



The Annual Report of
the Georgia Council on Lupus Education and Awareness
For Fiscal Year Ending June 30, 2017

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I. Introduction

The Georgia Council on Lupus Education and Awareness (GCLEA) presents its Annual Report for the fiscal year ending June 30, 2017. The GCLEA is the only state sponsored mandate in Georgia to tackle lupus, an incurable autoimmune disease that continues to be a public health concern and financial concern for the people of the State of Georgia. Through state legislation, GCLEA is charged with investigating education and awareness concerning lupus throughout the State of Georgia, developing lupus educational material on lupus and presenting such material on the website of the Georgia Department of Community Health, improving patient access to care through the creation of an online directory of healthcare providers, and making recommendations for legislative action.

The appointed members of the GCLEA consist of two lupus patients, Kim Schofield and J. Christopher Reed, Dr. Janice Carson of the Georgia Department of Community Health, Dr. S. Sam Lim, Professor of Medicine at Emory University School of Medicine and Chief of Rheumatology at Grady Health Systems, State Senator Renee Unterman, and State Representative Betty Price who replaced State Representative Randy Nix. In addition to these individuals, the GCLEA could not function without the assistance of Lisa Marie Shekell and Brandy Sylvan of the Georgia Department of Community Health and LaToya Osmani of the Georgia Department of Public Health. The GCLEA held meetings on July 11, 2016, November 7, 2016, December 12, 2016, January 31, 2017, February 6, 2017, April 3, 2017, and June 5, 2017. The GCLEA adopted its bylaws on July 11, 2016.

As required by O.C.G.A. § 31-49-1 *et. seq.*, this report documents the GCLEA's work during its second year including GCLEA's effort to raise public awareness about lupus by hosting a statewide workshop of key medical providers, health educators, community advocates,

and public health professionals. The workshop's aims were to build sustainable partnerships with attendees, known as stakeholders, facilitate the dissemination of information about lupus by educating attendees, and develop a lupus action plan for Georgia from the broad array of constituents that attended. This action plan has been used by the GCLEA to help identify and outline the GCLEA's legislative recommendations for achieving the goals of the council and improving the lives of people impacted by lupus. This report also outlines the GCLEA's legislative recommendations for achieving the goals of the council and improving the lives of people impacted by lupus.

Mission Statement and Goals of the Organization

The Georgia Council on Lupus Education and Awareness (GCLEA) was established by the Georgia General Assembly in 2014, to improve the lives of Georgia residents who live with lupus by improving public education and awareness, improving access to resources for patients and family members, and developing information that will inform current and future public health efforts. It is the Council's hope that these efforts will increase appropriate diagnoses of lupus by non-rheumatologists.

The GCLEA aspires to

1. develop resources that will improve the level of education and awareness concerning lupus for healthcare providers and the general public,
2. develop resources for communities that lack access to specialized lupus healthcare providers, based upon the incidence and prevalence of lupus in the State of Georgia, and
3. develop resources that encourage professional development and specialization in the diagnosis of lupus and the care, management, and treatment of people with lupus.

II. The GCLEA's Statewide Workshop

The GCLEA, in partnership with the Lupus Foundation of America-Georgia Chapter, convened a workshop of 35 professionals to learn about lupus, share resources, build sustainable relationships, and to develop an action plan for lupus in Georgia. The workshop, titled "Lupus As a Public Health Concern," was funded by a \$15,000 grant from the National Association of Chronic Disease Directors (NACDD) with funds from the CDC. Speakers included State Senator Renee Unterman, Dr. S. Sam Lim, Dr. Michael Madaio Chair of the Department of Medicine at Augusta University, Dr. Jean O'Connor of the Georgia Department of Public Health, LaToya Osmani of the Georgia Department of Public Health, and Dr. Cristina Drenkard, Associate Professor of Medicine, Emory University School of Medicine. Attendees came from every region of Georgia and included physicians, social workers, nurse practitioners, clinical administrators, epidemiologists, health educators, public health professionals, representatives from 5 of 6 Area Health Education Centers in Georgia, and community organizers.

Based on survey results, the workshop was a success. Attendees increased their own lupus literacy, learned ways to educate their own communities about lupus, and gained valuable insight on how current health disparities impact Georgians. The most successful aspect of the workshop was the synergy created by bringing together these professionals who shared ways that stakeholders can incorporate lupus into our own professional and public health agendas. This synergy facilitated a dialogue on how Georgia can better tackle the complexities of lupus and the needs of the lupus patient through a state action plan that includes incorporating lupus into a telemedicine program, establishing a statewide lupus registry, and conducting lupus literacy surveys. Most participants in the workshop left the event with their own action plan that outlined mechanisms they and/or their organization could use to increase awareness of lupus, and

improve access to care and services for people living with lupus. Since the workshop, attendees and other entities have reached out to the GCLEA's chair and vice-chair for information and sent invitations for speaking engagements. The work of the GCLEA was on display at the NACDD national conference in January of 2017. The NACDD has also invited the GCLEA to participate in future grant opportunities in 2017 and 2018.

III. The Future - Telemedicine

One of the most popular ideas discussed at the GCLEA's workshop was the potential use of the telemedicine program in Georgia to expand access to specialty care for individuals with lupus. An overarching challenge to getting those at highest risk for lupus to be evaluated and treated is the lack of specialists (most commonly rheumatologists) in rural and underserved areas of Georgia. The Georgia Telemedicine Act defines telemedicine as, "the practice, by a duly licensed physician or other health care provider acting within the scope of such provider's practice, of health care delivery, diagnosis, consultation, treatment, or transfer of medical data by means of audio, video, or data communications which are used during a medical visit with a patient or which are used to transfer medical data obtained during a medical visit with a patient." O.C.G.A. § 33-24-56.4. Since the enactment of the Georgia Telemedicine Act, which requires private payers to reimburse telemedicine services in the same way as in-person medical services, the use of telemedicine in the state has increased. The Georgia Department of Public Health, the Georgia Department of Community Health, Augusta University, Emory University, Georgia Partnership for Telehealth and Stratus Healthcare are just some of the entities in Georgia that utilize some form of telemedicine. Currently, providers utilizing telemedicine services have not engaged with rheumatologists for assistance with the management of lupus patients. Based on

the results of interviews of current telemedicine utilizers conducted this year by Highland Nonprofit Consulting, LLC, there are barriers to providing rheumatology services via a telemedicine platform. Rheumatologists and lupus patients have not been educated about the delivery of rheumatology services via telemedicine; rheumatologists have not been informed about the billing codes to be used when rheumatologists deliver care through telemedicine; and rheumatologists have not obtained the equipment to provide care through telemedicine. The GCLEA and its partners desire to participate in the resolution of some of these barriers by educating the public and providers about the benefits of using telemedicine for lupus patients. A particular focus will be educating Georgia residents living in rural counties across the state who oftentimes do not have access to the specialty medical care they need. The Georgia Department of Public Health and the Georgia Department of Community Health have recommended that GCLEA utilize their resources to determine the geographic need for lupus education and awareness. A survey of providers, conducted in a pilot area, about their level of awareness about lupus followed by the implementation of a pilot program in that area to educate those providers and their patients about lupus would be extremely informative to the GCLEA. The GCLEA hopes to conduct such a survey with family medicine physicians and general practitioners, to determine their level of knowledge, need and interest relative to lupus. Once survey results have been compiled and analyzed, the Council will facilitate partnerships between rheumatologists and the telemedicine programs within the state to optimize equipment utilization and processes for lupus evaluations and management.

IV. Legislative Recommendations

a. Epidemiology

While contemporary US and international lupus consortia have greatly advanced our

knowledge regarding the disease, many argue that such registries suffer from referral bias and do not accurately represent the spectrum of disease at the population level. In contrast, population-based cohort studies encompass the spectrum of mild through severe cases of SLE and can estimate incidence and prevalence. Yet identifying the full range of cases for this disease across a given population requires multiple data sources with precisely interpreted clinical, laboratory, and even pathology data. These factors have made lupus one of the most challenging diseases to research through epidemiologic or administrative data. Moreover, the few existing US population-based SLE cohorts summarized in a 2009 review^{xiv} are now largely outdated or had described lupus prevalence and incidence rates in small, homogeneous, geographic regions. Those studies reported widely varying rates of lupus, likely related, at least in part, to differences in methodology. Updating contemporary lupus population-based epidemiology is critically important to framing the current public health burden and status of SLE care in the US.

SLE is a disease with substantial direct and indirect costs over the patient's lifespan and with well-known health disparities. Important health disparities, including higher renal complications and mortality rates, have been noted in groups defined by low socioeconomic status, black race, Hispanic ethnicity, or Asian ethnicity. Prior reports from US referral cohorts representing some of these vulnerable populations are criticized for missing mild cases and patients with limited access to care. To include such cases, it is important to have a broad definition of case ascertainment and to search multiple points of entry into the health care system, ranging from tertiary centers to community clinics and hospitals, or even laboratory and pathology services. To date, the lack of a comprehensively defined population-based "denominator" to accurately represent the number of lupus cases in the US has limited our ability to answer many important questions. For example, without accurate numbers of existing lupus

cases, it has been difficult to adequately quantify the burden of lupus in the US, let alone reassess health disparities and lupus quality of care on a population level.

The State of Georgia received one of only 5 population-based lupus registries (The Georgia Lupus Registry) in the country funded by the CDC to offer much needed updates on the epidemiology of lupus. Led by Dr. Lim and colleagues at Emory University, key contributions of their work were the pivotal partnerships with the CDC and the Georgia Department of Public Health. These groups cooperated under a state public health surveillance exemption to Health Insurance Portability and Accountability Act (HIPAA) to facilitate comprehensive regional searches for lupus cases. Investigators ascertained all pediatric and adult cases of lupus encountered between 2002 and 2004 in hospitals, dermatology, nephrology, and rheumatology clinics, pathology and laboratory centers, and the US Renal Data System for end-stage renal disease (ESRD). The results of this study were derived from Fulton and DeKalb counties and provide contemporary data on lupus incidence and prevalence in these regions.

This rigorous study updated the epidemiologic data on lupus with improved precision, highlighting the magnitude of the disease burden, including important health disparities for lupus patients. The Georgia Lupus Registry found 5.6 incident lupus cases per 100,000 person years and 73 prevalent cases per 100,000. The study confirmed heightened lupus incidence and severity in young black women, including far more cases of ESRD. Although many renal diseases disproportionately burden black Americans due to a combination of genetic factors, comorbidities, and socioeconomic challenges, the finding of 3-7 fold higher rate of ESRD in young black with lupus documents the need to prioritize rheumatology care quality and research agendas to minimize this adverse outcome. Moreover, this registry also offers an excellent

platform from which to address the remaining questions regarding other organ-specific manifestations and disease outcomes over time.

Unfortunately, there is no ongoing funding of active surveillance of lupus in Georgia on a population level and across the state, particularly in rural Georgia, where many factors that contribute to racial health disparities are magnified. The State of Georgia currently has funded an Alzheimer's Registry and Cancer Registry through the Georgia Department of Public Health. The Georgia Lupus Registry has a successful history of working with the state to do lupus surveillance and maintains the infrastructure to expand to the rest of the state with appropriate support and resources. Therefore, the GCLEA recommends that appropriations be made to continue and expand the Georgia Lupus Registry to include suburban and rural populations in this state so that agencies and organizations can monitor trends and decrease the racial health disparities of lupus in the state.

APPENDIX

A Primer on Lupus

Lupus, which was first identified in the early 1800s, is a chronic autoimmune disorder with no known cause or cure.ⁱ 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.ⁱⁱ Patients with SLE are frequently affected by organ damage and comorbid conditions that emerge as a consequence of disease activity, disease-related chronic inflammation and tissue damage, and/or the side effects of the drugs used to treat the disorder.ⁱⁱⁱ

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.^{iv} The American College of Rheumatology (ACR) began publishing classification criteria for a diagnosis of lupus in 1971.^v The most recent version of the ACR criteria, consisting of 11 criterion, was published in 1997.^{vi} 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.^{vii}

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.^{viii} 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.^{ix} In 2011, the 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.

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.^{xi} The Lupus Foundation of America, Georgia Chapter, estimates that there are 55,000 Georgians living with lupus. 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.^{xii} The prevalence of lupus in African Americans is higher than in

any other racial, ethnic or other group. 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%).^{xiii}

ⁱ Ruiz, R., Unlocking The Secrets of Lupus. *Forbes*. 2010, 185(2):40.

ⁱⁱ Pollard, C., Hartz, S., Leage, S.L. et. al. Elicitation of health state utilities associated with varying severities of flares in systemic lupus erythematosus. *Health and Quality of Life Outcomes*. 2015;13(1):1-10.

ⁱⁱⁱ Cislo, A.M., Aseltine, R.H. Lupus in Connecticut: 2013. East Hartford: University of Connecticut 2013.

^{iv} *Ibid.*

^v Hochberg, M.C. Updating the American College of Rheumatology revised criteria for the classification of systemic lupus erythematosus. *Arthritis Rheum*. Sep. 1997, 40(9):1725.

^{vi} *Ibid.*

^{vii} *Ibid.*

^{viii} Norgaard, J.C., Stengaard-Pedersen, K. et. al. Antimalarials in the Treatment of Systemic Lupus Erythematosus: A Registry-Based Cohort Study in Denmark. *Lupus*. 2015, 24:299.

^{ix} Petri, M., Bechtel, B., et al. Burden of Corticosteroid use in Patients with Systemic Lupus Erythematosus: Results From a Delphi Panel. *Lupus*. 2014, 23:1007-1010.

^x Leroy, C., Rigot, J, et. al. Immunosuppressive Drugs and Fertility. *Orphanet Journal of Rare Diseases*. 2015, 10:136-138.

^{xi} National Association of Chronic Disease Directors, Centers for Disease Control and Prevention and the Lupus Foundation of America. (2015). *The National Public Health Agenda for Lupus*.

^{xii} Lim, S.S. et al, The Incidence and Prevalence of Systemic Lupus Erythematosus, 2002-2004. *Arthritis & Rheumatology* 2014, 66:357-368. --
<http://onlinelibrary.wiley.com/doi/10.1002/art.38239/abstract>
Michigan registry article: Somers, E.C. et al, Population-Based Incidence and Prevalence of Systemic Lupus Erythematosus. *Arthritis & Rheumatology* 2014, 66:369.

^{xiii} Gómez-Puerta JA., Barbhuiya M, et al. Racial/Ethnic Variation in All-Cause Mortality Among United States Medicaid Recipients With Systemic Lupus Erythematosus: A Hispanic and Asian Paradox. *Arthritis and Rheumatology*. 2015; 67(3): 752-760.

^{xiv} Lim SS, Drenkard C, McCune WJ, Helmick CG, Gordon C, DeGuire P, et al. Population-based lupus registries: advancing our epidemiologic understanding. *Arthritis Rheum* 2009;61:1462-6.