

# Understanding Lupus: Public Awareness and Attitudes Ahead of World Lupus Day 2026

*Insights from around the globe*

*Brought to you by the World Lupus Federation*

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## 1. INTRODUCTION

Ahead of World Lupus Day on May 10, 2026, The Lupus Foundation of America conducted a global survey to better understand public awareness, attitudes and perceptions of lupus.

The research provides a regional view of how lupus remains widely misunderstood, with low familiarity, and persistent misconceptions about what the disease actually is, and how serious it can be. Across regions, public understanding is often anchored to a narrow set of symptoms, while lesser-known health effects, and stigma in everyday interactions, continue to shape how people living with lupus are perceived and supported.

As World Lupus Day approaches, the findings point to a clear opportunity to strengthen education and advocacy around the world, by leveraging trusted healthcare professionals, patient advocacy organizations, and credible online health content. By addressing key barriers, such as the limited understanding of lupus's potential severity and insufficient media visibility, we can help accelerate awareness of lupus, support earlier recognition and diagnosis, and build momentum toward better treatments, and improved quality of life.

*“Over the last 11 years, the World Lupus Federation has worked to drive global awareness of lupus by pushing for greater recognition of the disease’s full impact. This report reflects what we hear every day, that lupus is still too often misunderstood. By grounding our efforts in these insights, we can help more communities recognize lupus sooner, reduce stigma, and strengthen support for the millions of people affected by lupus.”*

*- Louise Vetter, President and CEO of the Lupus Foundation of America*

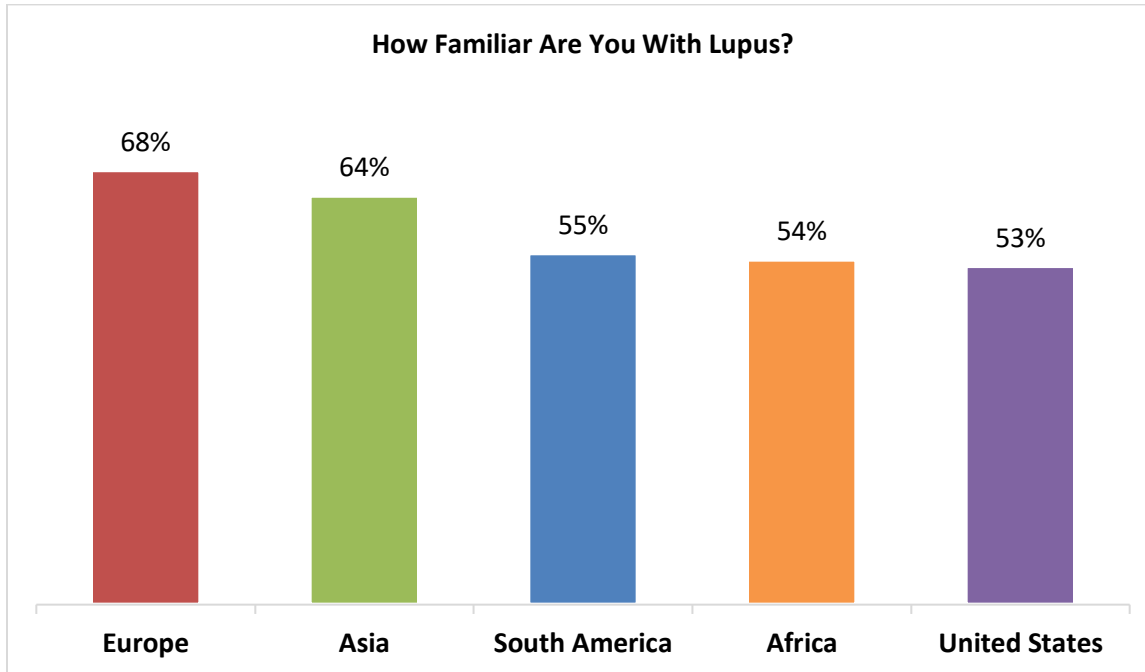
Read more to learn how lupus is recognized around the world.

## 2. WHAT IS LUPUS?

Lupus is a chronic autoimmune disease that affects millions globally, causing pain and inflammation throughout the body with symptoms ranging from debilitating fatigue and joint pain to impacting organs, including the skin, kidneys, brain, heart, and lungs. While lupus can affect anyone, 9 out of 10 people with lupus are women and it disproportionately affects certain racial and ethnic groups, including Black / African American, Hispanic / Latino, Native American and Asian / Pacific Islander populations. It is difficult to diagnose, challenging to treat, and can be life-threatening.

## 2. LUPUS AWARENESS AROUND THE GLOBE

Globally, lupus awareness is low, with respondents reporting limited familiarity to the disease. Nearly three in five (58%) respondents say that they know very little<sup>1</sup>, if anything, about lupus.



*\*Chart reflects respondents who answered that they know very little, if anything, about lupus*

This lack of familiarity with lupus is most pronounced in Europe (68%) and Asia (64%), compared to respondents located in South America (55%), Africa (54%), and the United States (53%). Additionally, just over one in three (34%) respondents located in Asia say that they have not heard of lupus. These gaps signal an opportunity for more resonant storytelling and widespread education, that makes lupus feel real, relatable, and easier to recognize, shifting the disease from an abstract concept to a lived experience. Sharing common lupus symptoms, amplifying online campaigns, and collaborating with health care providers can deliver the education needed to better understand the disease. By leveraging purple, the official color of lupus awareness, alongside increased frequency of community involvement and programs, we can spread awareness, meet people where they are, and move them to action.

A significant lack of knowledge of lupus continues to cloud the awareness landscape, as many respondents did not realize the disease's severity. In this research, more than two in five (46%) did not know or were not sure if lupus can be fatal, nearly half (48%) did not know or were not sure if lupus can affect any organ in the body, and more than two in five (41%) did not know or were not sure if symptoms can vary widely from person to person.

Misconceptions further complicate the awareness landscape as respondents located in Europe (17%) and South America (15%) are the most likely to incorrectly say that lupus being fatal is false. Similarly, respondents located in South America (17%) and Africa (17%) are the most likely to incorrectly say that lupus being able to affect any organ in the body is false.

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<sup>1</sup> Have not heard or Have heard but know nothing about or Have heard but know very little about

For many, pediatric lupus remains off the radar as nearly half (49%) of respondents did not know or were not sure if children could develop lupus. The daily reality for people living with lupus is also underestimated as two in five (43%) of respondents did not know or were not sure if lupus can often stop you from working or doing daily activities. This misconception towards lupus' ability to affect daily activities is highest amongst those located in South America (22%) and Africa (18%) and highlights a clear opportunity for targeted education that connects medical facts to lived impact.

To better understand knowledge depth, respondents evaluated a series of statements about disease activity, severity, and treatment options. Misconceptions revealed immediate confusion, with true statements dismissed as false and false statements accepted as true. Notably, falsehoods are most prominent in South America, followed by Africa, and Europe, reinforcing the need for communications that not only increases visibility of lupus, but actively corrects misinformation with clear, human-centered narratives.

*Respondents located in South America, followed by Africa and Europe, are the most likely to **incorrectly classify true statements regarding lupus as false.***

True Statements Seen as False	
"Medications for cancer and malaria are used to treat lupus"	South America (27%)
"Lupus can stop you from doing daily activities"	South America (22%)
"Lupus can affect any organ in the body"	South America (17%), Africa (17%)
"Lupus can be fatal"	Europe (17%)
"Lupus symptoms can vary widely from person to person"	South America (13%), United States (12%), Asia (12%)
"Children can develop lupus"	Africa (11%), Europe (10%)

*By contrast, false statements regarding the disease's diagnosis, were said to be true, most prominently amongst respondents located in African countries.*

False Statements Seen as True	
"There is a cure for lupus"	Africa (40%)
"Lupus can be diagnosed with a single test"	United States (35%)
"Lupus is contagious"	Africa (32%)
"Lupus affects more men than women"	Africa (22%)

These findings underscore a clear need to strengthen lupus education globally, to raise name recognition, and correct misunderstandings about what the disease is, how it is diagnosed, and how it is managed. As misconceptions vary by region and can shape everything from symptom recognition to support for those living with lupus, there is an opportunity to deliver clear, medically grounded information through high-reach channels and trusted voices. Closing the awareness gap will be essential to improving public understanding of the disease and helping more people recognize when lupus may be impacting themselves or someone they love.

### **3. DISEASE INVOLVEMENT: Locating the Many Side Effects of Lupus**

There are many reasons why lupus can be difficult to diagnose and treat. For example, there is no single test to diagnose lupus, and symptoms of the disease can mimic a wide range of other conditions. When thinking about lupus, respondents most commonly list extreme fatigue (44%), skin rashes, sores (43%), and painful or swollen joints (41%) as health effects for patients with lupus. Notably, respondents' top associations mirror the most common lupus symptoms. This knowledge is an encouraging sign that our education regarding signs and symptoms is breaking through, suggesting sustained efforts are helping more people associate lupus with the reality people living with lupus most frequently experience.

Knowledge of specific symptoms appeared higher in certain regions as respondents located in South America were most likely to say kidney disease (56%), painful or swollen joints (51%), and hair loss (40%). Those located in Africa (48%) were the most likely to recognize organ failure as a health effect.

These findings suggest that public understanding of lupus is anchored to a small set of familiar symptoms, while medically significant effects remain largely outside respondents' awareness. For medical providers, this creates a clear opportunity to broaden the narrative beyond fatigue and rashes by highlighting the full-body nature of the disease and the less-recognized impacts that can shape daily life and long-term outcomes. Expanding education in a clear, human-centered way can help improve recognition, reduce confusion, and reinforce why earlier identification and ongoing management are crucial to quality of life for people living with lupus.

#### **4. STIGMA: Confronting the Myths That Persist**

Respondents show signs of stigma around lupus, with some discomfort around close social interactions and activities. Despite lupus being a noncommunicable disease, nearly one in five (19%) falsely believe lupus to be contagious. Further, respondents also say that they are uncomfortable<sup>2</sup> sharing food (21%) and hugging (18%) people with lupus.

Such stigmas are slightly more prominent amongst those located in Africa as they are the most likely to say they are uncomfortable<sup>3</sup> hugging (23%), shaking hands (18%), sitting next to someone on a bus (18%), and sharing space (16%), with someone who has lupus, compared to respondents in other countries. By contrast, discomfort<sup>4</sup> for sharing foods (23%), was highest amongst respondents in Asia.

These moments of discomfort, whether sharing a meal or offering a hug, highlight how stigma can show up in everyday interactions and quietly shape how people with lupus are treated. For many, such hesitation reflects uncertainty rather than intent, underscoring the need for clear, accessible education that explains what lupus is (and is not) and helps correct misconceptions that can drive avoidance.

*Highlighting real stories of people living with lupus can make the disease more understood and relatable, while reinforcing a simple standard, that everyone deserves to be met with empathy, inclusion, and respect in the spaces where life happens day to day.*

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<sup>2</sup> Uncomfortable or Very uncomfortable

<sup>3</sup> Uncomfortable or Very uncomfortable

<sup>4</sup> Uncomfortable or Very uncomfortable

## 5. THE ROAD AHEAD: Education, Acceptance and Advocacy

Educating the general public about lupus is widely seen as essential, with nearly three in four (74%) respondents saying that public education is important<sup>5</sup>. However, the level of importance<sup>6</sup> varies by region, as those located in Europe (62%) and the United States (66%) are the least likely to prioritize public education of lupus compared to others located in Asia (69%), South America (88%), and Africa (88%). This points to a clear communications need: bring lupus out of the shadows with more widespread education including storytelling that makes the disease visible, and easier to understand, especially in markets where awareness is lagging.

When asked where they typically look for information about health conditions such as lupus, respondents predominantly look to healthcare professionals (46%) and online health websites and forums (44%), highlighting the key role of trusted medical and digital channels. Respondents located in Africa were the most likely to outline additional avenues for education, including AI tools (44%), social media (40%), and friends or family (28%). To close the awareness gap, lupus education should be delivered through the channels people already trust and use, combining medical guidance and community touchpoints, in an effort to truly meet audiences where they are.

Respondents list lack of understanding of the potential severe health effects of lupus (32%) and lack of media coverage (30%) as the biggest barriers to increasing public awareness of lupus. In Africa, lack of understanding of potential severe health effects (39%), lack of media coverage (38%), and limited education resources (31%), are the highest compared to the other regions surveyed. By comparison, respondents located in South America (36%) are the most likely to note misconceptions, stigmas, or common myths about the disease as the biggest barriers to increasing public awareness.

The barriers outlined point to a practical path forward to increased awareness: more lupus information through online / social media (38%), in traditional media (34%), and making lupus diagnosis and management a higher priority in the medical community (25%). Respondents located in Africa are the most likely to say more information online / social media (44%), educating government officials (35%), and community awareness and fundraising events (31%), compared to their counterparts. Requests for more information about lupus via traditional media (45%) are most common amongst those located in South America. A coordinated approach, harnessing trusted medical voices and high-reach media can correct misconceptions, deepen understanding of the disease's impact, and create a more informed and supportive public.

### WORLD LUPUS DAY: LIGHTING THE WAY FOR LUPUS AWARENESS

Each year on May 10, World Lupus Day creates a focused opportunity to bring the global impact of lupus into a sharper view. This day, established by the World Lupus Federation, is designed not only to raise awareness, but to rally the global public, lupus organizations, and people affected by the disease for a common purpose: driving greater attention, urgency, and resources toward ending lupus.

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<sup>5</sup> Extremely important or Very important

<sup>6</sup> Extremely important or Very important

To help that message travel farther, the World Lupus Federation encourages supporters worldwide to share lupus facts and elevate the diverse challenges people with lupus face, using an official World Lupus Day toolkit, which includes ready-to-use awareness resources, including social media shareables in English and Spanish. People across the globe are also invited to show visible solidarity by wearing purple and lighting buildings in purple, turning public spaces into a collective signal that the fight to end lupus is seen, shared, and gaining momentum.

## **6.1 OPPORTUNITIES: How to Accelerate Global Awareness**

- 1. Make lupus visible through education that meets people where they are.** With 58% of respondents saying they know very little about lupus, and awareness weakest in Europe and Asia, there is an urgent need to scale public education. Activate the channels they already trust most and ensure messaging is tailored by region to drive relevance and impact.
  - a. Develop and execute a year-round digital awareness campaign.** Maintain ongoing conversations and education about lupus through a year-round digital awareness campaign. Utilize various digital channels and formats to disseminate factual information about lupus and personal stories, encouraging followers to share and spread awareness.
  - b. Increase media engagement and provide influencers with educational content to share.** Conduct outreach to media to share accurate and comprehensive information about lupus, including in news stories and shows. Partner with influencers and public figures who can help amplify the message about lupus, using their platforms to reach a wider audience.
  
- 2. Educate health care professionals during and following medical school.** Work with partners to develop and promote programs that provide in-depth training on lupus symptoms, diagnosis, and treatment options for health care providers. Advocate for the inclusion of lupus education in medical school curricula to ensure future doctors are well-informed about the disease.
  - a. Broaden the narrative beyond “fatigue and rashes” to reflect full-body impact.** Public understanding is concentrated around a narrow set of symptoms, while many serious effects (e.g., blood clots, cognitive dysfunction, photosensitivity) remain underrecognized. Use education campaigns and experiences of people with lupus to expand what the public associates with lupus, supporting stronger public urgency for research and better treatments.
  
- 3. Correct misconceptions with clear, medically grounded storytelling.** Misclassification of lupus as cancer (United States: 12%), or an infectious disease (Europe: 17%), coupled with widespread confusion about diagnosis, severity, and treatment, shows that awareness alone isn’t enough. Prioritize myth-busting content and patient stories to replace misinformation and improve recognition.
  - a. Address stigmas directly to build acceptance and respectful behavior.** Discomfort with everyday interactions (sharing food, hugging) signals that misinformation can translate into exclusion. Pair education with empathy-led storytelling that reinforces lupus is not contagious and that people living with the disease deserve respect and acceptance. Mobilize advocates, partners, and media to normalize inclusion and turn awareness into community support and action.

## **6. CONCLUSION**

As World Lupus Day approaches, the findings paint a consistent picture: lupus remains poorly understood across regions, with limited familiarity, persistent misconceptions, and a narrow view of symptoms that can delay recognition and diagnosis, and shape how people living with the disease are treated.

Confusion regarding what lupus is, how it is diagnosed, and how serious it can be, paired with signs of stigma in everyday interactions, underscores that awareness is not simply about visibility, it is about accuracy, empathy, and relevance.

The path forward is a coordinated, story-led education effort that meets audiences where they already seek information, through trusted healthcare professionals and credible digital sources. It is also crucial to amplify reach across social and traditional media to increase coverage and correct misinformation. Respondents' ability to recognize the most common lupus symptoms suggests that our sustained, in-depth education efforts are landing with broader audiences. By elevating real experiences of people with lupus, alongside clear medical facts, advocates and partners can broaden the understanding of lupus, reduce stigma, and continue progress toward better treatments, and ultimately, a cure!

### **6.2 Research Methodology**

To gather global insights and explore public attitudes and perceptions of lupus, the World Lupus Federation partnered with market research agency, TEAM LEWIS, to survey 1,000 individuals (200 per region) in the United States, Europe, South America, Africa, and Asia. All respondents were 18 or older, and the sample was US census-balanced by age and gender. TEAM LEWIS collected data through an online survey fielded from March 10-20, 2026. The survey respondents were independently sourced from Veridata Insights with an overall margin of error of 3.1% and 95% confidence interval.

### **6.4 World Lupus Federation**

The World Lupus Federation (WLF) is a coalition of more than 200 lupus patient organizations, united to improve the quality of life for the approximately 5 million people around the world who are affected by lupus. Through coordinated efforts among its members, the Federation works to expand global initiatives that create greater awareness and understanding of lupus, provide education and services to people living with the disease and advocate on their behalf. The Lupus Foundation of America (LFA) co-founded the WLF with Lupus Europe in 2015 and the LFA currently serves as the Secretariat of the Federation.

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