



NATIONAL PUBLIC HEALTH AGENDA FOR LUPUS 2015

A BLUEPRINT FOR ACTION



NATIONAL ASSOCIATION OF
CHRONIC DISEASE DIRECTORS
Promoting Health. Preventing Disease.



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The Cruel Mystery
LUPUSTM
FOUNDATION OF AMERICA



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National Public Health Agenda for Lupus
A Blueprint for Action

The National Association of Chronic Disease Directors (NACDD) and the Lupus Foundation of America, with funding from the Centers for Disease Control and Prevention (CDC), are pleased to present the first-ever *National Public Health Agenda for Lupus*. The *Agenda* was developed to prioritize a coordinated and multi-faceted public health approach to lupus.

Lupus is an unpredictable and misunderstood autoimmune disease that ravages different parts of the body. It is difficult to diagnose, hard to live with and a challenge to treat. In lupus, the body's immune system becomes unbalanced, causing inflammation and tissue damage to virtually any organ system in the body, including the skin, joints, heart, lungs, kidney and brain. The symptoms and impact of lupus range in severity from mild to life threatening. Between 350,000 and 1.5 million Americans and 5 million worldwide live with a form of lupus.

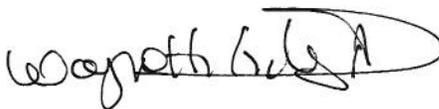
While we have seen improved care for individuals with lupus, we still have much work to do to improve the care and quality of life for people living with the disease, and the public health sector can contribute a great deal to this end. A *National Public Health Agenda for Lupus* provides a blueprint for all stakeholders to guide public health action surrounding future policy, planning and advocacy. Recommendations set forth in the *Agenda* are considered relevant and complementary to efforts in lupus biomedical research and clinical care.

The *National Public Health Agenda for Lupus* is the result of collaboration among a wide variety of stakeholders, including public health and lupus experts, clinicians and individuals living with lupus. The CDC Four Domains of Chronic Disease Prevention provided the framework for developing the public health approach for lupus.

We hope the thoughtful and innovative strategies and recommendations contained in the *National Public Health Agenda for Lupus* will help to advance the fight against lupus.



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Table of Contents

Executive Summary	5
Key Public Health Priorities	6
Agenda Contributors	8
The Need For Action	10
Background	11
Diagnosis and Treatment	11
Risk Factors	12
Burden of Disease	12
Health Disparities	13
Development of the Agenda	14
Agenda Methods	15
Four Domains of Chronic Disease Prevention	15
Key Values	16
Strategies and Recommendations	18
Domain 1 - Epidemiology and Surveillance	18
Domain 2 - Environmental Approaches	20
Domain 3 - Health Care Systems Interventions	22
Domain 4 - Community Programs Linked to Clinical Services	24
The Future	26
Glossary	28
Endnotes	30

Lupus is a complex, chronic, inflammatory autoimmune disease in which an unknown trigger causes the immune system to attack the person's own tissues. Lupus can impact virtually any organ system of the body, including the skin, joints, kidney, brain, heart, lungs, blood and blood vessels. There is no known cause or cure for lupus, which can cause severe kidney disease, stroke and premature cardiovascular disease.

While there are several forms of lupus, systemic lupus erythematosus (SLE), a chronic, autoimmune disease that can damage any part of the body, is the most serious form of lupus. Existing prevalence estimates range from 322,000 with definite or probable SLE¹ to 1.5 million Americans living with some form of lupus.² Lupus affects women nine times more often than men,³ with 80% of new cases developing between the ages of 15 and 44.⁴ Lupus is three times more common among women of color than white women.

While there has been progress in managing lupus over the past decade, there is still much work to do to improve the care and quality of life for people living with the disease. To help fight lupus and improve the quality of life for the people living with the disease, the Centers for Disease Control and Prevention (CDC) funded the National Association of Chronic Disease Directors (NACDD) in collaboration with the Lupus Foundation of America to develop a *National Public Health Agenda for Lupus*.

The *Agenda* is organized and framed under the CDC Four Domains of Chronic Disease Prevention that include epidemiology and surveillance; environmental approaches; health care system interventions; and community programs linked to clinical services. The *Agenda* also addresses health disparities and communication strategies.

This *Agenda* provides a broad public health approach to lupus diagnosis, disease management, treatment and research. The six priorities, 15 strategies and 63 recommendations set forth in the *Agenda* will guide the public health community to plan effective lupus initiatives, and will complement efforts in lupus biomedical research and clinical care.

National Public Health Agenda for Lupus

The *Agenda* outlines a series of strategies and recommendations aligned with the CDC Four Domains of Chronic Disease Prevention. Contributors to the *Agenda* defined six key public health priorities:

- **Create better case definitions of lupus** that are appropriate for clinical diagnosis, surveillance and research.
- **Expand epidemiology, surveillance and public health research** for incidence, quality of care, adverse outcomes and mortality, with a high priority for those studying health disparities.
- **Develop, improve and increase** the availability of evidence-based disease self-management programs and techniques.
- **Enhance local, regional and national capacity** to provide information and resources for people with lupus, their families, friends and caregivers, providers, public health practitioners and researchers.
- **Support the development of robust care coordination models** that facilitate collaboration between primary care providers and rheumatologists. This will help ensure people with lupus are diagnosed early and receive appropriate treatments, preventive health screenings and services and a smooth transition from pediatric to adult care.
- **Implement public awareness campaigns** clearly illustrating the complexities of lupus and the importance of early identification and diagnosis and effective disease management.



“Lupus is three times more common among women of color than white women”

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There is no known cause or cure for lupus, which can cause kidney disease, stroke and premature cardiovascular disease.

Background

Lupus is a complex, chronic, inflammatory autoimmune disease in which an unknown trigger causes the immune system to attack the person's own tissues. Lupus can affect virtually any organ system of the body, including the skin, joints, kidney, brain, heart, lungs, blood and blood vessels. There is no known cause or cure for lupus, which can cause kidney disease, stroke and premature cardiovascular disease.

There are several forms of lupus, with systemic lupus erythematosus (SLE) being the most serious form of lupus. Other forms of lupus include cutaneous lupus erythematosus, which is limited to the skin; drug-induced lupus erythematosus, a lupus-like disease caused by certain prescription drugs that typically ends when the drug is stopped and neonatal lupus which is a rare temporary condition caused by antibodies from the mother acting upon the infant in the womb. The term lupus is used throughout the *Agenda* to encompass all forms of the disease; however, some data cited may be specific to SLE, and is so noted.

People with lupus sometimes have symptoms that are characteristic of one or more of the other connective tissue diseases, such as rheumatoid arthritis, scleroderma, Sjögren's syndrome and various forms of vasculitis. Other conditions that can occur among people living with lupus include depression, cardiovascular disease and atherosclerosis.

Diagnosis and Treatment

There is no specific test to diagnose lupus, making diagnosis challenging for many primary care providers. This may result in delayed diagnosis and medical treatment. Many people with lupus report being incorrectly diagnosed or experience delays in obtaining an accurate diagnosis. Of those who report an incorrect diagnosis, more than half report seeing four or more different health care providers for their lupus symptoms before being accurately diagnosed.

Late diagnosis and delayed treatment contribute to poor outcomes and increased morbidity and mortality. Improved knowledge of lupus among health care professionals may result in earlier and more accurate diagnoses. This, in turn, could help to improve disease management and quality of life, while diminishing adverse effects for people living with lupus.⁶

The Need for Action

The clinical spectrum of lupus ranges from mild to life threatening. Lupus is a disease of flares in symptoms and disease activity. Complications can arise suddenly. As a multi-system disease, people living with lupus regularly see primary care providers as well as several medical specialists.^{7,8}

There are limited options available for treatment of lupus. Belimumab, approved by the FDA in March 2011, is the first and only drug designed specifically to treat lupus. Most other medications used to treat lupus are prescribed off-label. These medications do not cure lupus and often have significant side effects.

Risk Factors

Most risk factors for lupus are not modifiable. However, certain modifiable environmental factors have been linked to the development or aggravation of symptoms of lupus, such as exposure to fine particulate matter or silica. Many people with lupus find their disease is made worse by exposure to ultraviolet rays from sunlight or artificial light, which may require adaptations both at home and in the work setting.

Burden of Disease

Many people with lupus experience ongoing inflammation and damage, which contribute to general fatigue, chronic pain, mood disturbances, poor sleep quality and cognitive impairment.⁹ Fatigue is experienced by about 85% to 92% of people living with lupus; fifty percent of people living with lupus rate fatigue as the most disabling symptom of lupus.¹⁰ People with lupus can have a significantly lower quality of life than people with other chronic diseases.¹¹

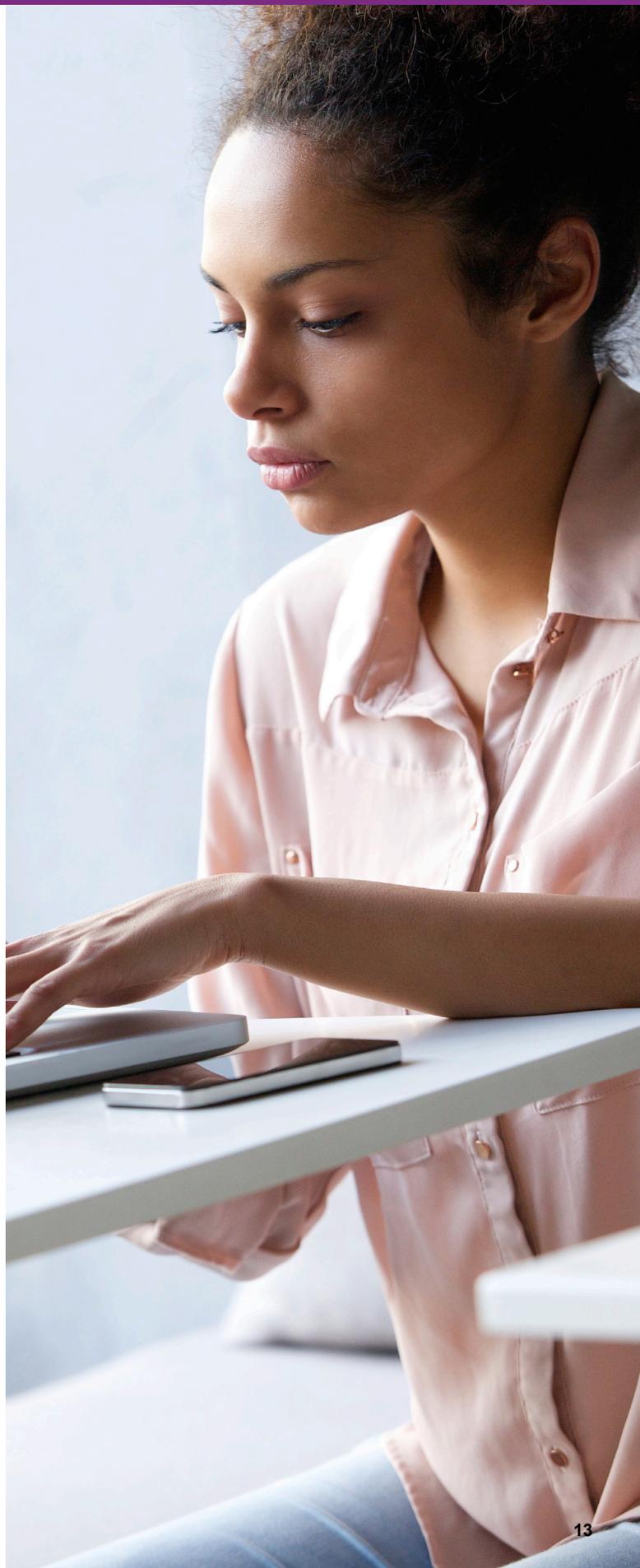
SLE is a costly condition. Mean annual expenditures for persons with SLE were \$12,238 greater than those for persons without SLE; for persons with SLE related nephritis, mean medical expenditures were \$46,862 greater than for persons without SLE. Persons with SLE related nephritis had the highest average per patient annual cost at \$64,195, when compared with 10 other chronic diseases.¹²

Lupus can interfere with work. One study found that more than 40% of people with SLE were no longer employed an average of 3.4 years after their diagnosis. Socioeconomic factors that contributed to not working were lower levels of education, lack of private health insurance, higher amount of physical activity required for the job and higher disease activity at the time of diagnosis.¹³

Health Disparities

Recent studies indicate that lupus incidence rates are almost three times higher in black women than white women, and affect 1 in 537 young African American women.^{14,15} Minority women tend to develop lupus at a younger age, experience more serious complications and have higher mortality rates—up to three times the mortality rate of white women.¹⁶

Young black women who have lupus nephritis tend to have a more severe disease course and are more likely to progress to end stage renal disease. In addition, non-white patients are more likely to suffer from lupus-related depression, cardiovascular disease and diabetes and have worse health-related quality of life than white patients.^{17,18} Health disparities are extremely complex, and may play a role in the burden of lupus nephritis in this population. Disparities may be due to genetics, disease comorbidities and a variety of social determinants that influence health outcomes.





Experts and stakeholders, including people living with lupus, convened to develop the strategies and recommendations for this *Agenda*.

Development of the Agenda

Agenda Methods

The Centers for Disease Control and Prevention (CDC) funded the National Association of Chronic Disease Directors (NACDD) in collaboration with the Lupus Foundation of America to develop a *National Public Health Agenda for Lupus*.

The *Agenda* provides a broad public health approach to lupus to help guide future policy, planning, advocacy and action initiatives.

A Steering Committee was established in September 2014 to provide guidance with project planning. The Steering Committee agreed on a comprehensive approach to the *Agenda* that used the CDC Four Domains of Chronic Disease Prevention and a set of key values. The Committee also sought a wide variety of experts and stakeholders in lupus and public health to contribute to the effort.

Four Domains of Chronic Disease Prevention

The *National Public Health Agenda for Lupus* is organized and framed under the CDC Four Domains of Chronic Disease Prevention.⁵

- **Epidemiology and Surveillance** to provide data to define and prioritize public health problems.
- **Environmental Approaches** to promote health and support healthy behaviors.
- **Health Care System Interventions** to improve the delivery and use of clinical and other preventive services.
- **Community Programs Linked to Clinical Services** to ensure access to preventive and self-management resources.



Development of the Agenda

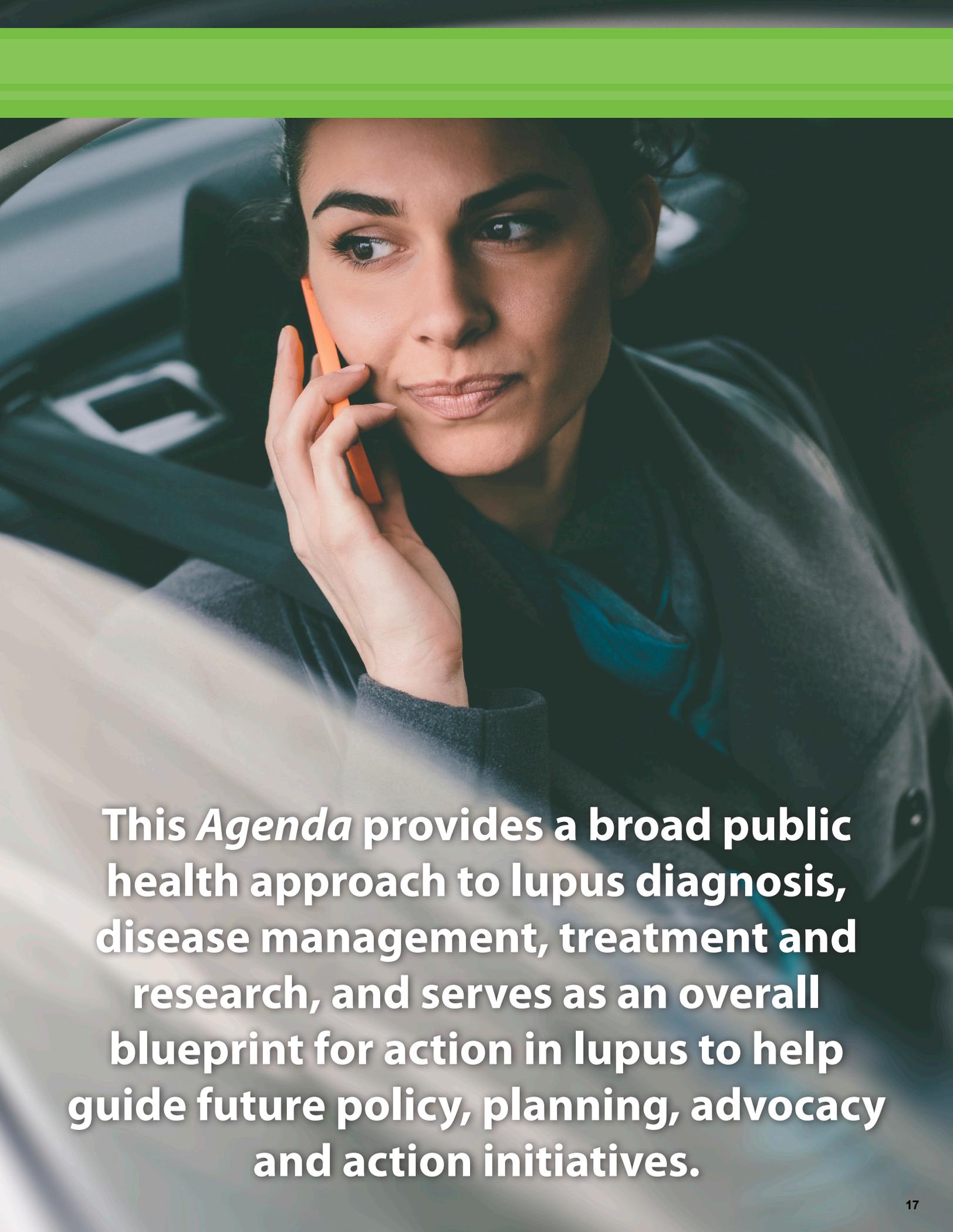
Recommendations to address health disparities and communication strategies are also included in this *Agenda*.

Key Values

The Steering Committee endorsed the following key values in support of a public health approach to lupus:

- **Enhance the capacity for lupus data collection and surveillance** to detect trends in diverse populations and across the U.S.
- **Increase the supply and distribution of trained health care providers** to provide early diagnosis, effective disease management and referral services.
- **Promote clinical and community-based resources** that support people living with lupus and their families.
- **Implement communication strategies** to illustrate evidence-based practices, effective treatment methods, and the burden of lupus.
- **Investigate factors** that contribute to inequities and disparities in health outcomes.

Subject matter experts and stakeholders participated in one of two February teleconferences to explain both lupus and public health. On March 10 and 11, 2015 in Washington, DC, more than 50 experts and stakeholders, including people living with lupus, convened to develop the strategies and recommendations for the *Agenda*. The result is the first-of-its kind *National Public Health Agenda for Lupus* that provides a wide-range of public health recommendations intended to complement efforts in lupus biomedical research and clinical care.

A close-up photograph of a woman with dark hair and eyes, wearing a grey jacket, sitting in the driver's seat of a car. She is holding an orange smartphone to her ear and looking thoughtfully out the window. The background is slightly blurred, showing the interior of the car.

This *Agenda* provides a broad public health approach to lupus diagnosis, disease management, treatment and research, and serves as an overall blueprint for action in lupus to help guide future policy, planning, advocacy and action initiatives.

Strategies and Recommendations

Domain 1: Epidemiology and Surveillance

Objective: To provide essential data to define and prioritize public health problems, identify populations most affected, guide solutions and monitor progress and information.⁵

Strategy 1-1: Monitor long-term **trends in the burden of lupus**

Recommendations

- Expand the study of incidence and prevalence of lupus among racial and ethnic minorities.
- Use a variety of existing national surveys to more accurately determine the burden of lupus.
- Analyze survey results over time, geographic area and demographics.
- Encourage states to use national and state-based data sources to determine the burden of lupus.
- Revise existing or develop new surveillance systems or measures to address lupus burden estimates.
- Increase the capacity of national, state and local partnerships to address lupus, including data collection and self-management resources.

Strategy 1-2:
Assess and monitor the **quality and timeliness of care** for people living with lupus

Recommendations

- Assess the percent of people with lupus who receive appropriate interventions including, but not limited to immunizations; preventive health and behavioral health screenings; medication use and adherence; use of complementary and alternative medicine; disease self-management techniques; family planning; and frequency of health provider visits.
- Develop and evaluate the implementation of uniform quality of care indicators in lupus.
- Examine disparities in quality of care indicators by age, gender, race/ethnicity, income and geographic location.
- Assess social determinants of health for people with lupus including, but not limited to, availability of resources to meet daily needs; access to health care services; transportation; social support; socioeconomic conditions; employment.
- Develop best practice guidelines for managing lupus with attention to the use of glucocorticoids.



Strategy 1-3:
Assess and monitor **quality of life** among people living with lupus

Recommendations

- Evaluate existing quality of life tools and develop new instruments as needed.
- Use multiple data sources to determine quality of life for people with lupus. Data sources may include surveys or assessment tools within lupus registries, at infusion centers, through patient advocacy organizations and in the general population.



Strategy 1-4:
Monitor the **knowledge of lupus** among health care professionals

Recommendations

- Evaluate the understanding by health care professionals of diagnosis, management, disease progression and other conditions associated with lupus; care coordination processes among specialists and referrals to self management resources; the transition from pediatric to adult care; and knowledge of pregnancy related issues, including the use of appropriate medications.
- Health care professionals to be assessed include, but are not limited to, practitioners of family and internal medicine, pediatrics, obstetrics and gynecology, rheumatology and dermatology (including physician assistants and nurse practitioners).

Strategy 1-5:
Expand research in lupus, including epidemiologic, surveillance and **public health research**

Recommendations

- Create better case definitions of lupus that are appropriate for clinical diagnosis, surveillance and research.
- Determine risk factors for developing lupus.
- Support research to improve ways to identify those at highest risk for developing lupus or those at risk for organ involvement, and that facilitates earlier diagnosis, disease monitoring and prediction of flares.
- Assess the impact of environmental risk factors at home and in the work place.
- Assess factors that influence access to care and adherence with management, including medications.

Domain 2: Environmental Approaches

Objective: To promote health and support healthy behaviors across the nation, in states and communities, and in settings such as schools, childcare programs, work sites and businesses.⁵

Strategy 2-1:

Implement **integrated, comprehensive, coordinated patient-centered care models** for lupus to improve overall health outcomes and quality of life

Recommendations

- Develop innovative and cost-effective models for integrated, comprehensive, coordinated patient-centered health care delivery for people with lupus and their families.
- Document the cost-effectiveness and improved health outcomes of the coordinated care models.
- Develop criteria for certification of the models as comprehensive lupus centers.



Strategy 2-2:

Ensure full **participation in the work force** and ability to **access services when work is not an option**

Recommendations

- Recognize lupus as a disease that may require Americans with Disabilities Act (ADA) accommodation such as flex time, work from home and potential physical accommodations.
- Work with the Social Security Administration (SSA) to support the inclusion of a diagnosis of lupus into the Social Security Disability Insurance (SSDI) Compassionate Allowances Program.
- Collaborate with the SSA to revise the SSDI guidance to accurately reflect the documentation of lupus intangibles, such as pain and fatigue, as well as the specific measurable assessments of visible physical health.

Strategy 2-3:

Work with the U.S. Department of Health and Human Services to establish a lupus specific section in **Healthy People 2030**

Recommendations

- Convene representatives from the lupus community and public health officials to establish lupus as a topic area separate from arthritis.
- Develop lupus specific goals and objectives for Healthy People 2030, including those specific to disparities faced by people living with lupus.

Strategies and Recommendations



Strategies and Recommendations

Domain 3: Health Care Systems Interventions

Objective: To increase the use and improve the quality of clinical and other preventive services.⁵

Strategy 3-1:

Ensure **early diagnosis and access to lupus care and treatments**

Recommendations

- Support the development and validation of diagnostic criteria including a case definition, and tools to help health care providers make an early and accurate diagnosis.
- Increase the role of technology in early detection and disease management by developing novel mobile apps and supporting the expansion and integrated use of tele-health and electronic health records.
- Support prescription drug formularies that do not delay access to effective lupus therapies and treatments.
- Eliminate policies, such as “fail first” that create barriers to accessing vital medications.
- Promote and support the establishment of the Patient Centered Medical Home model for people with lupus to ensure access to primary care and timely preventive screenings.

Strategy 3-2

Improve the quantity, distribution and education of health care providers who deliver care to people with lupus

Recommendations

- Support training and education that promotes an integrated approach to lupus care, inclusive of public health, nutrition, social work, pharmacy, behavioral health and medicine.
- Establish a task force to work with the Health Resources Services Administration (HRSA) to expand the National Health Service Corps Loan Repayment Program to include rheumatology as a qualified specialty.
- Increase the number and distribution of rheumatology fellowship programs.
- Encourage practitioner fluency in other languages, especially Spanish, or ensure the ready availability of translators to improve care, compliance and access to care.
- Develop a clinician certification program in lupus diagnosis and care.
- Collaborate with health professional associations to increase and develop educational opportunities about lupus, with a focus on educating primary care practitioners, obstetricians/gynecologists, ophthalmologists, dermatologists, mental health specialists, emergency room physicians, pharmacists, nurses and practitioners in urgent care settings.
- Expand Teaching Fellows in Lupus into additional areas with high minority populations who are at increased risk for lupus.
- Develop best practices on the use of alternative therapies.

Strategy 3-3:

Improve the **transition from pediatrics to adult care** for people with lupus

Recommendations

- Expand the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Registry to investigate long-term outcomes of childhood-onset lupus and the transition of care to adult rheumatologists.
- Develop recommended practice procedures for transition.
- Encourage HRSA to direct states to include children and adolescents with lupus as an essential part of the regularly scheduled state needs assessment for Title V funding.

Strategy 3-4:

Improve **health promotion and family planning** for people living with lupus

Recommendations

- Develop standards and models of care and education that address wellness and the special reproductive health needs of people with lupus, including fertility and family planning.
- Encourage and improve partnerships at the national and state level to support the use of best practices in health promotion such as smoking cessation.
- Improve the ability of state health departments to address lupus by developing a template lupus action plan for effective program planning for lupus that can be replicated in state health departments across the country.
- Encourage appropriate referrals to chronic disease early detection programs.

Strategy 3-5:

Increase **participation in clinical trials and research** with a focus on populations disparately affected by lupus or who are historically underrepresented in clinical trials

Recommendations

- Create culturally appropriate and sensitive educational materials about the benefits of participation in a clinical trial.
- Develop strong local and community leaders to create trust and promote participation in clinical trials and research.
- Promote the need and understanding to engage in clinical trials and use effective culturally appropriate recruitment mechanisms to improve the connection of people with lupus with clinical trials and academic sponsors.
- Support new and innovative clinical trial designs across clinical and sociodemographic subpopulations to facilitate drug discovery in lupus and identify new targets for drug development.



Domain 4: Community Programs Linked to Clinical Services

Objective: To ensure that people with or at high risk of a chronic disease, like lupus, have access to resources they need to prevent or manage their disease.⁵

Strategy 4-1:

Promote the development and use of effective **community-based self-management** resources

Recommendations

- Leverage collaborations among community and faith-based organizations, schools, health care systems and employers to promote and market community-based self-management services for people living with lupus.
- Ensure data sharing between community resources and the clinical setting to monitor impact/effectiveness of self-management service.
- Collaborate with lupus centers to develop a tool to support disease self-management for people with lupus, and integrate the tool into standards of practice.
- Examine existing self-management supports for people with chronic disease that may be adapted for lupus.
- Support the development, testing and validation of new evidence-based self-management programs for people living with lupus.
- Eliminate barriers to effective community-clinical linkages by addressing social determinants of health that may impede access to care and ongoing treatment, such as low income, inadequate health insurance, transportation or insufficient providers of primary care or rheumatology.

Strategy 4-2:

Increase **awareness of lupus** and available resources among all stakeholders

Recommendations

- Establish national awareness campaigns on lupus targeting a variety of audiences.
- Create educational materials with effective linkages to organizations that represent other diseases which may affect people living with lupus, such as cardiovascular and kidney diseases.
- Expand the 211 system in all states to include pathways for access to care, clinical and community support programs for people with lupus.
- Develop and enhance local, regional and national clearinghouse capacity for people with lupus and their families, as well as health care providers.
- Educate state health departments of the importance of implementing data collection systems for lupus or collaborating with lupus registries in their state.



Strategies and Recommendations



The Future

The implementation of the recommendations contained in the *National Public Health Agenda for Lupus* will require a strong commitment among local, state and national health and public health organizations, advocates, policy makers and people living with lupus.

It is crucial to develop communication strategies to continue the fight against lupus and to demonstrate the personal and economic toll of this disease.

The strategies and recommendations cited in the *Agenda* are far ranging, from improving data collection and research, the availability of self-management programs, access to information and resources, development of robust care coordination models and public awareness, and serve as a model of a comprehensive approach to lupus care and treatment.



Glossary

Community is a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings.¹⁹ For the purposes of this Agenda, this definition is expanded to recognize individuals who share ties through social connections and virtual communication methods.

Cutaneous Lupus Erythematosus is limited to the skin. Although cutaneous lupus can cause many types of rashes and lesions (sores), the most common—discoid rash—is raised, scaly and red, but not itchy. Areas of rash appear like disks, or circles. Another common example of cutaneous lupus is a rash over the cheeks and across the bridge of the nose, known as the butterfly rash. Other rashes or sores may appear on the face, neck, or scalp (areas of the skin that are exposed to sunlight or fluorescent light), or in the mouth, nose, or vagina. Hair loss and changes in the pigment, or color, of the skin are also symptoms of cutaneous lupus.²⁰

Drug-induced Lupus Erythematosus is a lupus-like disease caused by certain prescription drugs. The symptoms of drug-induced lupus are similar to those of systemic lupus, but it rarely affects major organs.²⁰

Evidence-Based Public Health is the process of integrating science-based interventions with community preferences to improve the health of the population.¹⁹

Fail First policies — also known as Step Therapy — are often an insurance practice which requires the least expensive drug in any class to be prescribed to a patient first, even if a patient’s physician believes a different therapy is medically in the best interest for their condition.²¹

Flare is a measurable increase in disease activity in one or more organ systems involving new or worse clinical signs and symptoms and/or laboratory measurements. It must be considered clinically significant by the assessor and usually there would be at least consideration of a change or an increase in treatment.²²

Health Disparity is a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.²³

Incidence rate A measure of the frequency with which a new event, such as a new case of illness, occurs in a population over a period of time. The denominator is the population at risk; the numerator is the number of new cases occurring during a given time period.²⁴

Lupus nephritis is an inflammation of the kidneys, making them unable to properly remove waste from blood or control the amount of fluids in the body. Abnormal levels of waste can build up in the blood, and swelling can develop. Left untreated, nephritis can lead to scarring and permanent damage to the kidneys and possibly end-stage renal disease (ESRD). People with ESRD need regular filtering of their body’s waste done by a machine (dialysis) or a kidney transplant so that at least one kidney is working properly.²⁰

Neonatal Lupus is a rare condition associated with anti-SSA/Ro and/or anti-SSB/La antibodies from the mother that affect the fetus. At birth, the baby may have a skin rash, liver problems, or low blood cell counts, but these symptoms typically disappear completely after six months with no lasting effects. The most

serious symptom is congenital heart block, which causes a slow heartbeat. This is usually detected when the fetus is between 18 and 24 weeks old. With proper testing, physicians can now identify most at-risk mothers, and the infant can be treated at or before birth.²⁰

Provider refers to health care practitioners who provide care for a person with lupus, such as family and internal medicine clinicians, pediatricians/adolescent medicine, college health, specialist providers in the fields of rheumatology, dermatology, cardiology, ophthalmology, emergency medicine, nurse practitioners, physician assistants, pharmacists, behavioral health, nutritionists/dieticians and other health team members.

Public Health Surveillance is the ongoing, systematic collection, analysis, and interpretation of health data, essential to the planning, implementation and evaluation of public health practice, closely integrated with the dissemination of these data to those who need to know and linked to prevention and control.²⁴

Systemic Lupus Erythematosus (SLE) is a chronic, autoimmune disease that can damage any part of the body (skin, joints, and/or organs inside the body). Chronic means that the signs and symptoms tend to last longer than six weeks and often for many years.²⁰

Teaching Fellows in Lupus is a program that uses fellows in rheumatology to deliver quality education to frontline providers to improve recognition of the signs and symptoms of lupus and improve the speed of referral for diagnosis and treatment.²⁵

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