use a video camera or tape recorder. Evaluate your facial expressions, gestures, stance, and/or how you sound. Practicing in front of family, friends, or colleagues will give you the opportunity to obtain feedback. You may also want to time a run-through of the presentation to see how close you are to the time available.
- Prepare and bring your notes to the presentation. Keep your notes organized by keeping each main topic on a separate page, have clear headings, and use different colors to highlight key points. You can also use the speaker notes on pages 9-18 of this presentation guide to help you during your presentation.
- 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).
- Know your audience. Utilize the ‘Lupus: Get the Facts’ Pre- and Post-Tests. The pre-test may help draw the audience’s attention to key portions of the presentation and encourages interaction. It will also allow you to gauge your audience and their level of knowledge.
- If you want more information on the presentation or lupus, feel free to contact us at LRAadvocacy@lupusresearch.org. Let us know how we can help you have a successful presentation!
<table>
<thead>
<tr>
<th>Slide #</th>
<th>Speaker Notes</th>
<th>Screenshot</th>
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<tbody>
<tr>
<td>1</td>
<td>N/A</td>
<td><img src="Lupus_Get_the_Facts_Slide1.png" alt="Image" /></td>
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<td>2</td>
<td>N/A</td>
<td><img src="Lupus_Get_the_Facts_Slide2.png" alt="Image" /></td>
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<td>N/A</td>
<td><img src="Lupus_Get_the_Facts_Slide3.png" alt="Image" /></td>
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</table>
Lupus is a serious disease of the immune system that can affect anyone. The immune system is our body’s defense against infection and disease. Lupus is a chronic and complex autoimmune disease in which your immune system attacks healthy cells by mistake – this can potentially damage many parts of the body. Lupus can affect the joints, skin, brain, lungs, kidneys, heart, and blood vessels, potentially causing widespread inflammation and tissue damage in the affected organ. The exact cause of lupus is not known and there is no cure for lupus. Lupus is not a contagious disease.

References:
1. www.lupusresearch.org

The most common type of lupus is called systemic lupus erythematosus (SLE), which affects many parts of the body.

Other types of lupus are:
- Cutaneous lupus, which causes a rash or lesion on the skin, usually when exposed to sunlight.
- Drug-induced lupus, similar to SLE, which is caused by an overreaction to certain medications. Symptoms usually disappear once the medicine is stopped.
- Neonatal lupus, which occurs in infants who acquire SLE from their mothers
- People can have both SLE and cutaneous lupus

During this presentation when we discuss “lupus,” we are most often referring to the most common type of lupus: systemic lupus erythematosus or SLE.

Reference:
1. www.lupusresearch.org
2. www.utsouthwestern.edu
One reason why lupus is so difficult to diagnose is that no two cases of lupus are the same. There are, however, a number of general symptoms that lupus patients often experience:

50-90% of people with lupus identify **fatigue** as one of their primary symptoms. Fatigue can significantly impact patients’ quality of life, including lessening the ability to function at home and at work.

Most people with lupus experience unexplained **fevers** (temperature over 100°F (37.8°C)). Roughly 30% of lupus patients experience a **malar rash**, also known as a butterfly rash, which covers the bridge of the nose.

Up to 90 percent of people with lupus will have arthritis, which is **inflammation or swelling of the joints**. The most common symptoms of arthritis are stiffness and aching, most often in the hands and wrists. Symptoms of arthritis can come and go and move from one joint to another. Pain and stiffness tend to be worse in the morning and improve as the day goes on. People with lupus can also experience pain in the joints without swelling or tenderness.

Patients may also experience **hair loss**, seizures, restriction of blood flow to the hands and feet, sensitivity to the sun, depression, gastrointestinal problems, bone thinning, weight changes, and dryness of the mouth and/or eyes.

**References:**

1. www.lupusresearch.org
2. www.hopkinslupus.org
3. www.mayoclinic.org
4. www.cedars-sinai.org
5. Medicine. Morbidity and mortality in systemic lupus erythematosus during a 10-year period: a comparison of early and
| 7 | Lupus symptoms are not predictable – they may be mild or severe, they may persist or resolve, and they may come on suddenly or gradually develop over time. When symptoms come on suddenly, this is commonly known as a “flare.” A flare in systemic lupus erythematosus (SLE) is characterized by a worsening of disease activity. Flares may be characterized by any group of symptoms that can affect many different parts of the body, including musculoskeletal involvement, skin issues, heart, neurological and many, many other complications. When a flare occurs, patients are encouraged to see their doctor to determine if any immediate steps must be taken. Lupus flares are often triggered by environmental factors. These factors may include: stress, sunlight exposure, weather/temperature changes, infection, work, and chemical exposure from home cleaning. Reference: 1. International Journal of Chronic Disease. The lived experience of lupus flares: features, triggers, and management in an Australian female cohort. 2014. |
Lupus is difficult to diagnose as there is no single test that confirms lupus. Instead, clinicians look at a number of factors to make a diagnosis, such as: medical history, physical exam, blood tests, and skin or kidney biopsies.

At least four of the eleven clinical criteria of lupus from the American College of Rheumatology are usually present for lupus to be diagnosed.

Reference:
1. www.lupusresearch.org

Here you can see the eleven clinical criteria that doctor's use for lupus diagnosis:

1. Photosensitivity – unusually strong reaction to sun light, causing a rash or flare. Because many people with lupus are sensitive to sunlight (called photosensitivity), skin rashes often first develop or worsen after being out in the sun.
2. Malar rash – about 30% of people with lupus experience a characteristic red “malar” rash or color change that may appear across the cheeks and bridge of the nose in the shape of a butterfly.
3. Discoid (skin) rash – raised red patches
4. Mouth and/or nose ulcers – usually painless
5. Nonerosive arthritis – inflammation in two or more joints
6. Cardio-pulmonary involvement – inflammation of the heart lining and/or lungs
7. Neurologic disorder – seizures and/or psychosis
8. Kidney disorder – increased protein or clumps of red blood cells in urine
9. Blood disorder – damaged red blood cells, low white cells, or low platelet count
10. Immunologic disorder – when your immune system attacks healthy cells

11. Positive antinuclear antibodies (ANA) test – positive blood test not induced by drugs

Reference:
1. www.lupusresearch.org

10

Anyone can get lupus. Systemic lupus erythematosus affects from 161,000 to 322,000 U.S. adults.

Some people have a greater risk of getting lupus:

- Women make up nine out of ten adults with the disease.
- Lupus most commonly first strikes between the ages of 15 & 44.
- Women of African American, Hispanic, Asian, or Native American origin also are more prone to lupus than Caucasians.
- African American women are three times more likely than Caucasian women to have lupus.
- A family history is also a risk factor for lupus.

References:
1. www.lupusresearch.org
2. www.arthritis.org
If you suspect that you or a loved one has lupus, the first step is to write down your symptoms and go to the doctor. We will be handing out some information at the end of this session with tips on where you can go to learn more about lupus.

You can also talk to your doctor and with their guidance, be referred to a rheumatologist for an exam. Lupus is generally treated by a team of physicians led by a rheumatologist. A rheumatologist specializes in arthritis and other inflammatory diseases.

Reference:
1. www.lupusresearch.org

While no two cases of lupus are alike, lupus can have a significant impact on daily life. Beyond the general symptoms of fatigue and inflammation, having lupus can put you at a greater risk for other serious health problems, such as cardiovascular disease, diabetes, and kidney disease.

While no cure for lupus currently exists, there are treatments that can reduce symptoms. The Lupus Research Alliance funds research that is aimed at learning more about lupus, creating more effective treatments, and hopefully one day identifying a cure.

References:
Lupus is a complex autoimmune disease that is difficult to diagnose, treat, and defeat, with only one treatment approved specifically for lupus in nearly 60 years. The Lupus Research Alliance is committed to funding promising investigations that help advance the understanding of lupus, develop an array of more effective treatments with fewer and less severe side effects, and ultimately find a cure.

The Alliance’s comprehensive grant program attracts new scientific talent to the field and provides opportunities for researchers to pursue the most novel ideas as well as to advance proven approaches that improve treatment.

Because the Board of Directors funds all Lupus Research Alliance administrative and fundraising costs, 100% of all other donations go directly to support research programs.

Reference:
1. www.lupusresearch.org

Now that you’ve learned more about lupus and lupus research, we want to make sure you’re aware of ways you can get involved.

The Lupus Research Alliance has resources available online for those who want to get involved in fundraising efforts and events.

A major goal of the Lupus Research Alliance is to raise awareness; you can help in this effort by talking to your friends and family about what lupus is and how lupus impacts those who have it.

If you have lupus, talk to your doctor about participating in a clinical trial. The Lupus Research Alliance is actively involved in recruiting for and facilitating clinical trials across the U.S.
### You may be wondering, “what is a clinical trial?”

Clinical trials help to answer the question, “Will this drug help people and is it safe?”

In clinical trials, people volunteer to test new treatments, interventions or tests, so researchers can determine what does and doesn’t work. Clinical trials also help researchers and doctors decide if the benefits outweigh possible side effects.

Lupus research has been greatly advanced by the caring people who participate in clinical trials. In these studies, scientists and participants work together to find safer, more effective ways to diagnose, prevent, and ultimately cure lupus.

All drugs must be tested in clinical trials to be approved by the U.S. Food and Drug Administration as treatments for lupus. And volunteers that represent every potential patient group are critically important.

In 2016, the Lupus Research Alliance launched the Lupus Clinical Investigators Network (also known as LuCIN). LuCIN is a Lupus clinical trials network, made up of almost 60 of the most prestigious academic research medical centers throughout North America. Founded and sponsored by the Lupus Research Alliance, LuCIN brings together experts to evaluate the safety and effectiveness of potential treatments for lupus. For more information on LuCIN or participating in a clinical trial, visit [lupusresearch.org/trials](http://lupusresearch.org/trials).