

Florida Public Health Plan for Addressing Lupus

2016-2021 State Action Plan



Florida Public Health Plan for Addressing Lupus

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Executive Summary

This document provides an overview of the proceedings from the Florida Lupus Summit, which convened on August 29, 2016, in Tallahassee, Florida. Sixty attendees, representing a varied number of community-based organizations, healthcare, academic institutions, researchers, lupus support organizations, and persons living with lupus contributed to the development of the *Florida Public Health Plan for Addressing Lupus (Plan)*. Following the meeting, members of the Lupus Summit Task Force, which assisted in planning the Summit, were charged with reviewing a draft plan, developed to include a series of state-specific strategies and recommendations that align with the Center for Disease Control and Prevention's Four Domains of Chronic Disease Prevention. The *Plan's* public health priorities provide an outline of strategies and recommendations to further engage the community and ensure the continuity of efforts to improve population health by addressing lupus statewide.

Background

Big Bend Rural Health Network (Network) is one of nine established in the state of Florida per Section 381.0406, *Florida Statutes*. Its mission is to improve health outcomes in rural counties with quality health education and resources. The Network led the challenge to create the *Plan* through a project that was supported by Grant Number 6 NU58DP006138-01-02; CFDA number 93.068, from the Centers for Disease Control and Prevention (CDC), for Developing and Disseminating Programs to Build Sustainable Lupus Awareness, Knowledge, Skills and Partnerships.



Community Engagement

Florida has a health care delivery landscape that is continuing to experience new challenges from an aging population, infectious and chronic diseases, environmental challenges, and the growing burden of diseases like lupus. Home to over 20 million residents, Florida is the third most populous state in the nation based on a 2015 report from the U.S. Census Bureau¹. Florida's large and diverse population presents challenges and opportunities for community-based interventions to improve public health outcomes. Community engagement plays a critical role when various stakeholders must work together.



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What Is Lupus?

According to the CDC, lupus is an autoimmune disease that triggers inflammation in different tissues of the body. Autoimmune diseases happen when the body's immune system attacks its own tissues². The most common type of lupus is systemic lupus erythematosus (SLE), which affects different parts of the body including internal organs. In addition to SLE, the National Institutes of Health describes other types of lupus as:

- Discoid lupus erythematosus—causes a skin rash that doesn't go away;
- Subacute cutaneous lupus erythematosus—causes skin sores on parts of the body exposed to sun;
- Drug-induced lupus—can be caused by medications; and,
- Neonatal lupus—a rare type of lupus that affects newborns³.



Lupus severity ranges on a spectrum from mild to severe, and in its most severe forms lupus can cause significant morbidity and mortality⁴. Lupus is also a disease of flares (the symptoms worsen and you feel ill) and remissions (the symptoms improve and you feel better)⁵.

Burden of Disease

As an unpredictable and misunderstood autoimmune disease that ravages different parts of the body, prevalence estimates range from 350,000, with definite or probably SLE⁶, to 1.5 million Americans living with some form of lupus⁷. The Lupus Foundation of America states that about 40% of those with lupus no longer work an average of 3.4 years after their diagnosis. Lupus often strikes women in their early working and childbearing years, and it can interfere with a woman's ability to work, raise a family, or, in some cases, even care for themselves, according to the National Institutes of Health. At the local level this would strain both the health care delivery and economic systems in the state of Florida. The Lupus Foundation of America Florida Chapter concludes that there are about 100,000 individuals living with lupus in the state of Florida⁸. This number is based on the national Lupus Foundation of America's finding of 1 in 185 people being affected by this disease. There are only eleven (11) known support groups throughout the state, including an online group to address lupus. Plans are currently underway to secure another support group in Orlando, which will make 12 support groups affiliated with the Lupus Foundation of America Florida Chapter. These support groups not only provide health education and sharing of resources to patients, but also help foster self-management of the disease, which could have a positive economic benefit to the state as costly emergency room visits are avoided.



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There is currently no statewide connection to resources for patients and providers. Several lupus organizations operate in Florida, but independently based on territory and funding. The burden of the disease would be better addressed by greater coordination statewide to educate the patient and public, improve rates of earlier diagnosis, allows for greater access to care for the treatment of patients, and the reduction of health disparities to improve population health.

Florida’s two largest ethnic minority populations are projected to see moderate to significant growth leading to 2045. Growth in these two cohorts is higher than the average⁹. The burden of lupus is two to three times more prevalent among women of color -- African Americans/Blacks, Hispanics/Latinos, Asians, Native Americans, Alaska Natives, Native Hawaiians, and other Pacific Islanders -- than among European American/Caucasian women¹⁰. These projected population growth rates could present additional challenges for the state unless a plan is put into place now to help alleviate future issues.

Table 1. Overall Ethnic Minority Population Projections in Florida¹¹

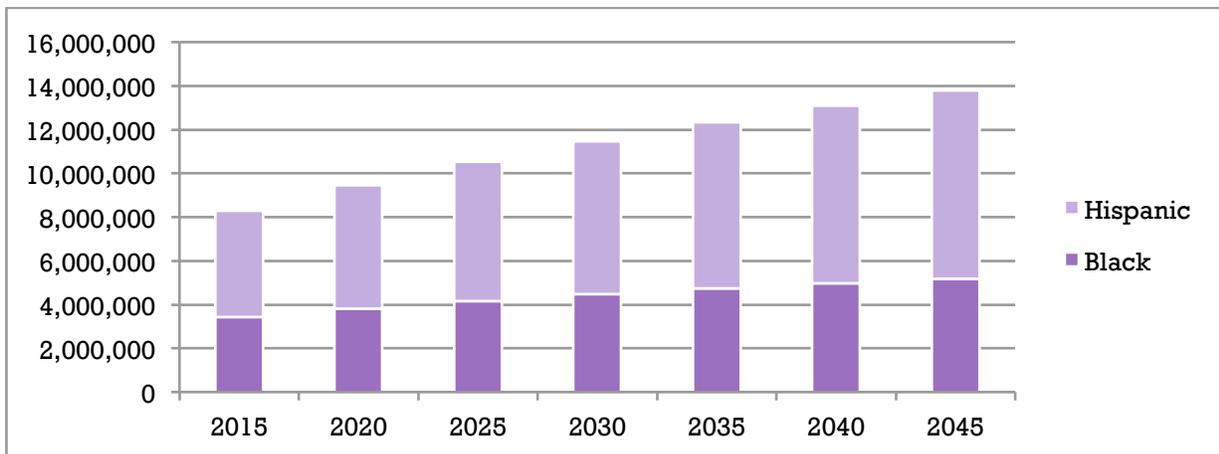
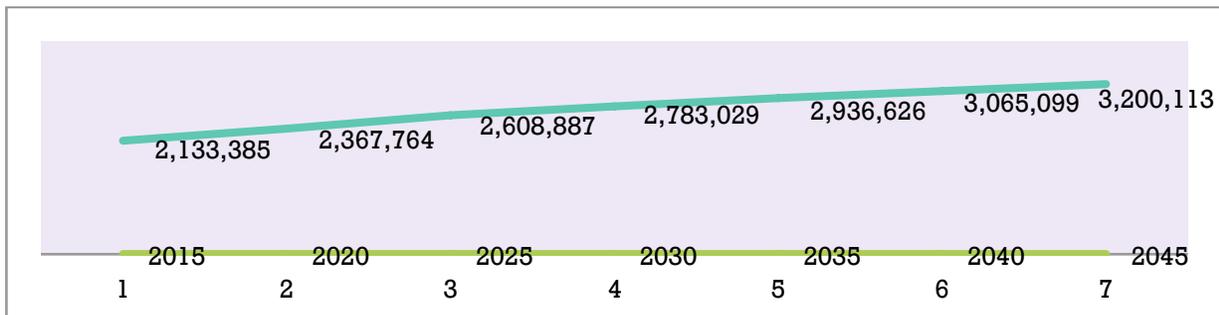


Table 2. Population Projections of Black and Hispanic Females Aged 15-44 in Florida¹¹



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Domain 1 – Epidemiology and Surveillance

Objective: To develop data collection systems to accurately determine the burden of lupus in Florida

Recommendations

1. Create a database on the prevalence of lupus in Florida with demographics to illustrate age, gender and race/ethnicity.
2. Collaborate with the Florida Department of Health to develop a state lupus module for inclusion in the Behavioral Risk Factor Surveillance System.
3. Collaborate with local health departments and potential funders to support community-based data collection capacity.

Domain 2 – Environmental Approaches

Objective: To develop a sustainable funding agenda

Recommendations

1. Convene representatives from the Florida Black Legislative Caucus, the Florida Department of Health's Bureau of Chronic Diseases, the Office of Minority Health and Health Equity and the Office of Rural Health to develop strategies to address the burden of lupus in Florida.
2. Develop a White Paper to educate funders about the burden of lupus, and update annually.

Domain 3 – Health Care System Interventions

Objective: Improve the education and training of healthcare providers about the symptoms and treatment of lupus

Recommendations

1. Provide lupus awareness and health education materials to at least five (5) medical associations/societies for membership distribution and approximate the number of individuals reached.
2. Secure lupus brochures and posters from the Lupus Foundation of America and request their placement in a minimum of five (5) waiting rooms and lobby areas



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of clinics and health centers in the Big Bend region.

3. Coordinate at least one (1) annual lupus continuing education credit (web-based) for licensed professionals with an existing organization like the Directors for Health Promotion and Education.

Domain 4 – Community Programs Linked to Clinical Services

Objective: To increase awareness of lupus and available resources

Recommendations

1. Discuss National Lupus Awareness and related activities via print media connections and/or public service announcements through radio, while tracking the listening audience, readership and counties reached.
2. Engage college interns to create a lupus-focused social media footprint to track the number of visits, comments, and/or likes.
3. Leverage the use of five (5) existing community health workers/health educators to inform the general public about resources that are available as part of their normal health promotion duties through at least two (2) thirty minute trainings each year.
4. Include at least two (2) tribal organizations based in Florida on public health awareness campaigns. The approximate number of individuals reached can be used to help guide future outreach and facilitate their needs.
5. Provide lupus awareness materials and health education details to at least fourteen (14) churches or faith-based organizations for dissemination during health and wellness ministry programs in Big Bend AHEC's catchment area of Florida (Bay, Calhoun, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Leon, Liberty, Madison, Taylor, Washington, and Wakulla counties).
6. Request the assistance of at least one (1) national pharmacy to assist with a lupus awareness campaign, e.g., butterfly pictures or a purple nose day to raise awareness and provide resources on lupus diagnosis and treatment within the first year.
7. Include at least two (2) fraternities and/or sororities (local, state or national) in community-based activities or programs to promote lupus awareness.
8. Engage two (2) collegiate athletic programs in the Big Bend Region to encourage student athletes to serve as unofficial lupus spokespersons through uniform



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modifications, e.g., purple socks or wristbands. Further awareness could be secured through the schools' game day media platforms.

9. Support the Florida Department of Health's communication plan to connect persons with lupus to community-based health promotion programs and provide materials for inclusion of on their state website.

Succession and the Future

The strategies and recommendations cited in the *Plan* have been initiated by community stakeholders and partners. The execution of this plan will require commitment, collaboration, and capital (social, human and economic) in order to be



successful over a period of time. Big Bend Rural Health Network will continue its work with organizations such as Big Bend AHEC to collaborate further on lupus grant funding for programs and activities directed towards lupus patients, health professionals and the public. Strengthened relationships will be sought with state-based organizations such as the Lupus Foundation of America Florida Chapter, the Lupus Support Network, the Lupus Foundation of Florida, and the Florida Society of Rheumatology to ensure that relevant partners are included in future planning and endeavors.

Our *Plan* will serve as a model specific to our state to approach lupus care and treatment to improve population health in Florida's future.



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Appendix A: Florida Lupus Summit Task Force

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