

LUPUS COMMUNICATION TOOLKIT

**Women of color are often
excluded from clinical trials.**

With lower participation rates,
they miss out on emerging
treatment opportunities for lupus.

Learn more about clinical trials
pertaining to lupus today.



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What is lupus?

Lupus is a persistent, long-lasting condition that can lead to inflammation and discomfort in any area of the body.

An autoimmune disease, the immune system, which ordinarily combats infections, targets and damages healthy tissue instead.

Areas most commonly impacted by Lupus include:

- Skin
- Joints
- Vital organs

Lupus critically affects minority communities and has a higher death rate in communities of color.

Please feel free to use the tools in this communications toolkit to help educate your community.

Key Resources

Online & Local Resources

- Lupus & You webinar educational series:
<https://www.lupus.org/resources/lupus-and-you>
- Subscribe to a 12-week Take Charge email series:
<https://www.lupus.org/resources/take-charge>
- Our health education specialists are specially trained to provide people affected by lupus with free non-medical support, disease education, information and helpful resources: <https://www.lupus.org/care-support/ask-a-health-educator>
- Support Groups listed by state:
<https://www.lupus.org/resources/find-support-near-you>
- Lupus Connect online community:
https://www.inspire.com/groups/lupusconnect/?utm_source=www.lupus.org
- “Could it be lupus?” Quiz:
<https://www.lupus.org/resources/could-it-be-lupus>
- IMPACT is a partnership between the Lupus Foundation of America and local faith communities to shine a light on African Americans and lupus clinical trials: www.lupus.org/IMPACT

Key Resources

Community Health Assessment Resources

- www.cdc.gov/places
- www.cdc.gov/publichealthgateway/cha/data.html
- www.countyhealthrankings.org
- www.mypalc.org
- www.naccho.org/programs/public-health-infrastructure/performance-improvement/community-health-assessment/mapp/phase-3-the-four-assessments
- www.nlm.nih.gov/nichsr/stats_tutorial/section3/mod1_surveys.html

Clinical Trial Locator Resources

- LupusTrials.org
- [RAY: Lupus Research Accelerated by You](#)
- [Find Lupus Clinical Trials near you](#)

Key Messaging for General Public

- Lupus is an autoimmune disease, which means that it attacks the healthy parts of our body. Women between the ages of 18 and 44 are most likely to get diagnosed with lupus.
- Lupus is two to three times more common in Black and Hispanic/Latina American women than in white women.
- Women that are experiencing a rash on the face, hair loss, appetite loss or fatigue, should talk with their doctor.
- There has not been a lot of advancement in treatments for lupus. There are clinical trials that are currently looking at innovative treatments, but there are not enough Black and Hispanic women participating in these trials to help ensure that these treatments work well for them.
- The thought of participating in a clinical trial can be scary or uncomfortable, but there are a lot of protections in place to keep participants safe. Every medicine that you've ever taken, either over the counter or prescription, has been through the clinical trial process.
- Learn more about clinical trials so that you can have access to new medicines and help ensure that future generations have access to high quality treatments.

Key Messaging for Faith Leaders

Use these talking points for discussion with your parishioners.

- Lupus is an autoimmune disease, which means that it attacks the healthy parts of our body. Women between the ages of 18 and 44 are most likely to get diagnosed with lupus.
- The women in our community are most affected lupus. This disease is two to three times more common in our Black and Hispanic women than in white women.
- If you or a young woman that you know is experiencing a rash on the face, hair loss, appetite loss or fatigue, you should talk with your doctor.
- Lupus can take a heavy toll on the people who have it. We have to do our part to support them physically, emotionally, spiritually and mentally as they live with this complicated disease.
- While we should pray for a cure to lupus, we must also be diligent in supporting the work to find treatments and cures. If you have lupus, we encourage you to learn more about clinical trials so that you can have access to new medicines and help ensure that future generations have access to high quality treatments.
- The thought of participating in a clinical trial can be scary or uncomfortable, but there are a lot of protections in place to keep participants safe. Every medicine that you've ever taken, either over the counter or prescription, has been through the clinical trial process.
- Black and Hispanic people are not represented enough in clinical trials, we need to do our part to make sure we are asking about clinical trials and participating in them.

Key Messaging for Stylists/Barbers

Use these talking points for discussion with your clients.

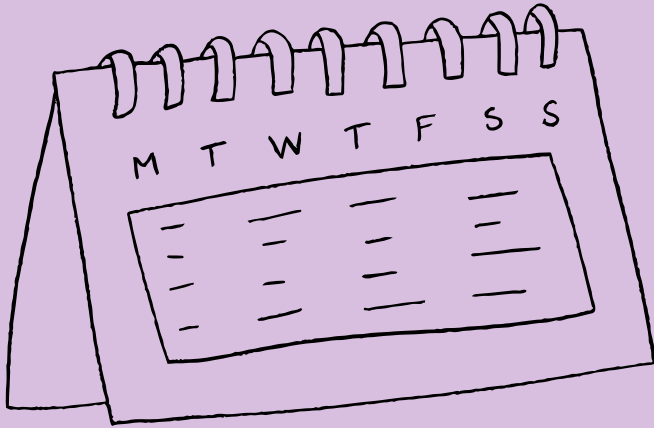
- Lupus is an autoimmune disease, which means that it attacks the healthy parts of our body. Women between the ages of 18 and 44 are most likely to get diagnosed with lupus.
- Lupus is most likely to affect our Black and Brown women. It is two to three times more common in Black and Hispanic women than in white women.
- I've noticed that you've had some unusual hair loss and want to check in with you to see if you've noticed it as well. Hair loss is a possible sign of lupus so you may want to consider having a conversation with your doctor, especially if you've also noticed any rashes, appetite loss or fatigue.
- There have not been a lot of advancement in treatments for lupus. There are clinical trials that are currently looking at innovative treatments, but there are not enough Black and Hispanic women participating in these trials to help ensure that these treatments work well for them.
- I know the thought of participating in a clinical trial can be scary or uncomfortable, but there are a lot of protections in place to keep participants safe. Every medicine that you've ever taken, either over the counter or prescription, has been through the clinical trial process.
- I encourage you to learn more about clinical trials so that you can have access to new medicines and help ensure that future generations have access to high quality treatments.

Social Media Best Practices

The following illustrated graphics and their accompanying messages were designed with the health of the community in mind.

They can be posted on any social media platform, as all social platforms work well with square media sizes.





Social Media Strategy

In this toolkit, you will find a set of expertly curated messages about lupus.

Feel free to pair any graphic with any message. It's perfectly fine to mix and match graphics and messaging to your needs. All of the graphics for all of the posts are stored in [this folder](#).

To create a social media post, save the image by clicking on the graphic link and copy and paste the messaging into your selected social media scheduling platform.

Black and Hispanic women ages 18-44 are two to three times more likely to get lupus, and need to be diagnosed earlier. The best platforms to reach Black and Hispanic women in that age range are

Post Strategy

Facebook

Facebook is a great place to share community-based messages and reach your audience. To generate the most reach and engagement, post on Tuesday through Friday between 9 a.m. and 1 p.m. local time. It's recommended to post no more than two times per day on Facebook. Hashtags are a great way to link your messages to other social media content. It is recommended that you use no more than two hashtags per post for best reach.

X (formerly Twitter)

With more than 368 million active accounts, X is a powerful social media platform to share compact, curated content. It is the only social media platform that has a low character limit for users that do not pay for its Blue verification. Posts on X can be up to 280 characters in length, including spaces. A carefully crafted post with the right message can easily reach thousands of people. Posting once or twice a day is sufficient. Tweets with no more than two hashtags perform the best. It's important to be as efficient as possible with hashtags and the character limit.

Instagram

Instagram is perfect for sharing eye-catching and emotionally-driven content. Post in the middle of the week between 10 a.m. and 1 p.m. for best results. Posting once a day is sufficient. Instagram allows up to 30 hashtags per post. However, Instagram performs best with approximately 10 hashtags. It's helpful to keep an evergreen list of relevant hashtags to use in your posts.

WhatsApp

WhatsApp is the name of a mobile messaging app for Android, iPhone, Windows Phone or for Mac or Windows PCs. With this tool, you can rapidly spread information and critical messages among members, encourage members to share and "forward" information to relatives and friends, and share broadcast messages to a community. You can message up to 256 phone contacts at the same time.

Social Media Messaging and Graphics

Messaging

- Lupus is 2 to 3 times more prevalent among Black and Hispanic/Latina women than among white women. Let's help improve lupus outcomes. Learn more: www.healthequitychampions.org
- Did you know? Lupus critically affects Black and Hispanic/Latino people. Let's work to improve lupus inequities! www.healthequitychampions.org
- Did you know lupus is more common in people of color? That's why I'm working to help my friends, family, and community members understand it. www.healthequitychampions.org
- Lupus symptoms can be severe, but therapies are available. Learn more at www.healthequitychampions.org.
- Black and Hispanic/Latino communities are severely underrepresented in clinical trial data for lupus. The time to change that is now. Learn more at www.healthequitychampions.org.
- Women of color are often excluded from clinical trials. With lower participation rates, they miss out on emerging treatment opportunities for lupus. Learn more about clinical trials pertaining to lupus today. www.healthequitychampions.org

Social Media Messaging and Graphics

Download Now



Latina/Hispanic women are often delayed in lupus diagnosis due to barriers in education, language and health care.

Help improve the outcomes for lupus in Latina/Hispanic communities. [Learn more.](#)



NATIONAL MINORITY QUALITY FORUM | **Center for Sustainable Health Care Quality and Equity** | **Biogen**

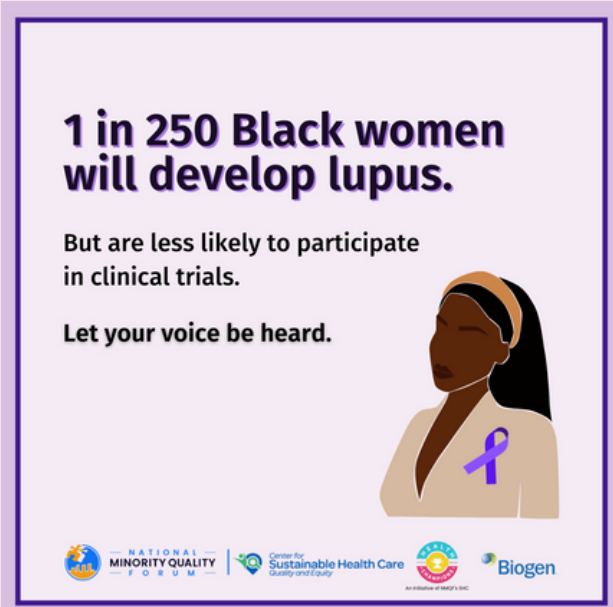


Latina/Hispanic women can develop lupus at a younger age compared to other ethnic groups.

Your voice is needed to help find treatment. [Learn more.](#)




NATIONAL MINORITY QUALITY FORUM | **Center for Sustainable Health Care Quality and Equity** | **Biogen**



1 in 250 Black women will develop lupus.

But are less likely to participate in clinical trials.

Let your voice be heard.



NATIONAL MINORITY QUALITY FORUM | **Center for Sustainable Health Care Quality and Equity** | **Biogen**



The voices of Black American women are needed now more than ever.

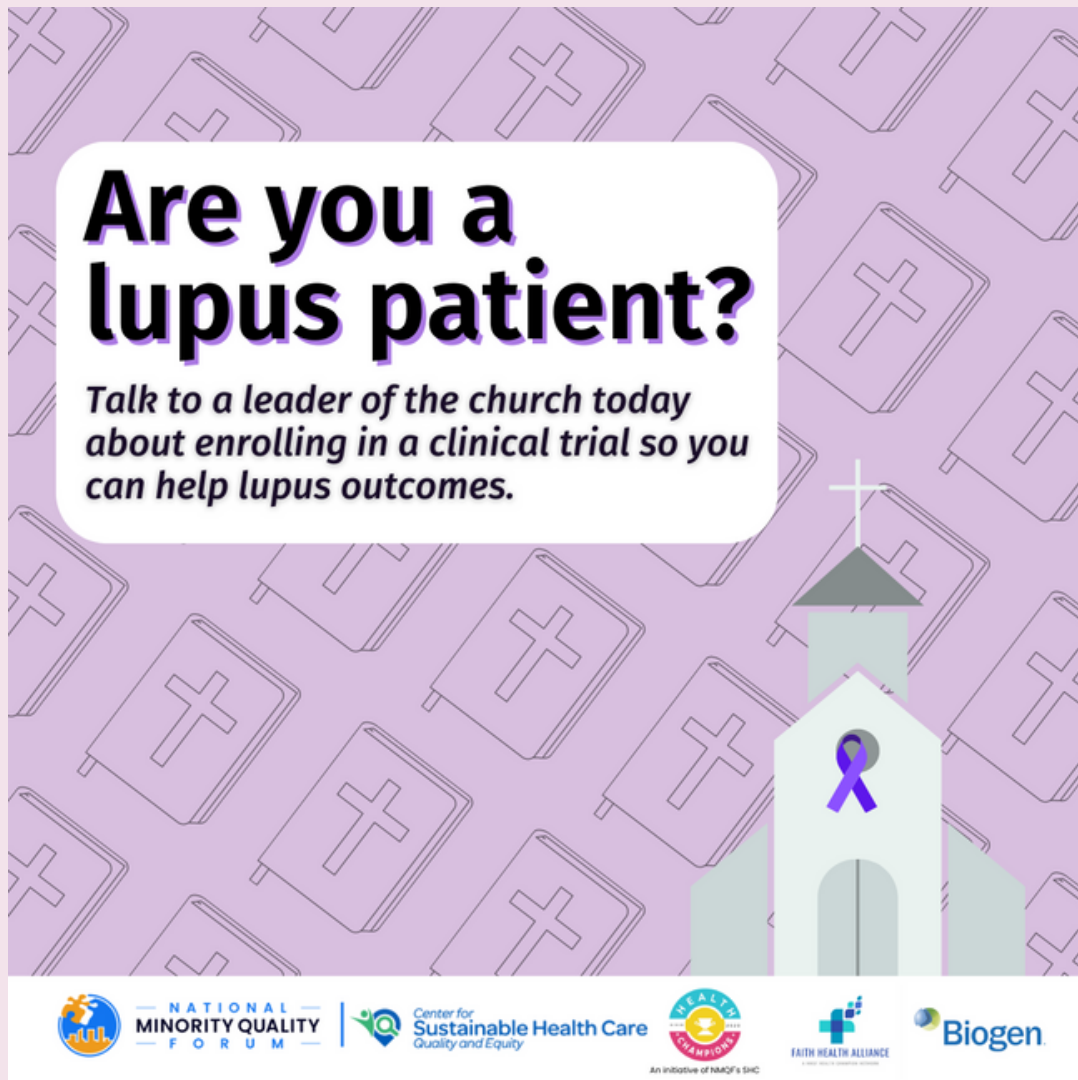
We need more women of color in clinical trials. [Learn more today.](#)



NATIONAL MINORITY QUALITY FORUM | **Center for Sustainable Health Care Quality and Equity** | **Biogen**

Social Media Messaging and Graphics: Faith






[Download Now](#)



The graphic features a light purple background with a repeating pattern of white crosses and church outlines. In the center, a white rounded rectangle contains the text: "Are you a lupus patient?" in large, bold, black font with a purple shadow. Below it, in a smaller black font, is the text: "Talk to a leader of the church today about enrolling in a clinical trial so you can help lupus outcomes." To the right of the text is a stylized illustration of a church steeple with a purple awareness ribbon around its neck. At the bottom, a white banner contains five logos: National Minority Quality Forum, Center for Sustainable Health Care, Health Champions, Faith Health Alliance, and Biogen.

Are you a lupus patient?

Talk to a leader of the church today about enrolling in a clinical trial so you can help lupus outcomes.

 NATIONAL MINORITY QUALITY FORUM |  Center for Sustainable Health Care Quality and Equity |  HEALTH CHAMPIONS |  FAITH HEALTH ALLIANCE |  Biogen.






An initiative of HMCQ's SHC

Social Media Messaging and Graphics: Barbers & Hair Stylists

[Download Now](#)

Are you a lupus patient?

Talk to one of our stylists about how to enroll in a clinical trial today.

 NATIONAL MINORITY QUALITY FORUM |  Center for Sustainable Health Care Quality and Equity |  HEALTH CHAMPIONS |  WELLNESS WARRIORS |  Biogen.

AN INITIATIVE OF NMAQF'S SHC



**Together, we
can improve
lupus outcomes
for communities
of color.**