

HOSPITAL
FOR
**SPECIAL
SURGERY**

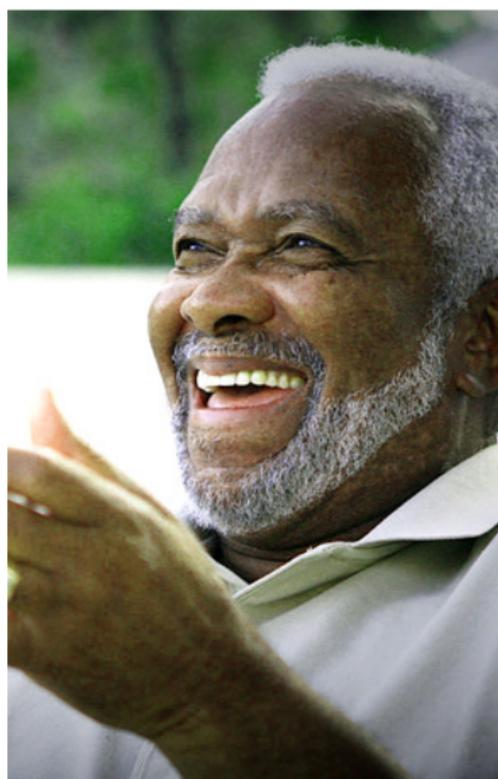
Myositis

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 autoimmune 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.

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:

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