



The
Playbook:
Local Lupus
Awareness
Activities for
Faith Based
Organizations

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The Playbook:

Local Lupus Awareness Activities

INTRODUCTION

What is the Playbook?

The Playbook is a step-by-step guide you can use to plan and implement lupus awareness activities in your community. The American College of Rheumatology (ACR) designed this Playbook to assist leaders within faith-based organizations (FBO), like you, raise lupus awareness among African American women ages 18-25.

The Playbook will provide you with the information you'll need to educate yourself and your supporters about lupus, spread the word about lupus through social media, implement a hands-on lupus awareness event in your community, and keep your efforts going through continuing activities.

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 can affect many parts of the body including joints, skin, kidneys, lungs, and 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 this affect me?

While anyone can develop lupus, women are affected more than men. Lupus is **two to three times more common in African American women** compared to White women. Lupus also usually begins during child-bearing years (15-44) and can seriously derail young women's goals for education, career, family, and health.

Lupus is a disease that is known for being difficult to diagnose, because the symptoms are different from person to person and they can come and go. It can sometimes take several years to receive an official diagnosis.

Early diagnosis of lupus is important to reducing the long-term effects of the disease. The first step is being aware that you may have symptoms that require medical attention.

How can I help?

You can help us decrease time to diagnosis by using this Playbook to raise lupus awareness in your community. The activities outlined in this Playbook can be customized and we encourage you to tailor your approach to best fit your specific organization and engage your audience.

What if I have questions?

If you have any questions about how to use the Playbook, about lupus, or the ACR, please contact us via email at lupus@rheumatology.org or by phone at 404.633.3777 x804.

Educate
your
supporters

Spread
the
word

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an
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going –
Continuing
activities



Educate your supporters

It all starts with you! As a driving force in your community, we want you to have the knowledge and resources you need to assume a leadership role in lupus awareness. Educating yourself and your supporters¹ about lupus sets the stage to engage others in efforts to increase lupus awareness in your community.

As previously stated, lupus is a complicated health problem, and even health professionals have difficulty recognizing and diagnosing it. It's critical for you to learn as much about lupus as possible before starting your social media campaign and hosting your hands-on event.

We've provided a downloadable [Lupus PowerPoint presentation](#) and [Presentation script](#) to help you prepare for and host a session to educate your FBO about lupus. We suggest that you review the presentation materials first before taking the next step in planning your lupus education presentation, social media campaign, and hands-on event.

¹By supporters, we mean worship center members and non-members, as well as other organizations and individuals with whom you are collaborating to increase lupus awareness in your community.



Activity:

Give a lupus presentation to increase lupus awareness among your supporters.



Objectives:

1. Increase your and your supporters' lupus awareness. We define lupus awareness as "knowledge" of the signs and symptoms of lupus and knowing what to do if lupus is suspected.
2. Encourage your supporters to learn more about lupus by reviewing the [Lupus fact sheet – detailed](#) and visiting the *Be Fierce. Take Control.*[®] website (befiercetakecontrol.org).
3. Establish work groups to take charge of the social media campaign and hands-on event.



Length of activity:

The presentation and discussion should last between 45-75 minutes.



What you need:

- ✓ [Lupus PowerPoint presentation](#)
- ✓ Computer and audio/visual equipment for projection of presentation to the audience
- ✓ Convenient location for in-person presentation
- ✓ [Presentation script](#)
- ✓ [Lupus fact sheet – detailed](#)



Optional steps:

- ✓ See [Appendix A. Fund your event](#) for suggestions on how to fundraise and budget for food and beverages if you would like to serve refreshments at your presentation.
- ✓ See [Guest speaker recruitment](#) for suggestions on how to get a guest speaker, such as a rheumatologist or someone with lupus, to speak to your FBO, if you want to expand your presentation.



Before the presentation:

1. Decide who will present the [Lupus PowerPoint presentation](#). This person should (1) have the time to review the materials carefully and prepare for the presentation, and (2) be able to engage group discussion.
2. Download the [Lupus PowerPoint presentation](#) and [Presentation script](#) and review both carefully.
3. Visit the campaign website *Be Fierce. Take Control.*[®] (befiercetakecontrol.org) to learn more about lupus.
4. Select a location and date to give the presentation.
 - Determine a convenient location and time for most of your supporters. Including the lupus presentation during a regularly scheduled meeting or holding a meeting after worship services might work best.
5. Submit the proper requests to book the location and any needed technology (when needed).
6. Once you have an approved location, date, and time, inform your supporters about the presentation.
 - Announce the presentation during worship services, post information about the presentation on your worship center's social media page, and/or send an email announcement – use the [Lupus presentation announcement](#) for sample flyers, social media posts, and email text.
7. Download and print the [Lupus fact sheet – detailed](#) to hand out during the session.
8. Arrive early on the day of the presentation to set up any audio/visual equipment you that are using and the [Lupus PowerPoint presentation](#).



During the presentation:

1. Use the [Presentation script](#) as your guide during the presentation.
2. Distribute copies of the [Lupus fact sheet – detailed](#) to your audience.
3. Engage your audience by asking questions about their experiences, feelings, and opinions about the content.
 - Remember, **lupus is two to three times more common in African American women compared to White women.** It is likely that you or your audience may know someone with lupus. It's important to let your audience express themselves and discuss what they already know (or don't know) about lupus. The [Presentation script](#) includes discussion starters for you to use during the presentation. Ensure that the audience respects privacy (e.g., not sharing names of people they may know who have lupus) and no one person dominates the discussion.
4. Discuss the importance of your supporters leading the charge on lupus. Discuss the next steps of the Playbook, including spreading the word through the social media campaign and hosting your lupus hands-on event.
5. Establish working groups to lead the social media campaign and the hands-on event. These working groups can help you to plan and manage the various tasks for these activities.

Now that you're community advocates, you're ready to spread the word to others!



Relevant resources and appendices:

- ✓ [Lupus PowerPoint presentation](#)
- ✓ [Presentation script](#)
pg. 40
- ✓ [Lupus fact sheet – detailed](#)
pg. 57
- ✓ [Guest speaker recruitment](#)
pg. 49
- ✓ [Lupus presentation announcement](#)
pg. 53
- ✓ [Appendix A. Fund your event](#)
pg. 17



Educate
your
supporters

Spread
the
word

Host
an
event

Keep it
going –
Continuing
activities



Spread the word

Your social media campaign will set the tone and build momentum for your hands-on event. The goal of the campaign is twofold: (1) increase lupus awareness in your local community, and (2) promote your hands-on event to African American women ages 18-25.

The social media campaign working group should use the [Social media planning sheet](#) and the [Social media assets bundle](#) to develop a strategy for your organization. We have included suggestions for when and how to post text, and graphics for posts, and suggestions for ways to engage your fellow supporters. But, these are only suggestions – you know more about what will catch the interest of your community. We only ask that you:

- Use scientifically accurate information when talking about lupus. We recommend using information provided in the [Social media assets bundle](#), the [Lupus fact sheet](#),¹ or on the *Be Fierce. Take Control.*® website (befiercetakecontrol.org). **If you're unsure of the accuracy – don't post it!**
- Use the hashtag #BeFierceTakeControl in every post.

¹This fact sheet is a modified version of the [Lupus fact sheet – detailed](#) that you and your supporters reviewed during the lupus presentation in [Educate your supporters](#). The facts in this sheet are the same, but shorter and easier to share via social media. This is the handout that we recommend providing to participants at your event (see [Host an event](#)).



Activity:

Over a period of two to three weeks, frequently post information about lupus and your upcoming hands-on event to raise awareness about lupus to African American women ages 18-25.



Objectives:

1. Plan and manage a social media campaign to increase lupus awareness in your community.
2. Use social media to promote your hands-on event.
3. Encourage followers to learn more about lupus by visiting the *Be Fierce. Take Control.*® website (befiercetakecontrol.org).
4. Empower African American women ages 18-25 to take control of their health by providing information and inspiration.



Length of activity:

You should begin your social media posts at least one week, but no more than three weeks before your hands-on event.



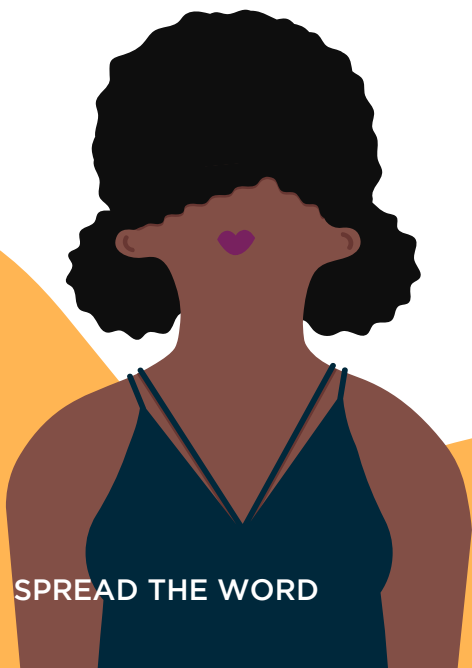
What you need:

- ✓ Social media accounts for your organization (Instagram, Twitter, Facebook, Snapchat*, etc.)
- ✓ [Social media planning sheet](#)
- ✓ [Social media assets bundle](#)
- ✓ [Lupus fact sheet](#)
- ✓ [#BeFierceTakeControl community contributions](#)
- ✓ [Tips to respond to social media questions](#)



Before the campaign:

1. Convene the social media campaign working group at least three weeks before the hands-on event and use the [Social media planning sheet](#) and the [Social media assets bundle](#) to develop a social media strategy.
 - Your social media strategy should include:
 - » Number and type (e.g., Facebook, Instagram) of posts your working group will develop. Make sure you have a mix of lupus awareness posts, photos from your supporters about taking control of their health (see [#BeFierceTakeControl community contributions](#)), and posts advertising your lupus event in your community.
 - » Calendar of dates/times you will post.
 - » Designated person(s) to develop the posts, publish the posts, and track the posts.
 - » Ideas to engage your fellow supporters to contribute to the campaign. See [#BeFierceTakeControl community contributions](#) for tips and examples.
 - » Method of tracking the performance of each social media post (e.g., number of likes, shares, views, etc.)
2. Customize the social media materials provided in the [Social media assets bundle](#). You may also want to:
 - Add your worship center's name, logo, and social media account information (i.e., profile name, profile tag, hashtag, etc.)
 - Add the date and location of your hands-on event for event-promotion posts.
 - Create your own social media materials – just remember:
 - » Use scientifically accurate information when talking about lupus. We recommend using information provided in the [Social media assets bundle](#), the [Lupus fact sheet](#), or on the Be Fierce. Take Control.® website (befiercetakecontrol.org).
 - » Use the hashtag #BeFierceTakeControl in your posts.
 - » Take a screenshot of each social media post you publish and share them with us at lupus@rheumatology.org.





During the campaign:

1. Launch your campaign and begin posting on social media.
 - Consider placing an announcement of your event in your worship center's email newsletter or community newspaper.
2. Ask your supporters, friends and family to use and share the social media assets for the campaign (e.g., Facebook cover page, profile badges, posts) and post photos on your worship center's social media accounts.
3. Use the hashtag #BeFierceTakeControl with all your social media posts. You may also insert a customized hashtag for your worship center or group.
 - **Example:** *Check out our upcoming event at Tate Plaza on Thursday, June 1 from 11:00 AM - Noon*
#BeFierceTakeControl #[insert custom hashtag]
4. Engage with your online community by replying, retweeting, or commenting to posts asking questions or making comments about lupus. We provide commonly asked questions and answers, which you can use when responding to questions in the [Tips to respond to social media questions](#).
 - *Example: If someone replies to your Twitter post asking what the most common symptoms of lupus are, you can reply to them using the information you learned in your education session, using the responses listed in the [Tips to respond to social media questions](#), or using the information in the [Lupus fact sheet](#).*
5. Promote selfies and other lupus awareness posts from your supporters, and ask followers to share images of themselves taking control of their health. Your followers can show all the different and unique ways they are taking control of their health and listening to their bodies. They can take selfies and use the hashtag #BeFierceTakeControl when they are making healthy choices in day-to-day life-or visiting the doctor, your followers can show all the different and unique ways they are taking control of their health and listening to their bodies. See [#BeFierceTakeControl community contributions](#) for tips and examples.
6. Connect with the [ACR](#) and [TLI](#) on social media.
We want to see all the cool things you're doing!

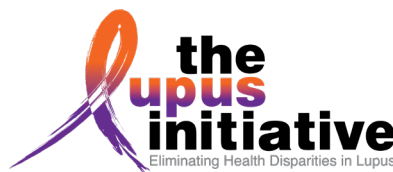


Relevant resources and appendices:

- ✓ [Social media planning sheet](#)
pg. 63
- ✓ [Social media assets bundle](#)
pg. 69
- ✓ [Lupus fact sheet](#)
pg. 57
- ✓ [#BeFierceTakeControl community contributions](#)
pg. 59
- ✓ [Tips to respond to social media questions](#)
pg. 61

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Educate
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Continuing
activities



Host hands-on event

Your hard work over the past weeks concludes with your hands-on event to raise lupus awareness. This event is called the *Be Fierce. Take Control.*® hands-on event (we just use the word “event” below). As leaders in your community, you will educate, spread awareness, and inspire young African American women in your community to take control of their health.

The main goal of the event is to get the attention of African American women in your community who are between the ages of 18-25, and inform them about: (1) what lupus is; (2) what the signs and symptoms of lupus are; and (3) what to do if they suspect they (or someone they know) has lupus.

The event work group should use the [Event planning sheet](#) and the [Event asset bundle](#) to plan and host your hands-on event. Be creative when developing your event concept. To help you decide on an event type or theme, think about what kind of events might interest young African American women ages 18-25 in your community. For a sample list of hands-on event ideas, see Appendix D.

For the purposes of this guide, we will focus on a hands-on event that encourages:

- Attendees [to create a sign](#).
- [Take a selfie with the sign](#).
- [Post the selfie on social media](#) to celebrate the ways they are fierce and what taking control of their health means to them, such as making healthy eating choices or making an appointment with a health care provider.

You and your supporters will engage people who are passing by the event to participate in the event and share information using the [Lupus fact sheet](#), so they can learn more about lupus.



Activity:

Hold a hands-on event to raise awareness about lupus among African American women ages 18-25.



Objectives:

1. Plan and hold a hands-on event to increase lupus awareness in your community.
2. Provide information about lupus to people who attend the event using the [Lupus fact sheet](#).
3. Encourage event attendees to learn more about lupus by visiting the *Be Fierce. Take Control.*® website (befiercetakecontrol.org).
4. Empower African American women in your community to take control of their health by increasing awareness.



Length of activity:

At least two hours,
but no more than
five hours.



What you need:

- ✓ Location/venue in community
- ✓ Photo booth prop signs (see [Event asset bundle](#))
- ✓ Writing utensils for selfie signs (markers, pens, etc.)
- ✓ Poster board or other materials for event signage
- ✓ Table, chairs and waste cans
- ✓ Printed copies of [Lupus fact sheet](#)
- ✓ [Event planning sheet](#)
- ✓ [Event asset bundle](#)
- ✓ [Event volunteer sign-up sheet](#)
- ✓ [Talking points for the event](#)



Before the hands-on event:

1. Convene the event work group and use the [Event planning sheet](#) and the [Event asset bundle](#) to develop the plan for your event.
 - Specifically, you should:
 - » Determine the proper location and date to host the event.
 - » Schedule the event during a time when people will be in the area and have time to participate in the event (e.g., before/after worship services, during a community festival, during a health fair, etc.)
 - » Schedule the event when there are no other conflicting events occurring that would take attendees away from your event.
 - » Select an indoor or outdoor location near popular walkway or other area with lots of foot traffic. Visit the location during the time(s) you plan to host your event.
2. Submit the proper requests to book the location and reserve tables, chairs, waste cans, electricity, etc. Many locations may require you to complete paperwork about your event, including: (1) an event description (see [Appendix A. Fund your event](#) for a sample); (2) safety forms; and (3) reservation forms for the specific date/location. However, each location is different, so check with the person in charge of that location for guidance to get your event approved.
3. Once approved, advertise the event using multiple strategies. We include several samples in the [Event asset bundle](#). Some strategies include:
 - Posting flyers on bulletin boards and other locations.
 - Posting event information in your worship center's bulletins and newsletters.
 - Handing out flyers around the community.
 - Encouraging supporters to talk about the event.
 - Posting about the event on any email lists or listservs to which your organization has access.
 - Social media (managed by the social media campaign work group, see [Spread the word](#)).



Tip:

Communicate with the social media campaign work group, that will promote the hands-on event on social media channels.

4. Prepare materials for the day of the event:

- Purchase enough writing utensils to accommodate your estimated number of attendees.
- Print enough photo prop signs to allow your attendees to take one or two selfie photos.
- Make signs about the event that include instructions for attendees to write or draw ways they are fierce and what taking control of their health means to them, such as making healthy eating choices or making an appointment with a health care provider. We included examples in the [Event asset bundle](#).
- Print copies of the [Lupus fact sheet](#) to share with attendees.

5. Ask supporters to volunteer for specific time slots for the event using the [Event volunteer sign-up sheet](#). You will need volunteers to help set up the event, engage attendees during the event, and clean up after the event. One to two days before the event, schedule a location walk-through with volunteers.

- Supporters who volunteer to engage attendees during the event must:
 - » Attend the [Lupus PowerPoint presentation](#) (see [Educate your supporters](#)).
 - » Review [Lupus fact sheet – detailed](#).
 - » Review the [Talking points for the event](#).



Optional next steps:

- ✓ See [Appendix A. Fund your event](#) for suggestions on how to fundraise and then budget for food, beverages, and other incentives (e.g. T-shirts, water bottles, pens, totes) for attendees. You don't need refreshments and swag to run a successful event, but such items often increase attendance!
- ✓ See [Guest speaker recruitment](#) for suggestions how to find and retain an expert or person living with lupus to enrich your event.
- ✓ See [Appendix B. Measure your event's impact](#) for information about how to evaluate the success of your event.

SELF
CARE
ISN'T
SELFISH



Day of the event:

1. Arrive early to set up for your event. The event work group and any other supporters who are helping set up for the event should:
 - Set up your table and chairs – this is a good place to put extra copies of the [Lupus fact sheet](#) for attendees to grab, information about the event, and art supplies.
 - Place large, noticeable signs around the event to inform attendees about what you are doing. Show attendees how to write or draw ways that they are fierce and what taking control of their health means to them, such as making healthy meal choices or making an appointment with a health care provider.
 - Make sure the selfie sign supplies, and other materials are easy for attendees to find and use.
 - You may want to ask a particularly artistic member of your organization to start things off by creating a large, central design to inspire or anchor the attendees' contributions.
 - Ask members of your organization to paint/chalk their experiences, so attendees can see examples.
2. Approach people who walk by in a friendly, welcoming manner and explain the event. Ask them to share their experiences and participate in the event.
3. Use the information from the lupus presentation and [Talking points for the event](#) to provide attendees with information about lupus. Give attendees copies of the [Lupus fact sheet](#) and encourage them to visit the *Be Fierce. Take Control.*® website (befiercetakecontrol.org).
4. Encourage attendees to take pictures of what they write/draw and share it on their social media accounts using the hashtag #BeFierceTakeControl.
5. Document all the artwork created by attendees with photos. Share the photos on social media, tag us in your posts (see the “Follow us” section on page 15), and use the hashtag #BeFierceTakeControl whenever possible.



Relevant resources and appendices:

- ✓ [Guest speaker recruitment](#)
pg. 49
- ✓ [Lupus fact sheet](#)
pg. 57
- ✓ [Event planning sheet](#)
pg. 63
- ✓ [Event asset bundle](#)
pg. 73
- ✓ [Event volunteer sign-up sheet](#)
pg. 63
- ✓ [Talking points for the event](#)
pg. 67
- ✓ [Appendix A. Fund your event](#)
pg. 17
- ✓ [Appendix B. Measure your event's impact](#)
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Integrate social media:

During the event, the social media work group should take pictures and post on social media and share attendee posts.

Use #BeFierceTakeControl

Educate
your
supporters

Spread
the
word

Host
an
event

Keep it
going –
Continuing
activities



Keep it going – Continuing activities

The Playbook activities described previously are only a few of the many creative ways you and your fellow supporters can promote lupus awareness in your community.

If you would like to complete additional lupus awareness activities, we provide some ideas in [Appendix A. Fund your event](#) and [Appendix B. Measuring your event's impact](#).

Plan a larger *Be Fierce. Take Control.*® hands-on event

Larger on-site events with food, beverages, and/or incentives for attendees often require more funding support. Therefore, you may need to seek additional funding (see [Appendix A. Fund your event](#)) to expand your event. You may wish to include multiple organizations to plan an event that involves the community. You may also consider contacting speakers such a rheumatologist or person with lupus to come to your event (see [Guest speaker recruitment](#)).

Collaborate with other organizations in your community

Community health centers, health clubs, hair and nail salons, locally owned stores and shopping centers, and local community service organizations can be perfect partnership opportunities. Collaborating with other organizations expands the reach of your event and combines two or more funding sources. Suggested first steps to collaborate with another organization include:

- Approach friends, community leaders and other local influencers.
- Share the Playbook and the results from your evaluation of your activities with them (if available).
- Discuss the importance of lupus awareness and what you've learned so far.
- Schedule a meeting with all collaborating organizations' supporters to discuss the possible partnership for another lupus awareness event or creating a community-wide "health fair" where other organizations' health-focused activities complement your lupus event.

Partner with other organizations outside your community

There are many organizations with whom you can collaborate on lupus awareness activities, such as national conferences, national and local health associations, local organizations focused on women or young adults, etc. When approaching other organizations to collaborate on lupus awareness activities:

- Develop a one-page event description and specific talking points to discuss with the organization.
- Email or call points of contact at organizations with whom you'd like to collaborate.
- Share the Playbook with interested collaborators, the results from your evaluation (if available), and your event description.
- Schedule a meeting with the collaborating organization's leadership to discuss the details of your event, the collaborator's potential role, and implementation.

Stay connected

Remember to stay connected with us on social media to share your continuing efforts and show us what you're doing in your community to raise lupus awareness.

Follow us

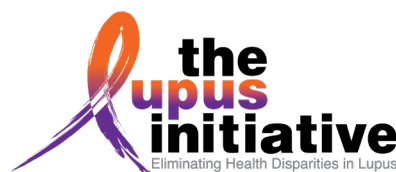


Relevant resources and appendices:

- ✓ [Guest speaker recruitment](#)
pg. 49
- ✓ [Appendix A. Fund your event](#)
pg. 17
- ✓ [Appendix B. Measure your event's impact](#)
pg. 21

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LEARN HOW TO FIGHT BACK



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left blank.

Fund your event

The cost to complete the activities described in the Playbook is relatively low. However, if your organization needs funds for supplies or wants to provide food, beverages, and/or additional incentives, you may need to seek additional funding.

There are **four** main types of funding sources:

1. Fundraising – Your organization can raise funds by hosting a bake sale, fashion show, etc.

- Talk with your fellow supporters and see what fundraising events have been most successful for your organization in the past.

2. Requesting funds from your organization’s financial office – Visit your organization’s website for more information on the requirements to request funds.

- Your organization likely requires completed forms about the event and why you need the funds. See the budgeting and event description sections below for help.

3. Requesting funds from your regional or national conference –

Visit your regional or national conference website or ask your point of contact, such as a national representative, for more information on the requirements to request funds.

- You may be required to complete official forms or provide a written proposal for the funds. See the budgeting and event description sections below for help.

4. Requesting funds from local businesses or organizations – Visit local businesses and organizations (or their websites) and ask if they are interested in sponsoring or supporting your event.

- To persuade local businesses or organizations to help, write a proposal with information about why you need the funds, including your budget and a description of the event. It also might help to offer local businesses or organizations promotion at the event, such as their logo and information saying, “Sponsored by _____.”



Tip:

Use your evaluation results to demonstrate why a funder should consider providing additional funds for you to complete the event again (see [Appendix B. Measure your event’s impact](#)).

No matter which method you choose to raise additional funds, you may want to recruit your organization treasurer or consider establishing a specific budget and fundraising work group to carry out the tasks.

Budgeting

The first step to funding your event is creating a budget that can help you estimate exactly what materials you will need, the estimated material costs, and what funds you will use to pay for the materials.

To start, make one table for your event expenses and one table for your event funds (see the sample below). The tables should include lines for each of the estimated items and costs for your event. As you buy each of the items or receive funds, you should make note of the actual cost or funds.

Expenses		
Item	Description	Cost
Tables	Provided by venue	\$0.00
Four medium pizzas	Purchased from local pizza place	\$52.65
Two cases of bottled water	Purchased at local grocery store	\$6.12
Total expenses:		\$58.77

Funds		
Item	Description	Cost
Budget funds	Organization miscellaneous event budget	\$75.00
Additional funds	Additional funds received from partners or other funding sources.	\$50.00
Total expenses:		\$125.00



Tip:

Other examples of expenses are:

- Food/beverages
- Cups, forks, spoons, etc.
- Office materials, printing
- Incentives, such as T-shirts, water bottles, totes, etc.
- Technology not from your organization, laptop, speakers/microphones, etc.



Tip:

Use the blank spaces to fill in the expenses and funding for your event!

Event description template

You may choose to use this description of the Playbook activities to increase lupus awareness in your proposals for additional funding.

[Organization name] is participating in the Playbook Project – a campaign developed by the American College of Rheumatology (ACR). The goal of the campaign is to raise awareness of the signs and symptoms of lupus, and ultimately help reduce health disparities by reducing the time to diagnosis.

Lupus is a chronic disease, meaning it is a long-term disease that should be managed. Lupus can affect many parts of the body, including joints, skin, kidneys, lungs, and brain. While anyone can develop lupus, women are affected more than men. Lupus is two to three times more common in African American women compared to White women. Lupus also usually begins during child-bearing years (15-44), so it can seriously affect young women's goals for education, career, family, and health.

As leaders in our organization, we educated ourselves about lupus and increased our own lupus awareness, and learned: (1) what lupus is; (2) what the signs and symptoms of lupus are; and (3) what to do if you suspect you (or someone you know) has lupus, using a scientifically accurate presentation provided by the American College of Rheumatology. After increasing our lupus awareness, we created a social media campaign work group to plan and implement a social media strategy to further increase lupus awareness in our community.

Now, as a grand finale, we are planning to host an event called the *Be Fierce. Take Control.*® hands-on event that encourages attendees to create selfie signs and post selfies on social media that celebrate the ways that they are fierce and what taking control of their health means to them, such as making healthy meal choices or making an appointment with a health care provider. The goal of our visual hands-on event is to get the attention of local women, especially African American women. Additionally, we want to further increase lupus awareness in our community. We will engage people who are passing by the event to participate in the event and share information through a scientifically accurate lupus fact sheet that addresses (1) what lupus is; (2) what the signs and symptoms of lupus are; and (3) what to do if they suspect they (or someone they know) has lupus.

As a leader in our community, we would greatly appreciate your help by providing funds for our event. We have attached a budget, which details more information about our estimated expenses and funding. If you are interested in helping support the *Be Fierce. Take Control.*® hands-on event, please contact us at **[contact information]**.



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Measure your event's impact

Seeing your fellow supporters and attendees engage with your social media campaign and on-site visual demonstration event is exciting, but how can your organization both document and measure the impact of your efforts? The short answer: evaluation.

Evaluation is a process to answer the questions: Was this event successful? Did this event make an impact? Why or why not? Be sure to make it clear to those who participate in the evaluation that you are looking to understand how useful your own presentation was to helping them learn more lupus and what to do. **It is important to make sure those who participate do not feel like you are ‘testing them’;** rather, you are looking for good information on how you can do a better job sharing good information.

Measuring your event's impact can provide several benefits

- Discover the strengths and weaknesses of the event to improve the event in the future.
- Discover the strengths and weakness of your organization's abilities to host this event and similar events.
- Demonstrates the impact of the event (e.g., number of people reached, knowledge gained).
- Provides results for requesting additional funding.

To evaluate your lupus presentation, social media campaign, and/or hands-on event, you will need to collect data from participants. Data are many things, including a collection of numbers, words, measurements, observations, or descriptions.

Sharing your evaluation results with your fellow supporters, regional and national organizations, local organization administrators, and any funders is important for showing the impact of your efforts. As you develop your evaluation plan, think about who you will share the data with, what that audience might want to know about your event, how you will analyze the data, and how you will present those results to your selected audience(s).

Evaluate your lupus presentation:

Since your fellow supporters will be engaging people on social media and during the hands-on event, it is important to know the extent to which they understand the information in the [Lupus PowerPoint presentation](#). You can measure your fellow supporters' lupus awareness by using the [Lupus awareness questionnaire](#) based on the information in the [Lupus PowerPoint presentation](#). Handing out hardcopy questionnaires immediately before and after the presentation while attendees are still in the room will give you the highest response rates. However, you can also use electronic resources, such as Survey Gizmo or Survey Monkey, to create an online questionnaire – using the same method of taking the questionnaire before or after the presentation.



Tip:

- If you ask your supporters to answer the same questions before the presentation and directly after, you can more accurately measure their knowledge gains (e.g. what they knew before and what they know after).
- The longer the time between the presentation and the survey, the less the participants will remember for the survey.



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Use the [Lupus presentation evaluation checklist](#) (provided below) to help you plan and measure the impact of your lupus presentation.

Lupus presentation evaluation checklist		
Task		Notes
<input type="checkbox"/>	Define the goal of the evaluation.	
<input type="checkbox"/>	Identify what information from the Lupus PowerPoint presentation you want to test. You can use questions provided in the Lupus awareness questionnaire .	
<input type="checkbox"/>	Draft survey questions.	
<input type="checkbox"/>	Identify how you will administer the questionnaire to your supporters (hardcopy or online).	
<input type="checkbox"/>	Create and finalize the survey – either print hardcopies or program the online questionnaire.	
<input type="checkbox"/>	Identify when and where you will give the questionnaire to your supporters.	
<input type="checkbox"/>	Identify who will administer the questionnaire to your supporters.	
<input type="checkbox"/>	Determine how to analyze and report the results of the questionnaire.	
<input type="checkbox"/>	Identify who will analyze the results of the questionnaire.	
<input type="checkbox"/>	Use results to improve the event and/or secure additional funding.	



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Lupus awareness questionnaire

1. Men are affected by lupus _____ women.
 - a. More than
 - b. Equal to
 - c. None of the above
 - d. Don't know/unsure
2. Which of the following are TRUE?
 - a. African American women are at up to three times higher risk of developing lupus compared to White women
 - b. African American women and White women have equal risk of developing lupus
 - c. African American women are at up to three times higher risk of developing lupus compared to White men
 - d. None of the above
 - e. Don't know/unsure
3. At what age are patients usually diagnosed with lupus?
 - a. Between ages 0 to 14
 - b. Between ages 15 to 44
 - c. Between ages 45 to 75
 - d. None of the above
 - e. Don't know/unsure
4. The lupus “butterfly rash” appears:
 - a. On the chest or back
 - b. Across the nose and cheeks
 - c. Across the pelvis
 - d. Between the shoulder blades
 - e. All of the above
 - f. Don't know/unsure
5. What type of specialists focus especially on autoimmune diseases and treat lupus?
 - a. Nephrologists
 - b. Radiologists
 - c. Rheumatologists
 - d. Oncologists
 - e. Endocrinologists
 - f. None of the above
 - g. Don't know/unsure



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Lupus awareness questionnaire answer key

1. Men are affected by lupus _____ women.
 - a. More than
 - b. Equal to
 - c. None of the above**
 - d. Don't know/unsure

2. Which of the following are TRUE?
 - a. African American women are at up to three times higher risk of developing lupus compared to White women**
 - b. African American women and White women have equal risk of developing lupus
 - c. African American women are at up to three times higher risk of developing lupus compared to white men
 - d. None of the above
 - e. Don't know/unsure

3. At what age are patients usually diagnosed with lupus?
 - a. Between ages 0 to 14
 - b. Between ages 15 to 44**
 - c. Between ages 45 to 75
 - d. None of the above
 - e. Don't know/unsure

4. The lupus "butterfly rash" appears:
 - a. On the chest or back
 - b. Across the nose and cheeks**
 - c. Across the pelvis
 - d. Between the shoulder blades
 - e. All of the above
 - f. Don't know/unsure

5. What type of specialists focus especially on autoimmune diseases and treat lupus?
 - a. Nephrologists
 - b. Radiologists
 - c. Rheumatologists**
 - d. Oncologists
 - e. Endocrinologists
 - f. None of the above
 - g. Don't know/unsure



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Evaluate your social media campaign:

One of the goals of your social media campaign is to increase lupus awareness. Therefore it's important to know the extent to which your social media messages are (1) reaching young women in your community and (2) the extent to which young women are engaging with the materials. You can measure how many young women you are reaching by tracking the number of impressions or views of your posts (e.g., reach) and how many women engage with your posts by the number of shares, favorites, retweets, comments, likes, etc. your posts receive. Use the [Social media campaign tracking table](#) (provided below) to help keep track and measure the impact of your social media campaign.

Social media campaign tracking table

Social media platform: Facebook

Post content	Date of post	Number of views	Number of likes/reactions	Number of comments	Number of shares	Notes

Social media platform: Twitter

Post content	Date of post	Number of views	Number of likes/reactions	Number of comments	Number of shares	Notes

Social media platform: Instagram

Post content	Date of post	Number of views	Number of likes	Number of comments	Notes

Evaluate your hands-on lupus event:

The goal of your lupus event is to get the attention of your intended audience. Therefore it's important to know how many people participate in your event and their satisfaction with the event. For the *Be Fierce. Take Control.*® hands-on event, you should keep track of how many people stop by your event and how many people participate in the event. You can measure your event attendees' satisfaction using the [Satisfaction questionnaire](#) (on the next page). You can hand out hardcopy questionnaires during the event or you can use an electronic resource, such as [Survey Gizmo](#) or [Survey Monkey](#), to create an online questionnaire.

Use the [On-site lupus event evaluation checklist](#) to help you plan and measure the impact of on-site lupus event.



Tip:

- If it's easier, you can collect your event attendees' email addresses and/or phone numbers. Then, you can send the online questionnaire to them after the event.



Tip:

- Participants are more likely to complete questionnaires if they receive an incentive (e.g., T-shirts, water bottles, pens, totes).
- See [Appendix A. Fund your event](#) for suggestions on how to fundraise and budget for incentives for attendees who complete the survey.

Satisfaction questionnaire

1. Overall, how satisfied were you with the *Be Fierce. Take Control.*® hands-on event?
 - a. Strongly satisfied
 - b. Somewhat satisfied
 - c. Neither satisfied nor dissatisfied
 - d. Somewhat dissatisfied
 - e. Strongly dissatisfied

2. Overall, how satisfied were you with the lupus information shared during the *Be Fierce. Take Control.*® hands-on event?
 - a. Strongly satisfied
 - b. Somewhat satisfied
 - c. Neither satisfied nor dissatisfied
 - d. Somewhat dissatisfied
 - e. Strongly dissatisfied

3. Would you attend a similar event to the *Be Fierce. Take Control.*® hands-on event again?
 - a. Definitely would
 - b. Probably would
 - c. Neither would nor would not
 - d. Probably would not
 - e. Definitely would not

4. Would you recommend the *Be Fierce. Take Control.*® hands-on event to a friend?
 - a. Definitely would
 - b. Probably would
 - c. Neither would nor would not
 - d. Probably would not
 - e. Definitely would not

5. What is one aspect about the *Be Fierce. Take Control.*® hands-on event that you liked?

6. What is one aspect about the *Be Fierce. Take Control.*® hands-on event that you would change?



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Hands-on lupus event evaluation checklist

Task	Notes
<input type="checkbox"/> Define the goal of the evaluation.	
<input type="checkbox"/> Identify how you will track the number of event attendees, participants, and their satisfaction. You can use questions provided in the Satisfaction questionnaire .	
<input type="checkbox"/> Draft questionnaire.	
<input type="checkbox"/> Identify how you will administer the questionnaire to your event attendees (hardcopy or online).	
<input type="checkbox"/> Create and finalize the questionnaire - either print copies or program the online questionnaire.	
<input type="checkbox"/> Identify when and where you will give the questionnaire to the event attendees.	
<input type="checkbox"/> Identify who will track the number of event attendees and participants.	
<input type="checkbox"/> Identify who will administer the questionnaire to event attendees.	
<input type="checkbox"/> Determine how to analyze and report the results of the questionnaire.	
<input type="checkbox"/> Identify who will analyze the results of the questionnaire.	
<input type="checkbox"/> Use results to improve the event and/or secure additional funding.	



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The *Be Fierce. Take Control.*[®] campaign is designed to educate and empower young African American women. For information about the campaign, visit befiercetakecontrol.org. For more detailed information about using campaign assets, please review the *Be Fierce. Take Control.*[®] Brand Guidelines.

Using campaign assets

Campaign assets include the [Social media assets bundle](#) and [Event asset bundle](#), the campaign logo, approved colors, and approved fonts. Lupus is often called the great imitator. Therefore, it is important to make sure that the visual elements of the campaign are consistent, recognizable, and used properly – regardless of where they appear.

Campaign logo, color, and font guidelines

- The logo can appear in black or white, depending on the background color it will be set against. Be Fierce and Take Control should be used with the same color, black or white, at all times.
- Do not recreate the logo.
- Do not recreate the logo design style.
- Avoid scaling, stretching, or condensing the logo relative to its original proportions.
- Do not modify or change the colors or fonts of the campaign assets.
- Do not use the logo or graphics outside of those provided in the Playbook.



Campaign language and formatting guidelines

- Always use #BeFierceTakeControl
 - » CORRECT: #BeFierceTakeControl
 - » INCORRECT: #befiercetakecontrol
- Always use befiercetakecontrol.org.
 - » CORRECT: befiercetakecontrol.org
 - » INCORRECT: www.befiercetakecontrol.org
- Always italicize *Be Fierce. Take Control.*[®] with the registered trademark symbol (®) that can be found in the MS Word command ribbon under the “Insert/Symbols” tab.
 - » CORRECT: *Be Fierce. Take Control.*[®]
 - » INCORRECT: *Be Fierce. Take Control.*[®]
 - » INCORRECT: *Be Fierce. Take Control.*

Campaign assets provided in the bundles

To make it easier to follow the above guidelines, we provide preapproved graphics for your organization to use on different social media platforms in the [Social media assets bundle](#) and [Event asset bundle](#). Customizing the assets for your specific event and community is important – you know more about what will interest your audience. That’s why we’ve provided instructions for you to customize the assets in the [Social media assets bundle](#) and [Event asset bundle](#) resources.

Always keep in mind when posting assets:

- Use scientifically accurate information when talking about lupus. We recommend using information provided in the [Social media assets bundle](#), the [Lupus fact sheet](#), or on the *Be Fierce. Take Control.*® website (befiercetakecontrol.org). If you’re unsure of the accuracy – don’t post it!
- Abide by the campaign logo, color, and font guidelines above. If you’re unsure that your custom asset will break the guidelines – don’t post it!

SELF
CARE
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SELFISH

Event ideas



A well-designed hands-on community event can be a very effective way to raise lupus awareness. Relevant, engaging, entertaining activities can grab the attention of your intended audience and get them to spread messages about lupus awareness. To decide what type of event you should hold, think about the types of activities that would interest African American women age 18-25 who live in your community.

The list below represents a wide range of hands-on events that can be held in your community:

BE FIERCE. TAKE CONTROL.® GIRL'S NIGHT

Partner with a local beauty salon, nail salon, lash salon, beauty supply store to host a girl's night event. Invite guest speakers (e.g., local rheumatologist, medical expert, fitness expert, beauty expert, women with lupus, etc.) to spur a conversation about lupus awareness and the importance for African American women age 18-25 to take control of their health. Encourage attendees to post about the event on social media with the #BeFierceTakeControl hashtag.

BE FIERCE. TAKE CONTROL.® POP UP GALLERY

Recruit young artists to create their own lupus awareness posters using the Be Fierce. Take Control.® theme. Host a "gallery opening" to highlight the art and inspire a conversation about lupus awareness and the importance for African American women age 18-25 to take control of their health. Encourage attendees to post about the event on social media with the #BeFierceTakeControl hashtag.

BE FIERCE. TAKE CONTROL.® OPEN MIC NIGHT

Encourage African American women between the ages of 18-25 to participate in an open mic night to share their stories containing themes of "fierceness" or "taking control" through spoken word, visual art, performance art and original music. Encourage attendees to post about the event on social media with the #BeFierceTakeControl hashtag.

BE FIERCE. TAKE CONTROL.® SCREENINGS

Show the Be Fierce. Take Control.® lupus awareness video before or after worship services or other large group gatherings and events. Invite a local African American woman with lupus to share her lupus journey and spur a conversation with the audience about lupus awareness and taking control of their health. Encourage attendees to post about the event on social media with the #BeFierceTakeControl hashtag.



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RESOURCES

<u>Presentation script</u>	40
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Presentation script

Slide Screenshot

Script

SLIDE 1



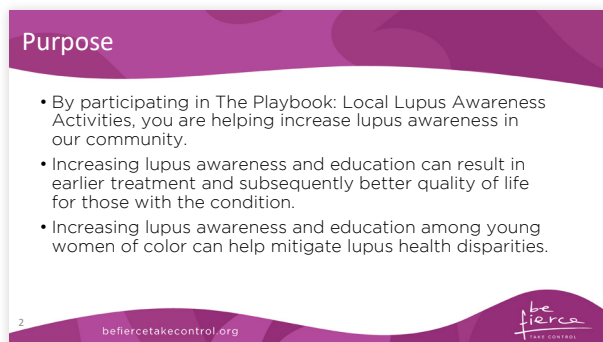
DO: [Welcome supporters to the education session.]

SAY: *The American College of Rheumatology (ACR) has launched the Playbook, a set of local lupus awareness activities, which we will implement in our community. The goal of the campaign is to raise awareness of the signs and symptoms of lupus and ultimately help reduce health disparities by reducing the time to diagnosis.*

This education session includes information about lupus, its disproportionate impact on women, African American women, and why it's important for us to do something. With this information, we will be equipped to hold a hands-on lupus awareness event and answer questions about lupus on-site.

DO: [Advance to the next slide.]

SLIDE 2

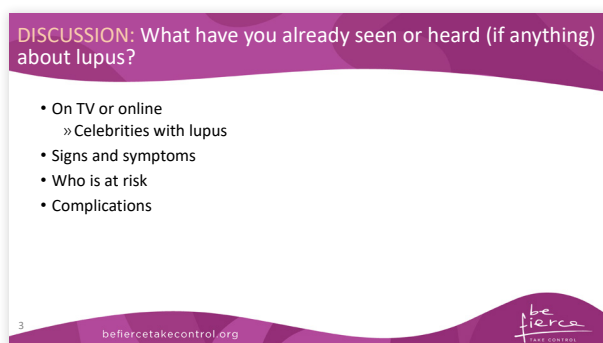


SAY: *By participating in The Playbook: Local Lupus Awareness Activities, we are helping to increase lupus awareness in your community, which can result in earlier treatment and better quality of life, and help mitigate lupus health disparities.*

Later, I'll explain how you can help by volunteering for the hands-on event and increasing lupus awareness among friends and family!

DO: [Advance to the next slide.]

SLIDE 3



DO: [Open the education session with a brief discussion. Allow plenty of time to have an open discussion, and encourage active participation.]

SAY: *Before we learn more about lupus, let's discuss what we have already seen or heard (if anything) about lupus.*

DO: [Call on 3-5 supporters to discuss celebrities who have lupus and what they may have seen on TV and online about lupus.]

SAY: *Thank you for sharing what you have seen and heard about lupus. Now, I'm going to take a few minutes to share some facts about and definitions of lupus with you.*

DO: [Advance to the next slide.] Continued on next page ➤

SLIDE 4

What is lupus?

- Systemic lupus erythematosus, referred to as SLE or 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 can cause pain, inflammation, and tissue damage to various organs in the body like the kidneys, liver, heart, lungs, and brain.
- While there is no cure for lupus, medical treatments and lifestyle changes can help control it.

4

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SAY: *Lupus is a chronic disease, meaning it is a long-term disease that should be managed. Lupus is also an autoimmune disease. In autoimmune diseases, like lupus, the immune system is out of control and mistakenly attacks healthy tissue.*

Lupus can cause pain, inflammation, and tissue damage to various organs in the body like the kidneys, liver, heart, lungs and brain. Some lupus patients experience kidney involvement that if not managed, can lead to organ damage. While there is no cure for lupus, medical treatments and lifestyle changes may help control it.

DO: [Advance to the next slide.]

SLIDE 5

What are the signs and symptoms of lupus?



Joint pain or swelling

Extreme exhaustion

Rashes

Low-grade fevers

Mouth sores

5

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SAY: *Lupus has many different signs and symptoms. Lupus is hard to detect because symptoms look like the symptoms of other diseases.*

Some of the most common signs and symptoms of lupus are:


- Pain or swelling in your joints that always seems to come back
- Reoccurring sores in your mouth
- Rashes on your skin
 - The lupus "butterfly rash" appears across the nose and cheeks
- Low-grade fevers you can't explain
- Extreme exhaustion no matter how much sleep you get

Lupus symptoms can show up in many different ways. Sometimes they appear out of the blue, and sometimes they can linger. Each person's experience with lupus is unique.

DO: [Advance to the next slide.]

SLIDE 6

Examples of joint swelling and face rash



Joint swelling

Butterfly rash

6

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SAY: *The first picture shows an example of joint swelling. The second picture shows a butterfly rash, which is a butterfly-shaped rash on the cheeks and nose.*


DO: [Advance to the next slide.]

Continued on next page

SLIDE 7

DISCUSSION: Do you know someone with lupus?

- How has that experience affected you?
- How did the signs and symptoms of lupus affect them?
- How were you supportive of your loved one's needs?

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DO: [Lead a brief, 5-10 minute discussion about supporters' personal experiences with lupus, either in their lives or in the lives of others. Allow time to have an open discussion, and encourage active participation.]


SAY: *It's important to remember that lupus affects real people. Would anyone like to share how it's touched your life or the life of a friend or family member? When you share your experiences, please don't mention names. Also, please be respectful of others: experiences shared in this session, stay in this session.*

DO: [Advance to the next slide.]

SLIDE 8

What causes lupus?

- The cause of lupus is unknown, but many scientists believe lupus is linked to environmental, genetic, and hormonal factors.
- Most people with lupus do not have family members with the disease; however, some people with lupus do have a family history of lupus.
- This means lupus isn't always hereditary.

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SAY: *The cause of lupus is unknown. Scientists don't have a clear answer of what causes lupus, but believe lupus is linked to environmental, genetic, and hormonal factors. This means that lupus isn't always hereditary.*


But, people with lupus can live full and active lives, especially when they receive an early diagnosis and begin treatment. This is why our goal is to spread awareness in our community – we want anyone who may be experiencing lupus symptoms to talk to their doctor.

DO: [Advance to the next slide.]

SLIDE 9

Who is at risk for lupus?

- Approximately 160,000 to 320,000 people in the U.S. have lupus.
- Lupus affects women more than men.
 - » Approximately 90 percent of individuals with lupus are female.
 - » Lupus also usually begins during child bearing years (15-44).
- African Americans, Latinos, Asians, and American Indians/Alaska Natives—are affected more than Whites.
- Lupus is two to three times more common in African American women compared to White women.

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SAY: *While it is unclear why lupus occurs, and there is no way to prevent lupus, we do know that some populations are affected by lupus more than others. Approximately 160,000 to 320,000 people in the U.S. have lupus. However, the true number of people affected by lupus remains unknown.*

Lupus affects women more than men, and lupus usually begins during childbearing years (15-44). Racial and ethnic groups are affected more than Whites. African American women are also affected more than White women – lupus is two to three times more common in African American women compared to White women.

These numbers emphasize the importance of seeing a doctor when you begin experiencing symptoms or just “feel off” to get a proper diagnosis and treatment to prevent poor health outcomes.

DO: [Advance to the next slide.]

Continued on next page ❖

SLIDE 10

Lupus Health Disparities

- When certain preventable diseases, death, and disability are more common in specific populations, it is sometimes called a "health disparity".
- Health disparities result from the complex interaction among genetic and environmental factors (e.g. race, low socioeconomic status) and health behaviors (e.g. treatment adherence, health knowledge).
- Some researchers think that lupus health disparities may be, in part, due to limited health care access and lack of disease knowledge among affected populations.

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SAY: *As I just mentioned, lupus is two to three times more common among African American women. This is an example of a health disparity, which is when certain diseases are more common or adverse in specific populations.*

Health disparities result from genetic and environmental factors and health behaviors. Some researchers think that lupus health disparities may be, in part, due to limited health care access and lack of disease knowledge among affected populations.

DO: [Advance to the next slide.]

SLIDE 11

DISCUSSION: Why do you think awareness about lupus is low?

- In your community
- Among your friends and family
- Nationwide

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DO: [Take this time to have a short discussion about lupus awareness. Allow plenty of time to have an open discussion, and encourage active participation.]

SAY: *Think about the facts I shared earlier in this presentation. Why do you think lupus awareness is low?*

DO: [Call on three to five participants to discuss awareness among peers, family, and nationwide.]

SAY: *What new facts surprised you and what will you take away from this session to share with people during the hands-on event? What were some prior misconceptions you had about lupus?*

DO: [Advance to the next slide.]

SLIDE 12

How is lupus diagnosed?

- Lupus is hard to detect because the signs and symptoms are similar to other diseases and may come and go.
- Lupus can often be misdiagnosed if only a single blood test is used for diagnosis.
- A health care provider should evaluate your symptom history, conduct a physical exam, and conduct a series of lab tests for a diagnosis.
- Because diagnosis can be challenging, your health care provider may refer you to a rheumatologist, a doctor that specializes in autoimmune diseases.
- Getting an early diagnosis of lupus is critical to preventing long-term consequences of the disease.

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SAY: *Lupus is hard to detect because the signs and symptoms are similar to other diseases and may come and go, making it challenging for many health care providers to recognize. Lupus can often be misdiagnosed, and a health care provider should evaluate a symptom history, conduct a physical exam, and conduct a series of lab tests for a diagnosis.*

Because diagnosis can be challenging, a health care provider may refer a patient to a rheumatologist, a doctor that specializes in autoimmune diseases. Sometimes, other specialists, like a dermatologist, may also be involved, because lupus can affect so many different organs.

Getting an early diagnosis of lupus is critical. Late diagnosis and delayed treatment can contribute to health complications and increased poor health outcomes. It is important for patients to share detailed information about their medical history with their health care providers to help them make an accurate diagnosis.


DO: [Advance to the next slide.]

Continued on next page

SLIDE 13

How is lupus treated?

- The goals of lupus treatment:
 - » Work with health care providers to manage medications, side effects, and healthy life style choices.
 - » Stop and reverse ongoing organ inflammation.
 - » Prevent or limit irreversible organ damage.
- Lupus requires a team approach, because it can affect so many different organs.
- Common treatment includes immunosuppressive drugs (hydroxychloroquine) and anti-inflammatory drugs (corticosteroids).
- **Early diagnosis** and proper medical care significantly improve function and quality of life for lupus patients.

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SAY: The most important goal of lupus treatment is to work with health care providers to manage medications, side effects, and healthy lifestyle choices. Lupus treatment stops and reverses organ inflammation, which can prevent or limit damage to major organs.


While a rheumatologist provides an official diagnosis, lupus is often managed by a team of doctors and a supportive network of family and friends. Getting an early lupus diagnosis is critical to improving the quality of life for lupus patients, and preventing long-term consequences of the disease.

DO: [Advance to the next slide.]

SLIDE 14

The importance of early diagnosis

- Getting an early lupus diagnosis is critical to preventing long-term consequences of the disease.
- Causes of premature death associated with lupus are mainly organ failure, infection, or cardiovascular disease.
- Lupus, especially when not treated, can lead to organ damage and reduce physical, mental, and social health.
 - » Survival rates for lupus patients have improved drastically over the past 50 years due to earlier diagnosis, more effective treatments, and better management of organ inflammation.

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SAY: Getting an early diagnosis of lupus is critical. Late diagnosis and delayed treatment can contribute to health complications and increased poor health outcomes like organ failure, infection, or cardiovascular disease.

While there is no cure for lupus, medical treatments and lifestyle changes can help control it. Survival rates for lupus patients have improved drastically over the past 50 years, due to early diagnosis.


For this reason, it's critical that people seek medical care to get an early lupus diagnosis and treatment to prevent serious organ damage.

DO: [Advance to the next slide.]

SLIDE 15

Be Fierce. Take Control.®

- The **Be Fierce. Take Control.®** campaign is designed to educate and empower young women of color.
 - » Use the resources in The Playbook: Local Lupus Awareness Activities
 - » Visit befiercetakecontrol.org – a website that provides more information and resources to help.
 - » Watch the campaign video – <https://youtu.be/tj8WTQSEyDE>

15 befiercetakecontrol.org 

SAY: The American College of Rheumatology (ACR) wants supporters, like you, to use this Playbook to get you and your community to Be Fierce. Take Control. The goal of the campaign is to raise awareness of the signs and symptoms of lupus, and ultimately help reduce health disparities by reducing the time to diagnosis. The campaign uses social media, video, digital advertising, and audience engagement to reach young African American women and educate them about lupus via the campaign website: befiercetakecontrol.org.

DO: [Play the campaign video in a separate window.]

DO: [Advance to the next slide after the video ends.]

Continued on next page 

SLIDE 16

Next steps

- Review the [Lupus fact sheet – detailed](#) and other Playbook resources.
- Establish committees to lead the social media campaign and the hands-on event.
 - Volunteers to promote the event on our social media accounts.
 - Volunteers for event set-up, tabling, and event clean-up.
- Host the hands-on awareness event.
 - Spread lupus awareness in the community.
 - Celebrate the ways local women are *being fierce* and *taking control* of their own health.

16 befiercetakecontrol.org *be fierce TAKE CONTROL*

DO: [Hand out copies of the [Lupus fact sheet – detailed](#) and pass around the interest sheet for supporters to sign up for event planning work groups.]

SAY: *Next, we all need to review the Playbook and its resources, and decide who will serve on event planning work groups, and host the on-site awareness event. During the on-site awareness event we will pass out information about lupus and encourage people to stop by our table and use the art supplies (i.e., markers, paint, paper, etc.) to celebrate the ways they're taking control of their health. The Playbook has easy-to-use talking points for us to use as attendees stop by the table with questions about lupus.*

DO: [Advance to the next slide.]

SLIDE 17

DISCUSSION: How do you feel about spreading the word about lupus on campus?

- Concerns you might have
- What excites you
- Ideas for how to engage your peers

17 befiercetakecontrol.org *be fierce TAKE CONTROL*

DO: [Take this time to have a short discussion about spreading the word in the community. Allow plenty of time to have an open discussion, and encourage active participation.]

SAY: *Now, we're at the end of the session. But our work is not over! How do you feel about spreading the word about lupus around the community?*

DO: [Advance to the next slide at the end of the discussion.]

SLIDE 18

Takeaways

- Think you have the symptoms? – schedule a doctor's appointment.
- Early diagnosis is critical to preventing long-term consequences of the disease.
- Share the campaign website with friends: befiercetakecontrol.org

18 befiercetakecontrol.org *be fierce TAKE CONTROL*

SAY: *If you've been experiencing symptoms (one or more), it's time to schedule an appointment to talk to your health care provider! There is a guide on the campaign website if you're not used to scheduling your own health appointments.*

If you think a friend may be experiencing symptoms of lupus, share befiercetakecontrol.org – a website that provides more information and resources to help.

When spreading the word on social media, don't forget to include the hashtag(s) #BeFierceTakeControl and [insert organization hashtag if applicable] on Twitter, Facebook, Instagram and Snapchat!

DO: [Advance to the next slide.]

Continued on next page

SLIDE 19

DISCUSSION

Any further questions about lupus?

19 befiercetakecontrol.org

DO: [Open the discussion floor for final questions. Allow plenty of time to have an open discussion, and encourage active participation.]

SAY: *Does anyone have any further questions about lupus?*

DO: [Advance to the next slide.]

SLIDE 20

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20 befiercetakecontrol.org

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SLIDE 21

AMERICAN COLLEGE OF RHEUMATOLOGY
EDUCATION • TREATMENT • RESEARCH

the lupus initiative
A COMMITMENT TO PROMOTING HEALTH AND WELL-BEING

This Playbook was supported by the Grant or Cooperative Agreement Number, 6 NUS8 DP006138, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

www.befiercetakecontrol.org

SAY: *Thanks for coming! We'll be following up soon about the upcoming social media campaign and hands-on event.*

DO: [End presentation.]

Lupus fact sheet – detailed

What is lupus?

Systemic lupus erythematosus, referred to as SLE or 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 can cause pain, inflammation, and tissue damage to various organs in the body. While there is no cure for lupus, medical treatments and lifestyle changes can help control it.

Who is at risk for lupus?

The cause of lupus is unknown, but many scientists believe lupus is linked to environmental, genetic, and hormonal factors. While anyone can develop lupus, women are affected more than men. Lupus is two to three times more common in African American women compared to White women. Lupus also usually begins during child-bearing years (15-44).

What are the complications of lupus?

Because lupus usually begins during child-bearing years (15-44), it can seriously affect young women's goals for education, career, family, and health. Lupus, especially when not treated, can lead to organ damage and reduce physical, mental, and social health.

What are the signs and symptoms of lupus?

Lupus symptoms can show up in many different ways. Sometimes they appear out of the blue, and sometimes they can linger. Each person's experience is unique, so your symptoms may not be the same as someone you know who has been diagnosed with lupus.

Below are some of the most common signs and symptoms of lupus:

- Pain or swelling in your joints that always seems to come back
- Reoccurring sores in your mouth
- Rashes on your skin
- Low-grade fevers you can't explain
- Extreme exhaustion no matter how much sleep you get

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How is lupus diagnosed?

Lupus is hard to detect because the signs and symptoms are similar to other diseases and may come and go. Lupus can often be misdiagnosed if only a single blood test is used for diagnosis. A health care provider should evaluate your symptom history, conduct a physical exam, and conduct a series of lab tests for a diagnosis. Because diagnosis can be challenging, your health care provider may refer you to a [rheumatologist](#), a doctor that specializes in autoimmune diseases.

How is lupus treated?

Lupus requires a team approach, because it can affect so many different organs. Common treatment includes immunosuppressive drugs (hydroxychloroquine) and anti-inflammatory drugs (corticosteroids). Early diagnosis and proper medical care significantly improve function and quality of life for lupus patients.

What can I do?

Getting an early diagnosis of lupus is critical to preventing long-term consequences of the disease. If you've been experiencing symptoms (one or more), it's time to schedule an appointment to talk to your health care provider. If you think a friend may be experiencing symptoms of lupus, share befiercetakecontrol.org – a website that provides more information and resources to help.

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Guest speaker recruitment

Guest speakers can give additional information and enrich both your lupus presentation and your *Be Fierce. Take Control.*® hands-on event. Some types of guest speakers you might want to invite are:

Medical professionals

- Reach out to your university health center, local rheumatologist, local hospital, or local doctor's office to see if they have a nurse or doctor who knows about lupus.
- Use the [American College of Rheumatology's directory](#) to find a rheumatologist near you.

Advocates for lupus awareness

- Reach out to local community organizations that focus on lupus awareness or public health.
- Reach out to national organizations, such as the [American College of Rheumatology](#).

Individuals with lupus

- Ask your fellow supporters if they have friends or family members who have lupus.
- Use social media to ask members of your community if they have or know someone who has lupus and would be interested in speaking at your event.

Once you have a list of potential contacts, use the email and call script templates below to reach out to potential guest speakers.

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Email template – *Be Fierce. Take Control.*® hands-on event examples

If emailing an organization or medical professional

Dear **[Name]**,

Hello, my name is **[Name]** and I am a part of **[organization name]**. We write to ask you if you would be interested in speaking at or attending our *Be Fierce. Take Control.*® hands-on event. We're holding this event and conducting other activities as a part of a campaign to raise awareness of the signs and symptoms of lupus, and ultimately help reduce health disparities by reducing the time to diagnosis. These activities were developed by the American College of Rheumatology.

As a leader in the field, with experience caring for people with lupus, your participation in our event would enrich our community's lupus awareness. We're tentatively planning the event for **[time, location, and date]**.

We would be happy to talk about this in more detail if you are interested in speaking at or attending the *Be Fierce. Take Control.*® hands-on event. You can contact us at **[contact information]**.

If emailing an individual with lupus

Dear **[Name]**,

Hello, my name is **[Name]** and I am a part of **[organization name]**. We write to ask you if you would be interested in speaking at or attending our *Be Fierce. Take Control.*® hands-on event. We're holding this event and conducting other activities as a part of a campaign to raise awareness of the signs and symptoms of lupus, and ultimately help reduce health disparities by reducing the time to diagnosis. These activities were developed by the American College of Rheumatology.

As an individual with lupus, your participation in our event would significantly enrich our community's lupus awareness and knowledge by providing your unique experiences and perspectives. We're tentatively planning the event for **[time, location, and date]**.

We would be happy to talk about this in more detail if you are interested in speaking at or attending the *Be Fierce. Take Control.*® hands-on event. You can contact us at **[contact information]**.

Continued on next page 

Call script template – *Be Fierce. Take Control.*® hands-on event examples

If calling an organization or medical professional

Hello, my name is **[Name]** and I am a part of **[organization name]**. I'm calling to ask if you would be interested in speaking at or attending our *Be Fierce. Take Control.*® hands-on event. We're holding this event and conducting other activities as a part of a campaign to raise awareness of the signs and symptoms of lupus, and ultimately help reduce health disparities by reducing the time to diagnosis. These activities were developed by the American College of Rheumatology.

As a leader in the field, with experience caring for people with lupus, your participation in our event would enrich our community's lupus awareness. We're tentatively planning the event for **[time, location, and date]**.

If interested, I would be happy to talk about this in more detail.

If they say no:

We understand. Thank you for your time and have a nice day!

If they ask for more event details:

Our event will involve encouraging young women in our community to celebrate the ways they are fierce and what taking control of their health means to them. This could range from making healthy food choices or making an appointment with a health care provider. The goal of our visual hands-on event is to get the attention of our community, especially young African American women. We also plan to distribute lupus fact sheets around the community that address (1) what lupus is; (2) what the signs and symptoms of lupus are; and (3) what to do if you suspect you (or someone you know) has lupus.

Do you have any questions?

Thank you very much and have a nice day.

If calling an individual with lupus

Hello, my name is **[Name]** and I am a part of **[organization name]**. I'm calling to ask if you would be interested in speaking at or attending our *Be Fierce. Take Control.*® hands-on event. We're holding this event and conducting other activities as a part of a campaign to raise awareness of the signs and symptoms of lupus, and ultimately help reduce health disparities by reducing the time to diagnosis. These activities were developed by the American College of Rheumatology.

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As an individual with lupus, your participation in our event would significantly enrich our community's lupus awareness campaign by providing your unique experiences and perspectives. We're tentatively planning the event for **[time, location, and date]**.

If interested, I would be happy to talk about this in more detail.

If they say no:

We understand. Thank you for your time and have a nice day!

If they ask for more event details:

Our event will involve encouraging our community to **[insert activity description, e.g., selfie project]**. This could range from making healthy choices while dining or making an appointment with a healthcare provider. The goal of our visual hands-on event is to get the attention of our community, especially young African American women. We also plan to distribute lupus fact sheets that address (1) what lupus is; (2) what the signs and symptoms of lupus are; and (3) what to do if you suspect you (or someone you know) has lupus.

Do you have any questions?

Thank you very much and have a nice day.

If leaving a voicemail

Hello, my name is **[Name]** and I am a part of **[organization name]**. I'm calling to ask if you would be interested in speaking at or attending our *Be Fierce. Take Control.*[®] hands-on event.

We're holding this event and conducting other activities as a part of a campaign to raise awareness of the signs and symptoms of lupus, and ultimately help reduce health disparities by reducing the time to diagnosis. These activities were developed by the American College of Rheumatology.

I'd be happy to talk about this in more detail if you are interested in speaking at or attending the event. You can contact me at **[contact information]**.

I look forward to speaking with you!

Thanks.

Lupus presentation announcement

Are you interested in learning about a disease that hides in plain sight?

Find out if it means something.

FEELING OFF
IS A REAL THING

Lupus often hides in plain sight – getting an **early diagnosis** is critical to preventing the long-term consequences of lupus.

*be
fierce*
TAKE CONTROL
befiercetakecontrol.org
#BeFierceTakeControl



Tate Plaza is participating in The Playbook: Local Lupus Awareness Activities, which is a campaign developed by the American College of Rheumatology (ACR).

We are in a position to change the level of lupus awareness in our community! If you want to **#BeFierceTakeControl** of your health – come to our special lunch and learn event at

Tate Plaza on Thursday, May 18 from Noon – 1:00 PM

See Tate Plaza's Community Relations Director (xyz@xyz.com) with any questions or concerns.

Continued on next page ➤

Examples of social media posts

Feeling off is a real thing: Find out if it means something – come to our lupus lunch & learn on Thursday, May 18 at Mt. Olive AME Zion Church. [#BeFierceTakeControl](#) [#TATE](#)

Attn: YAMs – we can change the level of [#lupus](#) awareness in our community! Come to our special lunch & learn event to learn more on Thursday, May 18 at Mt. Olive AME Zion Church. [#BeFierceTakeControl](#) [#TATE](#) [#OLIVE](#)

Let's talk about [#lupus](#): a disease that hides in plain sight – come to the meeting tonight for a special presentation [#BeFierceTakeControl](#) [#TATE](#) [#OLIVE](#)

Meeting tonight will feature a special [#lupus](#) presentation – make sure you're there! [#BeFierceTakeControl](#) [#TATE](#) [#OLIVE](#)

Examples of email text

Fellow **[organization name]** members,

Our group is participating in The Playbook: Local Lupus Awareness Activities, which is part of a campaign developed by the American College of Rheumatology (ACR). As part of this campaign, we are hosting a special lupus presentation at our meeting on Thursday, May 18 from 10:00 AM – Noon.

Lupus is a chronic disease, meaning it is a long-term disease that should be managed. While anyone can develop lupus, women are affected more than men. Lupus is two to three times more common in African American women compared to White women. Lupus also usually begins during child-bearing years (15-44), so it can seriously affect young women's goals for education, career, family, and health.

We are in a position to change the level of lupus awareness in our community! If you are interested, make sure you attend our meeting on Thursday, May 18 from 10:00 AM – Noon.

Contact our Community Relations Director (xyz@xyz.com) with any questions or concerns.

Thanks,

Social media planning sheet

Post #	Post text	Designated developer	Social media platform	Type of post	Scheduled date	Designated poster	Designated responder to comments	Notes
#1	Feeling off is a real thing – find out if it means something. #BeFierceTakeControl	Keisha	Facebook	Lupus awareness with image from Social media assets bundle .	May 11, 2019 at 11:00 AM	Laura	Laura	Use Lupus fact sheet to answer any comments/questions about lupus on the post.
#2	@OLIVE is taking control by making Sundays home cooked dorm meal day. #BeFierceTakeControl	Lana	Instagram	Taking control of your health selfie.	May 18, 2019 at 6:00 PM	Lana	Lana	Offer a \$10 Starbucks gift card giveaway for TAU members. Every selfie is an entry to win.
#3	Check out our upcoming event at Tate Plaza on Tuesday, June 1 from 11:00 AM – Noon. #BeFierceTakeControl #YAMS	Melody	Twitter	Advertisement for event with image from Event asset bundle .	May 25, 2019 at 8:00 AM	Melody	Melody	Make sure TAU members retweet the post and tell their friends about the event.



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Lupus fact sheet

What is lupus?

Lupus is a chronic disease, meaning it is a long-term disease that needs to 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 attacks healthy tissue.

Who is at risk for lupus?

While anyone can develop lupus, women are affected more than men. Lupus is two to three times more common in African American women compared to White women. Lupus also usually begins during child-bearing years (15-44).

What are the complications of lupus?

Because lupus usually begins during child-bearing years (15-44), it can seriously affect young women's goals for education, career, family, and health. Lupus, especially when not treated, can lead to organ damage and reduce physical, mental, and social health.

What are the signs and symptoms of lupus?

The most common signs and symptoms of lupus are: pain or swelling in your joints that always seems to come back; reoccurring sores in your mouth; rashes on your skin; low-grade fevers you can't explain; and extreme exhaustion no matter how much sleep you get.

How is lupus diagnosed?

Lupus is hard to detect because the signs and symptoms are similar to other diseases and may come and go. Because diagnosis can be challenging, your health care provider may refer you to a [rheumatologist](#), a doctor that specializes in autoimmune diseases.

What can I do?

If you've been experiencing symptoms (one or more), it's time to schedule an appointment to talk to your health care provider. If you think a friend may be experiencing symptoms of lupus, share befiercetakecontrol.org – a website that provides more information and resources to help.

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#BeFierceTakeControl community contributions

Take a look at examples of how other people are starting conversations about lupus on social media. Post-worthy activities might include:



Visit the Centers for Disease Control and Prevention's (CDC) [Guide for Writing Social Media](#) for more direction and examples of how to develop a social media marketing plan.

Search the hashtag (#BeFierceTakeControl) across different social media platforms (Facebook, Twitter, Instagram) to see how it's being used. Carefully review each post for accuracy and appropriateness, then repost and use those examples of community activities on your organization's social media platforms.



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Tips for responding to social media questions

Frequently asked questions and answers you can use when responding to questions on social media:

What is lupus?

A: A chronic autoimmune disease that attacks healthy tissue. Check out befiercetakecontrol.org.

How is lupus diagnosed?

A: Doctors look at your symptom history, do a physical exam, and get a series of lab tests for a diagnosis. Check out befiercetakecontrol.org.

A: A rheumatologist, a doctor that specializes in autoimmune diseases, is often involved in the diagnosis. Check out befiercetakecontrol.org.

What are the most common symptoms of lupus?

A: Painful or swollen joints, rashes across the nose and cheeks, and extreme exhaustion that lasts for weeks. Check out befiercetakecontrol.org.

Why is it hard to diagnose lupus?

A: Symptoms may come and go, so it's important to keep track. Check out befiercetakecontrol.org.

A: Lupus is “the great imitator” because the signs and symptoms are similar to other diseases. Check out befiercetakecontrol.org.

How do I prepare for a doctor's appointment?

A: Use the [Patient-Physician Dialogue Tool](#) from The Lupus Initiative site: thelupusinitiative.org.

A: Track your symptoms in a journal, take pictures of rashes and other symptoms to show your doctor what's going on. Check out befiercetakecontrol.org.

A: Be detailed and accurate when talking to your doctor. Check out befiercetakecontrol.org.

What resources are available for someone who may be experiencing signs and symptoms of lupus?

A: Share the lupus awareness campaign with friends and family at befiercetakecontrol.org.

A: Check out befiercetakecontrol.org and thelupusinitiative.org.

What are some tips of good ways to cope with lupus?

A: Build a support network of family and friends. Check out befiercetakecontrol.org.



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Event planning sheet

Use this handout to plan your organization's lupus awareness event.

Task	Done?	Notes and Ideas
Choose a date and time for the event.	<input type="checkbox"/>	
Reserve space for event.	<input type="checkbox"/>	
Buy art supplies and posterboard for event signs.	<input type="checkbox"/>	
Map out logistics (e.g., places to make signs and take selfies at participating venue.)	<input type="checkbox"/>	
Decide on places to post flyers and obtain permission to post them.	<input type="checkbox"/>	
Make event sign and print copies of the Lupus fact sheet .	<input type="checkbox"/>	
Brainstorm fundraising strategies. See Appendix A. Fund your event .	<input type="checkbox"/>	
Submit event descriptions to community announcement listservs.	<input type="checkbox"/>	
Determine the number of volunteers needed.	<input type="checkbox"/>	
Post Event volunteer sign-up sheet(s) .	<input type="checkbox"/>	
Brainstorm social media strategy. See Spread the word .	<input type="checkbox"/>	
Brainstorm event activities. See Host an event .	<input type="checkbox"/>	
Decide if you will evaluate your event. See Appendix B. Measure your event's impact .	<input type="checkbox"/>	



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Event volunteer sign-up sheet

Set up	Date _____	
Hour block	Volunteer name	Contact number and email

Event	Date _____	
Hour block	Volunteer name	Contact number and email

Take-down	Date _____	
Hour block	Volunteer name	Contact number and email



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Talking points for the event

Mission: To raise awareness about lupus: (1) what lupus is; (2) what the signs and symptoms of lupus are; and (3) what to do if you suspect you (or someone you know) has lupus.

Here are some quick responses you can have ready for visitors who pass by the event table:

What is this display about?

- We're using The Playbook: Local Lupus Awareness Activities to spread the word about lupus in our community.

What does it mean to #BeFierceTakeControl?

- Being fierce is about advocating for yourself, listening to your body, and taking action to live a healthier life.

What is lupus?

- Lupus is a chronic disease, meaning it is a long-term disease that needs to 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 attacks healthy tissue.
- Lupus symptoms can vary and make it difficult to diagnose, because the signs and symptoms are similar to other diseases and may come and go.
- While anyone can develop lupus, women are affected more than men. Lupus is two to three times more common in African American women compared to White women.

Why do I need to know about lupus now? I'm young!

- Early detection may prevent potential long-term damage to your health.
- Because lupus usually begins during child-bearing years (15-44), it can seriously affect young women's goals for education, career, family, and health.

Am I at risk? What can I do to prevent it?

- Make an appointment with a health provider to get checked out if you feel you may have lupus symptoms.
- There is no current cure and no definitive answer on how to prevent lupus, but early diagnosis is key to managing the disease.

I don't have lupus, but I know people who do. How can I help?

- Check out befiercetakecontrol.org to find more info on how to be a supportive friend or take control of your own health.

How can I stay involved?

- Join the campaign by using the hashtag #BeFierceTakeControl on social media!
- Visit the website befiercetakecontrol.org for more information about lupus and take control of your health.



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Social media assets bundle

The social media assets bundle provides you with social media posts, images, and strategies that you can use along with your [Social media planning sheet](#). During your social media work group planning meeting, use these assets and your [Social media planning sheet](#) to decide the best social media strategy for your organization.

As a reminder, the objectives of your social media campaign are to:

1. Increase lupus awareness in your community.
2. Encourage young women to learn more about lupus by visiting the *Be Fierce. Take Control.*® website (befiercetakecontrol.org).
3. Empower young women in your community to take control of their health.

Please keep the following in mind:

- Avoid stretching, condensing, or resizing the assets.
- Avoid recoloring the assets.
- Do not recreate the assets. Use the files provided.
- Do not recreate the design style.

See [Appendix C. Be Fierce. Take Control.](#)® for more specific guidelines on using these images and copyright disclaimers.



Facebook/Instagram posts (no restrictive character limit)

- Self-care isn't selfish. Take control of your health at befiercetakecontrol.org. #BeFierceTakeControl
- Feeling not quite like yourself? It's time to stop procrastinating and take control of your health. Your symptoms could mean something – go to befiercetakecontrol.org to learn more. #BeFierceTakeControl
- If you're getting plenty of sleep but you're still exhausted, your body might be trying to tell you something. Find out more at befiercetakecontrol.org. #BeFierceTakeControl

Twitter posts (140 characters)

- Let's talk about #lupus—a disease that hides in plain sight. #BeFierceTakeControl
- Learn the signs of #lupus at befiercetakecontrol.org. #BeFierceTakeControl
- @OLIVE is #BeFierceTakeControl of our health. Are you? – go to befiercetakecontrol.org to learn more.
- If you've been feeling not quite like yourself but can't pinpoint what's wrong, it's time to #BeFierceTakeControl. Learn more at befiercetakecontrol.org.

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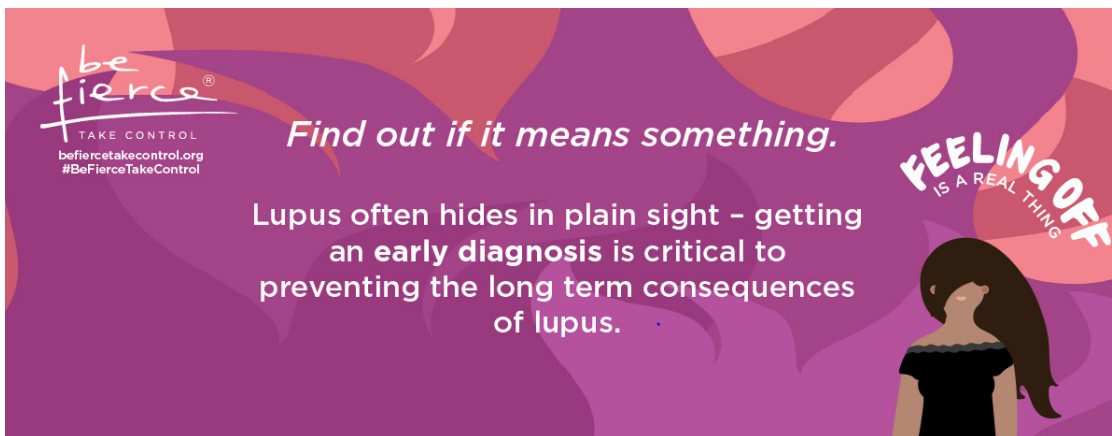
Profile badges

Promote your social media campaign by uploading these profile badges as your organization's profile picture on Facebook, Twitter and Instagram. Ask your fellow supporters to also make it their profile picture on their personal accounts!



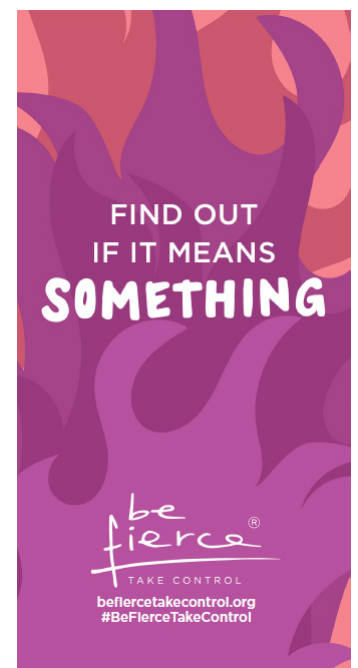
Cover photo

Promote your social media campaign by uploading this cover photo as your organization's cover photo on Facebook and Twitter. Ask your fellow supporters to also make it their cover photo on their personal accounts!



Lupus awareness images

Post these lupus awareness images on your organization's social media platforms. These images are aimed to promote lupus awareness, defined as (1) what lupus is; (2) the signs and symptoms of lupus; and (3) what to do if they suspect they (or someone they know) has lupus.



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Create a story for your campaign

Creating a story on Instagram and/or Snapchat can be a great way to share your campaign messages.

To create a new Snapchat story, go to the stories homepage and then click on the plus sign in the upper right-hand corner. You can then name your story (#BeFierceTakeControl) and select between a few options. You can geofence an area and chose to either (1) let any of your Snapchat friends within that area contribute or (2) let any of your Snapchat friends and friends of your Snapchat friends within that area contribute. However, you can also manually select all your Snapchat friends to create a story where they can all contribute without using the geofence option.

To add to your Instagram story, click on “your story” at the upper left-hand corner. You can then take pictures or videos to add to your story. Your followers can then send you message replies about your story.

Also, make sure to share the campaign Snapchat QR code for the *Be Fierce. Take Control.*® campaign website on your story!



Tip:

Get more Snapchat friends by posting your organization’s Snapchat username and scannable QR code on other social media posts!



Snapchat Geofilter

Snapchat also allows organizations to create a custom filter, pick dates, and set a Geofence for their filter. Snapchat charges for this service; however, they also offer community Geofilters for public places. For more information, see snapchat.com/geofilters.

IMPORTANT: In order to fully document your social media campaign, please make sure you save your Snapchat posts and interactions before they expire.

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Key messages

Want to spread the word about *Be Fierce. Take Control.*® in a different way? Use the key messages below as a starting place for crafting your own communications about lupus awareness.

- While many people have heard of lupus, few know much about the disease beyond its name. Lupus is a chronic, autoimmune disease that can cause pain, inflammation, and tissue damage to various organs in the body.
- Lupus is challenging to diagnose, because it shows up in unique ways in everyone who has it. Its symptoms—things like joint pain, exhaustion, and skin rashes—are similar to many other diseases, and are not the same from person to person.
- Early diagnosis is critical to preventing long-term consequences of lupus. If not treated, lupus continues to damage the body. This is why it's so important to raise awareness about lupus—the sooner someone receives a lupus diagnosis, the sooner they can manage the disease and its impact on the body.
- [The American College of Rheumatology](#) (ACR) wants young leaders, like you, to use this Playbook to get your community to *Be Fierce. Take Control.*® The Playbook is designed especially for young African American women, and encourages women to take control of their health, the way they run the other important areas of their lives.
- Go to befiercetakecontrol.org to learn more about lupus, its symptoms, and what to do if you or a loved one are experiencing symptoms. You can also share information on social media using #BeFierceTakeControl. By sharing you are becoming a vital partner in raising awareness to those who need it most.

Revisit the [Lupus PowerPoint presentation](#) and [Lupus fact sheet – detailed](#) for more scientifically accurate messages about lupus.

Event assets bundle

The event assets bundle provides you with social media posts, images, and strategies that you can use along with your [Event planning sheet](#). During your event work group planning meeting, use these assets and your [Event planning sheet](#) to decide the best social media strategy for your organization.

As a reminder, the objectives of this part of your lupus awareness campaign are to:

1. Use social media to promote your hands-on event.
2. Encourage women to learn more about lupus by visiting the *Be Fierce. Take Control.*® website (befiercetakecontrol.org).
3. Increase lupus awareness and empower your peers to take control of their health.

Please keep the following in mind:

- Do not stretch, condense, or resize the assets.
- Do not recolor the assets.
- Do not recreate the assets. Use the files provided.
- Do not recreate the design style.

See [Appendix C. Be Fierce. Take Control.](#)® for more specific guidelines on using these images and copyright disclaimers.



Facebook/Instagram posts (no restrictive character limit)

- Let's talk about #lupus at Tate Plaza on Monday, June 1 from 10:00 AM - Noon #BeFierceTakeControl
- Self-care isn't selfish. Show us how you take control of your health at Tate Plaza on Monday, June 1 from 10:00 AM - Noon #BeFierceTakeControl
- Feeling not quite like yourself? Come see how to take control of your health at Tate Plaza on Monday, June 1 from 10:00 AM - Noon #BeFierceTakeControl
- If you've been feeling not quite like yourself but can't pinpoint what's wrong, it's time to #BeFierceTakeControl - come to Tate Plaza on Monday, June 1 from 10:00 AM - Noon

Twitter posts (140 characters)

- Check out our upcoming event at Tate Plaza on Monday, June 1 from 10:00 AM - Noon #BeFierceTakeControl
- Come express how you take control of your health - Tate Plaza on Monday, June 1 from 10:00 AM - Noon #BeFierceTakeControl
- @TATEPLAZA is #BeFierceTakeControl of our health. Learn more at Tate Plaza on Monday, June 1 from 10:00 AM - Noon

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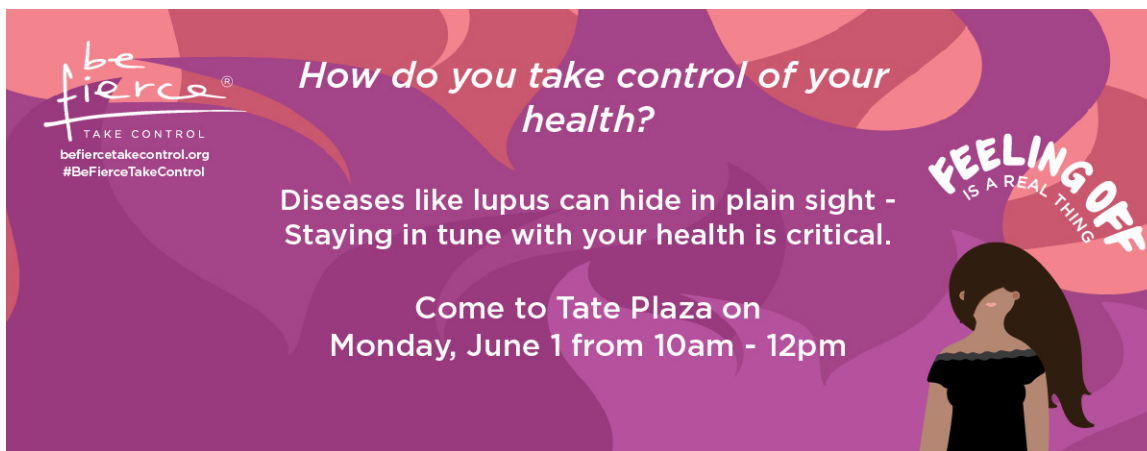
Profile badges

Promote your event by uploading these profile badges as your organization's profile picture on Facebook, Twitter and Instagram. Ask your fellow supporters to also make it their profile picture on their personal accounts!



Cover photo

Promote your event by uploading this cover photo as your organization's cover photo on Facebook and Twitter. Ask your fellow supporters to also make it their cover photo on their personal accounts!



Create a story for your campaign

Creating a story on Instagram and/or Snapchat can be a great way to share your event with your attendees and others in your community.

To create a new Snapchat story, go to the stories homepage and then click on the plus sign in the upper right-hand corner. You can then name your story (*Be Fierce. Take Control.*® Hands-On Event) and select between a few options. You can Geofence an area and chose to either (1) let any of your Snapchat friends within that area contribute or (2) let any of your Snapchat friends and friends of your Snapchat friends within that area contribute. However, you can also manually select all your Snapchat friends to create a story where they can all contribute without using the Geofence option.

To add to your Instagram story, click on “your story” at the upper left-hand corner. You can then take pictures or videos to add to your story. Your followers can then send you message replies about your story.

Also, make sure to share the campaign QR code for the *Be Fierce. Take Control.*® campaign website on your story and during your event (See [Social media assets bundle](#)).



Tip:

Get more Snapchat friends by posting your organization's Snapchat username and scannable QR code on other social media posts!

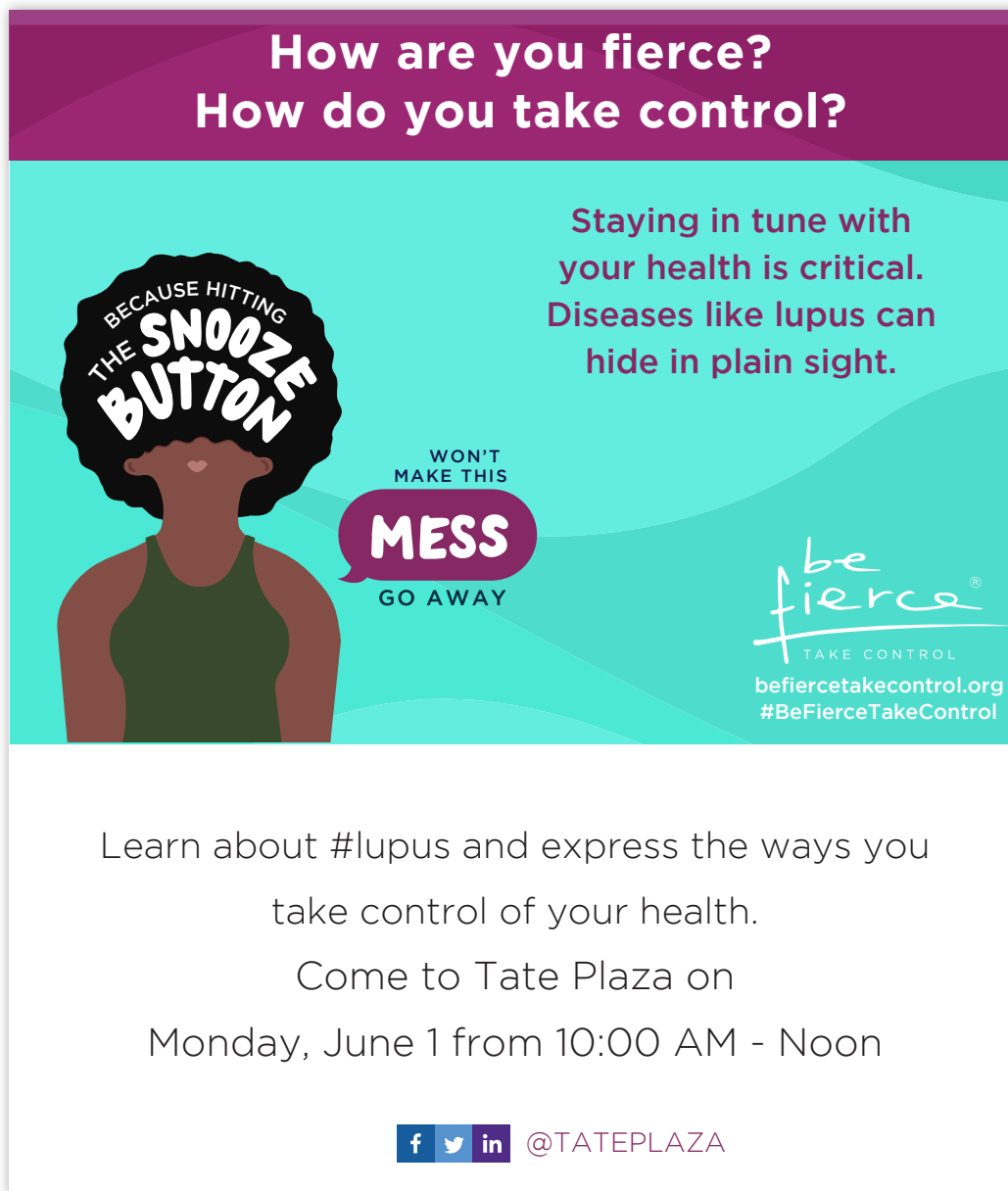
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Snapchat Geofilter

Snapchat also allows organizations to create a custom filter, pick dates, and set a Geofence for their filter. Snapchat charges for this service; however, they also offer community Geofilters for public places. For more information, see snapchat.com/geofilters.

Flyer

Use this flyer to advertise for your event in the community.



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Photo release form

Use this form if you will be publishing (print or online) pictures of your attendees from the event.

Location of Event (street, city, state, zip): _____

Permission to Use Photography

I grant to the ACR and _____ its representatives and employees (representatives) the right to take photographs of me and my property in connection with the above-identified subject. I authorize these representatives, its assigns and transferees to copyright, use and publish the same in print and/or electronically. I agree these representatives may use such photographs of me with or without my name and for any lawful purpose, including, for example, such purposes as publicity, illustration, advertising and Web content.

Sign below to recognize you have read and understand the above text.

#	Last name	First name	Phone number	Signature (guardian if under 18)
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				

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Sign-in sheet template

Use this template to get contact information from your event attendees. This is especially helpful if you want to send them a survey after the event.

#	Last name	First name	Phone number	Signature (guardian if under 18)
1				
2				
3				
4				
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7				
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11				
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The Playbook is a campaign developed by the American College of Rheumatology (ACR). The goal of the campaign is to raise awareness of the signs and symptoms of lupus, and ultimately help reduce health disparities by reducing the time to diagnosis. For more information about the campaign, see [Appendix C. Be Fierce. Take Control.](#)® The ACR developed this Playbook to help you and your organizations make an impact in your community by increasing lupus awareness through fun, customizable activities.

This Playbook 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 the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

For more information, contact lupus@rheumatology.org.

AMERICAN COLLEGE
of RHEUMATOLOGY
Empowering Rheumatology Professionals

