



Long Island / Queens Affiliate

ANNUAL REPORT

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LUPUS ALLIANCE OF AMERICA
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Lupus

Lupus is a chronic autoimmune disease which causes inflammation of various parts of the body, especially the skin, joints, blood and kidneys. The body's immune system normally makes proteins called antibodies to protect the body against viruses, bacteria and other foreign materials. These foreign materials are called antigens. In an autoimmune disorder such as lupus, the immune system loses its ability to tell the difference between foreign substances (antigens) and its own cells and tissues. The immune system then makes antibodies directed against its own tissues and cells, i.e. against "self". These antibodies, called "auto-antibodies," react with the "self" antigens to form immune complexes. Immune complexes can build up in the tissues and cause inflammation and injury.

More people have lupus than cerebral palsy, multiple sclerosis, sickle-cell anemia and cystic fibrosis combined. Market research data show that between 1,400,000 and 2,000,000 people reported to have been diagnosed with lupus. (Study conducted by Bruskin/Goldring Research, 1994) For most people, lupus is a mild disease. For others, it may cause serious and even life-threatening problems. Thousands of Americans die each year from lupus-related complications.

There are three types of lupus. Cutaneous lupus (also known as discoid lupus) is limited to the skin and is identified by a rash that may appear on the face, neck, or scalp. The rash may be more apparent on areas of the skin exposed to ultraviolet light (e.g., sunlight, fluorescent light). Although there are many types of lupus rash, the most common is raised, scaly and red, but not itchy.

Systemic lupus erythematosus (SLE) is usually more severe than discoid lupus. This type of lupus can cause inflammation in a number of organs. For some people this may be limited to skin and joint involvement, in others, the joints, lungs, kidneys, blood or other organs/or tissues may be affected. SLE may include periods in which few, if any, symptoms are evident ("remission") and other times in which the disease becomes active ("flare").

Certain prescribed drugs can create a lupus-like syndrome (called drug induced lupus) which is similar to SLE. This type of lupus very rarely affects either the kidneys or the nervous system. Not everyone who takes these drugs will develop drug-induced lupus. When the medications are discontinued, the symptoms of lupus usually fade.

Although the cause of lupus remains unknown, both genetic and environmental factors may play a role in its development. While an individual's genetic structure may increase the chance of developing lupus, it probably takes some kind of environmental factor to trigger the illness. Infections and surgery may also trigger the symptoms of lupus.

Since lupus occurs 10-15 times more frequently in women than in men, especially women of color, researchers believe that hormonal factors may also influence the development of the disease.

Currently, there is no cure for lupus. However, early diagnosis and proper medical treatment can significantly help control the disease. Symptoms often vary from one individual to another and treatment is based on specific indications in each person.

The outlook for lupus patients has significantly improved over the last two decades. Better diagnostic techniques, evaluation methods and a more cautious use of medications have given physicians the tools to more effectively manage lupus symptoms and complications.

Twenty years ago only 40% of the people with lupus were expected to live more than three years following diagnosis. Today, with early diagnosis and current methods of therapy, more than 90% of people with lupus can look forward to a normal lifespan.

HUMAN HEALTH and WELFARE SERVICES
LUPUS ALLIANCE OF AMERICA, LI/QUEENS AFFILIATE
FISCAL YEAR 2009-2010

The Lupus Alliance of America, Inc., Long Island/Queens Affiliate is a not-for-profit organization, incorporated under the laws of New York State is celebrating 57 years of providing services to the counties of Nassau, Suffolk, and Queens. The Agency, directed by men and women who volunteer their time, is dedicated to raising funds for patient services and research into lupus, and providing moral support and group strength to those diagnosed or suspected of having the disease. We promote education and understanding of lupus to the lay and professional community.

- Responded to over 7200 inquiries both by phone and on our monitored and updated web site
- Provide financial aid thru our Quality of Life program, to assist with needs not covered by other programs of help.
- Have a children's program which provides free trips and fun to children with lupus as well as children whose families are affected by lupus
- Translated lupus brochures into Spanish
- Referred over 2,000 requests for lupus specialists
- Hold meetings in local libraries on lupus and chronic illnesses
- Quarterly meetings on Living Well topics followed by a open discussion on living with a chronic illness.
- Maintained tables or provided information over 62 health fairs, speaking to thousands of people about lupus
- Mailed over 10,000 copies of our quarterly newsletter and 3500 copies of our end of year newsletter
- Referred over 900 clients to other agencies or support personnel
- Distributed over 6200 press releases and public service announcements to 164 newspapers, radio and television stations as well as 11 Spanish media outlets
- Offer 4 educational days each year for diagnosed patients and their families
- Maintain an office 5 days a week, with staff and over 800 volunteers who
- donated over 10,000 hours to lupus
- Presentations at school health classes by a nurse with lupus and advocacy and support for parents who are dealing with school and a ill child
- Distributed over 75,000 leaflets and brochures
- Sent updated literature, free of charge, to all who ask
- Maintain a library of articles, current books and videos on lupus and its complications, available on loan free of charge

We have 5 support groups which meet at different locations throughout Nassau, Suffolk and Queens. They meet a total of 156 times per year and service over 1237 clients. We have managed to provide this service free of charge to our already financially burdened members for more than 35 years. These groups are now led by our patient service coordinator, who is has a master in social work and is a lupus patient. The foundation has a telephone counseling service for those clients who are unable to attend the support groups. Our social services department works as an advocate for our clients with government entitlements as well as the medical profession.

MISSION STATEMENT

To serve, educate, and find the cause and cure for those affected by lupus.

The purpose of the Alliance is to:

- **Provide information, education and referral for those affected by lupus and to promote the development and enhancement of health and social welfare services at the local level to assist individuals suffering from lupus;**
- **Promote public education to increase knowledge and understanding of the disease and its ramifications;**
- **Encourage support of research programs related to the diagnosis, treatment, cure and prevention of lupus;**
- **Promote the exchange of information among health professionals and collaborate with the professional community to improve the standards of diagnosis, care and treatment of those affected by lupus.**

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