



# ANNUAL REPORT

## 2017

**Lupus and Allied Diseases Association, Inc.** is a national 501(c)(3) organization founded in Utica, NY in 1978 that is dedicated to improving access to care and quality of life for those impacted by lupus and allied diseases and conditions of unmet need by fostering collaboration among stakeholders and supporting innovative advocacy, education, awareness and biomedical research initiatives that will identify causes, and discover better diagnostics, superior treatments, and cures. As a passion-driven, patient-focused charity led by individuals with lupus and their loved ones, we promote patient-centered healthcare, patient empowerment programs and patient-focused research to ensure that the patient perspective is included and recognized as an equal voice in healthcare and across the research continuum.

## **MISSION**

*The mission of the Lupus and Allied Diseases Association, Inc. is to advocate for those affected by lupus and allied diseases through awareness and research program initiatives to improve quality of life.*

## **ABOUT LUPUS**

Systemic Lupus Erythematosus is a chronic inflammatory autoimmune disease in which a triggering agent causes the immune system to attack the patient's own tissue. It can affect virtually any organ system of the body; including the skin, joints, kidney, brain, heart, lungs, blood and blood vessel and there is no known cause or cure. Lupus ranges from mild to life-threatening and is a leading cause of kidney disease, stroke, and premature cardiovascular disease in young women and is unpredictable, highly individualized, extremely volatile, life-altering, debilitating, life-diminishing and potentially fatal. By the most conservative estimates, there are at least 322,000 Americans with definite or probable lupus with recent independent surveys suggesting a prevalence as high as 1.5 million. The disease affects women 9 times more often than men with 80% of new cases developing between the ages of 15 and 44 during the prime of life.

Lupus is also a costly multi-system disease as patients must see several specialists regularly and because it can affect virtually any part of the body, it is known as the prototypical autoimmune disease. It is 2 to 3 times more prevalent in African Americans, Asians, Hispanics and Latinos, and Native Americans. While approximately 8 of 10 new cases of lupus develop among women of childbearing age; men, women, and children also develop the disease. Lupus is NOT infectious, rare, or cancerous, and although the cause is unknown, researchers suspect that both genetic and environmental factors can play a role in its development.

In addition, public and professional knowledge of the symptoms and effects of lupus and autoimmune diseases are often lacking, resulting in delayed diagnosis and proper medical intervention. We realize that early diagnosis and treatment are vital components in reducing the physical and economic impact of these conditions and are committed to increasing community and health professional awareness.

In 2017 Lupus and Allied Diseases Association advocated for public policies to increase government funding for lupus and autoimmune research and public awareness and education program initiatives that will benefit all affected by lupus and other diseases of unmet need. Increased research funding will enable scientists to identify causes, develop better diagnostic measures, discover safer and more effective treatments and ultimately, eradicate lupus and other conditions of unmet need. Although cures for diseases like lupus remain elusive, promising research studies are taking place.

The prognosis for those living with lupus and allied disease has become more promising through expanded research initiatives including collaborative public-private partnerships. Improved diagnostic techniques and evaluation methods combined with a more innovative approach to treatment will give physicians the tools to more effectively manage disease symptoms and complications. Many individuals with lupus and allied disease and their loved ones are also taking a more active role in their own health care by participating in education programs and developing strong coping and self-management skills. Elevating the public's awareness of diseases like lupus also increases the number of individuals who seek medical attention and can lead to earlier diagnosis, treatment interventions, and a more positive prognosis. Individuals who empower themselves by developing a good knowledge of their disease and a strong support system increase their chances for a better disease outcome and improved quality of life.

During the past year, Lupus and Allied Diseases Association enhanced its public education and awareness programs, advocacy and research initiatives, collaborated with other interested partners to serve the needs of the lupus and unmet disease communities, and provided representation regarding important lupus-related issues at local and national advocacy events and broadened its resources in order to provide these services. We continued our long-standing reputation for aggressively pursuing stronger patient protections and driving research and development forward with the person with lupus as an equal stakeholder.

## **ACCOMPLISHMENTS**

Lupus and Allied Diseases Association believes it is critical for all healthcare stakeholders to collaborate on advocacy and research initiatives. As an organization led by individuals with lupus and loved ones who directly experience the healthcare and clinical research systems on a daily basis, we are uniquely positioned to provide a true patient perception regarding quality of life, value, outcomes, clinical research, and treatment benefits vs. risks. We confront healthcare issues as they arise, often taking the lead to organize advocacy efforts within the nation or states; boldly inserting ourselves into the regulatory, legislative, and research communities whenever necessary to guarantee a patient perspective is both included and heard.

We recognize that because diseases of unmet need like lupus are extremely unpredictable and highly individualized, maintaining disease stability by having access to the full array of treatments is critical to patient well-being. Lupus and Allied Diseases Association has been and continues to be very active on both the state and national level regarding healthcare reform and

access issues that impact those affected by lupus and all Americans including: the ACA preservation, the biosimilars regulatory process, advancing health information technology, protecting entitlement programs, repealing IPAB, supporting CHIP and PDUFA VI reauthorizations, providing stronger patient protections, promoting more inclusive drug formularies and stimulating patient-centric research. In 2017 we provided forty-six support memos and letters, eight op-eds, ten media interviews, and testimony in twenty-six states on biologic medications, step therapy reform, non-medical switching, prescriber prevails, tier pricing, high co-pays, formulary changes, and other important issues.

We are passionately committed to ensuring that all Americans receive the most appropriate therapies as directed by their providers and that public policy keeps pace with biomedical research innovation. Because current research for diseases of unmet need like lupus is both under-funded and deficient, and treatment options are totally inadequate, we are expanding our collaborative efforts with other healthcare stakeholders to promote patient-involved care and patient-engaged research. This will ensure the pace of biomedical research and development and drug discoveries accelerate rapidly to improve quality of life.

Lupus and Allied Diseases Association's public awareness, education and advocacy programs are designed to not only empower individuals to actively participate in their own healthcare but to also become engaged in the public policy process in order to influence positive change and enhance their quality of life.

We continue to promote:

- "The Power of Advocacy—Promoting Participation to Improve Care and Advance Research" an informative presentation on how to become an effective personal and public advocate with an overview of current access and health policy initiatives;
- "I Love Someone with Chronic Disease, So..." a light-hearted presentation for loved ones, caretakers, and individuals living with a chronic disease given by a loved one drawing from his personal experiences in coping with family members' chronic conditions;
- "Hope is on the Horizon" an inspiring program to educate "patient to patient" on the importance of clinical research trials and the significance of participation in getting new therapies to those who need them while providing current trial information.

We remain committed to ensuring that the Biosimilars regulatory pathway recognizes the complexities of lupus and autoimmune patients and that products are safe, efficacious and have distinguishable nonproprietary names. We submitted comments on Biosimilars to the FDA, FTC, and WHO, are active members of two Biologic Coalitions, and serve as a Steering Committee Member for the Biosimilars Stakeholder Workshop, and supported patient protection legislation in forty-one states to date. We also participated in a 5-minute advocacy video about non-medical switching and biologicals, led advocacy efforts in New York state resulting in legislation for Lupus Awareness, Education & Outreach Programs and Biologic Drug Substitution Laws being passed, and participated as a panelist at a state briefing on non-medical switching. We supported lupus and allied disease programs for individuals with lupus and their loved ones,

health professionals and others in the community during 2017 through the tireless efforts of our outstanding volunteers who logged 5,378 hours.

Lupus and Allied Diseases Association submitted comments on the 21st Century Cures and Senate Healthier Americans Initiatives, provided public comments to CMS regarding Medicare Parts B and D and Medicaid issues and led and supported sign-on efforts. We continued to co-lead the collaborative effort for the lupus community's Externally-led FDA Patient-Focused Drug Development Initiative and are participating as a Workgroup Member on the FDA Quinacrine Compounding Access Issue for Lupus. We continue to participate as an active member of the NIAMS Lupus Federal Working Group (LFWG) and are a Member of the LFA's National Lupus Partners Network. We also continue to serve as the only Patient Advocacy Representative on the IUS/WHO/AF/CDC Auto-antibody Standardization Committee.

Lupus and Allied Diseases Association sponsored Public Awareness and Information programs by educating the public, physicians and other health professional about lupus symptoms, diagnosis and treatment, promoting public awareness to the local community through public service announcements, media interviews, press releases, social media, and speaking engagements. We also disseminated up-to-date treatment and research information through our telephone line, a physician referral list, and distribution of lupus inquiry packets and materials including brochures, local newsletters and national publications. We distributed materials at health and wellness events, the Lupus Agencies of New York State (LANYS) 9<sup>th</sup> Annual Lupus Awareness Day in the NYS Capital, BIO's International Meeting, and the American College of Rheumatology's (ACR) Annual Scientific Meeting and through multiple listings with local and community resource and referral agencies. Elevating public and professional awareness of lupus helps to increase the number of people who seek medical attention and raise the level of professional knowledge about the disease, which in turn leads to earlier diagnosis and intervention and a more positive prognosis.

Lupus and Allied Diseases Association supports all Lupus and Autoimmune Research and funded a \$25,000 pediatric lupus research grant at The Lupus Foundation of America in Washington, DC and a \$75,000 lupus research grant at The Lupus Research Alliance in New York, NY. We attended several annual scientific research meetings held by: the Lupus Research Alliance (LRA), American College of Rheumatology (ACR), New York BIO (NY BIO), BIO New Jersey (BIO NJ), and BIO, and participated in advocacy initiatives for: LRA, BIO, NY BIO, CSRO and the ACR; and attended BIO's Patient Advocacy Summit, the Externally-led Lupus Patient-Focused Drug Development (PFDD) Meeting, the Biosimilars Stakeholders Workshop, the National Coalition of Autoimmune Patient Groups' (NCAPG), ACR's and National Institute of Arthritis and Musculoskeletal, and Skin Diseases' (NIAMS) Lupus Federal Working Group Events in Washington, DC, and Patients' As Partners Meeting to better understand and in turn educate others about the importance of advocacy and research.

Lupus strikes young people in the prime of their lives and drastically impacts their future. For far too long, those affected by lupus have been disappointed with the lack of research progress being made in discovering new treatments, especially given that only one drug has been

approved by the FDA for lupus in the past six decades. We strongly support innovative research initiatives that include cross-sector collaborations, public-private partnerships and robust basic, clinical and translational projects that enable scientists to: investigate disease pathogenesis and physiology, design better clinical trial methodologies, improve diagnostic tests, identify biomarkers, develop superior treatments, prevent complications, and ultimately discover cures.

## **Lupus and Allied Diseases Association, Inc.**

### **Board of Directors**

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# Lupus and Allied Diseases Association, Inc.

## Statement of Functional Expenses

For the year ended September 30, 2017

### PUBLIC SUPPORT AND REVENUE

Public Campaign Contributions	714
Direct Contributions	226,935
Interest Income	1,318
Special Events Revenue	91,553
Volunteer Contributions*	150,907

Total Cash Revenue \$320,520

Total In-kind Revenue \$150,907

**TOTAL REVENUE \$471,426**

### EXPENSES

Advocacy Program Expense	14,528
Awareness Program Expense	15,740
Education Program Expense	15,142
Research Support	100,000
Management & General	914
Fundraising	477
Special Events Expense	18,706
Volunteer Labor Expense	150,907

Subtotal Expense \$165,507

Subtotal In-kind Expense \$150,907

**TOTAL EXPENSE \$316,404**

**REVENUE OVER EXPENSE \$155,013**

\*Lupus and Allied Diseases Association is an all-volunteer organization that relies entirely on donated manpower hours to achieve our mission and provide our program services. In 2017, 78 total volunteers, including our Board of Directors, accumulated 5,378 hours of volunteer-contributed services. Based on the Independent Sector's State Values of Volunteer Time NYS 2016 rate \$28.06 per hour, LADA raised an additional \$150,907 in financial support, making our total annual revenue \$471,426.