Help Us Solve The Cruel Mystery **LUPUS**[®] FOUNDATION OF AMERICA

EXECUTIVE SUMMARY

Lupus Health Disparities in the United States:

A FRAMEWORK OF BARRIERS AND FACILITATORS FOR REDUCING DISEASE BURDEN IN RACIAL AND ETHNIC MINORITIES

ABOUT THE LUPUS FOUNDATION OF AMERICA

Our mission is to improve the quality of life for all people affected by lupus through programs of research, education, support and advocacy. We are focused on achieving the following disease-specific outcomes: reduce time to diagnosis, ensure people with lupus have an arsenal of safe and effective treatments, and expand direct services and increase access to treatment and care. We have been leading the fight to end lupus for more than four decades with over 400 funded research studies and fellowship to find cures, 8 million people who count on us every year for answers, support, and advocacy. Lastly, we've stimulated \$684 million in federal funds for lupus research and education.

ABOUT THIS EXECUTIVE SUMMARY

In October 2020, the Lupus Foundation of America convened a panel of lupus and health disparity experts to address barriers and facilitators for reducing health disparities in people with lupus. Together, the panel provided expert opinion about structural factors that result in unequal distribution of resources. This unequal distribution of resources drives the development of social inequities and barriers to access to care that facilitate the development of health disparities. They also synthesized lupus disparities data that outlines barriers and solutions related to lupus health disparities. This executive summary highlights those key findings and provides a framework to build upon for developing key strategies and solutions to reduce lupus-related health disparities in people who are at increased risk for lupus.

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The Lupus Foundation of America is committed to using interdisciplinary approaches to create patient-centered solutions that address structural and social determinants of health that facilitate the development of health disparities.

The views outlined in this report are those of the Lupus Foundation of America and do not necessarily reflect the Lupus Foundation of America's contributors' views or the policies of entities who have supported the work. American Indian/Alaska Native, Black/African Americans, Asian Americans/Pacific Islanders, and Hispanic/Latino populations are disproportionately burdened by lupus. Data from the National Lupus Patient Registry at the Centers for Disease Control and Prevention clearly indicates an increased prevalence, incidence, morbidity and mortality in people from some racial and ethnic groups.

The Lupus Foundation of America has both conducted and funded lupus research for over 40 years to identify the cause of lupus and to discover improved methods for diagnosis, symptom management and treatment. While genetic differences play a role in disease burden, studies have consistently shown that differences in living and working circumstances, access to physician care and treatment, access to transportation and healthy foods, behavioral and psychosocial factors, institutional bias or institutional racism, and experiences of racial discrimination contribute to disparate outcomes in lupus.

The Lupus Foundation of America recognizes the need to gain a better understanding of interventions necessary to mitigate documented social determinants of health that perpetuate health disparities in lupus. Additionally, the COVID-19 pandemic has highlighted key social and economic disadvantages that have and continue to be detrimental to the health of historically socially disadvantaged populations living in the United States (U.S.). As a result, the public and private sectors focused on important challenges faced by communities from some racial and ethnic minority groups who have limited resources and options for establishing economic safety nets that ultimately protect health.

The intent of this report is to provide an overview of (1) key contributors to lupus health disparities, (2) specific barriers that exist upstream and downstream at the individual/ community, healthcare system, and structural/political levels, and (3) current ongoing programs, research studies and recommendations from the scientific literature proposed to mitigate or address the identified barriers.

While findings in this report, at the outset, may appear grim, overall lupus mortality rates have drastically improved over the last 50 years. Moreover, three new therapies to treat lupus have been developed in the past 10 years. These developments provide hope that a brighter future for people with lupus is on the horizon if we continue to work together to provide multidimensional solutions to directly address the impact of social determinants of health on people with lupus, increase access to care, and improve the quality of care for all people impacted by lupus.

LFA has observed the need to gain a better understanding of interventions needed to circumvent documented social determinants of health (SDoH) that perpetuate the health disparities narrative in lupus.



The Hispanic/Latino, Black/ African American, and Asian American/Pacific Islander people with lupus have accrued more damage over time and at a faster pace than White people with lupus⁴. The Lupus Foundation of America estimates 1.5 million people live with lupus in the US. The most common form of lupus is systemic lupus erythematosus (SLE). This form of lupus disproportionately affects women and people from some racial and ethnic minority groups. Women make up 90% of all people with SLE.

This report outlines SLE disparities in Black/African American, Hispanic/Latino and Asian American/Pacific Islander populations in detail. Data on American Indian/ Alaska Native communities is limited. While disparities in pediatric populations (including neonatal lupus and childhood-onset lupus) exist, most available research on disparities in lupus focuses primarily on adults living with SLE. In addition, disparities in cutaneous lupus subtypes will not be covered. Therefore, the term "lupus" throughout the rest of this report will refer to adults with SLE unless otherwise specified.

People of color, who have higher lupus prevalence, are also more likely to have active, severe disease.

Black/African American females are 3 times more likely to be diagnosed with lupus compared to White females. Geographical regions with lower socioeconomic status also have a higher lupus prevalence than areas with high socioeconomic status¹. Black/ African American patients have more active and severe disease and higher odds of greater disease damage and comorbid conditions (SLE comorbidity index (SLE CI) >= 2)^{2,3}. The SLE CI is a total score for the following weighted health conditions: HIV/AIDS,

Table 1:

SLE Prevalence Based on Race & Ethnicity

Race/Ethnicity	SLE Prevalence per 100,000	
American Indian or Alaska Native		
Female	270.6	
Male	53.8	
Asian or Pacific Islander		
Female	84.4	
Male	8.9	
Black or African American		
Female	230.9	
Male	26.7	
Hispanic or Latino		
Female	120.7	
Male	18	
White		
Female	84.7	
Male	11.2	

Table 1. Data from the Centers for Disease Control on SLE Prevalence in the US by Race/Ethnicity.

malignancy, cerebrovascular accident, chronic renal failure, congestive heart failure, diabetes mellitus, nephritis, metastatic disease, myocardial infarction, pericarditis, peripheral vascular disease, pleuritis, severe liver disease, and thrombocytopenia.

The Hispanic/Latino, Black/African American, and Asian American/Pacific Islander people with lupus have accrued more damage over time and at a faster pace than White people with lupus⁴. Black/African American and Asian American people develop lupus earlier and are less likely to achieve remission than White people with lupus^{5,6}.

Kidney involvement or progression to lupus nephritis impacts Black/African American, Hispanic/Latino, and Asian American populations more than others.

The incidence rate of all-cause end stage kidney disease is 4 times higher among Black/African American lupus patients in comparison to White lupus patients (13.8 vs 3.3 per 1,000 patient-years, respectively). This is due to Black/African American people with lupus developing kidney disease much earlier in the disease course and having a delayed diagnosis⁷. This could result from a number of disparities Black/African Americans experience in receiving healthcare, including delays in evaluation referral, incomplete evaluations, or varying insurance status⁸.

Black/African American and Hispanic/Latino people with lupus have the highest lupus-related death rates.

Overall, increased disease severity and greater risk of comorbidities leads to aggressive lupus progression resulting in higher mortality for people of color or with a lower socioeconomic status^{9,10,11}. Lupus mortality is highest in the U.S. South, and it is associated with poverty, Black/African American race, and Hispanic/Latino ethnicity^{9,10}. Black/African American people with lupus had significantly and persistently higher mortality from time of diagnosis, with deaths occurring sooner after diagnosis and at a mean age of 13 years younger compared to White people with lupus¹¹. Lupus mortality rates from 1979-1998 were 5 times higher for women than men. Moreover, mortality rates were the highest and fastest growing for Black/African American women^{6,12}. Based on lupus mortality data in from 1999-2016, mortality in Black/African American people with lupus has remained consistently 3 times higher than mortality in White lupus patients (Table 2)¹³.

Table 2:

Lupus Mortality Rates per 100,000 Persons by Race and Ethnicity,1999-2016

Race/Ethnicity	Mortality	Mortality Rate per 100,000
American Indian or Alaska Native*	221	0.5
Asian or Pacific Islander	831	0.3
Black or African American	7,478	1.1
Hispanic or Latino	2,924	0.3
White	10,976	0.3

Table 2. Lupus mortality/rates per 100,000 persons by race and ethnicity based on CDC data between 1999-2016.

*This data may be unreliable due to underreporting on the American Indian/Alaska Native population with lupus

Aspects of disease and psychological outcomes, related comorbidities and other adverse events can negatively impact quality of life for people with lupus.

Disparities in lupus extend to disparities in the impact of lupus on quality of life. Access to healthcare, social support, financial resources, and residential environment (i.e., outdoor space, fresh air, clean water, air conditioning), may all be factors in exacerbating disparities in lupus outcomes. Decreased physical function associated with higher lupus severity leads to lower patient-reported quality of life and can result in increased rates of depression after disease onset¹⁴. Aspects of quality of life that are impacted by higher disease activity, negative lupus outcomes and psychological toll on people with lupus include their emotions, social life, family/leisure/ daily activities, cognition, sleep, appearance, employment and independence¹⁵. IMPACT OF SOCIAL DETERMINANTS OF HEALTH ON LUPUS DISPARITIES

Symptoms of lupus mimic other diseases; therefore, people with lupus lacking education related to the disease can experience diagnostic delays and worsening of symptom severity.³⁵ Interactions between social determinants of health, which include an individual's living and working circumstances, access to medicine, transportation and food, result in disparities impacting racial/ethnic groups that have been historically socially marginalized.

Barriers to accessing lupus care may arise from these determinants, and can be seen at the individual, community, healthcare system and political system level. Primary socioeconomic, community and access determinants negatively impact the mental, emotional, physical and financial health of all people with lupus. But this is especially true for Black/ African American, American Indian/Alaska Native, Asian American, and Hispanic/Latino people with lupus.

Social determinants of health are well-documented contributing factors to racial/ ethnic disparities in lupus. As part of the U.S. Department of Health and Human Services (HHS) and the Office of Disease Prevention and Health Promotion (ODPHP)'s joint Healthy People 2030 initiative to improve nationwide health and well-being, their social determinants of health objectives are classified into five primary categories: Social and Community Context, Economic Stability, Education Access and Quality, Healthcare Access and Quality, and Neighborhood and Built Environment (Figure 1). The Lupus Foundation of America recognizes that these five categories may not be all-inclusive of social determinants that people with lupus may experience. For ease of categorization, however, this framework, which is built

Figure 1 :

Lupus Foundation of America Framework to Target Racial Health Disparities in Systemic Lupus Erythematosus

Adapted from the World Health Organization's conceptual framework and the National Institute on Minority Health and Health Disparities Research framework.



on the HHS and the ODPHP standardized social determinants of health domains in addition to domains adopted from the World Health Organization's framework and the National Institutes on Minority Health and Health Disparities research framework on disparities, is presented.

The U.S. has a history of designing systems that disproportionately and negatively impact racial/ethnic groups that have been marginalized, contributing to ongoing systemic racism¹⁶. Consequently, systemic racism directly affects all five of the outlined social determinants of health domains and creates and perpetuates disparities impacting Black/African American, Hispanic/Latino, and Asian American/ Pacific Islander people with lupus (Figure 1)¹⁷.

ECONOMIC STABILITY

Differences in socioeconomic status and economic stability can disproportionately affect racial/ethnic groups that have been marginalized. These effects can be even more compounded for people who live with lupus. Racial/ ethnic health disparities exist resulting from varying levels of economic stability, resulting from core economic factors including:

- Underemployment/unemployment¹⁸.
- Poverty¹⁷.
- Income inequality¹⁸.

- Wealth inequality¹⁹.
- Lower socioeconomic position and prestige^{20,21}.
- Unequal employment opportunities due to disability status and intermittent flares^{22,23}.

In a study conducted in 2014 by Drenkard et al., Black/African American people living with lupus were two times more likely to lose their jobs after lupus diagnosis compared to White people with lupus²². This suggests that people with more severe disease activity (including disease flares) are more likely to become unemployed or under-employed²². Collectively, these factors have a tremendous impact on the ability to access healthcare, which remains significantly tied to employment in the U.S. For many people with lupus that remain employed, flares can necessitate adjustments to their work schedule, intensity, and/or responsibilities, which often result in unpaid leave, reduced hours, or job loss²³. Continuous loss of income coupled with lack of financial safety nets and access to wealth lends itself to poverty. Yelin et al. showed that poverty increased the rate of damage accumulation in patients with lupus, leading to mortality 13.9 years earlier in comparison to non-poor patients in the Lupus Outcomes Study cohort²⁴. Moreover, studies in this cohort showed that lupus patients who permanently exited poverty had similar damage accumulation to those patients who never experienced poverty²⁵.



People living with lupus who have disadvantage in educational attainment, income, and/or occupation are more likely to experience inequities in other social determinants of health domains (see Figure 1)²⁰. People living with lupus who have a lower socioeconomic status also tend to experience more psychosocial stressors, a decreased quality of care and less satisfaction with care received from healthcare professionals^{26,27}. Moreover, this same group has treatment access barriers, increased lupus severity and higher rates of mortality²⁸.

EDUCATION ACCESS AND QUALITY

One key factor contributing to poorer outcomes for people living with lupus is both a lack of formal education and patient-provider health literacy related to lupus risk factors, manifestations, and outcomes²⁹. Barriers associated with less-than-optimal health literacy for people with lupus are multifactorial and include the following:

- Baseline inequalities in socioeconomic status in comparison to White people with lupus³⁰.
- A lack of formal education and fewer education options³¹.
- Lack of general health literacy³¹.
- Lack of awareness about SLE and autoimmune disease³².
- Lack of exposure to patient-friendly lupus-focused educational materials³³.
- Lower access to high-speed internet and technology³⁴.

Symptoms of lupus mimic other diseases; therefore, people with lupus lacking education related to the disease can experience diagnostic delays and worsening of symptom severity³⁵. A lack of health literacy may also impact the ability to proactively seek care to manage lupus. People living with lupus who have a lower level of education may not know what resources to use to find more information about lupus. They could also face barriers accessing that information due to lack of Internet connectivity or lack of access to patient-friendly lupus educational materials^{31,36}. Decreased health literacy is more common amongst people of color compared to White people with lupus, and low health literacy has also been linked to higher lupus disease activity^{37,36}.

HEALTHCARE ACCESS AND QUALITY

Environmental and financial barriers can lead to disparities in lupus healthcare access and utilization. Racial/ethnic disparities in access to primary care, level of insurance coverage, and number of physician visits for each person living with lupus persist^{38,39}. Some examples of healthcare system factors that can negatively impact people of color living with lupus include:

• Limited access to high-quality rheumatology care⁴⁰.

Studies have shown that Black/African American and Hispanic/Latino people with lupus may be less likely to have access to quality food and decreased ability to make healthier changes to their diet⁵⁹.

- Lack of patient-clinician relationship stability and shared-decision making^{41,42}.
- Limited access to lifesaving, quality of life-preserving treatment⁴¹.
- Limited community health workers/social workers⁴³.
- Lack of clear guidelines for holistic treatment approaches^{44,45}.
- Existing healthcare administrative demands/ requirements/incentives for levels of treatment^{46,47}.

Black/African American, Hispanic/Latino, and Asian American people with SLE can also face barriers to receiving quality lupus care due to travel burden and lack of specialist access. Reliance on caregivers, meeting financial priorities and pain/physical limitations were primary concerns about travel burden⁴⁸. Moreover, lack of child or elder care when needed are risk factors for low adherence in Black/African American people with lupus, due to the time and financial resources needed to support other family members⁴⁹. Furthermore, specialist referrals after a lupus diagnosis from primary care providers (PCPs) or general practitioners (GPs) were lower for Black/African American and Asian American/ Pacific Islander people with lupus leading to a decrease in care provided by a rheumatologist⁴⁰. This can lead to these patients having significantly fewer overall visits to a rheumatologist compared to White people with lupus⁶. Lack of access to specialist care can result in an initial misdiagnosis, further delaying proper care, symptom mitigation and receiving treatment⁵⁰.

Lower quality patient-physician interactions may lead to a decrease in overall guality of care received. A working alliance between physicians and lupus patients, including positive trust, and communication of treatment goals, is a predictor of high patient satisfaction with care received, patient treatment adherence and quality of life outcomes⁵¹. Black/ African American patients perceived hurried communication with providers, resulting in a more negative interaction with providers⁵². The stability that comes with developing and maintaining a relationship with either a primary care provider or a rheumatologist is also less likely if a patient perceives negative interactions, which can lead to switching primary healthcare providers often and inconsistent patterns of care⁵³. Diverse racial/ethnic groups living with lupus can also experience lower self-efficacy in their role in the lupus treatment decision process, decreasing the quality of the patient-provider shared-decision making experience⁵².

People of color and persons with a lower socioeconomic status experience challenges related to cost and lack of insurance that limit access to critical lupus related therapies often prescribed by their healthcare provider^{32,54}.

According to Redbook, the retail prices of approved branded lupus therapies are expensive – \$4,000 per weekly treatment⁵⁵. While insurance coverage is highly variable by plan, some lupus medications (e.g., Benlysta) are largely (>60%) covered across commercial, Medicare, and Medicaid plans⁵⁶. However, newly approved lupus treatments may not obtain comprehensive insurance coverage immediately after approval, resulting in limited access for people with lupus. Likewise, pharmaceutical company patient assistance programs for newer, extremely expensive medications often require extensive paperwork and present insurmountable barriers for patients with the greatest needs. Moreover, payer step edits and prior authorizations, provide further barriers to access and treatment delays^{57,58}. These requirements can be cumbersome for both patients and healthcare providers to navigate and are particularly common for lupus patients given frequent off-label prescriptions⁵⁷. Treatment affordability concerns and access restrictions can exacerbate existing racial/ethnic disparities in lupus.

NEIGHBORHOOD AND BUILT ENVIRONMENT

The neighborhoods in which people with SLE live can have a great impact on their overall health and well-being, as well as lupus manifestation and outcomes. The following are pervasive in communities where historically marginalized groups with lower socioeconomic status reside:

- Food deserts⁵⁹.
- Neighborhood poverty⁶⁰.
- Lack of access to healthcare professionals and hospitals in neighborhood⁶¹.
- Air pollution or closer proximity to toxic sites^{61,62}.
- Non-beneficial land use mix, street connectivity, and transportation systems^{63,62}.
- Increased presence of litter, abandoned buildings and broken windows⁶⁴.
- Decreased walkability and green space^{63,62,65}.
- Higher crime rates⁶³.

Studies have shown that Black/African American and Hispanic/Latino people with lupus may be less likely to have access to quality food and decreased ability to make healthier changes to their diet⁵⁹. This may worsen disparities in lupus

Studies have shown that Black/African American and Hispanic/Latino people with lupus may be less likely to have access to quality food and decreased ability to make healthier changes to their diet⁵⁹.

symptoms which could potentially be mitigated by dietary change, especially those associated with cardiovascular risks and comorbidities⁶⁶.

Receiving lupus treatment may not be a priority for people of color if they are lacking food, housing and/or financial security, which may result in reduced treatment adherence/compliance and poorer lupus prognosis⁶⁷.

Racial inequity exists in longitudinal exposure to poor neighborhoods. Neighborhood poverty also necessitates a choice relating to day-to-day care of food, housing, and medical needs, often postponing attention given to lupus flares⁶⁸. Moreover, low neighborhood socioeconomic status is associated with high levels of depression in lupus patients⁶⁰. Exposure to neighborhood crime could be a stressor for worsening lupus disease activity⁶⁹. Those living in the most disadvantaged neighborhood quartile can experience up to 60% lower retention of lupus care⁷⁰. In addition, poorer neighborhoods are less likely to have access to specialist care, and patients may need to travel farther outside their neighborhood to receive initial and continuing care for lupus⁷¹.

SOCIAL AND COMMUNITY CONTEXT

Existing social constructs, as well as the community surrounding an individual (including family, friends, colleagues and others), have a large impact on future health outcomes. The level of social support that an individual with lupus receives from a community throughout the course of disease can affect psychological and emotional health, as well as directly impacting lupus severity or outcomes. These social and community factors which many people with lupus from racial/ethnic groups experience include:

- Discrimination^{72,73}.
- Prejudice^{72,73}.
- Stress⁷⁴.
- Physical/emotional/financial violence^{75,76}.
- Limited social capital, social cohesion, and social control⁷⁷.

Discrimination and prejudice that Black/African American, Hispanic/Latino, and Asian American SLE patients may face can negatively impact lupus outcomes due to the exacerbation of stress on the patient. Unfair treatment and racial discrimination are associated with greater lupus damage in African American women, even after adjusting for socioeconomic and health-related covariates^{72,73}. Likewise, vicarious exposure to racism induced stress amongst Black/ African American women living with lupus and has been linked to greater disease activity⁷⁴. Racism also causes psychological distress in African American women living with lupus and this type of distress serves as a mediator for increased disease severity⁷⁸.

High levels of psychological distress can lead to depression which is a common comorbidity in Black/African American women living with lupus. Depression in lupus patients is most prevalent amongst Black/African American women living in highly segregated census tracts. However, the causes for an increased presence of mental health complications in these environments require additional investigation⁷⁹. While social support has not been implicated as a mediator of disease damage in Black/African American women with lupus, social support may provide alleviation from depressive symptoms often experienced by Black/African American women living with lupus⁸⁰.

Furthermore, in the healthcare system, mistrust of and lack of support from providers contribute to disparities in quality of healthcare. Black/African American lupus patients report higher rates of discrimination in healthcare. This perceived racism in provider interactions can result in lower trust in physicians^{34,81}. Black/African American people were less willing to receive potent immunosuppressive treatment than White people with lupus, due to decreased trust in physicians and perception of treatment effectiveness⁸². Increased mistrust of healthcare systems can lead to reluctance to seek proper treatment⁸³.

Lupus patients are not only impacted by social and community implications during their disease course, but adverse childhood experiences (ACEs) may impact lupus development⁸⁴. Adverse childhood experiences were more prevalent in female, Black/African American and Hispanic/ Latino lupus patients⁷⁶, while childhood abuse was associated with higher lupus incidence in Black/African American women⁴⁰.

Collectively, these findings suggest that strategies are needed to reduce racial/ethnic health disparities in lupus. Table 3 outlines ongoing programs, activities and recommendations from the published literature focused on reducing health disparities in lupus.

Table 3: UPSTREAM INTERVENTIONS TO REDUCE LUPUS DISPARITIES

UPSTREAM INTERVENTIONS	HEALTH CARE ACCESS & QUALITY	Optimize healthcare access in disadvantaged populations and neighborhoods $^{\scriptscriptstyle \dagger}$
		Medicare Access for Patients Rx [™]
		FLY-IN Advocacy Summit
		National Lupus Advocacy Summit
		Market Access Working Group

Table 4:

MIDSTREAM INTERVENTIONS TO REDUCE LUPUS DISPARITIES

	HEALTH CARE ACCESS & QUALITY	Material to Increase Minority Involvement in Clinical Trials (MIMICT)*
		Community health worker clinical trials training (LuCTT)*
		Patient Advocates for Lupus Studies (PALS)*
		Programs to address lack of diverse representation in lupus clinical trials (PURPLE)*
MIDSTREAM INTERVENTIONS		Develop tools for early detection †
		Enhance provider communication efforts around medication cost to guide shared decision making [†]
		Outline strategies for improving treatment adherence†Error! Bookmark not defined.
		Evaluate psychological factors in multidisciplinary healthcare professional setting ^{†26}
		Deliver culturally and linguistically relevant clinical trial education [†]
	CLINICAL EDUCATION ACCESS & QUALITY	Practice Improvement Education (PIVOT)*
		Lupus Education Advancement (Project) for improving specialist referral by PCP (LEAP)*
		Develop innovative tools to increase awareness of lupus
		Improve health literacy through patient-focused education materials ⁺³⁶
		Increase provider awareness about impacts of SDOH/race/ethnicity on health $^{\scriptscriptstyle \dagger}$
		Increase Minority Participation and Awareness in Clinical Trials (IMPACT+) for Lupus*
		Encourage clinician engagement in LFAs/OMRF's EMPOWER initiative*
	SOCIAL & COMMUNITY CONTEXT	Utilization of Popular Opinion Leader model to disseminate lupus education and increase awareness in African American communities
		Peer-to-peer self-management mentorship amongst African American Women (PALS)*
		Place patient with SW/CHW to enhance access to primary care ^{†38}
		Lupus Research Action Network

Table 5:

DOWNSTREAM INTERVENTIONS TO REDUCE LUPUS DISPARITIES

DOWNSTREAM INTERVENTIONS	EDUCATION ACCESS & QUALITY	Continue to provide LFA TakeCharge Email series*
		Be Fierce. Take Control™*
		Active information dissemination to patients and providers ^{†92}
	HEALTH CARE ACCESS & QUALITY	LFA Self-Management (SELF)*
		LFA Support Groups, Lupus & You events, Expert Series, the National Resource Center & Research Accelerated by You*
		Individualized Decision Aid (IDEA-WON)*

† Recommendations from literature

Established Lupus Foundation of America (LFA) program (See Appendix A)

A PATH FORWARD FOR REDUCING DISPARITIES IN LUPUS

> The Lupus Foundation of America recognizes that changing the systems that affect individual and population health is a challenging task.

However, recent scientific advances and an emerging public focus on health disparities provide a renewed opportunity to address the barriers to achieving the best possible health for everyone but especially those in populations experiencing disparities in healthcare. We are committed to working across disciplines to create people-centered solutions that will serve as a buffer against the negative effects of structural and social determinants of health. We plan to do this by engaging people with lupus, communities, service providers, industry professionals, health insurance companies and policymakers. Our collaborative efforts across the lupus community will continue with efforts to improve the health of all people living with lupus and to eliminate disparities in health status and outcomes among Black/African American, American Indian/Alaska Native, Hispanic/Latino, and Asian American people living with lupus.

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Medicare Access for Patients Rx[™]

MAPRx brings together more than 60 national beneficiary, patient, family, caregiver, and health professional organizations committed to protecting the health and wellbeing of individuals with chronic diseases and disabilities by improving access to affordable prescription drugs through Medicare Part D.

FLY-IN Advocacy Summit & National Lupus Advocacy Summit

Once a year, hundreds of lupus advocates gather in Washington D.C. to raise their voices. As part of the experience, we host an educational seminar to educate on the latest news in lupus research, treatments, progress, etc.

Market Access Working Group

Convenes leaders from across the lupus community to identify and advance initiatives that improve access to care for people living with lupus. Some of the key issues include insurance coverage, step therapy, health disparities, telehealth, SDOH, etc.

Increase Minority Participation and Awareness in Clinical Trials (IMPACT+) for Lupus

Utilizes nurse and people with lupus led educational initiatives to increase awareness about clinical trial participation and lupus and the Black/African American community.

LFAs/OMRF's EMPOWER Initiative

Educating My Patients on Ways to Safely Engage in Research (EMPOWER) seeks to reduce lupus-related health disparities among racial and ethnic minority populations – who are disproportionately affected by lupus – by improving knowledge about lupus, its treatments, and clinical trials. This program was developed by the Oklahoma Medical Research Foundation. It is supported by the U.S. Department of Health & Human Services Office of Minority Health National Lupus Outreach and Clinical Trial Education Program.

Lupus Research Action Network

LRAN is a program to train approximately 30 individuals with lupus on the importance of clinical trials, how to participate, what the process is like, why diversity is needed, then we provide them with tools to go out and share what they learned with their network. Training is provided by a rheumatologist, LFA staff, and clinical trial professionals.

LFA Take Charge Email Series

A weekly education email series for people with lupus, including those recently diagnosed. Each week for 12 weeks, you'll get an email from our Health Educators with tips and resources that can empower you to take charge of your health.

Be. Fierce. Take Control[™]

This program is designed to educate and empower young African American and Latino women, who are most at-risk for developing lupus.

LFA Self-Management (SELF)

The SELF program offers personalized support at each participant's own pace to adopt four key lupus selfmanagement behaviors: managing symptoms, stress, medications and working with their health care team.

LFA Support Groups

Our lupus support groups across the U.S. provide a warm and caring environment where people with lupus, their family members, caregivers, and loved ones can share their experiences, gather credible information, develop coping methods, and provide insights into living with a chronic illness.

Lupus & You Events

Quarterly national educational webinar series that features topics relevant to people with lupus. Lupus & You features experts that present information in an engaging way, then finishes with a mission moment, typically done by a celebrity connected to lupus.

Expert Series

LFA's monthly podcast that features interviews with experts on different topics that are of interest to the lupus community. Topics range, but some examples: mental health, skin rashes, clinical trial involvement, lupus flares, etc.

National Resource Center

The core of lupus.org is the depth and breadth of our resources that help people navigate their journey with lupus. With more than 600 medically reviewed resources and over 10 million content pages, it is the #1 lupus resource in the world.

