# TAKE CONTROL

Lierce

The Playbook: Local Lupus Awareness Activities

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# The Playbook: Local Lupus Awareness Activities

## INTRODUCTION

### What is The Playbook?

This Playbook is a step-by-step guide you can use to plan and implement lupus awareness activities on your campus. The Playbook provides the information you'll need to learn about lupus, educate your organization membership about lupus, and use social media and campus events to raise lupus awareness. The activities outlined in this Playbook are customizable, so you can tailor your approach to fully involve your campus and raise awareness about lupus.

### 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 can 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. Early diagnosis of lupus is critical to preventing long term consequences of the disease and the first step is being aware that you may have symptoms that require medical attention.

### How can I help?

The American College of Rheumatology (ACR)

wants young leaders, like you, to use this Playbook to get you and your campus to raise lupus awareness at your school.

This Playbook will help you learn about lupus, and spread the word through social media and a hands-on event. These efforts will increase the number of students who know the signs and symptoms of lupus and what to do if they (or someone they know) show signs.

### 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 <u>lupus@rheumatology.org</u> or via phone at 404.633.3777 x804.

## Educate your leaders

## Spread the word

Host an event

## Keep it going – Continuing activities

# **Educate your leaders**

It all starts with you. As the driving force on your campus, we want to empower you with the knowledge and resources you need. Educating yourself and your fellow leaders<sup>1</sup> about lupus sets the stage for you to engage your fellow students and increase lupus awareness on campus. As we mentioned earlier, lupus is a complicated health problem and even health professionals have difficulty recognizing and diagnosing lupus. However, it's critical for you to learn as much about lupus as possible before starting your social media campaign and hosting your event.

You and your leaders will become your campus advocates to increase lupus awareness on your campus. Don't worry, we've provided a downloadable <u>Lupus PowerPoint presentation</u> and <u>Presentation script</u> to help you prepare for and host a session to educate your leaders about lupus.

<sup>1</sup>By leaders, we mean members in your organization and other organizations with whom you are collaborating to increase lupus awareness on your campus.

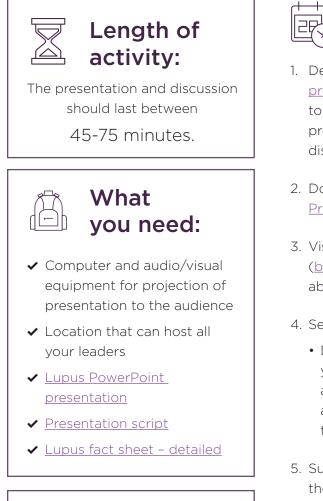


## Activity:

Give a lupus presentation to increase your fellow leaders' lupus awareness.

# Objectives:

- Increase your and your leaders' lupus awareness. We define lupus awareness as "knowledge" of the signs and symptoms of lupus and what to do if lupus is suspected.
- Encourage your leaders to learn more about lupus by reviewing the <u>Lupus</u> <u>fact sheet - detailed</u> and visiting the *Be Fierce. Take Control.*<sup>™</sup> website (befiercetakecontrol.org).
- Establish committees of your leaders to take charge of the social media campaign and campus event.





### Optional next steps:

- ✓ See <u>Appendix A. Fund your</u> event for suggestions on how to fundraise and budget for food and beverages if you want to host a "lunch and learn" for your leaders.
- ✓ See Guest speaker recruitment for suggestions how to get a guest speaker, such as a rheumatologist or someone with lupus, to speak to your organization, if you want to expand your presentation.



## Before the presentation:

- 1. Decide who will present the Lupus PowerPoint presentation. This person should have (1) the time to review the materials carefully and prepare for the presentation, and (2) be able to engage fellow leaders in 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 host the session.
  - Determine a convenient location and time for most of your leaders. Including the lupus presentation during a regularly scheduled meeting or holding a "lunch and learn" event in a campus classroom might work the best.
- 5. Submit the proper requests with your school to book the location and technology (when available). Schools usually also allow organizations to request/rent the audio/visual equipment in classrooms, so make sure to look into your schools' specific policy.
- 6. Once you have an approved location, date, and time, inform your leaders about the presentation.
  - Announce the presentation at a regular meeting, post about the event on your organization's social media page, and 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 the audio/visual equipment and the Lupus PowerPoint presentation.

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### During the presentation:

- 1. Use the <u>Presentation script</u> as your guide during the presentation.
- 2. Hand out copies of the <u>Lupus fact sheet detailed</u> to your leaders.
- 3. Engage your leaders 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, so you or your leaders may know someone with lupus. It's important to let your members express themselves and discuss what they already know (or don't know) about lupus. The <u>Presentation script</u> includes discussion starters for you to use during the presentation. Ensure that no one person dominates the discussion and that participants respect privacy (e.g. not sharing names of people they may know who have lupus).
- 4. Discuss the importance, as campus leaders, for you to lead the charge on lupus. Discuss the next steps of the Playbook, including spreading the word through the social media campaign and hosting your own event on lupus.
- 5. Establish committees to lead the social media campaign and the hands-on event. These committees can help you to plan and manage the various tasks for these activities.

Now that you're campus advocates, you're ready to spread the word to your fellow students!

## Relevant resources and appendices:

- ✓ <u>Lupus PowerPoint</u> <u>presentation</u>
- Presentation script
   pg. 31
- Lupus fact sheet detailed pg. 39
- <u>Guest speaker recruitment</u>
   pg. 41
- <u>Lupus presentation</u> <u>announcement</u> pg. 45
- Appendix A. Fund your event
   pg. 17

## Educate your leaders

## 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 two-fold: (1) increase lupus awareness at your school, and (2) promote your hands-on event.

The social media campaign committee should use the Social media planning sheet and the Social media assets bundle to develop a social media strategy for your school. We have included suggestions for when and how to post, text, and graphics for posts, and suggestions for ways to engage your fellow students. But, these are only suggestions - you know more about what will catch the interest of your school's student population. 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,<sup>1</sup> 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.



## **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.

## **Objectives:**

- 1. Plan and manage a social media campaign to increase lupus awareness at your school.
- 2. Use social media to promote your hands-on event.
- 3. Encourage students to learn more about lupus by visiting the Be Fierce. Take Control.™ website (befiercetakecontrol. org).
- 4. Empower students at your school to take control of their health.

<sup>&</sup>lt;sup>1</sup>This fact sheet is a modified version of the <u>Lupus fact sheet</u> - detailed that you and your leaders reviewed during the lupus presentation in <u>Educate your leaders</u>. 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).



# Length of activity:

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



### What you need:

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



## Before the campaign:

- Convene the social media campaign committee and use the <u>Social media planning sheet</u> and the <u>Social media</u> <u>assets bundle</u> to develop a social media strategy for your school.
  - Your social media strategy should include:
    - » Number and type (e.g. Facebook, Instagram) of posts your committee will develop. Make sure you have a mix of lupus awareness posts, photos from your leaders about taking control of their health (see <u>#BeFierceTakeControl community contributions</u>), and posts advertising your lupus event on campus.
    - » Calendar of dates/times you will post.
    - » Designated person(s) to develop the posts and then post them on social media.
    - » Ideas to engage your fellow students to contribute to the campaign. See <u>#BeFierceTakeControl community</u> <u>contributions</u> for tips and examples.
- 2. Customize the social media materials provided in the <u>Social media assets bundle</u>. You may also want to:
  - Add your organization's name, logo, and social media account information.
  - 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 <u>Social media assets bundle</u>, the <u>Lupus fact sheet</u>, or on the Be Fierce. Take Control.<sup>™</sup> website (<u>befiercetakecontrol.org</u>).
    - » Use the hashtag #BeFierceTakeControl in your posts.

SPREAD THE WORD



## During the campaign:

- Launch your campaign and begin posting on social media.
  - Consider placing an announcement of your campaign in the school daily email announcement or newspaper.
- 2. Ask your members to use and share the social media assets for the campaign (e.g. Facebook cover page, profile badges, posts) and post photos on your organization's social media accounts.
- 3. Use the hashtag #BeFierceTakeControl with all your social media posts.
  - Example: Check out our upcoming event at Tate Plaza on Thursday, June 1 from 11am – 12pm #BeFierceTakeControl #TAU
- 4. Engage with students on your campus by replying, retweeting, 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 <u>Tips to respond to social</u> <u>media questions</u>.
  - Example: If a student replies to your organization's Twitter 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 <u>Tips to respond to social media questions</u>, or using the information in the <u>Lupus fact sheet</u>.
- 5. Promote selfies and other lupus awareness posts from your leaders and ask other students to share images of themselves taking control of their health. By taking selfies and using the hashtag when they are making healthy choices at the dining hall, going for a walk around campus with their friends, or visiting the school nurse, students can show all the different and unique ways they are taking control of their health and listening to their bodies. See <u>#BeFierceTakeControl community</u> <u>contributions</u> for tips and examples.
- Connect with the <u>ACR</u> and <u>TLI</u> on social media.
   We want to see all the cool things you're doing!

## Relevant resources and appendices:

- Social media planning sheet pg. 47
- Social media assets bundle pg. 61
- ✓ <u>Lupus fact sheet</u> pg. 49
- #BeFierceTakeControl community contributions pg. 51
- Tips to respond to social media questions
   pg. 53



## Educate your leaders

## Spread the word

Host an event

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## Keep it going – Continuing activities

# Host an 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 at your school, you will educate, spread awareness, and inspire your fellow students to take control of their health.

The goal of the event is to get the attention of your school's student population. Then, you will inform your friends and classmates, especially young African American women 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 committee should use the <u>Event</u> <u>planning sheet</u> and the <u>Event asset bundle</u> to plan and implement your hands-on event. The handson event encourages students on your campus to use chalk/paint or other art supplies to celebrate the ways they are fierce and what taking control of their health means to them, such as making healthy choices at the dining hall or making an appointment at the health center.

You and your leaders will engage students who are passing by the event to participate in the event and share information using the <u>Lupus fact sheet</u>, so they can learn more about lupus.



Hold a hands-on event to raise awareness about lupus.



- Plan and hold a hands-on event to increase lupus awareness at your school.
- Provide information about lupus to students who attend the event using the <u>Lupus fact sheet</u>.
- Encourage students to learn more about lupus by visiting the *Be Fierce*. *Take Control*.<sup>™</sup> website (befiercetakecontrol.org).
- 4. Empower students at your school to take control of their health.



- ✓ Location on campus
- Chalk/paint or other art supplies
- ✓ Table and chairs
- Poster board or other materials for event signs
- Printed copies of <u>Lupus fact</u>
   <u>sheet</u>
- ✓ Event planning sheet
- ✓ Event asset bundle
- ✓ Event volunteer sign-up sheet
- ✓ Talking points for the event





## Before the event:

- Convene the event committee and use the <u>Event</u> <u>planning sheet</u> and the <u>Event asset bundle</u> to develop the plan for your event.
  - Specifically, you should:
    - » Decide the proper location and date to host the event.
    - » Schedule the event during a time when students will be on campus and have time between classes (e.g. lunch time through late afternoon as students finish classes).
    - » Schedule the event when there are no other large events occurring.
  - » Select a location with a road or sidewalk (to paint/ chalk on) near an important campus building or walkway where students often walk. Visit the location during the time(s) you plan to host your event. If you are using a different art medium (e.g. markers and poster board), you will need to select an appropriate indoor location with tables and a lot of foot traffic.
- 2. Submit the proper requests with your school to book the location and technology (when needed/available) and obtain permission to use paint or chalk on surfaces at the event location. Many schools require you to complete paperwork about your event, including: (1) an event description (see <u>Appendix A. Fund your event</u> for a sample); (2) safety forms; and (3) reservation forms for the specific date/location. However, each school is different, so check with the specific department(s) in
  - charge of student events (e.g. Department of Student Affairs or Student Life) for guidance to get your event approved.
- Once approved, advertise the event using multiple strategies. We include

# Γip:

Communicate with the social media campaign committee, who will promote the hands-on event via social media channels. several samples in the <u>Event asset bundle</u>. Some strategies include:

- Posting flyers on bulletin boards and other locations.
- Handing out flyers around campus or in student dorms.
- Encouraging members 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 committee, see <u>Spread the word</u>).
- 4. Prepare materials for the day of the event:
  - Purchase chalk/paint or art supplies.
  - Make signs about the event that include instructions for students to write or draw ways they are fierce and what taking control of their health means to them, such as making healthy choices at the dining hall or making an appointment at the health center.
  - Print copies of the <u>Lupus fact sheet</u> to share with attendees.
- 5. Ask leaders to volunteer for specific time slots for the event using the <u>Event volunteer sign-up sheet</u>. You will need leaders to help set up for the event, engage students during the event, and clean-up after the event. One to two days before the event, schedule a location walk-though with volunteers.
  - Leaders who volunteer to engage students during the event must:
    - » Attend the <u>Lupus PowerPoint presentation</u> (see <u>Educate your leaders</u>).
    - » Review Lupus fact sheet detailed.
    - » Review the Talking points for the event.



# See <u>Appendix A. Fund your</u> <u>event</u> for suggestions on

- 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 <u>Guest speaker</u> recruitment for suggestions how to find and retain an expert or person living with lupus to enrich your event.
- See <u>Appendix B. Measure</u> <u>your event's impact</u> for information about how to evaluate the success of your event.



## Day of the event:

- Arrive early to set up for your event. The event committee and any other leaders 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 <u>Lupus fact sheet</u> for students to grab, information about the event, and some paint/chalk.
  - Place large, noticeable signs around the event to inform students about what you are doing. Show students how to write or draw ways they are fierce and what taking control of their health means to them, such as making healthy choices at the dining hall or making an appointment at the health center.
  - Make sure the paint/chalk, flyers, and other materials are easily accessible for participants to use.
  - You may want to ask a particularly artistic member of your organization to start things off by creating a large, central design to anchor the participants' contributions.
  - Ask members of your organization to paint/chalk their experiences, so attendees can see examples.
- 2. Approach students who walk by, explain about the event. Ask them to share their experiences by painting/chalking on the road or sidewalk.
- 3. Use the information from the lupus presentation and <u>Talking points for the event</u> to provide your fellow students with information about lupus. Give students copies of the <u>Lupus fact sheet</u> and encourage them to visit the *Be Fierce. Take Control*.<sup>™</sup> website (befiercetakecontrol.org).
- Encourage students to take pictures of what they write/draw and share it on their social media using the hashtag #BeFierceTakeControl.
- 5. Document all the artwork created by students with photos. Share the photos.

## Relevant resources and appendices:

- ✓ <u>Guest speaker recruitment</u> pg. 41
- ✓ <u>Lupus fact sheet</u> pg. 49
- ✓ Event planning sheet pg. 55
- <u>Event asset bundle</u>
   pg. 65
- ✓ Event volunteer sign-up sheet pg. 57
- <u>Talking points for the event</u>
   pg. 59
- Appendix A. Fund your event pg. 17
- Appendix B. Measure your event's impact
   pg. 21

### Integrate social media:

During the event, the social media committee should take pictures and post on social media and share posts by students attending the event.

### Use #BeFierceTakeControl

## Educate your leaders

## 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 the creative ways you and your fellow leaders can promote lupus awareness at your school.

For leaders who want to complete additional lupus awareness activities, we provide some ideas: <u>Appendix A. Fund your event</u> and <u>Appendix B. Measuring your event's impact.</u>

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

Larger campus events with food, beverages, and/or incentives for attendees often require more funding than your organization's typical event budget. Therefore, you may need to seek additional funding (see <u>Appendix A. Fund your</u> <u>event</u>) to expand your event. You may wish to include multiple organizations at your school or 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 <u>Guest speaker recruitment</u>).

# Collaborate with other organizations on campus

Organizations such as health clubs, sororities and fraternities, the student health center, and others are 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 or other student leaders you know on campus.
- Share the Playbook with them and the results from your evaluation of your activities (if available).
- Discuss the importance of lupus awareness and what you've learned so far.
- Schedule a meeting with all collaborating organizations' leadership to discuss the possible partnership for another lupus awareness event or creating a campus-wide "health fair" where other organizations' health-focused activities complement your lupus event.

### Partner with other organizations outside your campus

There are many organizations outside your school with whom you can collaborate on lupus awareness activities, such as your national organization, chapters at other universities, and other organizations dedicated to lupus awareness. 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 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 on your campus to raise lupus awareness.

### Follow us

resources and appendices: ✓ Guest speaker recruitment pg. 41 ✓ Appendix A. Fund your event pg. 17 ✓ Appendix B. Measure your event's impact pg. 21

Relevant



# **LEARN HOW TO** FIGHT BACK



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## Appendix A. 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, talent show, or pageant on campus.
  - Talk with your fellow leaders and see what fundraising events have been most successful for your organization in the past.
- Requesting funds from your school or student government association (SGA) – Visit your school or SGA's website for more information on the requirements to request funds.
  - Your school or SGA 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 national chapter** Visit your national chapter's website or ask your point of contact, such as a national representative, for more information on the requirements to request funds.



Use your evaluation results to demonstrate why a funder should consider providing additional funds for you to complete the event again (see <u>Appendix B. Measure your</u> <u>event's impact</u>).

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- Your national chapter likely requires completed forms or 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 \_\_\_\_\_\_."

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 committee 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			Funds		
Item	Description	Cost	Item	Description	Cost
Tables	Provided by school	\$0.00	Budget funds miscellaneous		\$75.00
Four medium pizzas	Purchased from local pizza place	\$52.65 Student		budget Student government	
Two cases of bottled water	Purchased at local grocery store	\$6.12	government association (SGA) funds		\$50.00
	Total expenses:	\$58.77			
Tip:				Total expenses	\$125.0
• Other example	expenses are:				
• Food/beve	erages		Ť <b>₽</b> <sup>−</sup> <b>Tip:</b>		
• Cups, forks	s, spoons, etc.			lank spaces to	
Office materials, printing			fill in the expenses and		
<ul> <li>Incentives, such as T-shirts, water bottles, totes, etc.</li> </ul>			funding f	or your event!	
	y not from your university eakers/microphones, etc.				

### **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 on our campus, we educated ourselves about lupus and increased own lupus awareness, defined as (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 committee to plan and implement a social media strategy to further increase lupus awareness at our school.

Now, as a capstone, we are planning to host an event called the *Be Fierce. Take Control.*<sup>™</sup> hands-on event that encourages students on our campus to use chalk/paint or other art supplies to celebrate the ways they are fierce and what taking control of their health means to them, such as making healthy choices at the dining hall or making an appointment at the health center. The goal of our visual hands-on event is to get the attention of our school's student population, especially African American women. Additionally, we want to further increase lupus awareness at our school. We will engage students 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.*<sup>™</sup> hands-on event, please contact us at **[contact information].** 



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### Appendix B.

## Measure your event's impact

Seeing your fellow leaders and students engage with your social media campaign and on-campus 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?

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 leaders, national organization, student government association, school administration, and any funders is important to show 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).

### Tip:

 If you ask your leaders 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).

CONTROL

• The longer the time between the presentation and the survey, the less the participants will remember for the survey.

### Measure your lupus presentation:

Since your fellow leaders will be engaging students on social media and during the hands-on event, it is important to know the extent to which they understand the information in the <u>Lupus PowerPoint</u> <u>presentation</u>. You can measure your fellow leaders' lupus awareness by using the <u>Lupus awareness</u> <u>questionnaire</u> based on the information in the <u>Lupus PowerPoint presentation</u>. Handing out hardcopy questionnaires immediately before and after the presentation will give you the best data. However, you can also use electronic resources, such as Survey Gizmo or Survey Monkey, to create an online questionnaire – using the same methodology of taking the questionnaire before or after the presentation.

Use the <u>Lupus presentation evaluation checklist</u> (provided below) to help you plan and measure the impact of your lupus presentation.

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

### 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

### 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

### Measure 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 students on your campus and (2) the extent to which students are engaging with the materials. You can measure how many students you are reaching by tracking the number of impressions or views of your posts (e.g. reach) and how many students engage with your posts by tracking the number of shares, favorites, retweets, comments, likes, etc. your posts receive. Use the <u>Social media campaign tracking table</u> (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	

### Measure your on-campus lupus event:

The goal of your on-campus lupus event is to get the attention of your school's student population, therefore it's important to know how many students participate in your event and their satisfaction with the event. For the *Be Fierce. Take Control.*<sup>™</sup> hands-on event, you should keep track of how many students stop by your event and how many students participate in the event by chalking/painting the ways they take control of their health. You can measure your event attendees' satisfaction using the <u>Satisfaction questionnaire</u> (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 <u>On-campus lupus event evaluation checklist</u> to help you plan and measure the impact of oncampus lupus event.



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



- Participants are more likely to complete questionnaires if they receive an incentive (e.g. T-shirts, water bottles, pens, totes).
- See <u>Appendix A. Fund your event</u> 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 *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?

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

## Appendix C. Be Fierce. Take Control.™

The *Be Fierce. Take Control.*<sup>™</sup> campaign is designed to educate and empower young African American women. For information about the campaign, visit <u>befiercetakecontrol.org</u>. For more detailed information about using campaign assets, please review the *Be Fierce. Take Control.*<sup>™</sup> Brand Guidelines.

### Using campaign assets

Campaign assets include assets provided in the <u>Social media assets bundle</u> and <u>Event asset bundle</u>, 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: <u>befiercetakecontrol.org</u>
  - » INCORRECT: <u>www.befiercetakecontrol.org</u>
- Always italicize *Be Fierce. Take Control.*™ with the trademark symbol (™).
  - » CORRECT: Be Fierce. Take Control.™
  - » INCORRECT: Be Fierce. Take Control.TM
  - » INCORRECT: Be Fierce. Take Control.



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 <u>Social media assets bundle</u> and <u>Event asset bundle</u>. Customizing the assets for your specific event and campus is important – you know more about what will catch the interest of your school's student population. That's why we've provided instructions for you to customize the assets in the <u>Social media assets bundle</u> and <u>Event asset bundle</u> resources.

Always keep in mind when posting assets:

- Use scientifically accurate information when talking about lupus. We recommend using information provided in the <u>Social media assets bundle</u>, the <u>Lupus fact sheet</u>, or on the *Be Fierce. Take Control.*<sup>™</sup> website (<u>befiercetakecontrol.org</u>). 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!



# RESOURCES

31	Presentation script
39	<u>Lupus fact sheet - detailed</u>
41	<u>Guest speaker recruitment</u>
45	Lupus presentation announcement
47	Social media planning sheet
49	Lupus fact sheet
51	<u>#BeFierceTakeControl</u> <u>community contributions</u>
53	<u>Tips to respond to social media questions</u>
55	Event planning sheet
57	<u>Event volunteer sign-up sheet</u>
59	Talking points for the event
61	Social media assets bundle
65	<u>Event asset bundle</u>
1	

## **Presentation script**



### **Slide Screenshot**

### SLIDE 1



#### DO: [Welcome leaders to the education session.]

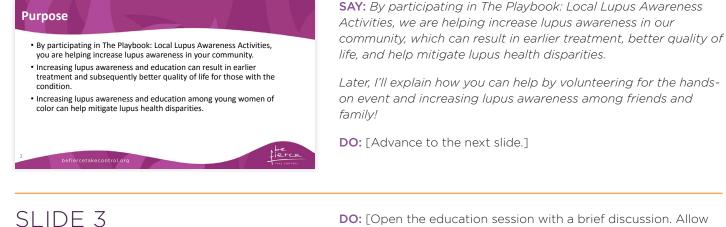
**SAY:** The American College of Rheumatology (ACR) has launched The Playbook, a set of local lupus awareness activities, which we will implement on our campus. The goal of the campaign is to raise awareness of the signs and symptoms of lupus and ultimately help reduce health disparities by reducing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

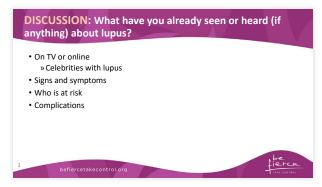
Script

This education session includes information about lupus, it's 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 campus.

DO: [Advance to the next slide.]

### SLIDE 2





**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 leaders 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 and definitions of lupus with you.

DO: [Advance to the next slide.]

Continued on next page …

#### 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, live, heart, lungs, and brain.
- While there is no cure for lupus, medical treatments and lifestyle changes can help control it.

**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, live, 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 can help control it.

## SLIDE 5

befiercetakecontrol.org



**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



**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 .....

DISCUSSION: Do you know someone with lupus?

How has that experience affected you?

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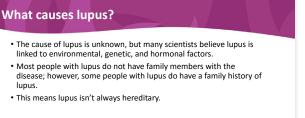
- How did the signs and symptoms of lupus affect them?
- How were you supportive of your loved one's needs?

**DO:** [Lead a brief, 5-minute discussion about leaders' personal experience with lupus, either in their lives or in the lives of others. Allow plenty of 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 [unless otherwise stated].

DO: [Advance to the next slide.]

## SLIDE 8



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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 on our campus – 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).
- Minority groups—African Americans, Latinos, Asians, and American Indians/Alaska Natives—are affected more than non-Hispanic 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 child bearing years (15-44). Minority 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 .....

#### Lupus health disparities

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- The National Institute of Health defines health disparities as "the differences in the incidence, prevalence, mortality, and burden of disease and other adverse health conditions that exist among specific population groups."
- 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 literacy).
- 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.

**SAY:** As I just mentioned, lupus is two to three times more common among African American women. This is a 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



**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 3-5 leaders 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?

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- 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.

**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. Lupus can often be misdiagnosed, and 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. 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 to share as much information as you can about your medical history with your health care providers to help them make an accurate diagnosis.

DO: [Advance to the next slide.]

Continued on next page …...

#### 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

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- · 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.

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

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.

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.™

efiercetakecontrol.org

- 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

fierce

- information and resources to help.
  - » Watch the campaign video <u>https://youtu.be/tj8WTQSEyDE</u>

SAY: The American College of Rheumatology (ACR) wants young leaders, like you, to use this Playbook to get you and your campus 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.]

# SLIDE 16

#### Next steps

- Review the <u>Lupus fact sheet detailed</u> and other Playbook resources.
- Establish committees to lead the social media campaign and the oncampus event.
  - Volunteers to promote the event on our social media accounts.
     Volunteers for event set-up, tabling, and event clean-up.
- Host the on-campus awareness event.
   Spread lupus awareness on campus.
  - Celebrate the ways students on campus are *being fierce* and *taking control* of their own health.

**DO:** [Hand out copies of the <u>Lupus fact sheet – detailed</u> and pass around the interest sheet for leaders to sign-up for event planning committees.]

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

**DO:** [Take this time to have a short discussion about spreading the word on campus. 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 campus?

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



## SLIDE 18



- 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: <u>befiercetakecontrol.org</u>



**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 of time to have an open discussion, and encourage active participation.] • Any further questions about lupus? SAY: Does anyone have any further questions about lupus? **DO:** [Advance to the next slide.] SLIDE 20 SCRIPT BLANK **Works Cited** American College of Rheumatology. (2015). Lupus. Retrieved from http://www.rheumatology.org/i-Am-A/Patient-American College of Rheumatology, (2015). LUDIS. Neurowa Unrum INUKZZYTRALITSUMMONG LANGELCOMPLANDERS, Caracterized Consenses-Conditionation (2017). LUDIS. Neurowa Unrum INUKZZYTRALITSUMMONG LANGELCOMPLANDERS, Bruce, N. (2013). LUDIS: The new diabetes. Size and chronic disease management. Lupus, 22(12), 1203-1204. Common Consenses and Consenses and Consenses and Consenses and Consenses and Consenses. Water Consenses and Consenses of Systemic Lucus Erythematoxus. Current Opinion In Mehamatology, 21(1), 102–109. Lun, S.S., Bayakiy, A. R., Helmick, C. G., Gordon, C., Easley, K. A., & Dernkard, C. (2014). The incidence and prevalence of systemic Lupus erythematoxus. Current Opinion In Mehamatology, 21(1), 102–109. Lun, S.S., Bayakiy, A. R., Helmick, C. G., Gordon, C., Easley, K. A., & Dernkard, C. (2014). The incidence and prevalence of systemic Lupus erythematoxus. Disco22-2004: the Gengia Lupus Registry. Arthrist & Rheumetology, 68(2), 357-368. National Institutes of Healtin, (2017). Health Disparities. Retrieved from https://www.chi.angl.com/matheology.com/matheolog https://www.nhlb.nh.gov/heith/vdsucational/heithdiap
Pons:Estel, G. J. Ataron, G. S., Sofelle, J., Reinibl, J. & Cooper, G. S. (2010). Understanding the epidemiological progression of systemic lupus enythematosus. *Seminors in Arthritis and Rheumatism*, 39(4).
Somers, E. C., Marder, W., Capaoll, P., Weis, E. E., Dediue, P., Gordon, C., a Leien, J. (2014). Population-based incidence and prevalence of systemic lupus enythematosus: The Michigan lupus epidemiology and surveillance program. *Arthritis: & Rheumatology*, 66(2), 369-78. fierca befiercetakecontrol.org SLIDE 21 SAY: Thanks for coming! We'll be following up soon about the upcoming social media campaign and hands-on event.

AMERICAN COLLEGE DE CALON • TREATMENT • RESEARCH DE CALON • TREATMENT • RESEARCH NUSB DP06138, funded by the Cantor C COOPENITe Agreement Number, funded by the Cantor C COOPENITe Agreement Number, funded by the Cantor C COOPENITe Agreement Number, funded by the Cantor S C Coopenite Agreement Number, funded by the Cantor S C Coopenite Agreement Number, funded by the Cantor S C Coopenite Agreement Number, funded by the Cantor S C Coopenite Agreement of S C Coopenite or the Department of Health and Human Service. . . . .

DO: [Open the discussion floor for final questions. Allow plenty

DO: [End presentation.]

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# Lupus fact sheet - detailed

### What is lupus?

Systemic lupus erythematosus, referred to as SLE or lupus, is a 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

Continued on next page ….....

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#### References

American College of Rheumatology. (2015). Lupus. Retrieved from http://www.rheumatology.org/l-Am-A/Patient-Caregiver/Diseases-Conditions/Lupus Bruce, I. N. (2013). Lupus: the new diabetes. SLE and chronic disease management. *Lupus, 22*(12), 1203-1204. Centers for Disease Control and Prevention (CDC). (2017). Lupus Basic Fact Sheet. Retrieved from <a href="http://www.cdc.gov/lupus/basics/index.html">www.cdc.gov/lupus/basics/index.html</a>

Dall'Era, M. (2013). Chapter 21. Systemic Lupus Erythematosus. In J. B. Imboden, D. B. Hellmann, & J. H. Stone (Eds.), CURRENT Diagnosis & Treatment: Rheumatology, 3e. New York,

NY: The McGraw-Hill Companies. Lim, S. S., Bayakly, A. R., Helmick, C. G., Gordon, C., Easley, K. A., & Drenkard, C. (2014). The incidence and prevalence of systemic lupus erythematosus, 2002–2004: the Georgia Lupus Registry. *Arthritis & Rheumatology, 66*(2), 357-368.

Pons-Estel, G. J., Alarcon, G. S., Scofield, L., Reinlib, L., & Cooper, G. S. (2010). Understanding the epidemiological progression of systemic lupus erythematosus. Seminars in Arthritis and Rheumatism, 39(4) Somers, E. C., Marder, W., Cagnoli, P., Lewis, E. E., DeGuire, P., Gordon, C., ... & Leisen, J. (2014). Population-based incidence and prevalence of systemic lupus erythematosus: The

Michigan lupus epidemiology and surveillance program. Arthritis & Rheumatology, 66(2), 369-378.

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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 that knows about lupus.
- Use the <u>American College of Rheumatology's directory</u> 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 leaders if they have friends or family that have lupus.
- Use social media to ask students on your campus 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.

Continued on next page ….

### 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]** at **[school name]**. We write to ask you if you would be interested in speaking or attending our *Be Fierce. Take Control.*<sup>™</sup> 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 campus' 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 or attending the *Be Fierce. Take Control.*<sup>™</sup> 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]** at **[school name]**. We write to ask you if you would be interested in speaking or attending our <u>Be</u> <u>Fierce. Take Control.<sup>™</sup> hands-on event.</u> 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 campus' 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 or attending the *Be Fierce. Take Control.*<sup>™</sup> hands-on event. You can contact us at **[contact information].** 

### 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]** at **[school name]**. I'm calling to ask if you would be interested in speaking or attending our *Be Fierce*. *Take Control*.<sup>™</sup> 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 campus' 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 students on our campus to use chalk/paint on the campus sidewalks to celebrate the ways they are fierce and what taking control of their health means to them. This could range from making healthy choices at the dining hall or making an appointment at the health center. The goal of our visual hands-on event is to get the attention of our school's student population, especially young African American women. We also plan to distribute lupus fact sheets around campus 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]** at **[school name]**. I'm calling to ask if you would be interested in speaking or attending our *Be Fierce*. *Take Control*.<sup>™</sup> 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.

Continued on next page …

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Guest speaker recruitment **43** 



### If leaving a voicemail

Hello, my name is **[Name]** and I am a part of **[organization name]** at **[school name]**. I'm calling to ask if you would be interested in speaking or attending our *Be Fierce*. <u>Take Control</u>.<sup>™</sup> 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 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.*

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

befiercetakecontrol.org #BeFierceTakeControl

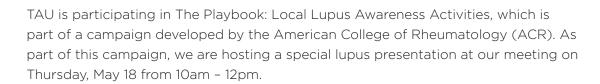
TAU is participating in The Playbook: Local Lupus Awareness Activities, which is a campaign developed by the American College of Rheumatology (ACR).

As leaders at our school, we are in a position to change the level of lupus awareness on our campus. If you want to **#BeFierceTakeControl** of your health – come to our special lunch and learn event at

Tate Plaza on Thursday, May 18 from 12pm - 1pm

See TAU leadership (<u>TAU@gau.edu</u>) with any questions or concerns.

Continued on next page .....



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.

As leaders at our school, we are in a position to change the level of lupus awareness on our campus. If you are interested, make sure you attend our meeting on <u>Thursday</u>, <u>May 18 from 10am – 12pm</u>.

See TAU leadership (<u>TAU@gau.edu</u>) with any questions or concerns.

Thanks,

moers,

# **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 <u>Social media</u> assets bundle.	May 11, 2017 at 11:00am	Laura	Laura	Use <u>Lupus fact</u> <u>sheet</u> to answer any comments/ questions about lupus on the post.
#2	@TAU is taking control by making Sundays home cooked dorm meal day. #BeFierceTakeControl	Lana	Instagram	Taking control of your health selfie.	May 18, 2017 at 6:00pm	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 11am – 12pm. #BeFierceTakeControl #TAU	Melody	Twitter	Advertisement for event with image from <u>Event asset</u> <u>bundle.</u>	May 25, 2017 at 8:00am	Melody	Melody	Make sure TAU members retweet the post and tell their friends about the event.





# Lupus fact sheet



### 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.

### 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.

#### References

- American College of Rheumatology. (2015). Lupus. Retrieved from http://www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Lupus
- Rince, I. N. (2013). Lupus: the new diabetes. SLE and chronic disease management. *Lupus*, 22(12), 1203-1204. Centers for Disease Control and Prevention (CDC). (2017). Lupus Basic Fact Sheet. Retrieved from <u>www.cdc.gov/lupus/basics/index.html</u> Dall'Era, M. (2013). Chapter 21. Systemic Lupus Erythematosus. In J. B. Imboden, D. B. Hellmann, & J. H. Stone (Eds.), *CURRENT Diagnosis & Treatment: Rheumatology*, 3e. New York, NY: The McGraw-Hill Companies.
- Lim, S. S., Bayakly, A. R., Helmick, C. G., Gordon, C., Easley, K. A., & Drenkard, C. (2014). The incidence and prevalence of systemic lupus erythematosus, 2002-2004: the Georgia Lupus Registry. Arthritis & Rheumatology, 66(2), 357-368.

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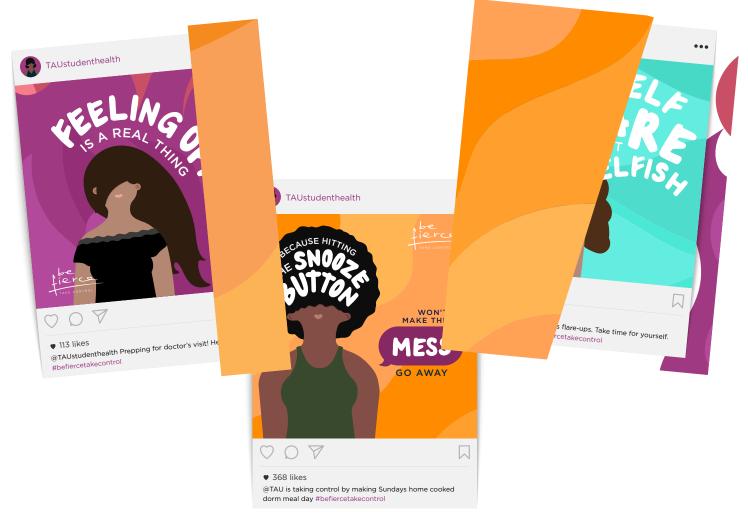
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# **#BeFierceTakeControl community contributions**



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



Visit the Center for Disease Control and Prevention's (CDC) <u>Guide for Writing Social Media</u> 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.



# Tips to respond 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 <u>befiercetakecontrol.org</u>.

### How is lupus diagnosed?

A: Doctors look at your symptom history, conduct a physical exam, and conduct a series of lab tests for a diagnosis. Check out <u>befiercetakecontrol.org</u>.

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

# What are the most common symptoms of lupus?

**A:** Painful or swollen joints, rashes across the nose and cheeks, and extreme exhausion that lasts for weeks. Check out <u>befiercetakecontrol.org</u>.

### Why is it hard to diagnose lupus?

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

**A:** Lupus is "the great imitator" because the signs and symptoms are similar to other diseases. Check out <u>befiercetakecontrol.org</u>.

# How do I prepare for a doctor's appointment?

**A:** Use the <u>Patient-Physician Dialogue Tool</u> from The Lupus Initiative site: <u>thelupusinitiative.org</u>.

**A:** Track your symptoms in a log, take pictures of rashes and other symptoms to show your doctor what's going on. Check out <u>befiercetakecontrol.org</u>.

**A:** Be detailed and accurate when talking to your doctor. Check out <u>befiercetakecontrol.org</u>.

### 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 <u>befiercetakecontrol.org</u>.

**A:** Check out <u>befiercetakecontrol.org</u> and <u>thelupusinitiative.org</u>.

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

**A:** Build a support network of family and friends. Check out <u>befiercetakecontrol.org</u>.



# **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.		
Reserve space on campus.		
Buy art supplies and posterboard for event signs.		
Map out places to chalk/paint around campus.		
Decide on places to post flyers around campus.		
Make event sign and print copies of the <u>Lupus fact sheet.</u>		
Brainstorm fundrasing strategies. See Appendix A. Fund your event.		
Submit event descriptions to student announcement listservs.		
Determine the number of volunteers needed.		
Post <u>Event volunteer sign-up sheet(s).</u>		
Brainstorm social media strategy. See <u>Spread the word.</u>		
Brainstorm event activities. See <u>Host an event.</u>		
Decide if you will evaluate your event. See Appendix B. Measure your event's impact.		

### befiercetakecontrol.org



# 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



# 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 visual display.

### What is this display about?

• We're using The Playbook: Local Lupus Awareness Activities to spread the word about lupus on our campus.

### 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 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 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 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 <u>befiercetakecontrol.org</u> 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 <u>befiercetakecontrol.org</u> for more information about lupus and take control of your health.



# 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 <u>Social media planning sheet</u>. During your social media committee planning meeting, use these assets and your <u>Social media planning sheet</u> to decide the best social media strategy for your school.

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

- 1. Plan and manage a social media campaign to increase lupus awareness at your school.
- 2. Encourage students to learn more about lupus by visiting the *Be Fierce. Take Control.*™ website (<u>befiercetakecontrol.org</u>).
- 3. Empower students at your school 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 <u>Appendix C. Be Fierce. Take Control.™</u> 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 <u>befiercetakecontrol.org.</u> #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 <u>befiercetakecontrol.org</u> 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 <u>befiercetakecontrol.org</u>.
   #BeFierceTakeControl

### Twitter posts (140 characters)

- Let's talk about #lupus—a disease that hides in plain sight. #BeFierceTakeControl
- Learn the signs of #lupus at <u>befiercetakecontrol.org</u>. #BeFierceTakeControl
- @TAU is #BeFierceTakeControl of our health.
   Are you? go to <u>befiercetakecontrol.org</u> 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 <u>befiercetakecontrol.org</u>.

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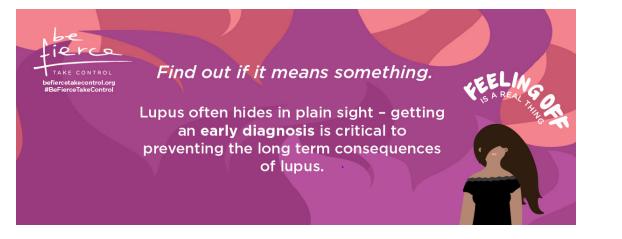
### Profile badges

Promote your social media campaign by uploading these profile badges as your organization's profile picture on Facebook, Twitter, and Instagram. Ask your fellow leaders 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 leaders 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.







Continued on next page …...

befiercetakecontrol.org

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

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. You 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!



### 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, such as a university. For more information, see <u>snapchat.com/geofilters</u>.

Continued on next page ….



Revisit the <u>Lupus PowerPoint presentation</u> and <u>Lupus fact sheet – detailed</u> 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 <u>Event planning sheet</u>. During your event committee planning meeting, use these assets and your <u>Event planning sheet</u> to decide the best social media strategy for your school.

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 students to learn more about lupus by visiting the *Be Fierce. Take Control.*™ website (<u>befiercetakecontrol.org</u>).
- 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 <u>Appendix C. Be Fierce. Take Control.™</u> 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 10am – 12pm #BeFierceTakeControl
- Self-care isn't selfish. Show us how you take control of your health at Tate Plaza on Monday, June 1 from 10am – 12pm #BeFierceTakeControl
- Feeling not quite like yourself? Come see how to take control of your health at Tate Plaza on Monday, June 1 from 10am – 12pm #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 10am - 12pm

### Twitter posts (140 characters)

- Check out our upcoming event at Tate Plaza on Monday, June 1 from 10am – 12pm #BeFierceTakeControl
- Come express how you take control of your health – Tate Plaza on Monday, June 1 from 10am – 12pm #BeFierceTakeControl
- @TAU is #BeFierceTakeControl of our health. Learn more at Tate Plaza on Monday, June 1 from 10am - 12pm

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befiercetakecontrol.org

Event assets bundle

#### **Profile badges**

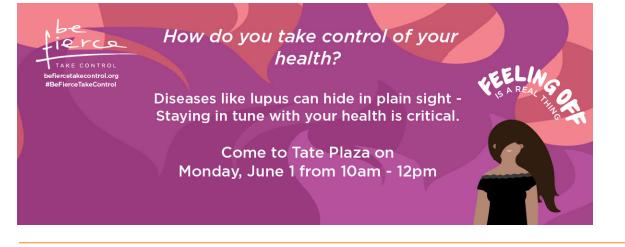
Promote your event by uploading these profile badges as your organization's profile picture on Facebook, Twitter, and Instagram. Ask your fellow leaders to also make it their profile picture on their personal accounts!



### LEARN HOW TO FIGHT BAGK Tate Plaza on Monday, June 1 from 10am - 12pm befiercetakecontrol.org #BeFierceTakeControl

#### Cover photo

Promote your event by uploading this cover photo as your organization's cover photo on Facebook and Twitter. Ask your fellow leaders 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 on your campus.

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*<sup>™</sup> 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.



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

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. You 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 <u>Social media assets bundle</u>).

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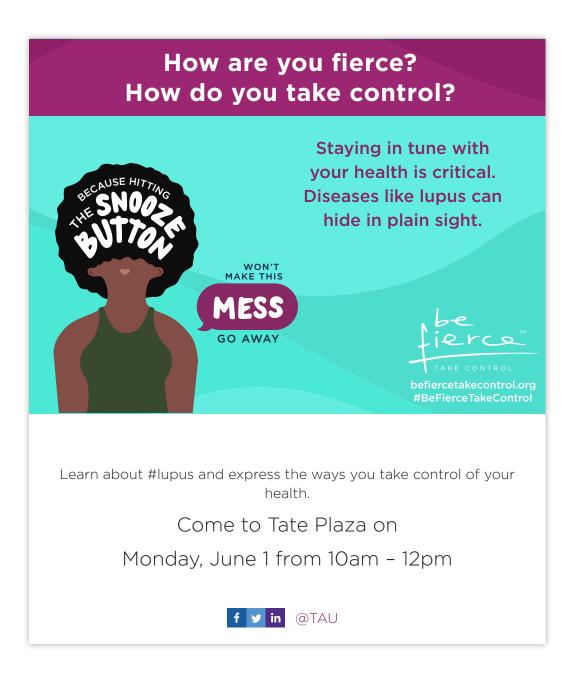
### befiercetakecontrol.org

### 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, such as a university. For more information, see <u>snapchat.com/geofilters</u>.

#### Flyer

Use this flyer to advertise for your event around campus.



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### Photo release form

Make sure to 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.

#	Last name	First name	Phone number	<b>Signature</b> (guardian if under 18)
1				
2				
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4				
5				
6				
7				
8				
9				
10				
11				
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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				
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### TAKE CONTROL

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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 <u>Appendix</u> <u>C. Be Fierce. Take Control.<sup>TM</sup></u> The ACR developed this Playbook to help you and your organizations make an impact on your campus 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 <u>lupus@rheumatology.org.</u>

