

Providing information on Charcot-Marie-Tooth disease (or Peroneal Muscular Atrophy),  
the most common inherited neurological disease

## How to Start a CMT Support Group



*Ann Lee Beyer, the mother of a CMT patient, started a CMT support group in Upper Saddle River, New Jersey. They meet every other month at Englewood Hospital. The NFPMA recognizes the importance of local support groups in helping people learn about and cope with CMT. In this article Ann offers some practical tips for organizing a support group in your area.*

Starting a support group for those with Peroneal Muscular Atrophy is not difficult, but just requires some time, energy, persistence, and patience. Support groups can remove the feelings of isolation and frustration that people with rare diseases often experience. Here is a guide to forming a CMT support group in your area.

### A MEETING PLACE

You need a place to hold your support group meetings. Ideally this place should be barrier-free, have parking facilities for the handicapped, and be easy to find. Local hospitals usually

meet all of these criteria and often have meeting rooms available for community use. Usually all it takes is a phone call, followed up with a face to face meeting, and sometimes a letter stating the purpose of your group and requesting the use of a meeting room. If meeting in a local hospital is not possible, consider a church, shopping mall or even a local library. All usually have community meeting rooms.

### PEOPLE

Once you have a place to meet, you can start to look for others with CMT. This is not hard; they're out there. Be prepared to start small and don't get

caught up in numbers. It might take a while to get a group going, especially if you don't live in a heavily populated area. Remember that two or three people make a group. An example of a support group which started very small is Alcoholics Anonymous. It began a number of years ago when two people came together to deal with their alcoholism. This group has expanded into a very successful world-wide organization. Once you're established and meeting regularly, people will come.

But how do you reach people with CMT? There are many ways. First

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*Robert E. Lovelace, M.D., chairman of the NFPMA Medical Advisory Board, speaks to Linda Phillips Goldfarb (left) and Lauren Ugell at the October 22 New York support group meeting at New York University Medical Center. Dr. Lovelace is a professor of neurology at the Neurological Institute of Columbia University College of Physicians and Surgeons. Linda and Lauren coordinate the New York NFPMA support group.*

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### *Support groups offer a chance to learn...*

contact the NFPMA; they will send an initial mailing to people in your area free of charge. Then get in touch with local neurologists, orthopedists, physical and occupational therapists, and podiatrists. Tell them about your group and ask them to post notices of your meetings on their bulletin boards or to let their patients know that you exist. Here again the NFPMA can help by supplying you with area lists of neurologists, orthopedists, physiatrists, and podiatrists at cost. You can also contact your state Muscular Dystrophy Association or local MDA clinic. Ask them to advertise your support group on their clinic bulletin boards. Also request copies of their booklet "MDA Services" which lists what is available free for those with CMT and provides the location of MDA clinics throughout the United States. This book is a valuable resource for people with CMT who are unaware of what the MDA has to offer. Sometimes the MDA will even send out announcements of your meetings to their patients. Also the state or local office for the handicapped may have a newsletter and will publicize your newly-formed group.

Many newspapers have columns devoted to community and area activities. They are usually very cooperative and will print notices of your group's meetings. Contact your area papers and ask how to place announcements in these columns.

Don't forget radio stations. They often have their own "community bulletin boards." Find out the procedure and get your meeting notice on the air.

You don't have to do everything at once or do it all yourself. It takes time to get a support group going. Ask for volunteers and assign specific jobs to members. When sending out announcements, remember that many people with CMT have never known anyone else with the disease and are delighted that someone has formed a support group. They are often very willing to drive a few hours to attend meetings so be sure to include everyone within a 150 mile radius.

There is one more place where you might get help. Many states have agencies whose sole function is to assist people in starting self-help groups. They are listed in the phone book under Community Services. Look for self help clearing houses, mutual help centers, and services for the handicapped or disabled. Frequently they have toll-free telephone numbers. They will not only list your group, but will also give you very practical advice on getting started.

#### **WHEN TO MEET**

Then there is the question of when to meet. You are not going to find a time or a place that suits everyone, but try to settle on something that suits the majority. Keep in mind that the group does have some special needs. Meeting at night can present problems. Places are easier to find in daylight and people with CMT often have trouble maneuvering outdoors.

When it's dark and the terrain is unfamiliar, there is a very real danger of falling. Also many people with handicaps are reluctant to come out to

evening meetings because they don't feel safe. Saturday mornings work very well and one group finds Sunday afternoons convenient. After you get your place, day, and time settled, try to be consistent (e.g. - the third Saturday of every other month at 10 AM). Of course, you will have to change things for holidays or to accommodate a guest speaker, but try not to change dates or times too often.

How often should you hold meetings and how long should they last? Once every two or three months seems to work very well. Your group might even decide that it wants to meet more frequently. However, it's a good idea not to let more than three months elapse between meetings or you will



### *...and to socialize.*

lose continuity and people will lose interest. Discuss this at the first meeting and remember you can always change things if they don't suit people's needs. One group started out meeting every three months at two hour meetings. Then members decided that wasn't often enough or long enough. They now meet every other month for three hours.

#### **EXPENSES**

Once your group starts meeting, there will be expenses- especially for meeting announcements. Paper, photocopying, envelopes, and postage

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## W.H.O. Conference Focuses on Peripheral Neuropathies

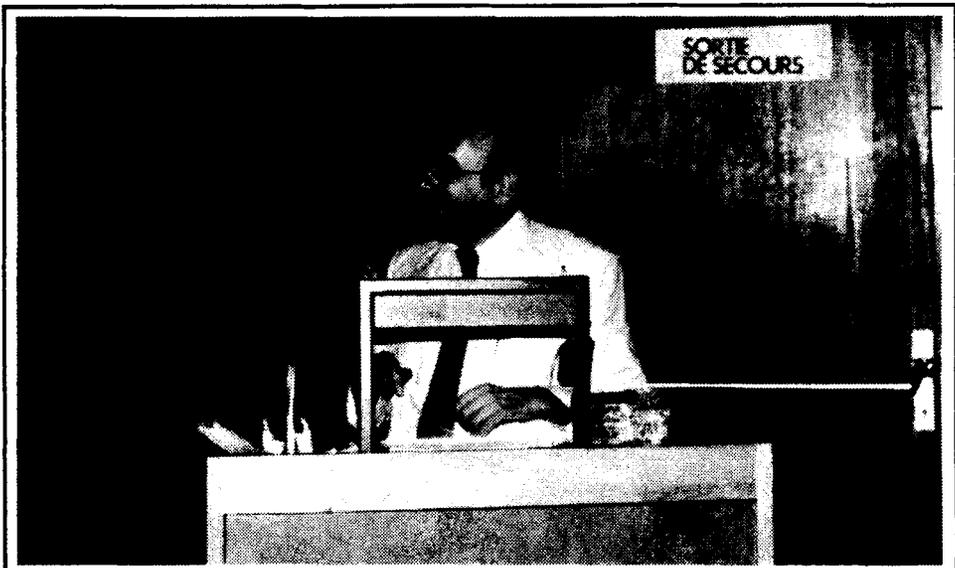
Some patients having Charcot-Marie-Tooth disease are relatively informed about their disorder. Others, sadly, have no idea why they are developing a progressive walking disability. And then there are those who mistakenly believe that their problem is "something like the muscular dystrophies or multiple sclerosis."

The muscular dystrophies are genetic disorders which directly affect muscle tissues. Multiple sclerosis, which is not a genetic disease, primarily strikes the brain and spinal cord.

Distinctly different, CMT is a true peripheral neuropathy, striking those **nerve cells** which connect the spinal cord to muscles in the legs and arms. Muscle wasting then occurs due to this nerve damage. This commonly leads to the progressive misapposition of foot bones which results in hammer-toes and more serious orthopedic problems.

CMT patients may be surprised to learn that there are many other diseases which specifically affect the peripheral motor and sensory nerves. Among those discussed at a WHO symposium in Geneva, Switzerland were neuropathies caused by: diabetes, aging, alcohol, trauma, vitamin deficiencies, and drugs. Patients suffering from these disorders experience many of the same disability problems.

The 1987 International Symposium on Peripheral Neuropathies was organized by Drs. Liana Bolis and Jean-Philippe Assal on behalf of the World Health Organization. Held August 31-September 2, this meeting was an outstanding opportunity for clinical and research authorities to discuss their most recent findings. NFPMA Director of Scientific Research, Dr. Howard Shapiro, was invited to participate in this important conference. This meeting stressed how much these disorders have in common and gave



*In his talk at the W.H.O. conference, Dr. Howard K. Shapiro of the NFPMA presented an overview of biochemical research studies on CMT during the past decade.*

new insights into current and future research opportunities.

**But perhaps most important, research on these allied disorders may pay off in improved clinical management of CMT. Successful research on one disease which damages peripheral nerves may well lead to improved care for patients experiencing similar problems.**

Here is a synopsis of the conference topics presented at the WHO symposium followed by some important recommendations for the CMT patient.

### Diabetic Neuropathy

Two general types of peripheral nerves (those outside the brain and spinal column) may be affected as a result of diabetes mellitus: the nerves to the extremities (sensory and motor nerves which regulate voluntary muscle movement) and the peripheral autonomic nerves which regulate a variety of "automatic" body functions.

As noted by Dr. A. Pernet, diabetic peripheral neuropathy of the limbs "is characterized by diminution or loss of pain and thermal sensation, diminution of loss of deep and superficial sensation, and partial or complete muscle denervation... Loss of deep sensation may also result in the progressive destruction and remodeling of the

bones and joints of the foot, known as Charcot's joints; this severe condition is due to repeated micro-traumatism, causing gross deformation of the foot." Sometimes this condition is accompanied by a spontaneous burning sensation known as paresthesia and muscle cramps in the legs which tend to predominate at night.

Dr. Pernet explained that diabetic peripheral autonomic neuropathy leads to dysfunction of several organ systems. Damage to various autonomic nerves may lead to poor regulation of heart beat and blood pressure, dysfunction of the stomach and small intestine, partial loss of bladder control, sexual impotence in males, and decreased function of sweat glands, leading to skin dryness in the extremities. Although some damage to autonomic nerves may be present in CMT patients, this damage is typically far less than that seen in association with diabetes.

### Peripheral Neuropathy of Aging

Dr. P.K. Thomas, keynote speaker at the WHO conference, noted that "normal individuals develop mild signs of peripheral neuropathy with aging... This is manifest by reduction of, or loss of ankle jerk (reflex), impaired vibration sense and sometimes impairment of other sensory modalities... I think there is clear evidence of loss of

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## W.H.O. (Continued from p.3)

peripheral nerve function in later life." This nerve loss begins at about 50 years of age. "It begins distally in the lower limbs," said Dr. Thomas, "and then subsequently involves the upper limbs distally and then spreads proximally (towards the body)."

### Alcoholic Neuropathy

Dr. M. Pollock noted that "alcohol-induced neuropathy is an increasing world-wide problem." besides liver and central nervous system damage, peripheral neuropathy is a common clinical result of alcoholism. The process by which nerves are damaged by chronic alcohol consumption is complex and not completely understood. "Deficiency or poor utilization of key nutrients, alcohol toxicity and genetic vulnerability are all important in the genesis of alcohol-induced neuropathy," Dr. Pollock commented.

### Traumatic Neuropathies

These may be caused by physical damage such as an accident leading to the crushing of a nerve fiber. Alternatively, traumatic neuropathies may be caused by a more subtle problem known as nerve entrapment. The term "entrapment" refers to the pinching or constriction of a nerve fiber by adjacent body tissues. Scar tissue, abnormal bone growth, cancerous tissues, local tissue swelling, internal bleeding or abnormal stretching of a nerve fiber are among the causes of nerve entrapment disorders. Entrapment neuropathies may affect both sides of the body, or only one.

Once a nerve fiber has been physically damaged, the segment of nerve located further out on the limb begins to degenerate. This, in turn, leads to loss of sensory and motor nerve function and secondary atrophy of muscles which have lost their normal nerve input. Some traumatic neuropathies may be treated by appropriate



*Dr. Nicole Baumann (left) of the Hôpital de la Salpêtrière, Paris is using antibodies specific for various peripheral nerve elements to study neuro-degenerative diseases. Prof. Mongi Ben Hamida (center) of the Institut National de Neurologie, La Rabta, Tunisia has done extensive clinical studies on North African CMT patients. Dr. Georges T. Serratrice (right), President of the University of Marseille, has also done extensive clinical studies on CMT and was the primary organizer of the first international conference on CMT disorders (1976). At the W.H.O. conference he co-chaired a lecture session on the physiology and biochemistry of peripheral neuropathies.*

surgical intervention, such as removal of impinging scar tissue. In some cases where peripheral nerves have been seriously crushed, treatment may involve surgical grafting of segments of sural nerve up to six inches long.

### Drug-induced Neuropathies

Sometimes a peripheral neuropathy can be induced unintentionally by a drug used for treatment of some other medical problem. This kind of problem is most common in later life. Dr. Thomas noted that drugs given for malignancy, cardiovascular disorders, respiratory disorders, and urinary tract infections may have neuropathic effects.

two examples of such drugs were considered in detail at the Geneva conference, the widely used anti-cancer drugs vincristine and cisplatin. Dr. B. Leyland-Jones observed that "neurotoxicity is usually the dose-

limiting side effect of vincristine, and is a significant side effect of cisplatin, especially at higher doses."

Dr. Leyland-Jones noted that vincristine may lead to axonal degeneration in the extremities, with depression of the Achilles tendon reflex as the earliest pathologic sign. He observed that "at conventional doses... cisplatin causes ototoxicity (hearing loss) and peripheral neuropathy in up to 30% of cases. However, in higher dose studies... neurotoxicity becomes major, with distal extremity numbness and tingling seen in over 90% and gait/ataxia problems in 37% of patients."

### Vitamin Deficiency Neuropathies

Two vitamin deficiencies are related directly to peripheral neuropathies. Dr. I. Chanarin addressed the issue of vitamin B<sub>12</sub> deficiency. He noted that

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peripheral neuropathy is present in up to 30% of patients with this dietary problem. Vitamin B<sub>12</sub> serves a supporting role for two metabolic pathways in the body. Although these metabolic pathways are known in some detail, much remains to be learned about how vitamin B<sub>12</sub> deficiency damages peripheral nerves. Some evidence available from animal studies suggests that B<sub>12</sub> deficiency leads to neuropathy by impairing the metabolism of methionine, an essential amino acid.

Vitamin E is also important for normal neurologic function. Dr. D. Muller pointed out that a chronic deficiency of this vitamin leads to a progressive neurological syndrome featuring loss of voluntary muscle control of the limbs, loss of nerve reflexes, loss of sensation, muscle weakness and damage to eye muscles. Although the underlying reason why vitamin E helps maintain nerve cells remains a mystery, studies are now in progress to further characterize the detrimental effects resulting from its limited availability.

### **Other Causes**

Many different disease mechanisms can attack the peripheral nerve cells:

chronic renal (kidney) failure  
disorders of immunologic functions  
viral neuropathies  
bacterial neuropathies  
parasitic neuropathies

Many viral, bacterial and parasitic neuropathies are common to developing countries. Notable among the viral-induced neuropathies is that of the HTLV-III virus, also known as the human immunodeficiency virus (HIV). This is the infamous AIDS virus. At the Geneva conference Dr. C. Gibbs of the National Institutes of Health (USA) mentioned that at least 20% of patients with AIDS have symptoms of peripheral neuropathy.

## **Towards Understanding the Causes of Peripheral Neuropathies**

During the past 10 years the focus of studies on peripheral neuropathies has shifted from clinical diagnostic work, such as nerve conduction and EMG studies, to biochemical investigations and drug studies based on an increased understanding of nerve function. From this international effort certain common themes are now emerging. For example:

\*Many neurologic disorders are associated with immunologic dysfunction. In some cases antibodies are made which are specific for targets in nerve tissue. Dysfunctions of the immune system may be responsible for a variety of slow, chronic disease states.

\*Several peripheral neuropathies, including CMT, show evidence of disruption of axoplasmic transport. This is the special transport

system which channels nutrients and cellular components down the long axon fiber of each nerve cell.

\*The metabolic origins of some peripheral neuropathies are being defined in greater detail. This is the case for alcoholic polyneuropathy, vitamin B<sub>12</sub> deficiency neuropathy and diabetic peripheral neuropathy.

\*The drug Cronassial (Fidia Pharmaceutical Corp.), a form of complex fat found normally in nerve tissue, has been shown to encourage peripheral nerve growth. Work done so far on CMT has not shown that Cronassial helps control this disorder. Yet further CMT studies with Cronassial may show that a different dosage or treatment schedule of this drug to have some positive effect. Several studies discussed at the Geneva W.H.O. conference documented that Cronassial is of some benefit in experimental treatment of diabetic peripheral neuropathy and in limiting the peripheral neurotoxic side effects of the anticancer drug vincristine.

### **Implications of the Conference Proceedings for CMT Patients**

\*CMT patients should seek the attention of medical specialists truly familiar with their disability.

\*Although not a treatment for CMT, adequate daily consumption of vitamins B<sub>12</sub> and E should be insured. These need only be taken at conventional doses.

\*Excess consumption of alcohol may accentuate the effects of CMT. There is no specific information available now to document that small amounts of alcoholic beverages make CMT worse. But as a good precaution, the less consumed, the better.

\*Some prescription drugs may have peripheral neurotoxic side effects. CMT patients under drug treatment for other disorders who notice a worsening of their CMT symptoms should bring this matter to the attention of their physicians promptly.

\*Improved doctor/patient relationships is a concept of importance. Dr. Assal commented, "Success of therapy in long-standing treatment strongly depends on the quality of patient education, i.e., how the doctor explains diagnosis and how he/she instructs the patient in the active management of his/her treatment."

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## W.H.O.

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### Perspectives for the Future

The proceedings of the Geneva W.H.O. conference underscored that peripheral neuropathies are a common public health problem. Who may develop a chronic peripheral neuropathy? The answer is anyone. For CMT patients the basis of the problem is genetic. Yet diabetic neuropathy, peripheral nerve damage associated with aging, traumatic neuropathy, and neuropathy induced as a side effect of drug treatment for other medical disorders are all similar clinical disabilities which may affect anyone's life.

As alcohol consumption is a part of virtually all cultures, alcoholic polyneuropathy is also a part of this picture. Few of these peripheral nerve diseases can now be treated with great success. Yet we are becoming increasingly aware that there are physiological, as well as clinical similarities among many of these problems. Underlying each of these clinical disorders there must be one or more specific reasons why peripheral nerve cells have been singled out for damage. As our understanding of these basic pathologic mechanisms increases, peripheral neuropathy will become less of a problem for CMT families and for the general public as well.

## SUPPORT GROUPS

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cost money! Many groups pass around a basket to cover expenses. You can also charge dues and request that people pay a certain amount to attend each meeting. Be flexible about this. Not everyone can afford to donate and often some people put in more than their fair share so it balances out.

### SPEAKERS

Some groups try to have speakers at every meeting, others, less often. Because information about CMT has been so unavailable, people want to know more about their disease and how to deal with it. They also need meetings where they can talk about various aspects of living with a progressive illness and how to cope with it. At your first meeting, and periodically, ask people for suggestions of topics they would like to have covered. When looking for speakers, consider your local physicians, especially neurologists and orthopedists. Some other suggestions are physical and occupational therapists, physiatrists (physicians who are trained in rehabilitative medicine), podiatrists, or genetic counselors. Just be sure that they are familiar with CMT. You can also consider professionals such as psychologists or counselors to talk about the emotional side of dealing with Charcot-Marie-Tooth Disease.

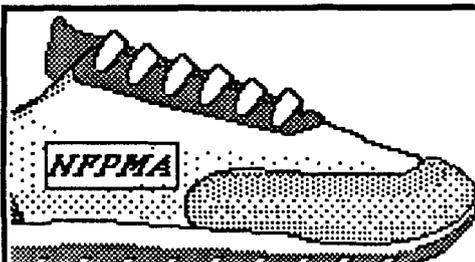
### REFRESHMENTS

Finally there is the question of refreshments. This is entirely a group choice, but having coffee or tea often serves as an ice breaker and gives people an opportunity to socialize. You can allow time for it at the beginning or end of meetings. Ask people to bring snacks, but try to keep them simple. Cookies and fruit are fine.

### RELAX

Don't get discouraged if things aren't moving as fast as you would like. It often takes three to five months to get a group going and a few more months before people coming to the meetings develop a sense of belonging and start to become actively involved.

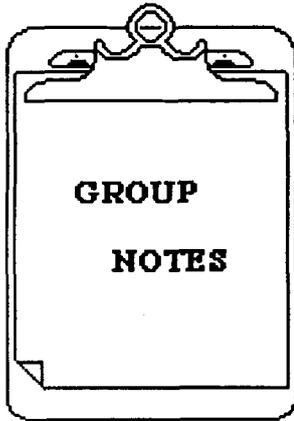
*There may already be an NFPMA support group functioning in your area. For more information see "Group Notes" on next page.*



Every CMT patient has his or her own foot story. For some patients buying shoes is only a minor problem, but for others it can be quite a dilemma. CMT patients would do well to visit a pedorthist, a person trained to provide prescription footwear and related devices to patients referred by the medical profession. For information about pedorthists in your area, contact the **NFPMA Report**.

Special thanks to Bayard Brown, Certified Pedorthist, for his interest and financial support. For special shoes in the Columbus, Ohio area, contact:

Brown Shoes, Inc.  
2108 Tremont Center  
Columbus, Ohio 43221  
(614) 486-4477



*A primary goal of the NFPMA is to become a truly successful advocate for those with CMT. Its message must reach the patients, their families, and the medical and research communities. Patient family support groups, a growing and vital part of the NFPMA program, inform and support anyone who must deal with this often overlooked disease.*

*There are already several NFPMA support groups. These chapters are spirited and growing stronger, but more groups are needed in other parts of the United States. The NFPMA will gladly help you to set up a chapter in your area. For information contact the NFPMA by mail or call (215) 664-6010.*

*Perhaps there is a chapter meeting near you. You are cordially invited to join these groups in their upcoming events.*

### New York

- Meetings:** held monthly
- Next:** Saturday, April 9, 1988 ; 1-4 PM
- Where:** Rusk Institute of Rehabilitation Medicine  
Room RR 610 (6th floor Research Wing)  
400 E. 34th St., New York, NY 10016
- Speaker:** Dr. Melvin Jahss, orthopedic surgeon  
specializing in triple arthrodesis and  
tendon transfer, The Orthopedic Institute, NYC
- Contact:** Linda Phillips Goldfarb (212) 481-3419
- Coming Up:** May 7, June 4  
New Jersey
- Meetings:** every other month
- Contact :** Ann Beyer (201) 391-4624
- Coming Up:** May 21, June 4, Aug 6

### Delaware Valley Newly Formed Group

On Saturday, February 6, 1988, Dr. Robert Krebb, a physiatrist (rehabilitation specialist), addressed a group of CMT patients in Drexel Hill, PA. This meeting was arranged by the NFPMA staff to help start a Delaware Valley support group. At that time a committee was formed and Rex Morgan, Jr., of Horsham, PA agreed to serve as acting chairman. Best of luck to this new chapter!

**Contact:** Rex Morgan, Jr. (215) 672-4169

### Greater Atlanta

On Saturday, April 9, 1988, NFPMA staff member Karol Hitt will conduct an organizational meeting for a support group in the Greater Atlanta area. Karol will be at the Scottish Rite Children's Hospital. Also present will be Dr. Donal Costigan, a neurologist who will speak about the etiology of CMT and Dr. Sushma Chandan, a physiatrist who will discuss physical therapy options. This program will offer an excellent opportunity to learn more about CMT and the NFPMA. There is no fee and all are invited to attend. The NFPMA thanks the Scottish Rite Children's Hospital for donating its conference room for this meeting.

**Meeting:** Saturday, April 9, 1988 ; 1-4 PM

**Where:** Scottish Rite Children's Hospital  
1001 Johnson Ferry Road  
Atlanta, Georgia 30363

**Directions:** Eastbound on I 285, take Glenridge  
Exit 18 to Johnson Ferry Road.

Westbound on I 285, take Exit 20.  
Turn left off ramp and right at 3rd light  
onto Johnson Ferry Road.

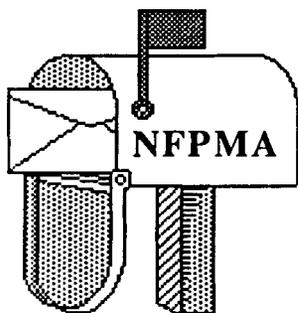
#### **Overnight Accommodations:**

Courtyard Marriot : 1- (800) - 321-2211  
Double Tree Hotel : 1- (800) - 528-0444

### Cleveland, Ohio

Mrs. Norma Markowitz is beginning a support group for patients and families in the Cleveland, Ohio area. Norma will be happy to hear from all potential members.

**Contact:** Mrs. Norma Markowitz (216) 247-8785



## NFPMA Mailbox

... I am appalled at the lack of knowledge in medicine about CMT. Recently my husband was hospitalized twice for major surgery. During each stay he was in contact with at least eight doctors. Not one knew what CMT was. It took twenty years for my husband to be diagnosed. Then he went to two highly recommended foot surgeons and neither one knew what CMT was. We walked out!

For the past year I have been reading everything I can find on CMT. ... Thank you for the **NFPMA Report**. It was the only thing I had to help me in dealing with this diagnosis. ...

S.R.M.  
Blairsville, GA

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I will never benefit from any of your research as I am 77 years old and handicapped since 1962. I do hope the future will be much brighter for the young ones.

It's about time something is being done. Keep up the good work.

L.M.I.  
E. Syracuse, NY

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... We rented the NFPMA video on therapy and CMT. It was wonderfully informative. It's just so amazing that we have a resource now with the NFPMA.

Our daughter turned six in December

and has had a year of wonderful growth. She will have had her AFO's (ankle-foot orthosis, one type of ankle brace) a year in February and what a difference, a brand new little girl. Much more confident and happy, after always being last. She now always wants to be first and usually succeeds.

D.J.  
Newport, RI

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... I'm 72 years old and do active physical therapy. Among the activities, I walk a treadmill at 1.7 mph for 15 minutes.

... When I am in Florida I go for aquasize exercise at an indoor pool three days a week ... Among the exercises, I jog in the water, hop across the pool, ... stand on my heels, and stand on my toes. I can do none of these exercises normally. The exercise period is 30-45 minutes. There are many more excellent exercises for the hands and the rest of the body. I thought you'd like to know.

F.L.  
New York, NY

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I recently received a packet of information from your organization including the 1987 newsletters. I must say I'm very excited to find out about the NFPMA! I've been going to clinics since 1980 and have basically been frustrated with their lack of understanding of CMT.

I am very interested in attending an NFPMA regional conference as described in the winter **NFPMA Report**. ... I would be interested in helping to organize a conference in the Southwest...

J.K.C.  
Mesa, AZ

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In October, 1987 in the **Asbury Park Press**, there was an article titled "Rare Nerve Disorder a Tough Nut to Crack." For some reason it caught my attention, and I am glad it did.

My father has suffered from CMT disease all his life, but did not find out until 1972. As my parents were planning to move to Florida, they had their house for sale and a doctor came to look at it. He saw my father walk, and started asking him some questions regarding a disease. My father kind of laughed it off, as he had always considered himself very healthy. He owned a trucking business, and not only drove, but packed and unpacked his own trailers in ice, snow, rain, etc. Eventually the doctor talked my father into going to the VA hospital for tests. Needless to say, my father was diagnosed as having CMT. He also found out that he could have genetically passed this down to his children.

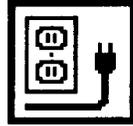
My sister had surgery when she was 11 years old to turn the bones of her legs and feet. She had had a terrible time walking and keeping her balance. The operations were considered successful although she is still physically limited.

I, too, have been approached within the last four or five years regarding my high arches, and trouble with my legs hurting and feet so tender and painful that there are times I could not walk.

... I am passing this article along to my father and sister, and thank you for finally bringing this little known disease to the public's interest.

L.B.  
Cedar Run, NJ





## GADGET INFO

**Ways and Means**, a company located in Romulus, Michigan, has gathered over one thousand items that represent the company's "capability concept"- to offer products that maximize people's capabilities by decreasing pain, increasing mobility and independence and in some cases, make the impossible activity possible, particularly for the elderly and disabled.

A 136 page catalog features products with helpful explanations and photographs. Categories include food preparation, health and fitness, housekeeping, gardening, hardware, and various reaching and carrying devices. There are over 300 products to extend reach, improve grip, and increase mobility (including jar openers, tap turners, special cutlery, and several styles of pen holders). This fascinating catalog is worth a look and the \$3.50 purchase price can be credited toward an initial mail order.

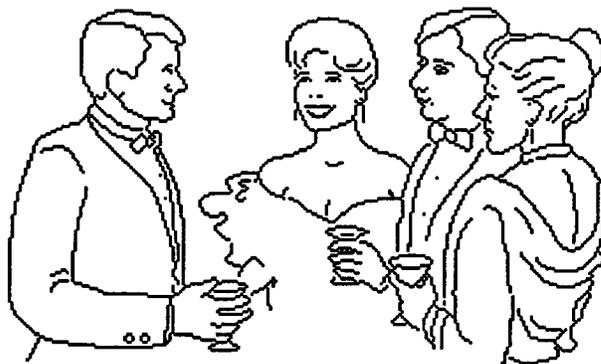
To obtain the Capability Collection Catalog contact: Ways and Means, 28001 Citrin Drive, Romulus, MI, 48174; outside MI 1- (800)-654-2345 ; MI residents 1-(800)-221-4413

**Maneuverability** is a Brooklyn-based retail store specializing in functional and easy to use gadgets, fixtures, and appliances. Due to its impressive range of items the store has gained in popularity and has recently published a catalog. The catalog includes such state-of-the-art inventions as an electronic fishing rod, a variable height sink, and a radar-controlled faucet that turns the water on when you place your hands under it and off when you take them away. There are also many less technical items including magnetic playing cards, electric vegetable peeler and cutter, and an extended brush.

To obtain a catalog contact Maneuverability, 4015 Avenue U, Brooklyn, NY 11234; 1-(800)-522-1213

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### *Puttin' on the Ritz*

The NFPMA is sponsoring an art show debut for Zdzislaw Lindner, an exceptionally talented young painter now gaining recognition in the New York metropolitan area. Proceeds from this event will help support the NFPMA program.

This will be a cocktail party with open champagne bar, hors d'oeuvres, music, and door prizes. Mr. Lindner's work will be on display. A good time will be had by all !

**Date:** Thursday, May 19

**Time:** 8:00-10:00 PM

**Place:** The Tunnel  
220 Twelfth Avenue  
New York, NY

**Tickets:** \$35. in advance;  
\$45. at the door

**Contact:** Kathy Jones  
430 East 86th Street  
New York, NY 10028  
(212) 628-7234

**NFPMA   Dedicated   Contributions**

**In Memory Of**

Dora Zack  
Donald Crawford  
Mr. & Mrs. Ben Levey  
Billy Clopper  
Maria Quenqua  
Rose Winchester

**Contributor**

Marilyn Prashker  
Karol Hitt  
Marty & Norma Markowitz  
Dr. Lorene Logsdon  
Dr. Lorene Logsdon  
Hilda Kaprow

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Irving Finkelman  
Sophia L. Bradwick  
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Irving Finkelman  
Linda Phillips Goldfarb  
Howard K. Shapiro, Ph.D.  
Henry & Priscilla Eldredge  
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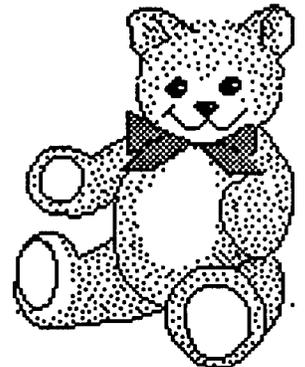
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**Pediatric Study**

Dr. Robert Lovelace, chairman of the NFPMA Medical Advisory Board and professor of neurology at the Neurological Institute of Columbia University College of Physicians and Surgeons, is seeking children of CMT parents to study. Dr. Lovelace would like to follow the development of these children on a regular basis to look for early clinical signs of CMT. The results of this study could provide pediatricians with additional knowledge of CMT for early diagnosis and treatment of these "children at risk." To volunteer for this study, write to :

Dr. Robert E. Lovelace, M.D.  
Box 157 Neurological Institute  
710 West 168 Street  
New York, NY 10032



## Get In Touch

You can keep up-to-date on our activities and help spread the message of the NFPMA. If this issue was not mailed to you, we invite you to join our mailing list by filling out the form below. If you are already on our list, kindly send the name of anyone else interested in the **NFPMA Report**. You can also use this form for VCR tape rentals. Mail this form to:

**NFPMA REPORT** University City Science Center  
3624 Market Street  
Philadelphia, PA 19104

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Telephone: ( \_\_\_\_\_ ) \_\_\_\_\_

*Tell us about yourself (optional):*

- |   |   |
|---|---|
| <input type="checkbox"/> CMT patient          | <input type="checkbox"/> Interested supporter |
| <input type="checkbox"/> Medical professional | <input type="checkbox"/> CMT family member    |
| <input type="checkbox"/> Research scientist   | Other _____                                   |

### ATTENTION FEDERAL EMPLOYEES!

You can support the work of the NFPMA by checking our name on your Federal Combined Appeal Program.

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## NFPMA REMEMBRANCES

Your gift to the NFPMA can honor a living person or the memory of a friend or loved one. Acknowledgement cards sent *in honor of* or *in memory of* will be mailed by the NFPMA on your behalf. These donations are a wonderful way to keep someone's memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank you gifts. You can participate in the memorial and honorary gift program of the NFPMA by completing the form below and mailing it with your check to **NFPMA, University City Science Center, 3624 Market Street, Philadelphia, PA 19104**.

Name: \_\_\_\_\_

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Phone Number: ( \_\_\_\_\_ ) \_\_\_\_\_

### Memorial Gift

In memory of: (name of deceased)  
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Send acknowledgement to:

Name: \_\_\_\_\_

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\_\_\_\_\_

## VCR Tape Rental

The NFPMA will rent four lectures which were taped at patient conferences sponsored by the Foundation. The tapes are for play on a VHS VCR. Beta tapes are not available. The speakers are authorities in their fields and lecture topics include: Neurology, Physical Therapy, CMT Genetics, and Orthopedic Surgery. Single lecture tapes (1 hour, 15 min.) rent for \$10, and the double lecture tapes (2½ hrs.) rent for \$15. The rental fee includes prepaid return postage. To order a tape, fill out our *Keep in Touch* form and send it with a check or money order to the NFPMA, University City Science Center, 3624 Market Street, Philadelphia, PA 19104.

Please check the appropriate boxes:

- |   |   |
|---|---|
| <input type="checkbox"/> Mailing list request                                   |   |
| <input type="checkbox"/> Physical Therapy—\$10                                  | <input type="checkbox"/> CMT Neurology—\$10 |
| <input type="checkbox"/> Orthopedic Surgery—\$10                                | <input type="checkbox"/> CMT Genetics—\$10  |
| <input type="checkbox"/> Physical Therapy/Orthopedic Surgery (on one tape)—\$15 |   |
| <input type="checkbox"/> Neurology/Genetics (on one tape)—\$15                  |   |

### Honorary Gift

In honor of: (person(s) you wish to honor)  
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Name: \_\_\_\_\_

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Occasion:

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Check if you would like the amount of your gift revealed.

## ***Peroneal Muscular Atrophy (CMT) ...***

The ***NFPMA Report*** is published by the National Foundation for Peroneal Muscular Atrophy, a tax exempt not-for-profit corporation incorporated in the Commonwealth of Pennsylvania (established 1983).

Editors of the ***NFPMA Report*** are Mary Cawley Tracy and Lydia Brennan. Letters and inquiries may be addressed to:

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(215) 664-6010

is the most common inherited neurological disease, affecting approximately 125,000 Americans.

is also known by its historical name, Charcot-Marie-Tooth disease, for the three doctors who first reported on it in 1886.

is slowly progressive, causing deterioration of peripheral nerves which control sensory information and muscle function of lower legs and forearm voluntary muscles.

causes degeneration of peroneal muscles (located on the front of the leg below the knee) subsequent atrophy of additional lower leg and forearm muscle groups.

causes foot-drop walking gait, foot bone abnormalities: high arches and hammer toes; problems with hand function; occasional lower leg and forearm muscle cramping; loss of some normal reflexes; occasional partial sight and/or hearing loss problems; and in more severe cases may cause scoliosis.

does not affect normal life expectancy.

has no effective treatment, although physical therapy and moderate physical activity are beneficial.

is present in the world-wide population, with no apparent link to any one ethnic group.

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## ***THE NFPMA REPORT***

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*information on Charcot-Marie-Tooth disease from the*

**National Foundation for Peroneal Muscular Atrophy**

University City Science Center  
3624 Market Street  
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TO:

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