THIS ISSUE IS FUNDED IN PART BY A CONTRIBUTION FROM HARRIS BOCK, ESQ. IN HONOR OF RUTH AND IRVING FINKELMAN

National Foundation for Peroneal Muscular Atrophy

THE NFPMA REPORT

Fall 1988 Issue Vol. 2 No. 3

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

INTERVIEW

CMT CHILDREN: Advice and Information

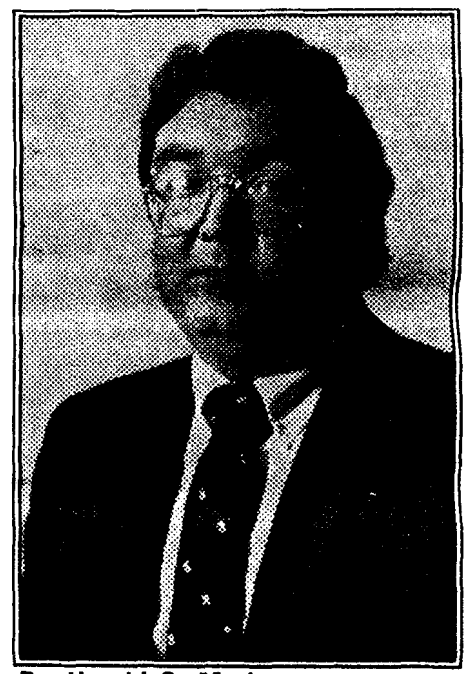
A leading pediatric neurologist discusses the issues.

Dr. Harold G. Marks was recently interviewed at the Alfred I. duPont Institute by Dr. Howard K. Shapiro of the NFPMA. Dr. Marks, who is Director of Neurology at the Institute, has substantial experience diagnosing and treating the CMT child. The Alfred I. duPont Institute is a multispecialty hospital for infants, children and adolescents located in Wilmington, Delaware.

INSIDE
The NFPMA Report

Dr. Marks, let us suppose that there is a CMT parent who has normal parents and siblings, would it be possible for this CMT parent to have a CMT child?

Yes, it is possible, and there are three different situations to explain this. Our first consideration would be a parent who inherited his/her disease as an autosomal recessive disorder. In this case the parent would not pass the disease to his/her children unless he marries a CMT patient or CMT carrier. This is very unlikely except when he/she marries a relative. The second possibility is that the CMT parent has autosomal dominant CMT and he/she represents a first generation mutation. His/her children would have a one in two chance of having CMT. The third possibility is that CMT has been present in the family, but totally undiagnosed. Autosomal dominant disorders like CMT have very varying degrees of severity even within the same family. Again the odds are one in two a child would be CMT. Another consideration would be sex-linked inherited CMT. If the CMT parent is male and inherited his disease as sex-linked, his children would be disease free, but his daughters would be carriers. Those daughters would have a one in four chance of having a male child with CMT.



Dr. Harold G. Marks

What are the early warning signs of CMT in children?

From the results of a study we did here the overwhelming majority of patients (93.8%) had a foot deformity. The most common of these

Continued on page 2

deformities was pes cavus (high arches, 84.6%), followed by claw-toes (39.5%) and varus foot (turned in foot, 25.4%).

What is the most common age for parents to seek help for a child and a diagnosis to be made?

Again from the study we did here, the median age of onset of CMT was 5.3 years + or -4.2 years with a range of age from 0 to 12.4 years of age. Almost all patients (80.9%) had symptoms of CMT before age 10. It was interesting to note that 60.5% of the patients were males compared to 39.5% females.

Would a one year old CMT baby walk normally?

Mostly they will, but as the disease progresses they develop high arches and foot deformities. Occasionally, babies with CMT are persistent toe walkers. However, there are other causes of toe walking. If there is a family history of CMT I would do nerve conduction studies and EMG's.

Can nerve conduction studies be done on a full age range of patients?

Yes, but I usually wait until a child is 2 years of age and then do an EMG.

By EMG, you mean you are testing the electrical function of muscle tissue?

Yes, nerve conduction studies test the peripheral nerve fibers.

When you do an EMG on a CMT patient what do you learn? How do they differ from a normal person?

With CMT, EMG's demonstrate changes in muscle electrical activity which is due to decreased nerve function. These changes are both acute and chronic.

With a child do you usually do both an EMG and a nerve conduction study?

Yes.

How do you get the cooperation of a young child?

It is a matter of experience. I do not do EMG's but rather use very experienced physicians who do them frequently. We have three physicians here who do EMG's.

Do you sedate a child?

No, it is not necessary. We try to get the child's cooperation. It is not ideal to do an EMG at a very young age. Since CMT is not a treatable disease, in the child with a family history of CMT when diagnosis is not wanted for genetic counseling, we wait until the child is older. Also, if the child shows an unusual fear of needles we will wait until the child can understand the reasons for testing.

When you do EMG's and nerve conduction studies on a child, are there needle electrodes involved?

In an EMG there are needle electrodes; for the nerve conduction test there are surface electrodes.

It sounds as if it is important to relate to the child.

Yes, it is very important, and I stress to the parents that there is minimal or no risk to the child. Once the test is finished there are no after effects.

How long does the test take?

Usually 30 minutes.

If a child has been diagnosed as having CMT, is there any way of predicting the severity of the disease?

It is my impression that children with the demyelinating form of CMT (HMSN I) are overall a little more severely involved than the axonal form (HMSN II). Others have reported in adults a correlation between age of onset of symptoms and severity of disease. In children this does not seem to consistently correlate. Finally, others have reported the sporadic or autosomal recessive forms of CMT to be more severe than the autosomal dominant.

Does the clinical history of the parent affect the degree of disability of the child?

No, there doesn't seem to be a way to predict that. As I said before, autosomal dominant disorders have varying degrees of severity even within the same family.

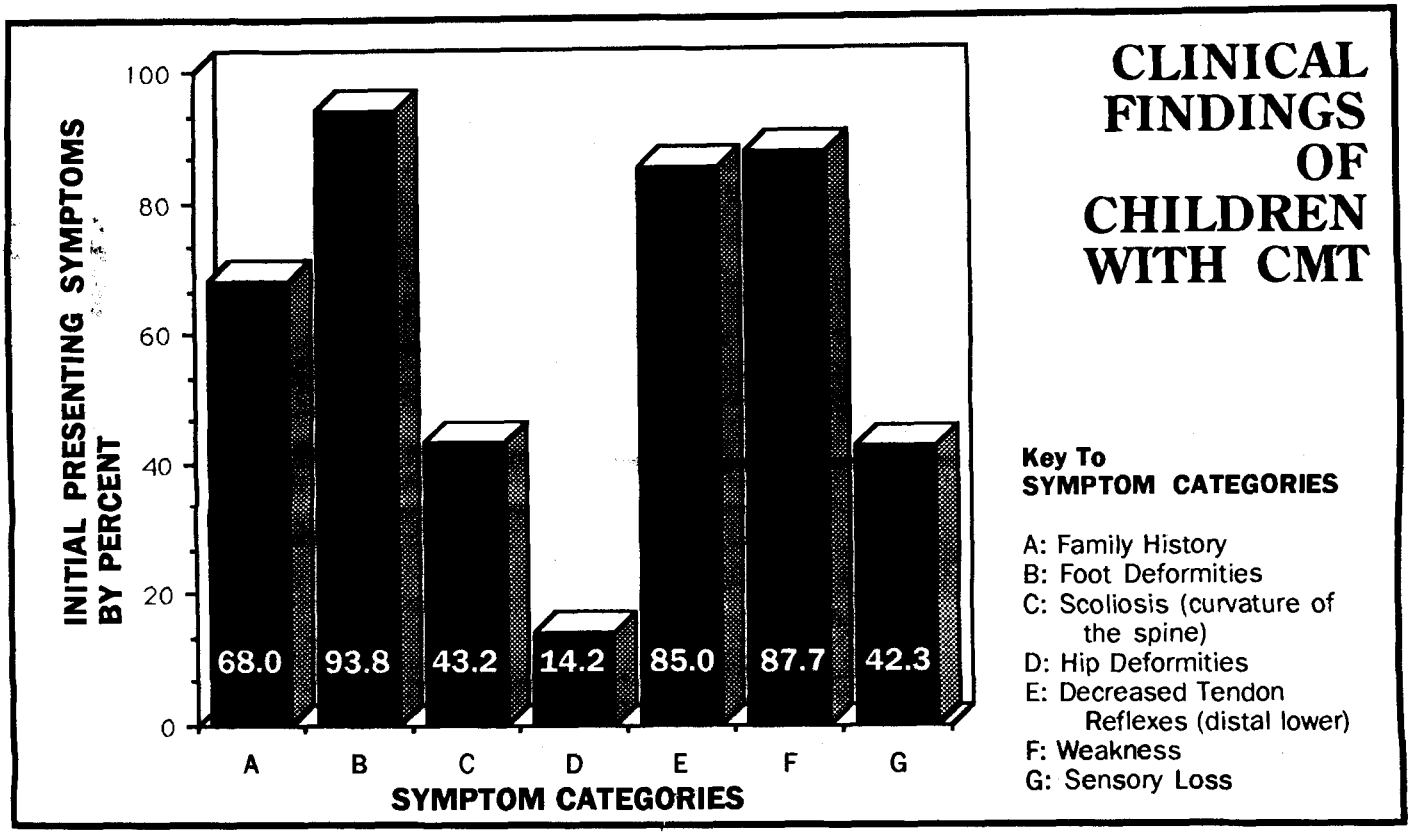
At what point do you think that a CMT child is a candidate for orthopedic referral?

We see patients here in a clinic setting. The clinic is attended by an orthopedist and me. Dr. Richard Bowen, the orthopedist, also continually monitors the child. Initially, we tend to put the children in AFO's (leg braces). As the disease progresses, they may go on to surgery, but this decision is made by Dr. Bowen and the parents.

I know Dr. Bowen prefers to wait until age 12-13 to operate. Is the decision ever made to operate earlier?

Yes. There are two indications for surgery. They are ankle instability resulting in repetitive ligamentous injury which is not

Continued on page 3



helped by nonsurgical means such as AFO's and progressive pes cavus deformity (high arches) which limits walking ability or causes pain.

What percentage of CMT children here are referred for surgery?

I would estimate less than 10%.

What determines if a child needs AFO's?

If the child is twisting his/her ankles frequently, or if he/she has a lot of pain in the ankles and arches and it affects his/her walking, we then recommend AFO's. If all he/she has is ankle weakness or high arches alone, I don't recommend the AFO. I try to wait until the child will clearly benefit from the AFO before I prescribe it. As you know, the AFO may cause disuse weakness. In addition, if children don't clearly benefit from AFO's they will refuse to use them.

Do children outgrow braces?

They usually last 1-2 years.

Do the children here come through the MDA clinic?

(Editor's note: MDA is the *Muscular Dystrophy Association*, an organization that is independent of the NFPMA.)

About one-tenth of them do and the others are privately referred. Almost all our CMT referrals are from orthopedic surgeons.

If a child needs leg braces does the MDA cover the cost?

Yes, MDA helps provide for their purchase and reasonable repair. Once A CMT child comes here I enroll the child with the MDA. He/she then has the choice of being followed at our MDA sponsored clinic, and if the child needs orthopedic aids such as braces, a wheelchair, crutches, etc. MDA will help provide for their purchase.

What about exercise and the CMT child?

I encourage them to be as active as possible, but I discourage them from participating in contact sports. However, I do not prohibit them from doing so. I have one patient who loves to play football and he has continued to play. As far as exercises, I initially send new patients with moderate to severe weakness to see a physical therapist for strengthening exercises. If I see a significant hand weakness, I send them to an occupational therapist. The therapists give them exercises to do at home, and the patient is reevaluated periodically usually every 3-6 months.

Do you see CMT children as having a balance problem that limits them in sports?

No, I haven't had a patient complain of this. In fact, I know of two CMT patients who are skiers. I know of no study showing therapy

Continued on page 4

helps, but I feel keeping the muscles stretched so they do not develop contractures and maintaining and improving muscle strength must benefit the children.

Is there anything you tell the children not to do?

No, not really except for the contact sports warning. I try to have the children live as normally as possible.

I know you have seen a child who is mentally retarded and has CMT.

Yes, but I feel she has two common diseases, having cerebral palsy and mental retardation as well as CMT. I have tested her for several other disorders that involve both the central nervous system and the peripheral nerves, but they have all been negative. Her brother, also a CMT patient, has normal intelligence.

In other words, you feel there is no correlation between CMT and mental retardation.

No, in fact most children I see with CMT are very bright. These children tend to focus their potential in academic areas rather than motor areas.

Have you referred any children to special education programs?

No, most CMT children don't have this need.

Should parents confer with the child's primary teacher and explain the disability?

In a few CMT children with hand weakness it is very difficult for them to copy school work or take notes. For these children I have asked the teachers that they be allowed to tape lectures and other class work. Additionally, I encourage these children to learn to use a word processor (if they have a computer at home) in order to type their assignments. In gym it is different. Activities such as running and rope climbing would be difficult and should be explained to the teacher. However, no parent has ever asked me about gym class. Gym teachers should not have unreasonable expectations for the CMT child.

Are pediatricians as a group trained to recognize the CMT child?

No, there is a need for education in this area. CMT is a relatively common problem. In the ten years I have been here I have seen 200-300 cases.

Are you aware of CMT children having chronic pain?

Yes, but it is not common. Some children complain of intermittent back pain, calf pain, thigh pain, and pain of the arches. This is more severe at night. I would guess 5-10% of the children have pain. With these children I send them to a physical therapist for stretching exercises.

Do you give drugs to children for chronic pain?

No, but most children do not have severe pain. If I had a patient with severe pain, then I would consider medication.

What is your philosophy about labeling the CMT child as disabled?

Although I recognize that children with CMT have limitations, I feel that they should lead as normal a life as possible. Their areas of strength should be identified and if physically able they should be encouraged to participate in activities that interest them. As I said before, I know persons with CMT who ski, run in marathons, and play high school football. Furthermore, I know CMT adults who are physicians, scientists, attorneys, and truck drivers.

If the child is wearing leg braces, can he/she participate in sports?

Yes, they can. To summarize, I encourage the child to be as normal as possible. I want the child to look upon himself as normal, not crippled. CMT patients go into all professions. Although, I do warn the children about choosing heavy labor occupations. As the disease progresses, some things would become difficult to do as the muscles weaken. For instance, a CMT patient should not become a bricklayer.

Then you would not encourage a musical CMT child to become a professional musician.

No, I would not if the child is interested in playing an instrument that requires great manual dexterity and was interested in a performance career. However, for the musically gifted CMT child I would certainly encourage their talents to be expressed in composing, teaching, conducting, or wherever their interests lie. Furthermore, I would always encourage them in their music for an avocation. What I do not want is for the CMT child to have to re-train in mid-life because of their disease. I also warn CMT patients about working with neurotoxic chemicals. In CMT there is an abnormality of the nerve and the nerve is very limited in its ability to withstand chemical as well as physical trauma.

Continued on page 8

This issue is dedicated to the memory of Irving Finkelman. Mr. Finkelman, a CMT patient, passed away in November, 1988. He was a long-time friend of our program, a dedicated fund-raiser, a major contributor, and worked tirelessly on behalf of our program. We will miss Irving.

NFPMA CONTRIBUTIONS

In Memory Of	Contributor
Murray Wolbach	Mary & Melvin Silverbrandt
Burton S. Wendkos	Joan & H. Newton Garber
Burton S. Wendkos	Frances & Lester Fertman
Robert G. Bradwick	R. Gordon Bradwick
Joseph Levy	Mimi & Don Vineburg
Louis Scarsella	Ed Scarsella
Rosalind & Sidney Dicker	Phyllis Dicker
Bessie Berry	Anita & Melvin Berry
Carl Hedman	Judith Burkhart & Friends
Clarence Kluenner	Edna L. Kluenner
L.H. Mitchum	Jacquelyn & David Gamble
Carl Hedman	Andrea Higginbottom
Gwen Pomerantz	Rebecca Brezel & Family
Jerome Rothman	Laura Pallay & Sarah D. Rothman

In Memory Of Irving J. Finkelman

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Delores N. Pennington	Patricia Ann Harper	Helen & Nathan Dresnin

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Rebecca Sand	Richard & Rosa Woolman
Karol Hitt	Sophia Bradwick
Howard & Doris Darnell	Karol Hitt
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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.*

HONORARY GIFT

In honor of: (person(s) you wish to honor)

_____

Send acknowledge to:

Name: _____

Address: _____

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Phone Number (____) _____

Occasion:

- ❑ Birthday
- ❑ Wedding
- ❑ Anniversary
- ❑ Holiday _____
- ❑ Thank You
- ❑ Other _____

MEMORIAL GIFT

In memory of: (name of deceased)

_____

Send acknowledge to:

Name: _____

Address: _____

_____

Amount Enclosed: $ _____

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

GIFT GIVEN BY

Name: _____

Address: _____

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1988 IN REVIEW

This has been a productive, busy year for all concerned with the NFPMA. We are growing and that delights us. We launched a comprehensive newspaper campaign which brought us many new CMT patients and families, but probably our best efforts were in our half day patient family conferences sponsored in four different cities. These conferences featured speakers from the individual areas and at the conclusion of his/her presentation each speaker answered questions from the audience.

The first of the series was in Philadelphia in February. At this conference, Dr. Robert Kreb, III spoke to the group on options in rehabilitation for the CMT patient. Not only is Dr. Kreb a board certified physiatrist and well qualified to address this issue, but he also is very interested in the CMT patient and his/her unique problems. Dr. Howard Shapiro of the NFPMA also spoke giving an update on the then pending FES study (functional electrical stimulation) being done with Dr. Gilbert Hice of the Pennsylvania College of Podiatric Medicine. From this meeting a lively, active support group for the Delaware Valley was begun under the able leadership of Rex Morgan, Jr.

After his lecture, Dr. William Zink discussed details of normal and pathological aspects of lower leg motion with several CMT patients.

The second conference was in April at the Shriner's Children's Hospital, Atlanta, Georgia. It was here that Dr. Donal Costigan, a neurologist with an expertise in neuromuscular disorders, and Dr. Sushma Chandan, a physiatrist, spoke to an enthusiastic group of CMT patients and families. At this meeting Dr. Costigan discussed the list of neurotoxic drugs that are to be avoided by CMT patients. (This list is published in the NFPMA Report). A support group for the Atlanta area is being formed under the guidance of Molly Howard.

The third meeting was in June at the Orlando Regional Medical Center in Orlando, Florida. Our speakers were Dr. Michael Pollack, a pediatric neurologist, and Dr. William Zink, an orthopedic surgeon. During the course of the afternoon this group of participants quickly went from an interested audience to a spirited support group. This was evidenced by this reporter observing Dr. Zink taking the leg braces from one patient to show to another patient. The exchange took place in an informal session following the program. Needless to say, from the Orlando conference an active support group led by Mary Beeler has developed.

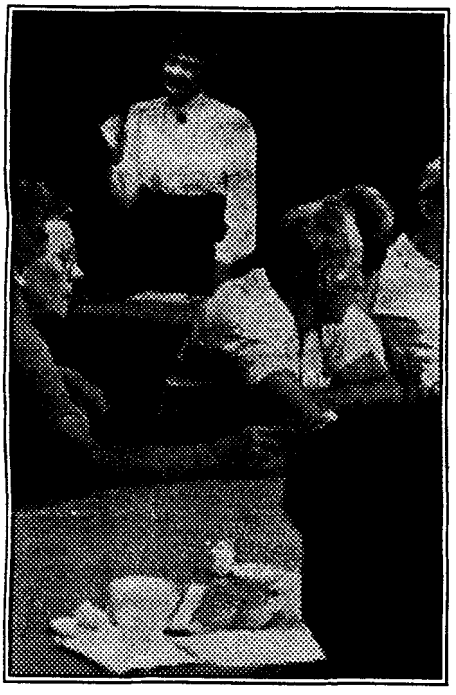
Dr. William Kingston speaking at Rochester conference.

Our fourth conference was in October at Strong Memorial Hospital in Rochester. Our participants here were from central and western New York, and again an interested and enthusiastic group. Dr. William Kingston, a neurologist specializing in neuromuscular disorders and Dr. Craig Hyser, a neurogeneticist, enlightened and informed us. Dr. Kingston, in response to a patient question, reaffirmed the neurotoxic drug list and also added to that list mega dos-

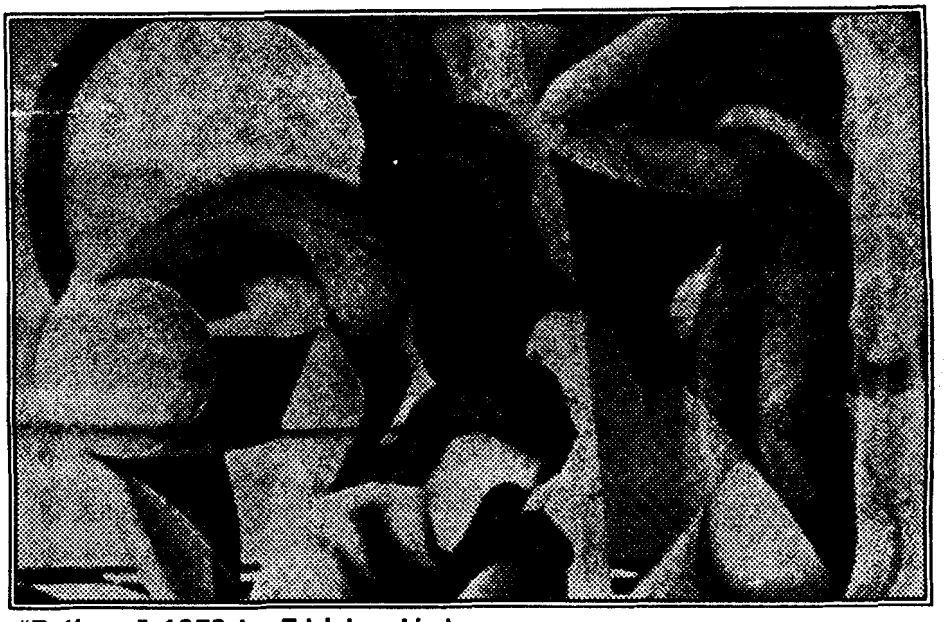
es of vitamins A and D. Therapeutic doses of B-6, A and D are alright, but mega doses of these vitamins are to be avoided by the CMT patient. Dr. Kingston further cautioned CMT patients about unnecessary carpel tunnel syndrome surgery. He stated CMT patients can certainly get carpel tunnel syndrome, but the CMT disease process can also produce symptoms that mimic this condition. Three people volunteered to act as support group organizers and they are planning their first meeting for January. The three are Joan Lubberts, Neale Bachman and Bernice Roll.

This series of meetings proved to be a great success in bringing information and encouragement to many CTM patients. We are pleased with the success of this program and plan to continue the meetings in many different cities throughout the country. We feel that the CMT patient is best served by these regional conferences.

Additionally this year we have continued to send out information kits to patients and professionals, continued the VCR tape rental program, distributed information about orthopedic shoe services, cooperated with researchers when CMT participants were needed, worked with the Pennsylvania College of Podiatric Medicine and the University of Pennsylvania on the FES study that is in progress now, and gave physician referrals to many. This last activity is an increasing service and we are now in the process of greatly expanding our list of doctors.



Karol Hitt convening the Rochester conference.



"Bathers," 1979 by Zdzislaw Lindner.

In January, several NFPMA members participated in a conference entitled "Psycho-social Well-Being in Muscular ~~Dystropy and~~ Allied Diseases III" which was sponsored by Columbia University and the Foundation of Thanatology. (A complete report of our participation at this symposium is in the Spring/Summer 1988 NFPMA Report.) At a May fund raising party in New York City, the works of Zdzislaw Lindner, an enormously talented artist and CMT patient, were featured. The NFPMA and the University City Science Center, 3624 Market Street, Philadelphia, PA are currently sponsoring an exhibit of Lindner's work. This exhibit will run through December 30. We encourage everyone who can to view this exceptional artist's work. The Science Center is open 9-5 daily and you are welcome in the gallery. It is located next to the University of Pennsylvania campus, is not difficult to find and generally parking is available in the area. Finally, work is progressing on the book that is being written from the Second International Conference on Charcot-Marie-Tooth Disorders. (This NFPMA sponsored conference was covered in the Summer/Fall 1987 NFPMA Report.) Publication is expected in the spring of 1989.

In conclusion, we would like to thank everyone who has helped us to make this year a year of growth and progress. The medical professionals who gave so freely of their time and knowledge, the facilities who opened their doors for our meetings, the people who licked stamps and stuffed envelopes, the support group leaders and members who spent time and money getting their organizations functioning, and those individuals who contributed the money so necessary for the NFPMA to exist are the people to whom we are deeply indebted. As we grow we are meeting some exceptional and wonderful people and in the future we are going to be highlighting them. Daily, we are meeting and working with very gifted, dedicated and capable people who happen to have CMT. ❋

MEDICAL ALERT

MEDICAL ALERT

Certain Drugs Toxic to the Peripheral Nervous System

This is a list of neurotoxic drugs which could be harmful to the CMT patient. Before taking any medication discuss it fully with your doctor for possible side affects.

Adriamycin
Amiodarone
Chloramphenicol
Cis-platinum
Dapsone
Diphenylhydantoin (Dilantin)
Disulfiram (Antabuse)
Glutethimide (Doriden)
Gold
Hydralazine (Apresoline)
Isoniazid (INH)
Mega Dose of Vitamin A
Mega Dose of Vitamin D
Nitrofurantoin (Furadantin, Macrodantin)
Nitrous Oxide (chronic repeated inhalation)
Penicillin (Large IV doses only)
Pyridoxine (Vitamin B^6)
Vincristine

INTERVIEW
Continued from Page 4

You are referring to industrial solvents?

Yes, the patient should ask his/her place of employment about toxins and consult with his/her doctor about them. Physical trauma is another factor. Some people have to wear heavy packs or belts which would subject them to physical trauma. Prolonged standing would also be very difficult.

As a final question, what about scoliosis in children?

Yes, scoliosis is present in about 40% of the CMT patients seen here at A.I. duPont Institute. About 15% of our CMT patients have come to us because of scoliosis and subsequently the CMT diagnosis was made. From our study 43.2% of the CMT children had scoliosis while an equal portion did not, leaving 13.6% for whom the information was not available. This would suggest that the true percentage for scoliosis is closer to 50%. The scoliosis was not usually severe and did not generally require surgery. However, 10-15% of CMT scoliosis patients may require surgery. ❄

FOR THE NFPMA

This material is presented for educational purposes only and is not meant to either diagnose or prescribe. While there is no substitute for professional medical care for Charcot-Marie-Tooth Disease, these briefs offer current medical opinion that the reader may use to aid and supplement a doctor's treatment.❄

ATTENTION

If you are moving please send your change of address to the NFPMA, University City Science Center, 3624 Market Street, Philadelphia, PA 19104. It will help us if you enclose your former mailing label from a previous NFPMA Report.❄

EDITOR'S NOTE

We wish to thank Teri Daino and Lauren Ugell for their assistance in the studies described in the previous edition of *The NFPMA Report*, entitled *Psycho-social Aspects of CMT*. The work they contributed is most appreciated.❄

Support Group Notes

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: every other month

Next: December 10

Where: Rusk Institute of Rehabilitation Medicine
Room RR 610 (6th Fl. Research Wing)
400 East 34th Street (at First Avenue)
New York, NY 10016

Time: 1:00-4:00 PM

Contact: Linda Phillips Goldfarb (212) 481-3419

New Jersey

Meetings: every other month

Next: December 10

Where: Englewood Hospital
Clinic Conference Room
350 Engle Street
Englewood, NJ 07631

Time: 10:00 AM

Contact: Ann Lee Beyer (201) 391-4624

Delaware Valley

Meeting: This group held its 3rd meeting at the Holy Redeemer Hospital in Meadowbrook, PA on Nov. 19th.

Next: January, 1989

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

Tidewater, VA Area

Meeting: January 28, 1989

Contact: Mary Jane King (804) 591-0516
Ellen Morton (804) 851-7046

Where: Riverside Hospital
School of Professional Nursing
J. Clyde Morris Blvd.
Newport News, VA

Greater Atlanta

Contact: Molly Howard (404) 253-5632

Cleveland, Ohio

Contact: Norma Markowitz (216) 247-8785

Orlando, Central Florida Area

Contact: Mary Beeler (407) 295-6215

Meeting: Third Saturday of Every Month

Fort Pierce Area, Florida (Atlantic Coast)

Contact: Dorothy Stefanovich (407) 461-1016

Greater Dallas, Texas Area

Contact: Dr. Karen Edelson, D.P.M. (214) 542-0048

San Diego, California

Meeting: Monthly on the 3rd Thursday

Time: 6 PM

Where: Children's Hospital

Contact: Gary Oleze (619) 792-1427

San Francisco, California

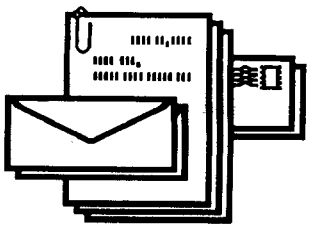
Meeting: January 21, 1989

Contact: David Berger (415) 461-3906
Leave a message on the tape.

Parsons, Kansas

Contact: Tammy Taylor (316) 421-5286

Call your nearest group today for more information!



LETTERS

a forum for NFPMA readers

Thank you for providing us with the information on Charcot-Marie-Tooth disease. I am sure that many of the physical therapists who read about the disease in the PT Bulletin will have gained some valuable insights into the disease and about some of their patients. Please keep us updated on any progress gained against CMT. We will be happy to pass the information along to our readers. Once again, thank you.

Monique Milner Smith, Associate Editor • PT Bulletin, American Physical Therapy Association • Alexandria, VA

We want to hear from you, so write us at:

Letters
The NFPMA, University City Science Center, 3624 Market Street, Philadelphia, PA 19104.

It was a great pleasure to meet you and to put faces to the signatures. We found the meeting most interesting and informative. It does help to hear CMT discussed in person--it puts things in a different perspective. I just wish we had had more time to talk with the doctors and the other CMT sufferers who were there. Perhaps that will come later when and if we organize a local support group. Thanks for organizing the meeting.

M.W., FL

Thanks a million for the tapes. We would welcome more tapes on exercise, especially in the water, also more on hands. This was the first time I understood my CMT legs and feet. I shared the tapes with my therapists (P.T.'s) and my doctor. So little is known about CMT--I have been mistreated for years.

M.H., NY

Received the packet of information on Charcot-Marie-Tooth disease and I am grateful. Being an old retired nurse with a 52 year old son and a mother who survived with CMT to age 91, I am interested in all the information I can obtain. I am 75 and have worn braces for six years. I feel with this new information that I have always had CMT. My eardrums are a bit concave, energy level always low, long hard to fit feet, though they served me well walking to age 67, humped shoulders from my teen years, falling upstairs as well as down and many little symptoms like aching joints and sleeplessness. Thanks for helping me.

J.B., WA

This is the first information I have found since I had my plastic supports made in 1982. I am very grateful to learn all I can about CMT. Thank you.

J.L.C., PA

I want to commend you on the last newsletter that was sent out. It was so very informative. It is very positive to know that others have the same problems. You have done a wonderful job. If you need anything I can help you with, let me know.

L.K., VA

NFPMA BOARD OF DIRECTORS MEET

The Board of Directors of the NFPMA met in New York City for its annual meeting on November 15, 1988. At the time of the meeting the Board members were Dr. Katheryn Pugh, New London, CT; The Rev. Lawrence Williams, Drexel Hill, PA; Dr. Robert Lovelace, Tenafly, NJ; Mr. Herman Cohen, Esq., Bloomfield, NJ; Dr. Neal Nathanson, Philadelphia, PA; Dr. Harry Harris, Philadelphia, PA; Mr. William Harra, New York, NY; Mr. George Crohn, Jr. New York, NY; Mrs. Marjorie Murray, Umatilla, FL; Dr. Lorene Shapiro, Tangerine, FL; Mrs. Ann Lee Beyer, Upper Saddle River, NJ; Ms. Linda Phillips Goldfarb, New York, NY; and Mrs. Karol Hitt, Wallingford, PA.

At the meeting two additional members were elected. They are Mr. J. Rodman Steele, Jr., Esq., West Palm Beach, FL and Ms. Diane Freaney, Ambler, PA. Dr. Pugh was re-elected president, Dr. Shapiro was re-elected secretary, Mr. Williams was re-elected treasurer, and Mrs. Hitt was elected vice-president.

During the meeting the Board discussed the rapid growth of the program during the past year and the resulting adverse financial situation. This development of program has brought help and information to patients, family members, and the medical professional community. However, our activities have outstripped our resources and we urge you to support the Foundation to enable us to continue our service to the CMT community, the medical community and the general public. ❋

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).

The NFPMA Report is produced by *The Journey Enhancement Group, Inc.*, a diverse desktop publishing and computer sales company, 3400 State Road, Drexel Hill, PA; (215) MAC-3000.

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Call (215) 664-6010 for more infomation.

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Tell us about yourself:

- ❑ CMT Patient
- ❑ Interested Supporter
- ❑ Medical Professional
- ❑ CMT Family Member
- ❑ Research Scientist
- ❑ Other

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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 hr., 15 min.) rent for $10, and the double lecture tapes (2 hrs., 30 min.) rent for $15. The rental fee includes prepaid return postage. To order a tape, fill out our *I want to be in touch!* form and send it to us with a check or money order payable to the NFPMA. Please check the appropriate boxes:

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OF INTEREST TO OUR READERS!

THE NFPMA REPORT welcomes your ideas and article suggestions. For example, you may submit a human interest story telling of your experience of living with CMT. Or, medical professionals can forward articles of a clinical or medical nature that would be of general interest to our readership.

The following back issues of *THE NFPMA REPORT* are available at $2.50 a copy:

Spring/Summer 1988
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Peroneal Muscular Atrophy (CMT)...

..... 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) and 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, occational partial sight and/or hearing loss problems and scoliosis (curvature of the spine) may be present.

..... does not affect normal life expectancy.

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

..... is usually inherited in an autosomal dominant pattern, affecting half the children in a family with one PMA parent.

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

THE NFPMA REPORT

information on Charcot-Marie-Tooth disease from the

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University City Science Center
3624 Market Street
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