



**The Georgia Council on Lupus Education and Awareness
Georgia Action Plan**

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I. Introduction

The Georgia Council on Lupus Education and Awareness (GCLEA) was established by the Georgia General Assembly and Governor Nathan Deal in 2014, to raise awareness about lupus, an incurable autoimmune disease that continues to be a public health concern and financial concern for the people of the State of Georgia. For example, nearly half of people in Georgia diagnosed with lupus (average age at diagnosis was 30.7 years old) become unemployed in 13 years. The proportion of patients who lost their jobs since diagnosis was almost twice for African Americans than for whites. 60% had an annual household income less than \$29,999.ⁱ The Georgia Lupus Registry (GLR), which is the only population-based epidemiologic study on lupus within the State of Georgia, determined that the rates of lupus in Fulton and DeKalb are among the highest reported in the United States.ⁱⁱ Using classification criteria from the American College of Rheumatology (ACR), the GLR determined that the age-adjusted incidence rate of lupus in both counties was 6.9 per 100,000 persons per year, with black women having the highest incidence rate of 17 per 100,000 persons per year.ⁱⁱⁱ In a study conducted between 2011 and 2012, researchers determined that 47% of people in the GLR study are unemployed compared to 23% of diabetes patients, 19% of asthma patients, and 33% of cardiovascular disease patients.^{iv}

The 2014 legislation, codified as O.C.G.A. § 31-49-1 *et al.*, establishing the GCLEA and its mandates is the only state sponsored mandate to tackle lupus. Through this state legislation, GCLEA is charged with investigating education and awareness concerning lupus throughout the State of Georgia, developing educational material on lupus, improving patient access to care through the creation of an online directory of healthcare providers, and making recommendations for legislative action. However, there are no state funds to carry out important lupus initiatives

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such as public awareness, public education, disease self-management, or patient care as there are with other chronic illnesses.

On August 6, 2016, the GCLEA and the Lupus Foundation of America-Georgia Chapter convened a workshop of 35 stakeholders called “Lupus As a Public Health Concern”. The workshop was the result of a nationwide effort to implement tenets of the National Public Health Agenda on Lupus. Our stakeholders included physicians, nurse practitioners, public health professionals, health administrators, health educators, clinical social workers, people living with lupus, and community organizers from across Georgia. The purpose of the workshop was to learn about lupus, share ideas and resources, and build sustainable relationships. In addition, our goal was to collaborate on an action plan for what we can do to increase awareness of lupus, and improve access to care and services for people living with lupus. As a result, this Georgia Action Plan delineates important steps to encourage and facilitate public and private action designed to combat lupus.

II. A Primer on Lupus

Lupus, which was first identified in the early 1800s, is a chronic autoimmune disorder with no known cause or cure.^v Lupus disrupts the body’s immune system through the creation of autoantibodies, which attack healthy tissues and cause inflammation, pain and potentially organ damage. There are two common forms of lupus. Cutaneous lupus erythematosus (CLE) affects the skin. Systemic lupus erythematosus (SLE), referred to as lupus in this report, can adversely affect the skin and joints, as well as multiple organ systems. For example, SLE may cause inflammation in the heart, brain, and kidneys, each of which may be affected at any given time. The disorder typically occurs in often unpredictable stages of flares and remissions.^{vi} Patients with SLE are frequently affected by organ damage and comorbid conditions that emerge as a

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consequence of disease activity, disease-related chronic inflammation and tissue damage, and/or the side effects of the drugs used to treat the disorder.^{vii}

Lupus is difficult to recognize and diagnose because it shares symptoms with many other disorders and conditions. As such, a lupus diagnosis may occur over time through a process of eliminating alternative explanations and establishing the presence of suggestive symptoms and signs by a rheumatologist, an expert in the diagnosis and care of individuals with lupus.^{viii} The (ACR) began publishing classification criteria for a diagnosis of lupus in 1971.^{ix} The most recent version of the ACR criteria, consisting of 11 criterion, was published in 1997.^x Even with the classification criteria, many patients are left without a definitive diagnosis for years, leaving them untreated and susceptible to increased risk of inflammation across multiple organ systems and in some cases organ damage. These diagnostic signs and symptoms include cardio-pulmonary inflammation, photosensitivity, hematologic blood disorder, kidney disorder, neurologic disorders such as seizures, malar skin rash, a positive antinuclear antibody test and arthritis.^{xi}

While treatments for lupus can be physically and financially costly, they are generally effective in managing the disease, though not entirely without potential side effects. Treatment with drugs such as non-steroidal anti-inflammatories, antimalarials, corticosteroids, and immunosuppressives (many of which are used off-label from cancer and organ transplantation indications) are common for patients with lupus.^{xii} The side effects of these treatments, coupled with the symptoms of the disorder, can limit a patient's ability to live a productive life and to work a full-time job. Side effects of treatment include alopecia, hypertension, migraines, cataracts, increased risk of cancer, infection, infertility, increased risk of osteoporosis, obesity, psychosis, increased risk of cardiovascular disease, nausea, and liver damage.^{xiii}^{xiv} In 2011, the

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Food and Drug Administration approved belimumab (Benlysta) for moderate to severe lupus (without kidney or brain involvement), the first medicine specifically developed and approved for SLE in over 50 years. While the drug has been deemed effective in certain instances of lupus, it is not yet clear which patient will optimally respond to the drug and costly with annual costs as high as \$35,000.^{xv}

The Centers for Disease Control and Prevention (CDC) national prevalence estimates are currently being developed. The Lupus Foundation of America estimates that there are 1.5 million Americans living with some form of lupus. Lupus affects women nine times more often than men,³ with 80% of new cases developing between the ages of 15 and 44. Lupus is three times more common among women of color than white women.^{xvi} The Lupus Foundation of America, Georgia Chapter, estimates that there are 55,000 Georgians living with lupus. The prevalence of lupus in African Americans is higher than in any other racial, ethnic or other group. Lupus may be the most common chronic disease among young African American women.^{xvii} A February 2015 article published in *Arthritis and Rheumatology* regarding lupus mortality rates in the Medicaid/Medicare populations from 47 states, found that the lupus mortality rate was highest among American Indians (27.52%), followed by African Americans (24.13%). This is compared with Whites (20.17%) and Hispanics (7.2%).^{xviii}

III. Georgia Action Plan

A. Community Awareness and Outreach—

Research indicates that early diagnosis and treatment play a significant role in improving the lives of lupus patients. A majority of lupus patients live a normal life-span with early diagnosis, early treatment, and adherence to treatment plans. However, access to public education and awareness programs is limited and public understanding about the disease is

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hampered by misinformation provided by unqualified sources. While early diagnosis requires access to a knowledgeable healthcare provider, a better understanding about lupus among the general population will encourage people that meet the criteria for the disease to seek proper diagnosis and treatment from a qualified healthcare provider. The ultimate goal is to improve the lives of people living with lupus.

The GCLEA launched a webpage on the website of the Georgia Department of Community Health on March 3, 2016, and it has plans to publish the same information on the Georgia Department of Public Health by the end of 2016. The contents of this website address many issues pertinent to lupus including the forms of lupus, the criteria required for a lupus diagnosis and common treatments for lupus. In addition, the GCLEA website contains a directory of health care service programs provided by the Lupus Foundation of America-Georgia Chapter and a list of all rheumatologists and dermatologists in the State of Georgia that are qualified to diagnose and treat lupus. We recognize the need to do more to expand public outreach and provide accurate lupus information to both persons living with lupus and health care providers. Outreach must clearly illustrate the complexities of lupus, the importance of early identification, diagnosis, and effective disease management. As a state, we have an opportunity and the ability to encourage further community outreach and to facilitate the implementation of the goals set forth in this action plan.

Strategies for the State of Georgia

- Investigate the level of awareness and education concerning lupus within the State of Georgia.
- Increase advertising campaigns in Georgia utilizing both print and television media.

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- Expand outreach using social media, blogs and event pages to publicize efforts in Georgia to increase lupus literacy.
- Expand outreach to patients by developing courses on disease self-management.
- Expand outreach efforts to population groups that have a higher incidence of lupus utilizing the resources of churches, schools, colleges and universities.
- Expand outreach efforts to employers about the impact of lupus on the workplace.
- Expand outreach to healthcare professionals that work on the frontlines of public medicine. These professionals include primary care practitioners, emergency room physicians, non-profit clinicians, physician's assistants, school nurses, prison health professionals, nurse practitioners.
- Incorporate the tenets of the National Public Health Agenda on Lupus on all current and future strategies of the GCLEA.

B. Epidemiology

The epidemiology of lupus is not well-understood. While the Lupus Foundation of America estimates that there are 1.5 million Americans and 55,000 Georgia with lupus, such numbers are based upon a non-scientific survey of a sampling of the population. The State of Georgia received one of only 5 population-based lupus registries in the country but was limited to the surveillance years of 2002-04 and the counties of Fulton and DeKalb. Currently, there is no ongoing funding of active surveillance of lupus in Georgia on a population level and across the state. The State of Georgia currently has funded an Alzheimer's Registry and Cancer Registry through the Georgia Department of Public Health. Ongoing population based studies on

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lupus will help researchers understand genetic, environmental, epigenetic, hormonal, and environmental factors associates with the manifestation of the disorder and the mortality of patients. Population studies and epidemiological numbers can provide patient information for future studies. These studies help researchers better understand the association between lupus patients, patients' lives, and health care systems costs and how they impact minority racial groups.

Strategies for the State of Georgia

- Continue the Georgia Lupus Registry, expand its efforts to include more rural areas in Georgia, and amend O.C.G.A. § 34-49-1 to provide funding for the same.
- Monitor current trends in order to determine burden of lupus on the State of Georgia and provide regular public health reports to the public and other stakeholders.
- Encourage Georgia to use national and state-based data sources to determine the burden of lupus.
- Incorporate the tenets of the National Public Health Agenda on Lupus.

C. Behavioral Risk Factor Surveillance System (BRFSS)

Collaborate with the Georgia Department of Public Health to develop a state component evaluating burden of lupus that could be included in an upcoming annual BRFSS.

D. TeleMedicine

An overarching challenge to getting those at highest risk for lupus to be evaluated and treated is the lack of specialists (most commonly rheumatologists) to refer to expeditiously and

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cost effectively. As discussed in the 2016 GCLEA Summit, telemedicine and telehealth was enthusiastically discussed as one potential solution to address these barriers, especially for residents of rural Georgia.

There are no universal definitions for the terms “telehealth” and “telemedicine,” which makes it impossible to differentiate them entirely from one another. Both terms are a modern concoction based on the evolution of developing technology. But while the line remains blurred regarding what each term covers, a few organizations have weighed in on the subject. The U.S. Department of Health and Human Services (HRSA) identifies telehealth’s definition as broader in scope than that of telemedicine, covering remote healthcare services that are both clinical and non-clinical (<http://www.hrsa.gov/ruralhealth/telehealth/>). The term “telemedicine,” on the other hand, refers solely to remote clinical services. Subsequently, the American Telemedicine Association (ATA) uses the two terms interchangeably, both encompassing a wide definition of remote healthcare. No matter which definition is used, the GCLEA strongly supports the exploration of the use of technologies with public and/or private resources. The overarching goals of telemedicine and telehealth must support the aims of the National Public Health Agenda for Lupus, GCLEA, and the CDC-funded “Developing and Disseminating Programs to Build Sustainable Lupus Awareness, Knowledge, Skills, and Partnerships” (CDC-RFA-DP15-1511). Specifically, the GCLEA acknowledges considerable efforts and infrastructure already established in this area by the Georgia Department of Health (DPH) and strongly urges partnership with the GCLEA, American College of Rheumatology, Emory University Division of Rheumatology, and other suitable organizations to work together on the following:

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Strategies for the State of Georgia

- Identify existing processes and infrastructure within DPH's telemedicine and telehealth efforts amenable to the goals of improving the lives of those with lupus throughout the state.
- Identify areas that need to be developed and/or improved as well as barriers to implementing telemedicine and telehealth to address lupus.
- Work towards developing a sustainable model for telemedicine and telehealth in Georgia.
- Identify key areas that will facilitate the expansion or integration of Georgia's efforts to other states in order to expand this opportunity to as much of the United States as possible.
- Identify and apply to relevant funding opportunities that will support the above goals.

E. Disease Management

One of the barriers to health equity is the absence of state and nationwide evidence-based disease management tools designed for people living with lupus. The goal of self-management interventions is to increase a patient's self-efficacy and skills in assessment of individual problems, goal-setting, problem-solving, and action-planning.^{xix} Benefits of effective self-management tools include improved health prognosis and reduction of the financial burden on individuals and the state healthcare system. As a state, we need to organize a disease self-management program for people living with lupus and use evidence based disease management tools to work with patients and their families. We have the opportunity and ability to be at the forefront of efforts to establish evidence based disease management tools for people living with

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lupus through collaborations efforts between the American College of Rheumatology, the Grady Lupus Clinic, and Emory University.

Strategies for the State of Georgia

- Leverage 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.
- 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.

F. Provider Outreach

The GCLEA, the American College of Rheumatology, the Lupus Initiative, the Georgia Department of Public Health, the Georgia Department of Community Health, and the Lupus Foundation of America continue provide healthcare provider education. Such programs clearly illustrate the complexities of lupus, the importance of early identification, diagnosis, and effective disease management by utilizing the materials and resources of the Lupus Initiative. We should further expand these provider programs and facilitate the inclusion of lupus in provider education programs throughout the state. The goals of these educational resources are to: increase the number of medical professionals with knowledge and expertise in the diagnosis and treatment of lupus; lessen missed and misdiagnoses; to support greater patient adherence to treatment regimens; and to increase the number of patients who take an active role in their disease management.

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Conclusion

The creation of the GCLEA comes at a crucial period for Georgia. As national efforts build to address an issue that clearly heavily burdens the Georgia population, the State of Georgia is positioned to ride the momentum of efforts that have had national implications in improving the public health and the lives of those who suffer from lupus. With additional support from the National Association of Chronic Disease Directors and the ACR, the GCLEA has been able to take the first step in facilitating the communication between crucial stakeholders throughout the state. Initial discussions clearly indicate enthusiasm, particularly among crucial partners, to pursue the strategies outlined in this report. We must ensure that this initial enthusiasm extends to tangible efforts that ultimately translates to improving the lives of all those who have lupus in the State of Georgia.

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