

HOSPITAL  
FOR  
**SPECIAL  
SURGERY**

**LupusLine**<sup>®</sup>

Support is a Phone Call Away





## **Do you or does someone close to you have lupus?**

Lupus, short for systemic lupus erythematosus, is a complex, chronic disease of the immune system. Lupus is called an autoimmune disease because the body attacks its own healthy tissues. It can affect any part of the body. Symptoms include painful or swollen joints, extreme fatigue, and skin rashes. Lupus can also cause problems you may not be able to see, such as damage to the kidneys, lungs, heart, brain, or nervous system.

Lupus is hard to diagnose because the symptoms can be vague and may resemble symptoms associated with other illnesses. We do know that you cannot catch lupus from another person, or give it to anyone else. It is not contagious. The illness is not a cancer, and it is not related to AIDS. Lupus can be very mild or life threatening. No two people have the same experience.

We don't yet know what causes lupus. It is possible that more than one factor is involved, including genes, viruses, and changes in the environment. Although there is not yet a cure for lupus, early and appropriate medical care is very important in order to control the complex symptoms people face.

## **You Are Not Alone**

Lupus affects approximately one million people in the United States. The illness occurs among women nine times as often as in men and is more common among African American, Asian American, and Latina women. Although anyone can be diagnosed with lupus, it most often occurs among women between the ages of 15 and 45.



212.606.1952  
or  
866.375.1427  
toll-free

## The Impact of Lupus

The physical, social, and emotional impacts of lupus can be enormous. Feelings of anxiety, sadness, depression, and isolation are common. The difficulty in diagnosing lupus and its unpredictable course can be especially stressful. Additional challenges include varied treatment options and their side effects, and the often invisible nature of the illness itself. If you or someone close to you has lupus, you may be concerned about how the illness will affect your family, your work, your sense of well-being, and your future.

## Our Commitment

Hospital for Special Surgery has a long history of helping patients with lupus – from researchers, who are trying to understand what causes the body to attack its own healthy tissues, to clinicians, whose focus is to provide advanced therapies and comprehensive teamwork to enhance quality of life.

## Calling for Support

In 1988, Hospital for Special Surgery established LupusLine – an innovative, free telephone peer counseling program *for* people with lupus *by* people with lupus. As a national peer support service, LupusLine has become a model program, which has been replicated by other organizations in the United States and Canada.

Following a talk with our professional social work manager, callers are individually matched with a trained volunteer, who shares the special understanding of living with the illness. All of our volunteers have lupus or have a family member with lupus.

Before they become peer counselors, they participate in an extensive training program. Once actively involved, they receive ongoing supervision in order to provide exceptional support, a listening ear, and help with problem-solving. LupusLine is ideal for people who want a one-to-one relationship via the privacy and convenience offered by the telephone. Talking with a peer can also provide a level of emotional comfort, sharing, and support that can help people with lupus cope with the challenges of living everyday life.

## How to Reach LupusLine

To use LupusLine, call our program manager in the Department of Social Work Programs weekdays between 9 am and 5 pm, Eastern Standard Time. Following a telephone screening, our manager will arrange a mutually convenient time, including evening and weekend hours, for you to connect with a LupusLine peer support counselor from the privacy of your home. To contact our program manager, call 212.606.1952 or 866.375.1427 toll-free from outside New York City.

## What Callers Have Said About LupusLine

Since it began, LupusLine has received over 20,000 phone calls, offering understanding and insight to people with lupus and their loved ones from around the country. Callers have told us that LupusLine is a unique and invaluable resource, helping with:

- Coping strategies
- Problem-solving
- Understanding symptoms
- Clarifying medical treatment options

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- Doctor-patient communication
- Impact on work, family, and friends
- Pregnancy and parenting issues
- Emotional support

As one caller shared, “The most powerful factor on this journey has been the healing between equals. The medical symptoms persist, but the sense of isolation and confusion does not. I’m in touch with a bright, brave woman who has walked on this path a few steps ahead.”

## Additional Resources

As part of our commitment to providing a comprehensive and integrated model of care for people with lupus and other rheumatologic diseases, Hospital for Special Surgery also offers the following programs:

**Charla de Lupus (Lupus Chat)<sup>®</sup>.** This peer health education program is staffed by trained volunteers who are lupus veterans, with a particular emphasis on reaching Spanish-speaking communities. The program is available on site at several New York City area hospitals, as well as by phone. In addition, volunteers participate in community health education presentations and health fairs in the New York City area. For more information, call 212.606.1958 or 866.812.4494 toll-free from outside New York City.

**Teen and Parent Lupus Chat Groups.** Our Teen Chat Group is a monthly, in-person service for teens, 14 to 18, with lupus. As an extension of the Charla de Lupus program, we also offer a simultaneous meeting for parents of teens with lupus. The groups are held at hospital sites in New York City. They offer informal discussion, support, special activities and celebrations, as well as guest speakers. Close friends and family





members are welcome. The program also offers education material specifically for teens with lupus. For more information, call 212.606.1958 or 866.812.4494 toll-free from outside New York City.

**SLE Workshop.** This monthly education and support group, held at HSS since 1995, is for people with lupus and for their families and friends. You can come to one meeting or attend every month. Lectures by lupus care experts are followed by informal discussions. For more information, call 212.774.7654.

**LANtern® (Lupus Asian Network).** This program is dedicated to enhancing the quality of life of Asian Americans with lupus and their families by creating networks of hope and understanding. LANtern provides telephone support and education by the social work manager and peer health education by trained peer volunteers fluent in Mandarin and Cantonese. The program also offers bilingual (Chinese) education programs and publications on lupus. LANtern is also available for community presentations in the New York City area.

For more information, call 212.774.2508 or 866.505.2253 toll-free from outside New York City. Visit the Hospital's website at: [www.hss.edu/social-work-programs](http://www.hss.edu/social-work-programs).

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## You Can Volunteer, Too!

Volunteers make it possible for LupusLine and our other community programs to reach more people. If you are 18 years or older, live in the New York metropolitan area, and would like to provide an extremely rewarding service, call us at 212.606.1952.

## World-Class Integrated Rheumatologic Care

LupusLine represents the longstanding commitment of HSS rheumatologists to comprehensive and integrated care to enhance patients' quality of life. Our rheumatologists interact closely with other health care professionals to address each patient's specific illness-related concerns. These include our world-class orthopedic surgeons, nurses, physical and occupational therapists, social workers, psychologists, chaplains, nutritionists, radiologists, anesthesiologists, research scientists, and support staff. As an academic medical center, HSS is dedicated to defining the clinical issues that affect our patients, finding the reasons they exist, and ultimately identifying a cure.

Hospital for Special Surgery has an established, collaborative, and multidisciplinary center dedicated to the care of patients with lupus and Antiphospholipid Syndrome (APS). The center's goal is to give patients a better quality of life by providing outstanding care in a supportive environment. Expert physicians partner with patients to manage their disease and scientists work with the team to define disease risk factors, mediators, and therapies.

In addition to a comprehensive assessment by premier physicians, patients access committed and talented social workers, researchers, nurses, and patient educators. For more information, call 877.SLE.CURE.

## About Hospital for Special Surgery

Hospital for Special Surgery is the world's leading institution for orthopedics and rheumatology. The Hospital's well-deserved reputation has been sustained for more than 140 years – beginning with its founding as the first orthopedic hospital in the United States. Today, the Hospital provides specialty care for individuals of all ages and for all stages of musculoskeletal disease.

Again named the top-ranked hospital in its fields in the Northeast by U.S. News & World Report, HSS takes great pride in the care we provide patients, in the specialty training we deliver to residents and fellows, and in our research, which will influence the future of musculoskeletal care. As specialists in mobility, our goal is to alleviate patients' pain, restore function, and enhance their overall quality of life.

If you suffer from a bone, joint, or muscle problem, our Physician Referral Service will help you find the most appropriate physician from HSS's panel of highly respected orthopedic surgeons and rheumatologists. To find a doctor, please call 212.606.1555 or 800.854.0071, 8 am to 5 pm, Monday to Friday. To learn more, visit [www.hss.edu](http://www.hss.edu).

**LupusLine is offered by the Department of Social Work Programs at Hospital for Special Surgery.**

**Call LupusLine at 212.606.1952 or 866.375.1427 toll-free from outside New York City or email us at [LupusLine@hss.edu](mailto:LupusLine@hss.edu)**

**Also visit us at [www.hss.edu/LupusLine](http://www.hss.edu/LupusLine)**

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Hospital for Special Surgery is an affiliate of New York-Presbyterian Healthcare System and Weill Cornell Medical College.