The Annual Report of
the Georgia Council on Lupus Education and Awareness
For Fiscal Year 2017 and Ending December 31, 2018

Submitted on April 30, 2019

J. Christopher Reed, Chair
State Representative Kim Schofield, Vice Chair
Cathy Craven, Georgia Department of Community Health
Dr. S. Sam Lim, Emory University School of Medicine and Grady Health Systems
State Senator Renee Unterman
State Representative Betty Price

Special Thanks to
Brandy Sylvan, Georgia Department of Community Health
Teri Emond, Lupus Foundation of America, Georgia Chapter
Dr. Jonetta Mpofu, Centers for Disease Control and Prevention

I. Introduction

The Georgia Council on Lupus Education and Awareness (GCLEA) presents its Annual Report from July 2017 through December 2018. The GCLEA is the only state-sponsored mandate in Georgia addressing lupus, a chronic autoimmune disease that continues to be a public health concern for the people in the State of Georgia. Through state legislation, GCLEA is charged with improving education and awareness of lupus throughout the State of Georgia, developing and disseminating educational material on lupus (such as on the website of the Georgia Department of Community Health), improving patient access to care (such as through the creation of an online directory of healthcare providers), and making recommendations for legislative action that improve the lives of those with lupus in the state.

The appointed members of the GCLEA consist of State Representative Kim Schofield and J. Christopher Reed, who both live with lupus, Cathy Craven 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. In addition to these individuals, the GCLEA functions with the valuable assistance of Brandy Sylvan of the Georgia Department of Community Health, Dr. Jonetta Mpofu of the Centers for Disease Control and Prevention, and Teri Emond of the Lupus Foundation of America, Georgia Chapter. The GCLEA held meetings on September 27, 2017 and June 18, 2018.

As required by O.C.G.A. § 31-49-1 *et. seq*., this report documents the GCLEA's efforts to develop three tenants of the Georgia Action Plan through grants provided by the National Association of Chronic Disease Directors and the American College of Rheumatology through funding provided by the Centers for Disease Control and Prevention (CDC). The goal of the three initiatives were to improve patient access to qualified healthcare providers, improve existing chronic disease tracking systems, and garner sustainable changes in policy that improve the lives of those with 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 School Nurses Project

Lupus is often diagnosed between the ages of 15 and 44 but can occur at younger ages. Given that adolescent onset of lupus has been known to result in more aggressive disease activity and worse outcomes, it is important to track disease activity among young people and improve patient access to knowledgeable health care providers.[1] Research indicates that chronic illnesses, such as lupus, can interrupt the learning environment and lead to more absences and poorer academic performance. Therefore, if the council can play a role in improving patient outcomes, the state has the potential of reducing the number of lupus patients who are too disabled to eventually enter the workforce and depend on government services.

In the Fall of 2017, the GCLEA educated over 450 school health nurses and nursing students in Georgia on the signs, symptoms, and treatments for. All school nurse participants were given pre-assessment and post assessment evaluations on their knowledge of the signs, symptoms, and treatments for lupus. In the Spring of 2018, the GCLEA added systemic lupus erythematosus to the Fulton County School System's patient data tracking system.[2] In the Fall of 2018, the GCLEA worked with pediatric rheumatologists to create a lupus care plan designed to be a tool used in schools by both nurse and patient. We also worked on a child to adult transition plan designed to help childhood-onset lupus patients better understand their condition, understand their medications, manage their symptoms, and navigate the health care system. Pilot plans are being distributed to Fulton and DeKalb County school nurses this year. All data collected as a result of this three-year project will be analyzed by Dr. Sinead Younge of Morehouse College once the program is complete in the Fall of 2019.

---

[1] Tucker, L.B., Uribe, A.G., Fernandez, M. et al, (2008). Adolescent onset of lupus results in more aggressive disease and worse outcomes. *Lupus*, 17(4), 314-22.

[2] The GCLEA learned that DeKalby County already includes lupus in its data tracking system.

III. Behavioral Risk Factor Surveillance System

The GCLEA partnered with the Georgia Department of Public Health (DPH) to include lupus in the 2019 Behavioral Risk Factor Surveillance System (BRFSS). BRFSS is the nation's premier system of health-related population-based telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. It is coordinated by the CDC. The DPH funded the entry of two questions on lupus into the 2019 BRFSS to better understand the burden of lupus in the state.[3]

IV. Telemedicine

The disparity between the relatively few physicians qualified to diagnose and treat lupus and the larger number of people living with lupus in the State of Georgia is of great concern. The majority of the approximately 100 rheumatologists in Georgia practice in the metropolitan Atlanta area. Therefore, persons living with lupus in other areas of Georgia, particularly rural areas, are greatly underserved. One of the most promising ideas to arise out of the Georgia Lupus (?) Action Plan is the potential use of a telemedicine[4] program to expand patient access to rheumatologists. The GCLEA received funding to plan and implement a telemedicine pilot study for persons living with lupus in rural southwest Georgia, which was completed from October 2017 to September 2018.

The GCLEA partnered with the Georgia DPH, Emory University, and the Georgia Department of Community Health to better understand, educate, and implement a pilot program utilizing already existing administrative telemedicine tools currently utilized and provided by these

---

[3] 1. Have you EVER been told by a doctor, nurse, or other health professional that you have lupus? 2. What type of doctor currently provides your lupus care?

[4] Telemedicine is "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.

partners. The results of that pilot plan can be found in the Feasibility Study attached herein as Appendix B. The GCLEA surveyed internal medicine physicians, physician assistants and nurse practitioners in southwest Georgia to assess the frequency of seeing lupus patients and their perception of the value of telemedicine in their practice. We also assessed the attitudes, behaviors and beliefs of various rheumatologists throughout the state about telemedicine. Furthermore, we gave a presentation on the importance of telemedicine in the treatment of lupus in underserved areas of Georgia to over 50 rheumatologists at the annual Georgia Society of Rheumatology meeting.

Conducting a pilot project on telemedicine would not be sufficient without understanding its onsite utilization and the needs of the community. The GCLEA met with members of the Albany Georgia Lupus Support Group and State Representative Winifred Dukes (District 154) to better understand the needs of those with lupus in southwest Georgia and the region’s current access to rheumatologists. A team of nine people from GCLEA, Emory University and Morehouse College conducted a site visit of the Dougherty County Health Department, our pilot site, to better understand how the clinic uses telemedicine in its prenatal program and treat children with sickle cell anemia. We met with Dr. Charles Ruis, Medical Director of 15 health clinics in southwest Georgia, and Vamella Lovett, Executive Director of the Dougherty County Health Department and Clinic, who explained the logistics of the program and examinations, the funding mechanism for the clinic and specialists, partnerships with local physicians, and the positive outcomes since the implementation of both programs in the region. We also had the opportunity to use the equipment and interview the clinic’s Obstetrics and Gynecology physician, who treats the clinic’s prenatal patients from her office in Atlanta, Georgia.

Our project culminated in a one-day pilot program. On August 31, 2018, Dr. S. Sam Lim and Dr. Aliza Lipson, rheumatologists from Emory University, conducted simulated examinations of five women from Albany, Georgia who live with lupus. Dr. Lim conducted his examinations from his office in Atlanta, Georgia while Dr. Lipson conducted her examinations from Miami, Florida. Our five lupus patients were examined in the Dougherty County Health Department using their existing telemedicine equipment with the assistance of the clinic's telemedicine presenter, Valenia Milling, R.N. All participants evaluated the project to determine the effectiveness of the equipment and viability of a larger pilot program. Based on the findings from the Telemedicine Pilot in Dougherty County, the survey results of health care providers in southwest Georgia and rheumatologists throughout the state, the implementation of telemedicine for lupus appears feasible and would fulfill a great need among lupus patients living in Georgia. However, certain considerations need to be made and steps taken before expansion, which can be found in the Feasibility Report.

V. Legislative Recommendations

The Council does not have any legislative recommendations for the upcoming legislative session.

APPENDIX A

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.[ixx] 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. Benlysta was approved for childhood-onset lupus in 2019.

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. Immunosuppresive 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., Barbhaiya 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.