PROCLAMATION

WHEREAS: Muscular Dystrophy Associations of America Inc. is a national voluntary health agency dedicated to the scientific conquest of muscular dystrophy andallied diseases of the neuromuscular system., and,

WHEREAS: MDAA'S program includes the support of free patient care clinics, physical therapy, orthopedic appliances, summer camps, and extensive scientific research both locally and throughout the country and,

WHEREAS: The health of this nation and community, so vital to its welfare and security is endangered by a disease whose cause and cure are unknown, and whose victims number many of our citizens; and these victims, the majority of whom are children, derive comfort from the Associations programs, and

WHEREAS: Traditionally during the month of October, MDAA conducts its annual appeal for financial assistance to support their activities:

NOW THEREFORE I, _____
DOhereby proclaim the month of October, 1970 as

MUSCULAR DYSTROPHY MONTH

In the _____,
and urge that all citizens of this community give full support to Muscular Dystrophy Associations of America, Inc.

IN WITNESS WHEREOF I have hereunto set my hand and caused our official seal to be affixed this _____ day of _____, 1970.

_____

BY

MUSCULAR DYSTROPHY ASSOCIATIONS of AMERICA, INC.

National Office—1790 Broadway, New York, N.Y. 10019 JU 6-0808

MRS. RICHARD M. NIXON
Honorary Chairman

HENRY M. WATTS, JR.
President

ADE T. MILHORAT, M.D.
Chairman, Medical Advisory Board

JERRY LEWIS
National Chairman

dedicated to the scientific conquest of neuromuscular diseases through basic and applied research into nerve, muscle and metabolism

PLEASE REPLY TO: 156 STATE STREET
BOSTON, MASSACHUSETTS 02109
Telephone: (617) 523-6000

Dear Sir:

Each year Muscular Dystrophy Associations of America, Inc. conducts its annual appeal during the month of October. We are now making preparations for this years drive.

Through the contributions we receive, MDAA is able to finance many local patient care services including free clinics at Boston University Hospital, New England Medical Center, summer camp in Haverhill Massachusetts, recreation, physical therapy, and orthopedic appliances. We also have six grants and four fellowships within our area totalling more than $95,000. In addition to research at Greater Boston institutions we contribute to the sponsorship of hundreds of scientific projects throughout the world.

To make the general public aware of our Association and activities we are asking that you issue a proclamation naming October as "Muscular Dystrophy month" in your community. A copy of the suggested text is enclosed. I have also enclosed some literature that may be of interest.

Thanks sincerely for your assistance.

Very truly yours,

Lawrence A. Jannello

Lawrence A. Jannello
District Director

MUSCULAR DYSTROPHY FACT SHEET

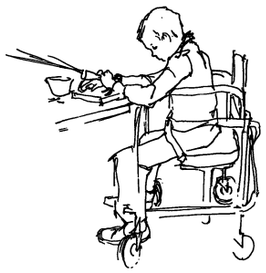
What is muscular dystrophy?

A general designation for a group of chronic diseases whose most prominent characteristic is the progressive degeneration of the skeletal or voluntary musculature.

The age of onset, the initial muscle groups affected, as well as the rate of progression, vary according to the type of dystrophy.

What are the early signs in children?

The disease starts so insidiously that it may go unnoticed for many months or even years. The child may have difficulty climbing stairs and rising from a sitting or lying position. There is a tendency to fall frequently. Later on the child may develop a waddling gait and his calf muscles may become enlarged.



What are the early signs in adults?

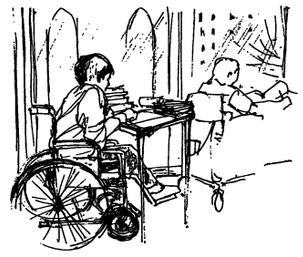
In adults the first signs are very slight. The patient has a "flat" smile and cannot whistle or drink through a straw. These signs may be noticeable, even in childhood, with no further significant symptoms for several years.

What is the rate of progression?

The rate of progression varies in the different types of dystrophy. As a rule, it can be said that the earlier clinical symptoms appear, the more rapid is the progression.

As the muscles deteriorate, the patient becomes weaker and more helpless. He loses the power of ambulation and becomes confined to a wheelchair and eventually to his bed. Finally he is unable to carry out the simplest activities of everyday life. Since he cannot combat intercurrent infections, death usually results from respiratory failure. In

some cases, however, it may be precipitated by involvement of the heart muscle.



Is dystrophy inherited?

Yes. For the most part, it is a hereditary condition. However, since dystrophy has one of the highest spontaneous mutation rates known in human genetics, a large number of victims are stricken without previous family history. The genetic pattern — and therefore the mechanism by which the disease is transmitted — varies in the different types of dystrophy.

What causes muscular dystrophy?

The initial error occurs in the hereditary materials. This error, in an as yet undetermined manner, gives rise to a metabolic defect. It is not known whether the primary lesion is in the muscles themselves or in some other part of the body. The liver or the hormonal system, each of which supply substances for various steps in the metabolic process, could be the site of origin.

Is there any treatment?

No. There is as yet no effective treatment for any of the dystrophies. Medical management is limited to relieving symptoms of the disease. Orthopedic devices may be prescribed at appropriate stages in progression.

How many victims are there in the United States?

The exact number is unknown. Because dystrophy is not a reportable disease, there is no official census of patients. Authoritative estimates have indicated that there are approximately 200,000 men, women, and children in the United States suffering from dystrophy. Because of the high prevalence of inaccurate and delayed diagnosis, and the

fact that the disease is not reportable, as well as the frequent desire for secrecy by patients, this figure is probably a conservative estimate. Approximately two-thirds of the known victims of dystrophy in the United States are children between the ages of three and thirteen.

In what area of the world is muscular dystrophy most prevalent?

Muscular dystrophy has been found in every part of the world in approximately similar percentages.

What are the major types of muscular dystrophy and their characteristics?

PSEUDOHYPERTROPHIC (Duchenne)

Hereditary pattern: recessive, sex-linked, transmitted through the female and affecting predominantly male offspring. Up to 50% of male children may develop the disease while 50% of female children may be carriers of the defective gene.

Clinical onset: between the ages of 2 and 6, occasionally soon after birth. Diagnosis can be established before appearance of clinical symptoms by means of serum enzyme tests, biopsy analysis and electromyographic readings.

Initial muscle involvement: proximal muscles of pelvic girdle, leading to postural defects (lordosis) a waddling gait and difficulty in ascending stairs and rising from floor. Muscles of shoulder girdle become involved in a few years.

Distinctive characteristic: apparent enlargement (pseudohypertrophy) of calf muscle, caused by greatly increased deposits of fat

which take the place of the wasting muscle tissue.

Progression: rapid, with no remission. In this, the most common and severe type of dystrophy, death usually occurs within 10 to 15 years of clinical onset. Since the advent of antibiotic therapy, however, some patients survive considerably longer.

FACIO-SCAPULO-HUMERAL (Landouzy-Dejerine)

Hereditary pattern: autosomal dominant, transmitted by either parent and affecting males and females equally, with 50% probability of incidence among offspring.

Clinical onset: usually in early adolescence, occasionally as late as mid-twenties. Initial muscle involvement: as indicated by the descriptive title, muscles of the face and shoulder girdle are the first to be affected, resulting in lack of facial mobility, difficulty in raising arms over head and characteristic forward slope of the shoulders.

Progression: very slow as a rule, with plateaus of significant duration. Of all the types of dystrophy, this may be the most benign. Average life span is rarely shortened though patients may suffer considerable disability.

LIMB-GIRDLE (including juvenile dystrophy of Erb)

Hereditary pattern: autosomal recessive. Unless both parents carry the defective gene, none of their children will manifest the disease. When they do, the chances are that 25% will be clinically affected, 50% will be normal but will carry the gene, and 25% will be completely free of the hereditary defect. Males and females are equally affected.

Clinical onset: anywhere from the first to the third decade of life.

Initial muscle involvement: usually the proximal muscles of the pelvic or shoulder girdle.

Progression: variable, sometimes quite slow and sometimes fairly rapid — though never as rapid as in the Duchenne type. Disability may be minimal and patients may reach advanced age.

MYOTONIC DYSTROPHY (Steinert's disease)

Hereditary pattern: autosomal dominant, transmitted by either parent and affecting males and females equally, with 50% probability of incidence among offspring. However, the complete syndrome may not be present in all family members.

Clinical onset: commonly in young adulthood though myotonic symptoms may appear as early as puberty.

Initial muscle involvement: unlike the other major types of dystrophy, where proximal muscle groups are the first to be involved, it is the distal extremities which are first affected. Stiffness in the limbs, especially after exposure to cold, is a common early symptom, as is difficulty in relaxing the handgrip.

Progression: disability becomes severe in 15-20 years from onset of symptoms; patients rarely live to normal age.

What are the less common types of muscular dystrophy?

CONGENITAL DYSTROPHY is already manifest at birth. Occasionally, the infant is born with multiple contractures, an indication that the pathological process is initiated at an early stage of fetal existence.

OPHTHALMOPLEGIC DYSTROPHY, an insidiously progressive disease, usually appears in adulthood. Extra-ocular muscles are the first involved and the pharyngeal muscles tend to become affected. The myopathic facies, and especially the ptosis of the eyelids, resemble those found in myasthenia gravis.

DISTAL DYSTROPHY has as its chief distinguishing characteristic the initial and primary involvement of the distal musculature, with the result that it is frequently confused with peroneal muscular atrophy, a neurogenic disease. It is the rarest sub-group of the dystrophies and is usually confined to single large families. In Sweden, however, its incidence is quite high and as yet unexplained.

Also sometimes included among the dystrophies are such congenital myopathies as central core disease, nemaline myopathy, mitochondrial disease, myotubular myopathy and idiopathic myopathy. These congenital conditions are characterized by familial incidence and diffuse, mainly proximal, symmetrical weakness. They are non-progressive in most instances.

Is there a test for detecting carriers of muscular dystrophy?

Yes, but only for the Duchenne or pseudohypertrophic type which is sex-linked. This test involves measurement of the level of the enzyme creatine phosphokinase (CPK) in the blood serum of unaffected female carriers.

Since this enzyme is confined almost exclusively to muscle, a leakage from this tissue is assumed to be responsible when higher than normal levels are observed in blood serum. The CPK level is clinically significant in confirming the Duchenne type of dystrophy; its determination is the most important single laboratory test. CPK testing of apparently unaffected younger siblings (usually male) of patients with Duchenne dystrophy enables physicians to detect preclinical cases.

The CPK test is 70% effective in detecting female carriers. Since CPK levels decrease with age, its accuracy is greater in young girls than in older women. In borderline cases, electromyography and/or biopsy may be used to confirm tentative findings.

Facilities for carrier testing are available at most MDAA clinics which also offer, when requested, expert counsel on family planning.

Where can I obtain further information?

Contact the MDAA office listed in your phone book for information on local services. Or you may wish to write directly to the national office at 1790 Broadway, New York, New York 10019.

What research is being done?

MDAA supports basic and applied studies in nerve, muscle and metabolism in the hope that these will lead to the complete scientific understanding of the biological processes that give rise to the muscular dystrophies.

Among the major areas of research study are genetics; protein synthesis and breakdown; muscle fiber types; muscle contraction and relaxation; neurotrophic and hormonal influences, etc.

MDAA annually spends more than $2,000,000 on its research program which includes grants to investigators both here and abroad and support for the MDAA-sponsored Institute for Muscle Disease in New York City.

MUSCULAR DYSTROPHY ASSOCIATIONS OF AMERICA

sponsors a broadly-conceived research program which embraces fundamental studies in the biochemistry and biophysics of normal muscle, as well as clinical studies of MD and a host of related disorders of the neuromuscular unit.

Many of these related disorders fall under the scope of MDAA's patient service program. The specific disease entities for which services may be rendered are:

The Muscular Dystrophies
Myositis and Other Primary Muscle Disorders
Amyotrophic Lateral Sclerosis
Peroneal Muscular Atrophy
Infantile Spinal Muscular Atrophy
Benign Congenital Hypotonia
Juvenile Spinal Muscular Atrophy
Spinal Muscular Atrophy of Adults

MUSCULAR DYSTROPHY ASSOCIATIONS OF AMERICA, INC.
1790 Broadway
New York, New York 10019

JERRY LEWIS, National Chairman

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MUSCULAR DYSTROPHY FACT SHEET

Muscular Dystrophy Associations of America.

C. C. 106

City of Cambridge

In City Council,

September 28, 1970.

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Alfred Vellucci
Mayor.

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9/28/70
Placed on File