

HOSPITAL  
FOR  
**SPECIAL  
SURGERY**



---

# Myositis Support Group Program

---

Creating a  
community  
for people  
with  
myositis,  
their  
families  
and  
friends



## ***What is myositis?***

- Myositis means inflammation of the muscles. This can have many causes.
  - The inflammatory myopathies are auto immune conditions. Autoimmune means the body is reacting against its own healthy cells and tissues.
  - There are four types of myositis: dermatomyositis, polymyositis, inclusion body myositis, and juvenile forms of myositis.
  - Although myositis can affect people of any age, most children who get the disease are between five and 15 years of age; most adults are between 30 and 60.
- 

## ***What are some signs and symptoms?***

These may include: muscle weakness and pain, general fatigue, difficulty climbing stairs, getting up from a seated position, reaching overhead, and possibly difficulty swallowing.

---

## ***How else can myositis affect you?***

Having myositis may affect your self-esteem, relationships, and career. Myositis can be challenging to diagnose. After diagnosis, many feel the frustration of dealing with a rare disease. Neither they, nor friends and family, have heard of the disease and are often left wondering where they can turn for help. It can be a lonely experience.

---

## *The Myositis Support Group: Who we are and how we can help*

- The Myositis Support Group at HSS is a free support and education program for people with myositis, their families and friends. The group meets monthly and is facilitated by a professional social worker.
- Ongoing since 1997, the Myositis Support Group is offered by the Department of Social Work Programs in collaboration with the Rheumatology Division.
- The mission of the Myositis Support Group is to enhance coping, reduce isolation, and increase understanding of polymyositis, dermatomyositis, and inclusion body myositis through creating a community for mutual support and education.
- Myositis may affect individuals not only physically, but also emotionally, socially, and financially. Group members share strategies to help cope with these changes through open discussions about relevant issues.
- Guided by our medical advisor and group feedback, health care specialists are invited to speak on topics of great interest to participants. Refreshments are provided.

---

A summary of each meeting is mailed to all group members, as part of a monthly newsletter. We recognize that not everyone can attend meetings. Selected summaries may be viewed on [www.hss.edu/myositisgroup](http://www.hss.edu/myositisgroup)

## ***What Myositis Support Group Members have shared:***

*“The support group is the only place where I can talk about the difficulties of living with myositis and know that everyone understands.”*

*“I go away from the meetings strengthened by hearing how the other members deal with their myositis challenges on an ongoing basis.”*

*“Thank goodness for the support of the group...”*

*“I enjoy reading the newsletter. Can't wait for the next issue....!”*

To learn more about the  
Myositis Support Group,  
please contact:  
Suzan Fischbein, LMSW,  
Group Coordinator  
Department of Social Work Programs  
212.774.7623  
E-mail: [fischbeins@hss.edu](mailto:fischbeins@hss.edu)