

Lupus Foundation of America, Georgia Chapter: History, Mission, and Program Summary

The Chapter is a 501(c)3 and it was founded in 1975 by a dedicated group of volunteers and doctors. The Lupus Foundation of America, Georgia Chapter (the Georgia Chapter) is led by a strong Board of Directors who provide governance, strategic advice, and development assistance. In addition, the Medical Advisory Board is an organization with 57 physicians in the state devoted to the treatment of lupus and related diseases with two main goals:

- To educate patients as well as the public throughout the state of Georgia.
- To support research that fosters excellence in the care of patients or advances our understanding of the disease.

The Georgia Chapter is part of a national force devoted to solving the cruel mystery of lupus while providing caring support to those who suffer from its brutal impact. We work with local health professionals and volunteers to provide programs and resources designed to educate people with lupus and their families. We also provide health professionals with programs and resources as a means to diagnose and manage the disease.

With the help of informed volunteers and committed supporters, we conduct activities to increase awareness of lupus, while advocating on their behalf. We raise funds to support research and education programs so the community affected by lupus can have an improved quality of life.

The impact on the Georgians we serve, inspire, and empower and our story of growth is compelling. As a voice of hope we are raising awareness and fighting for the 55,000 Georgians living with lupus. The growth of our volunteer leadership in the medical and corporate community has led to the expansion of programs, events, and awareness efforts as we reach new physicians, patients, and new communities.

As the only statewide valuable resource for the lupus community, the Georgia Chapter, provides thousands with free, valuable educational information, physician referrals, resources, support groups and educational programs. We are reaching patients in 121 of the 159 counties in Georgia. Ninety percent of every dollar donated stays in Georgia to support our programs. The chapter also supports the national research efforts of the Lupus Foundation of America, working to advance the science and medicine of lupus to bring down the barriers that have impeded progress in lupus research.

Despite its prevalence, lupus remains one of the least recognizable and most misunderstood diseases in both the medical and lay communities. The incidence has increased hugely in the past 20 years and yet, there is no known cause or cure. Current treatments are often very toxic, with side effects often rivaling the symptoms of the disease.

We reach out to our lupus constituents and their families with our year-round chapter programs and events in a variety of ways, from direct mail to online email blasts, website updates, and information placement in doctors' offices:

- Over 39,000 visitors to our website in this past year.
- Over 1,200 inquiries and chapter responses from patients and families for information, resources, and referrals.
- More than 16,800 Social Media followers.

- More than 58,700 constituents in our database.
- More than 25,900 constituents in our email database.
- In the past year, more than 1,200 people attended our virtual symposiums, seminars, and summits during COVID-19 pandemic.
- Our support groups have had a virtual attendance of at least 2,000 across the state.
- 200,000 What is Lupus? Brochures, in English and Spanish have been distributed in doctors' offices across Georgia.
- 7,500 walkers and families were inspired and empowered at the 2019 Atlanta Walk to End Lupus Now, one of the largest LFA walks in the nation. While all the events were virtual in 2021, we are excited to return to in-person walks in 2022 in Atlanta, Augusta, Columbus, and Macon. More than 3,000 walkers attended our event on April 30, 2022, at Piedmont Park in Atlanta and 250 attended our walk in Augusta. We have raised more than \$255,000 to date in our 2022 walk campaigns.

Our key accomplishments in 2021-2022 include:

- We have continued to provide all of our education programs in a virtual format.
 - Programs included webinars focused on minority health, lupus nephritis, depression, social security disability, clinical trials, access to financial resources, men, adolescents, and the general lupus population.
 - In addition to town hall meetings (see below), we participated in webinars dealing with the HCQ shortage and COVID-19 vaccines.
 - We promoted and participated in the national LFA's webinars delivering up-to-date disease education as well as national COVID-19 information.
- COVID-19 Virtual Town Hall Meetings, presented by Dr. Sam Lim, internationally respected rheumatologist, and epidemiologist, 43 to date. All calls are recorded and indexed on our website.
- Creation of a COVID-19 Patient Resource Center with local, state, and national resources.
- We held our sixth Support Group Retreat to train 21 Support Group Facilitators as professional activists in communities across Georgia.
- School Nurses Training for 360+ nurses across Georgia in partnership with the Georgia Council on Lupus Education and Awareness (GCLEA), the American College of Rheumatology, and the NACDD.
- Advocacy: In March 2020, we advocated for \$100,000 in research funds in Georgia. The funds were approved for fiscal 2021. We returned in March 2021 and March 2022 in a virtual format to advocate for health care reform including medical surprise billing and step therapy.
- Emergency Financial Assistance: The Georgia Chapter distributed funds to help people living with lupus who were in financial crisis. The Chapter paid utility bills, copayments for doctor visits, rent and much all the while counseling our constituents to help them find sustainable resources. We have awarded more than \$94,000 in assistance since 2014.
- The Georgia Chapter disseminated a Needs Assessment designed to identify the gaps in current services that are provided to people living with lupus across the state. The findings of the assessment will add to the body of information available to support the Georgia Chapter and its collaborative partners by enhancing existing programs, assisting patients in receiving optimal

treatment, and developing strategic initiatives that will ultimately help to improve health outcomes.

Our Chapter Goals for growth in 2022-2023 include the following:

- Continue to expand the reach of our educational programs and resources to new communities across Georgia. This year we are hosting our second annual Summer Series by presenting one topic seminars hosted during the work week.
- In August 2022, we will hold our first Ambassador Training. This select group will be trained to represent the Georgia Chapter at various programs and events across the state.
- In October 2022, we will hold our Annual Lupus Empowerment Summit in person for the first time since 2019 with an anticipated 150 - 200 attendees. The program will include a key-note speaker and breakout sessions on various topics.
- Participation in the LFA CDC funded grant to promote lupus awareness to minority communities through the LFA's Be Fierce, Take Control and Strategies to Embrace Living with Lupus Fearlessly (SELF) initiatives.
- 8,000 Lupus GA newsletters to be mailed and distributed to lupus patients and sent to doctors' offices across Georgia.
- Increase awareness and support of our programs in the doctor's offices of our Medical Advisory Board, (MAB) members and increase support and participation of our MAB members in our programs.
- Expand our support group training retreat to include community networking along with the new title of our Support Group Network – the Georgia Community Network.
- Work with our Support Group leaders to grow community awareness and grassroots advocacy efforts.
- Grow our Lupus Parent Project, a support network for parents, working in partnership with Children's Hospital of Atlanta.
- Partner with HBCU's to bring awareness of the signs and symptoms of lupus to those who are most affected by this disease.
- Build on the success of our state advocacy efforts and the passage of the 2014 lupus statute designed to ensure the continued increased awareness of lupus at the state level and the establishment of the Georgia Council on Lupus Education and Awareness.
- Partner with the Georgia Council on Lupus Education and Awareness to educate school nurses and to expand telemedicine for rheumatology patients in Georgia. The focus of the 2022 - 2023 trainings is to target schools where at least 50% of students are eligible for the free or reduced-price lunch program.
- Continue to grow our Lupus@Work initiative with presentations to support people living with lupus where they work.

Participation in Grants Targeting Minority Populations and Health Disparities:

- Deep South Health Equity Lupus Project (DS-HELP) - the Georgia Chapter is partnering with the University of Alabama and three other states in the southeast to educate black people living with lupus, black primary care physicians, and black researchers about participating in clinical trials. The focus of this HHS-OMH funded project is to improve minority participation in clinical trials through education and conversation.
- 2021 - 2022 LFA/CDC Partners United for Sustainable Lupus Education (PULSE) – The Georgia Chapter is involved in several initiatives including Community Health Worker Training, SELF – a new self-management tool, promotion of our national Lupus Resource Center, and Lupus Community Ambassadors.
- 2017- 2018 LFA/CDC Partners United for Sustainable Lupus Education (PULSE) – The Georgia Chapter trained lupus ambassadors to speak on HBCU college campuses and in black churches in the Metro Atlanta area.
- 2017 LFA/OMH agreement to develop an education plan on minority and/or disadvantaged populations' participation in clinical trials for lupus. The focus was to improve recruitment and retention through presentations at black churches in Metro Atlanta.

Funding ensures the continued growth of our education programs, awareness, and patient support efforts, providing vital resources in the management and treatment of lupus. The 55,000 Georgians with lupus along with their families need multiple opportunities across a variety of platforms to learn from medical experts and professionals presenting information on various topics. Our year-round advocacy efforts inspire and empower those touched by lupus, ensuring they know they are not alone, their community cares, and lupus is being taken seriously.

Twenty years ago, no one spoke of lupus, there was little awareness and understanding of the signs and symptoms and very little investment in research. No individual and no organ are safe. We have made great progress, but we must do more as we have lost so many of all ages and we cannot rest. We are relentless and tireless, but so is lupus.

We have barely begun, and we will reach even higher heights in the coming years.