The Annual Report of the Georgia Council on Lupus Education and Awareness For Calendar Years Beginning January 1, 2019 and Ending December 31, 2020.

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I. Introduction

The Georgia Council on Lupus Education and Awareness (GCLEA) presents its Annual Report from January 1, 2019, through and including December 31, 2020. The GCLEA has a mandate to address lupus, a chronic autoimmune disease that continues to have a significant public health impact for the people of the State of Georgia. *See* Appendix A. Through state legislation, the 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, facilitating patient access to care through the creation of an online directory of healthcare providers, and making recommendations for legislative action in line with the Council's mission statement and goals.

The appointed members of the GCLEA consisted of two individuals living with lupus, State Representative Kim Schofield and J. Christopher Reed. Other members included Cathy Craven of the Georgia Department of Community Health, and Dr. S. Sam Lim, Professor of Medicine at Emory University School of Medicine and Chief of Rheumatology at Grady Health Systems. State Senator Tonya Anderson was appointed by the Lt. Governor Geoff Duncan on July 31, 2020 and the state representative seat remained vacant the rest of the calendar year. The GCLEA appreciates the assistance of Brandy Sylvan and Kaitlin Ward of the Georgia Department of Community Health, Teri Emond the Chief Operating Officer of the Lupus Foundation of America, Georgia Chapter, Dr. Jonetta Mpofu of the Centers for Disease Control and Prevention (CDC), and our assistant Regina Moore. The GCLEA held meetings virtually or in person on January 10 and 22; February 28; March 5 and 23; April 9; May 13, June 9 and 11.

As required by O.C.G.A. § 31-49-1 *et. seq*., this report documents the GCLEA's efforts

to implement the tenants of its mission and the tenants of the Georgia Lupus Action plan. Included in this report is a summary of our work educating school nurses in five school districts in the state about lupus and introducing patient management plans produced by the American College of Rheumatology (ACR) to school nurses. This project, which was funded by the Centers for Disease Control and Prevention (CDC) through a grant to the ACR, also permitted the GCLEA to begin tracking the number of students living with lupus in these five school districts. This report summarizes the work of the Emory University School of Medicine-Division of Rheumatology, the Georgia Lupus Registry, and the Georgians Organized Against Lupus (GOAL) Cohort. This report also documents the GCLEA's establishment of a consortium of stakeholders who have the knowledge, skills, and experience to improve the lives of lupus patients by applying their expertise and leveraging the resources of their organizations. The overarching goal of this project is to establish a more comprehensive state action plan that meets the needs of clinicians, providers, patients, employers, and researchers in Georgia. Most importantly, this plan will provide the GCLEA with a mechanism to facilitate the development and implementation of programs that will improve the lives of people living with lupus by collaborating with stakeholders. The Council would like to thank the Georgia General Assembly for its ongoing support of our work through State appropriation of funds to support our aims and host outreach and education events.

II. Mission Statement and Goals of the Organization

The Georgia Council on Lupus Education and Awareness 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 and earlier diagnoses of lupus by non-rheumatologists.

The GCLEA aspires to

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

III. GCLEA's School Nurses Project

Lupus is often diagnosed between the ages of 15 and 44, earlier in people of color. Given that adolescent-onset of lupus is more aggressive and associated with worse outcomes compared to adult-onset of lupus, it is important to track its impact among young people and improve access to knowledgeable health care providers. Research indicates that chronic illnesses, such as lupus, can interrupt the learning environment and lead to more absences and poorer academic performance. Therefore, the GCLEA seeks to facilitate projects that help reduce disability due to lupus and, therefore, reduce dependency on government services and improve quality of life. The GCLEA, in partnership with the Lupus Foundation of America, Georgia Chapter and support from the National Association of Chronic Disease Directors (NACDD), the ACR, and the CDC, educated school nurses throughout Georgia about lupus. This training was also supported by funds appropriated by the Georgia General assembly to the GCLEA.

In 2019, the GCLEA partnered with the Emory University School of Medicine Division of Pediatric Rheumatology and Children's Healthcare of Atlanta to educate 55 school nurses in Fulton and DeKalb counties. The aim was to provide information and support to school nurses in helping students understand and navigate their diagnoses, manage their treatment plans and to help them transition to healthcare in the adult setting. All nurses received continuing nursing education credits and were asked to complete pre- and post-assessments.

On January 16, 2020, the GCLEA facilitated a training for 12 Gwinnett County Public School System school nurses. On February 17, 2020, the GCLEA facilitated a training for Atlanta Public School nurses. The GCLEA scheduled a training with Cobb County School District, but that training was cancelled due to statewide school closures. All nurses received continuing nursing education credits and were asked to complete pre- and post-assessments. The

GCLEA again partnered with Emory University School of Medicine Division of Pediatric Rheumatology and Children's Healthcare of Atlanta to train the nurses and provided them with a care and transition plan: Guidance to Caring for Students with Lupus (care plan) and Guidance to Independent Self-Care for Students with Lupus (transition plan). The care plan was designed by experts and tested by school nurses to provide support, care, and advice for students living with lupus. This plan is now being used in DeKalb, Fulton, Gwinnett, and Atlanta Public Schools and pediatric rheumatologists at Children's Healthcare of Atlanta. The GCLEA is helping to track the number of students living with lupus in four school districts and is working with the Georgia Department of Public Health and the Georgia Department of Education to expand this project statewide.

IV. Lupus and Related Autoimmune Diseases Workshop

The GCLEA held a Lupus and Related Autoimmune Diseases Workshop on August 30, 2019, which was designed to foster collaborations between providers, researchers, community leaders, private industry, non-profit organizations, legislators, government agencies, professional organizations, and academia in order to improve the lives of people impacted by lupus in Georgia. This workshop was made possible by funds granted by the Georgia General Assembly to the GCLEA. Forty-one attendees worked together to identify current needs in the lupus community and ways in which each of their respective organizations and institutions could collaborate to support, educate, and/or provide services to the lupus community. Organizations represented at this workshop included the Georgia Department of Public Health, Georgia Department of Community Health, Augusta University, Emory University School of Medicine – Division of Rheumatology, the Georgians Organized Against Lupus (GOAL) research cohort, the Arthritis Foundation, Emory University School of Medicine – Division of Nephrology,

Children's Healthcare of Atlanta, American College of Rheumatology, Goodwill Industries, Grady Health Systems, Emory Healthcare, Piedmont Hospital, members of the Georgia General Assembly, Georgians For a Healthy Future, the Jordan Savage Foundation, GlaxoSmithKline, and the Lupus Foundation of America, Georgia Chapter. Topics discussed included: increasing minority involvement in clinical trials; increasing awareness among non-rheumatologist service providers; creating a clearinghouse for rheumatologists who are interested in opportunities for volunteering and garnering ongoing commitments from participants towards future collaboration.

Attendees broke into workgroups with the goal to share current activities and achievements, provide perspective, create opportunities to collaborate in the future, and establish sustainable connections. The groups, which are defined in Appendix B, were divided into the following sections: 1) Outreach, Education, and Partnership, 2) Research 3) Provider Outreach, Education, and Support, 4) Patient Services, 5) Workforce Development, and 6) Policy. Each group was required to identify, among other things, projects related to lupus and related autoimmune diseases and/or identify projects that can be applied to lupus and related autoimmune disease; identify needs in the lupus community and current projects in the state's lupus community; and identify opportunities to collaborate on current and future projects. At the close of the workshop, invitees agreed to contribute their time to these workgroups, which, combined, formulated a consortium now called the Georgia Lupus Collaborative.

Although nearly half of the participants whose expertise included the fields of academic research, non-profit, healthcare, and clinical care reported that they were "extremely familiar" with GCLEA, a third of participants were only "somewhat familiar". However, all participants reported that their knowledge of the state of lupus in Georgia had increased as a result of this workshop. Overall, participants were excited about learning more and making plans to do more

to promote lupus awareness and education in Georgia and committed to remaining active with and connected to GCLEA through the Georgia Lupus Collaborative.

As a result of these discussions, the GCLEA committed its support and resources to further its plan to improve patient access to knowledgeable and experienced healthcare providers by leveraging the state's established telemedicine network and infrastructure to facilitate the earlier diagnosis and improved treatment of lupus in the coming year. Considering the effect of the COVID-19 pandemic on many chronically ill persons, particularly in rural Georgia, the GCLEA'S support of telemedicine in lupus care throughout the state is more important than ever.

Another workshop on August 14, 2020, brought together members of the Georgia Lupus Collaborative from last year to contribute their vision, solidify ideas, and engage additional partners. Additionally, the groups worked to develop projects to further the long-term goal of the GCLEA and the Georgia Lupus Collaborative, which includes developing and implementing a comprehensive state action plan on lupus that will enhance existing initiatives and create new initiatives to improve the lives of people living with lupus in Georgia.

V. Report on the Public Health Burden of Lupus in the State of Georgia

The Georgia Lupus Registry

Limitations in the ability to assemble large population-based cohorts of patients with systemic lupus erythematosus (SLE) and/or cutaneous lupus erythematosus (CLE) with validated diagnoses and with significant representation from previously underrepresented sociodemographic groups have been a significant barrier to better understand the true clinical burden of lupus, as well as the many unanswered questions related to treatment, health care

access, and natural history. Furthermore, it is also challenging and expensive to follow such a group over time and collect clinical and biological data, acknowledging the interaction of social and biologic factors.

The Georgia Lupus Registry (GLR) is one of five recently completed Centers for Disease Control and Prevention (CDC)–funded population-based lupus registries designed to minimize many of these limitations. In 2002, the CDC Arthritis Program supplied funding for the Georgia Department of Public Health (GA DPH) to conduct surveillance of SLE in 2 counties (Fulton and DeKalb) within the Atlanta metropolitan area with large African American populations. To avoid biased ascertainment and underreporting as a result of recruiting large numbers of community patients, the GA DPH, as a "public health authority," used its public health surveillance exemption to the Health Insurance Portability and Accountability Act Privacy Rule (45 CFR, 164.512[b]) to obtain protected health information without written consent of the patient. The GA DPH contracted with Emory University as its designated agent to provide lupus expertise and manage the project. The primary sources of potential cases included hospitals, rheumatologists, nephrologists, and dermatologists in and around the catchment area. Administrative databases were queried for billing codes for lupus and related conditions. Secondary sources included laboratories, renal and cutaneous pathology, and queries in other population databases.

In addition to obtaining more accurate incidence and prevalence rates of SLE, the GLR has contributed to our understanding of disparities in SLE, including persistent and significant disparities in end-stage renal disease and mortality in blacks compared to whites. Relative to SLE, research on cutaneous lupus erythematosus has been sparse with little known about the

epidemiology in minority populations. The GLR produced minimum estimates of the incidence of chronic cutaneous lupus erythematosus (CCLE) and found similar disparities as seen for SLE.

The Georgians Organized Against Lupus Cohort

The Georgians Organized Against Lupus (GOAL) Cohort is a population-based lupus cohort supported by the CDC of over 1,000 individuals with lupus derived, in large part, from the GLR. Institutional review board approvals allowed patients identified in the GLR to be contacted directly and offered the opportunity to consent to be prospectively followed in the GOAL Cohort, primarily through regular surveys utilizing patient-reported instruments, as well as receiving other research opportunities, including the collection of related biospecimens. To minimize survival bias and to compensate for attrition, SLE patients with <5 years of disease are continually recruited from diverse hospitals and community rheumatologists and through Lupus Foundation of America, Georgia Chapter (LFA-GA) outreach. CCLE participants have been enrolled from multiple sources, including the GLR, Grady Hospital and Emory University dermatology clinics, referrals by community practices, and self-referrals facilitated by LFA-GA advertisements.

Consecutive annual sets of surveys have been administered to the GOAL Cohort participants since 2012. All participants completed a self-report questionnaire to return via mail or completed via Internet or phone. In order to maximize participation, participants in the GOAL Cohort who received care at Grady Memorial Hospital were recruited to complete the survey during their regularly scheduled clinic visit, if not already completed. Grady Hospital provides care for Atlanta's indigent and underinsured and has the only clinic dedicated to lupus care in the area. This has been particularly helpful in capturing the most vulnerable patients, who are often

socially disadvantaged, have difficulty completing surveys remotely, and historically have had low participation in research.

Coordinating different questionnaire modalities and timelines for mailing and processing of returned surveys was accomplished through a sophisticated project management and database system developed for the GOAL Cohort. The system generates paper-based or internet-accessible surveys unique to each designated recipient. For clinic visits, the system generates web-based case report forms. For participants who request it, phone interview-assisted surveys are given by the research coordinators using a standardized script and responses.

Data Collection in the GOAL Cohort

The GOAL Research Cohort is a rich and diverse repository of clinical, biological, sociodemographic, psychosocial, and health services data as well as biological material that will improve our understanding of how various factors interact and may lead to interventions, on an individual as well as systems and societal level, that will help to mitigate the significant disparities that continue to exist in lupus.

Surveys have covered the domains of natural history, treatment, healthcare access and gaps, and disparities using validated instruments whenever possible. Sociodemographic information was obtained, including employment, income, education, insurance, household composition, and relationship status. The surveys also included a detailed psychosocial battery, with measures of discrimination, other psychosocial stressors, and current mental health (e.g. depression) and other social determinants that can potentially explain black/white disparities in this population.

Biospecimens from consenting GOAL participants have been collected and a variety of immune and inflammatory assays have been analyzed to better understand the immune pathways

across lupus phenotypes and the intersection between social determinants of health and biological processes. DNA, RNA, and aliquots of serum and plasma are banked.

GOAL participants, as well as those in the GLR, have been matched with state and national databases, including the Georgia Hospital Discharge Database, National Death Index, Georgia Comprehensive Cancer Registry, U.S. Renal Data System, and Georgia Birth Records. Furthermore, all participants' addresses have been geocoded and linked to census information (tract and block group levels) and other area-based databases for socioeconomic, neighborhood, and other information.

Disparities in Lupus

Lupus shows a disproportionate risk among specific age groups, genders, and racial groups. Most commonly affected by lupus are women between the ages of 15 and 45 representing more than 90 percent of the lupus population. African-American, Hispanic, Asian and Native American people are at a greater risk of lupus when compared to white people. The Atlanta, Georgia area is faced with a significant burden of SLE with an overall age-adjusted prevalence rate of 92.1 per 100,000 person-years when using data provided by the GLR, and this rate is among the highest reported in the US. Furthermore, the disparities in SLE are of great concern and has been confirmed in terms of gender, age, and race.

GLR/GOAL Studies and Publications

Gender

Lupus disproportionately affects women. There is a female to male ratio of 9:1 for the incidence of SLE. There is a higher female predominance and a peak of disease incidence during the reproductive years (age 20-30). For men, the peak of the disease incidence is during the later

middle age years (age 45-60) . The GLR reported that the prevalence rate of SLE among women is >8 times more than in men in the State of Georgia.

Overall, out of 344 newly diagnosed SLE patients in the GLR diagnosed from 2002-2004, 87% were female and 13% were male. The age-adjusted incidence rate for SLE in women was 6 times higher than men compared to the incidence rate for SLE in women being 5 times higher than men. The prevalence rate of SLE was 127.6 for women and 14.7 for men after adjusting for age, which confirms a 9-fold increase in blacks compared to whites.

Age

Black women in Fulton and Dekalb counties in 2002-2004 had a significantly higher incident rate in the age-range 30-59 when compared to white women, especially in the age-range 30-39. Overall, newly diagnosed SLE patients had a mean age of 36 years. Black individuals develop SLE at a younger age than their white counterparts, similar to individuals developing CCLE. Drenkard et al. (2019) reported that CCLE was diagnosed 4 years earlier in black persons compared with white persons; with a mean age of 44 and 48 at diagnosis for black and white persons, respectively, in the metropolitan Atlanta area.

Race/ethnicity

Racial disparities are present in the prevalence, disease course, and health outcomes of SLE patients. While minorities are faced with a greater and disproportionate risk of developing lupus, it is uncertain as to whether this is due to genetics, environmental factors, or a combination of factors. SLE is 3 to 4 times more prevalent in blacks when compared to whites. Overall, newly diagnosed patients in the GLR were 76% black and 24% white. The incidence rate of SLE for black men was 4.3 times greater than white men and 2.9 times higher in black

women than in white women, and the age-adjusted incidence rate for blacks was 3.2 greater than for whites.

Blacks with SLE are 3 to 6 times more likely to develop multi-organ damage, diabetes, end-stage renal disease (ESRD), and cardiovascular disease (CVD). Drenkard et al. (2019) found that blacks have a 3-fold to 5-fold increased incidence of CCLE when compared to whites. There is a 7-fold increase in the prevalence case among blacks. Stress disproportionately affects the black SLE community. An observational study found high levels of stress in the predominately black GOAL cohort of SLE population, with approximately 25% of the population having scores below the mean score of the general U.S. population.

Discrimination is yet another factor to consider in the debate about blacks and the disparities they face, especially those surrounding their health outcome. The GOAL cohort was used to examine the relationship between unfair treatment and cumulative disease damage among African American women with SLE. The Black Women's Experiences Living With Lupus (BeWELL) study, which recruited participants from the GOAL cohort, reported that 27.6% of the study's participants reported racial discrimination in getting medical care and greater racial discrimination was associated with higher disease activity and organ damage scores. Furthermore, indirect or vicarious exposure to racism was associated with greater disease activity and may contribute to racial disparities in SLE.

Organ involvement

Patients with SLE are often burdened by the occurrence of comorbid diseases that are usually preventable through appropriate screenings and surveillance. Primary care, immunizations, and regular check-ups have great potential in reducing comorbidities, including

the ones that are often the cause of mortality in SLE patients. Among the leading causes of mortality in patients with SLE are infections, cardiovascular disease (CVD), and cancer. Early lupus nephritis was present in 35% of newly diagnosed SLE patients in the GLR. End Stage Renal Disease (ESRD) reduces the survival of SLE patients from 92% to 88% at 10 years of disease. ESRD is a not uncommon phenomenon in SLE, being significantly more common in blacks compared to whites. The incidence of ESRD in the GLR was high, with a 5-year cumulative incidence of 6.4% among black patients versus 2.5% among white patients and incidence rates of 13.8 versus 3.3 per 1,000 patient-years among black and white patients, respectively.

Quality of Life/Disability

The quality of life is often affected by different illnesses and diseases, as they can sometimes be debilitating and inflict alterations to an individual's otherwise regular or normal lifestyle and behaviors. Often accompanied by disabilities and physical limitations, lupus has the potential to impact activities and capabilities, such as working, physical activity, and self-care. Health-Related Quality of Life (HRQOL) scores were low in the GOAL cohort, with an indication of poorer health in the SLE population compared to the general population. A decline in HRQOL is likely to increase as patients with SLE age and it is likely that lower HRQOL is associated with increased disease activity and greater accumulated damage. Recently, an investigation using a selection of SLE participants from the GOAL cohort study found that 35.7%, 14.3%, 41.1%, and 12.5% of the participants had difficulty with preparing food, housework, shopping, and transportation, respectively. Fatigue is a common issue reported by SLE patients, with 80-90% of self-reported fatigue amongst this group.

Socioeconomic Status/Education/Employment

SLE patients are at an increased risk of poor or worse disease outcomes and they experience loss of employment, physical limitations, and a reduced HRQOL. Relative to the poverty threshold, SLE patients with higher income have better physical functioning across several domains. Whether measured by income, educational level, wealth, medical insurance, and/or occupation. Individuals with lower socioeconomic status (SES) have higher rates of disease severity and mortality than those with higher SES. The effects of SES relative to health outcomes in the SLE population are complex and include access to appropriate medical care with delayed or/and poorer quality healthcare; poor medical understanding and medication adherence and low self-efficacy and confidence in the healthcare system and providers. Disadvantaged groups are faced with genetic and environmental factors that may trigger the development of SLE as well as disease progression.

In the GOAL Cohort and from August 2011 to July 2012 (n=777), 35% were employed, 31% had 16+ years of education, and 59% had 12-15 years of education. In this same population, 49% of the SLE patients earned <$20,000 in annual income.

Treatment/access to healthcare/insurance

Having health insurance coverage is important for people with chronic conditions. Those with SLE are particularly vulnerable given the disproportionate impact on young minorities and women. The GOAL Cohort was the first description of health insurance changes over time overall and by sociodemographic groups on a population level in SLE. The majority (~60%) with SLE have private insurance and Medicare, which has grown over time while those uninsured have dropped. The decrease in the uninsured mirrors national trends as the Affordable Care Act expanded coverage through Medicaid expansion and insurance exchanges. Georgia is

one of the states that has not expanded Medicaid, the impact of which is not entirely clear in the SLE population and deserves further exploration. There also appears to be a slight increase in those who switch insurance categories. It is important to learn how types of and changes in insurance coverage affect health care utilization, disease treatment and outcomes, self-reported health, and mortality in SLE, particularly given the disproportionate impact on socially vulnerable groups.

We could not estimate the gap between how many have lupus but are not being cared for or diagnosed throughout the state. This requires updated information from the Georgia Hospital Discharge Database, which is derived by the Georgia Department of Public Health. Due to the COVID-19 pandemic, these requests have been significantly delayed. At the time of this report, we do not have this data and were not able to address this issue.

Estimate of the Numbers of Residents with Lupus Throughout the State of Georgia

Background

Systemic lupus erythematosus is a rare disease, is not a reportable condition and can have various manifestations. For these reasons, it is challenging to obtain population-level estimates of SLE. From several SLE registries conducted at more local levels, it is known that the prevalence of SLE varies by sex, age and race/ethnicity. We used prevalence estimates for SLE stratified by these important demographics along with population estimates of SLE to generate estimated numbers of individuals living with SLE in each Georgia county.

Key Findings

- Overall, it is estimated that there are over 7,000 potential cases of SLE across the state of Georgia. Black women comprise the greatest proportion of these potential cases.

- Estimated counts varied by county, but large numbers of individuals with SLE appeared to be clustered around the major cities in Georgia: Savannah, Augusta, Columbus and especially Atlanta, and reflect the underlying population distribution of these counties.
- The five counties with the greatest estimated number of cases, Fulton, Gwinnett, DeKalb, Cobb and Clayton, are all part of the metropolitan Atlanta area. After these five counties, the county with the largest number of estimated cases is Chatham, which includes the city of Savannah.
- Fulton county had the greatest number of estimated total cases with over 800 cases. Fulton county also had the greatest number of estimated cases among the Black population and estimated cases among the White population. Gwinnett county had the greatest number of estimated cases among the Hispanic and Asian/Pacific Islander populations.

Data Sources

Population estimates**:** Georgia county populations by age group, race, ethnicity and sex for 2018 were obtained from publicly-available data from the Georgia Department of Public Health (https://oasis.state.ga.us/). Black race, White race and Asian/Pacific Islander race all excluded those of Hispanic ethnicity, which were captured in the Hispanic category. Hispanic individuals are therefore of any race. The total population category excludes the multiracial population in Georgia, for which we could not find estimates of SLE prevalence and reflects a very diverse population. The total population counts are the sum of estimated counts of Black, White, Hispanic and Asian/Pacific Islander individuals with SLE.

Systemic lupus erythematosus prevalence estimates**:** Prevalence estimates by sex, age group and race/ethnicity were obtained from two sources. Estimates for the Black and White

populations were provided by the researchers with the Georgia Lupus Registry. These estimates were generated using data from DeKalb and Fulton counties in Georgia. Prevalence estimates for the Hispanic and Asian/Pacific Islander populations were provided by researchers with the California Lupus Surveillance Project. These estimates were generated using data from San Francisco County.

Methods

The prevalence estimates were provided in the form of cases of SLE per 100,000 people. The prevalence estimates were multiplied by the population estimates for each county, accounting for the different sex, age and racial/ethnic distributions by county. It should be stressed that county-specific counts are estimates based on county population by race/ethnicity, age and sex and estimates of SLE prevalence, and not actual counts reflecting validated cases of SLE.

Estimated counts were summed for each county to generate total population estimates. Estimated counts for each county were categorized and mapped using ArcGIS software. The top 20 counties with the greatest number of estimated cases of SLE were also identified.

Minimum Estimates

Given the methods used in the Georgia Lupus Registry and the California Lupus Surveillance Project to determine the rate of SLE, prevalence estimates are presented as solid "floor" figures, with actual numbers undoubtedly being higher for several reasons. There was underascertainment of serologic test results, particularly in prevalent cases in which diagnostic tests could have occurred many years ago and the results were lost in the records, thus leading to lower rates of documented serologic tests than would have been expected in a prospective study. These estimates also do not capture or report those with incomplete/pre-lupus and some overlap

disease that don't completely meet lupus criteria, as well as other forms of lupus, including cutaneous and drug-induced lupus.

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.[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.

Lupus Prevalence Estimates

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 tha///n men, 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.[x] 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.[xi] 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%).[xii]

APPENDIX B

Georgia Council on Lupus Education and Awareness
Lupus and Related Autoimmune Diseases Collaborative

- **Outreach, Education, and Partnership:** Develop or enhance current education and awareness programs for the general public, especially communities that lack lupus education.
- **Research:** Develop research and/or expand current research efforts throughout the state in the areas of epidemiology, healthcare, sociology, economics, wellness with the goal of reducing health disparities among lupus patients.
- **Provider Outreach, Education, and Support:** Develop or enhance current professional education programs for non-rheumatologists, facilitate cohesion between professional services and patient services in this state, and support professional development and specialization in the diagnosis, care, management, and treatment of people with lupus.
- **Patient Services:** Develop or enhance current patient self-management programs, expand patient access to specialized providers, improve care resources for patients, enhance patient education, improve wellness initiatives, and leverage state agency and non-profit resources for people impacted by lupus.
- **Workforce Development:** Develop programs, resources, and services that assist people living with lupus with return to work resources and develop or enhance current workplace accommodation education specific to those living with lupus.
- **Policy:** Build on current lupus advocacy efforts and draft legislative recommendations on behalf of the members of the collaborative.

[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.

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