Free UK Membership

I wish to join the Myositis UK.

Title Mr / Mrs / Miss / Ms / Dr / other......................
(Please delete as necessary)

Name ....

Address ....

....

....

....

Post code ....

Telephone ....

Email ....

I have (please tick):

☐ Polymyositis
☐ Dermatomyositis
☐ Inclusion Body Myositis
☐ Juvenile Dermatomyositis
(or parents of a child with JDM)

Or

☐ I am a friend or relative
☐ I am a medical worker/student
☐ Other (please state)

....

I enclose a donation of ....

(Please make cheques payable to Myositis UK)

☐ I am a UK taxpayer and wish Myositis UK to claim back the tax on this donation.

Teddy-Bo

Teddy-Bo has Juvenile Dermatomyositis and he has his story about living with Myositis published in a book “Teddy-Bo is Feeling Tired” which is suitable for children. Teddy-Bo is an advocate for Myositis UK and is busy improving Myositis awareness and raising the profile of the Charity. His antics can be followed on Facebook as he meets up with celebrities and goes on adventures: www.facebook.com/TeddyBoJDM

MYOSITIS UK

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Registered Charity No. 327791

Registered with FUNDRAISING REGULATOR

MYOSITIS UK

Supporting those affected by Myositis

Dermatomyositis • Inclusion Body Myositis
Polymyositis • Juvenile Dermatomyositis

A Brief History of Myositis UK

Myositis UK is a registered charity supporting people affected by Myositis. It was formed in 1985 as a contact group for parents and guardians of children and was known as the Dermatomyositis and Polymyositis Support Group. By 1987 it evolved to include adults with Dermatomyositis, Polymyositis and Inclusion Body Myositis.

What is Myositis?

The muscles and connective tissues of the body are affected and the main symptom is muscle weakness, which may be progressive and can be severely disabling. Myositis can be accompanied by pain, depression and a general feeling of misery. The definitive cause is unknown, but both genetic predisposition and environmental factors are thought to play a part. Dermatomyositis, Polymyositis and Juvenile Dermatomyositis are autoimmune diseases. This is where the immune system attacks the body's own tissues. In Myositis this is mainly the muscles leading to persistent and chronic inflammation. The cause of Inclusion Body Myositis is speculative and may involve both autoimmune and degenerative processes. Myositis can affect people of any age and there is no way to predict who will be affected by it. There is no cure and treatment for many involves steroids and other toxic drugs. IBM is very difficult to treat. Fortunately, some sufferers do get better but for the majority it is a case of coping and trying to live as near a normal life as possible.

Dermatomyositis

Dermatomyositis (DM) affects people of any age and is more common in women than men. DM can have a visible skin “heliotrope” rash typically over the eyelids but also other parts of the body including neck and shoulders. Muscle weakness is symmetric initially involving the proximal (shoulder and pelvic girdle) muscles. Problems swallowing (dysphagia) are found in a third of cases and pain can be experienced. In some patients of a DM-subtype there is an increased risk of certain cancers.

Polymyositis

Polymyositis (PM) affects people of any age and is more common in women than men. Muscle weakness is symmetric and onset can be over a few weeks but is typically longer (months). Weakness typically begins with the proximal muscles. Dysphagia and pain can be experienced and Interstitial Lung Disease (ILD) can be an associated complication.

Inclusion Body Myositis

Inclusion Body Myositis (IBM) occurs more frequently in men than women and is the most common acquired muscle disease in people over 50. Even so, it is still a rare condition. IBM is rarely found in people younger than 50 years old. IBM progresses slowly and weakness is gradual over months though typically years. Distal muscles (forearm, lower leg and foot) and proximal muscles are affected and muscle wastage proceeds. Varying degrees of dysphagia occur in about half of patients but pain is uncommon. Its progressive nature means most will require a walking aid or wheelchair within 15 years.

Juvenile Dermatomyositis

Juvenile Dermatomyositis (JDM) occurs in children and affects more girls than boys. JDM features include the “heliotrope” rash and, proximal muscles weakness. This weakness displays as difficulty climbing stairs, getting up from the floor and lifting the head from lying down. Sometimes swallowing difficulties, weak voice, irritability and pain are experienced. Most children do get better with immunosuppressants and there are no known associations with cancer or Interstitial lung disease.

Charity Aims

- To provide information to sufferers and their families.
- To help give them a better understanding of their illness.
- To relieve the isolation felt by an individual when a rare illness is diagnosed.
- To guide sufferers in the right direction for treatment.
- To raise awareness of the conditions.
- To raise funds to promote research.

Supported Through:

Magazines & Flyers

Fundraising

Annual Conference

Online Community Board

Regional ‘Meet-Up’ Meetings

The charity continues to directly fund and assist in research projects throughout the UK and the international Myositis research community.

The continuing success has been achieved from the background of supporting and promoting a very rare illness which the general public and even some of the medical profession know little about. As you can appreciate, the Trustees are proud and delighted in what the Charity has achieved since 1987.