

# THE NFPMA REPORT

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Fall 1989

Vol.4/No.4

Providing information on Charcot-Marie-Tooth disease (or Peroneal Muscular Atrophy), the most common inherited neurological disease. Contents © 1989, NFPMA. All rights reserved.

## LIVING WITH A RARE DISORDER: Hope and Fear

By Mark Flapan, Ph.D.

The following article appeared in the Summer 1989 Orphan Disease Update, the newsletter of the National Organization for Rare Disorders. It is reprinted with NORD's permission. The author Mark Flapan, Ph.D. has scleroderma and is President of the Scleroderma Society. He is a psychologist in New York City and has a special interest in the emotional effects of chronic illness both on the patient and on family members.

All of us with chronic illness waver between feelings of hope and fear-- we hope we'll get better and fear we'll get worse. And it's the balance between hope and fear that, in part, determines how you cope with your condition. The vacillation between hope and fear began even before you had a diagnosis; it began when you first noted some physical change in your body. You may have noticed that something looked dif-



Dr. Mark Flapan

ferent, felt different or moved differently than it had. At first, you ignored these strange happenings in your body-- hoping they would soon go away.

### In Search of a Diagnosis

After a time, when these symptoms didn't go away or even got worse, you became concerned, and out of concern, called a doctor. But you also called the doctor with hope-- hope he would say you had nothing to worry about, and that he could easily rid you of your symptoms.

But it didn't work our that way. In all likelihood, your family doctor couldn't diagnose your illness and referred you to a

specialist. While this increased your apprehension, you continued to hope nothing was seriously wrong. But if the specialist, too, couldn't diagnose your illness, you were both apprehensive and bewildered. He might have told you he couldn't tell what you had because your symptoms could be due to any one of a number of diseases. Or maybe he didn't think you had anything, if all you complained about were vague aches, pains and fatigue. He didn't exactly say it, but he seemed to imply you were some kind of hypochondriac, which was insulting.

After you saw several more doctors and still had no diagnosis, even your family started thinking you were making it all up. This left you feeling hurt and alone. Then if still more time passed without a diagnosis, you too began to wonder if it was all in your head. In any case, without a diagnosis, there was no treatment; and without treatment there was no hope of getting back to you old self again.

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The NFPMA has moved.

Our new address is:

The NFPMA  
Crozer Mills Enterprise Center  
600 Upland Avenue  
Upland, PA 19015  
(215) 499-7486

## 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 effects.

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 B6)  
Vincristine

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**Hope and Fear** (cont'd from pg.1)

### *Learning You Had A Rare Disorder*

When the diagnosis of a disorder was finally made, the vacillation between hope and fear really got started. At first, you may not have been frightened when the doctor told you what you had, since you know no one who had it, and had never heard of it. After all, it wasn't cancer—that would really be something to be scared of.

If your diagnosis took a long time coming you may have even been relieved to find out you had a known disease; then, at least, doctors could do something for you. But when the doctor told you (or you later learned) that you had a potentially progressive illness for which there was no cure, you couldn't believe it. And when you did believe it, you were so frightened and depressed you could hardly think of anything else.

In the desperate hope of finding out it was all a mistake, you hunted for another doctor. Somewhere there had to be a "big doctor," a specialist who would know if you really had this strange disease. And if it turned out you did, he surely would know what to do for you. Your hope was shattered, however, when this specialist confirmed that you did, indeed, have the disease, and there was in fact no cure for it.

Your fear was a little relieved when he went on to say that although there was no cure for what you had, there were medications to treat your symptoms, and that many people with this condition did quite well. You felt hopeful that this knowledgeable and caring

doctor would see to it that nothing awful happened to you.

### *Knowledge Is A Mixed Blessing*

Soon after diagnosis, or maybe not until sometime later, you decided to learn what you could about your illness and about available treatments. You hoped through understanding your disease you could learn to take good care of yourself and make sure you were getting the best treatment possible. So you read whatever you could find about the disease, joined an organization formed for people who had this condition (if there was one), and went to meetings to hear doctors explain the disease.

But the more you learned, the more frightened you became. This was especially so if you read only medical textbooks written before many of the current treatments for controlling symptoms were available. Even if you read up-to-date medical books, you were still frightened by descriptions and pictures of advanced cases of your disorder. Medical books, after all, are written to teach doctors, not patients, about disease and therefore highlight "classical cases."

If you were fortunate, you first got a balanced perspective about your condition from booklets written for people with the illness. In that case, you were probably less frightened by what you read.

You may also have been frightened at meetings where doctors talked about the disease. You may have seen gruesome slides and heard about all the awful things that could happen. The people you saw and spoke to also frightened you by how they looked or the symptoms they complained about. At your first meeting or

(Continued, next page)

Hope and Fear ( continued from pg.2)

two you may have left feeling upset, depressed and scared to death.

However, these meetings also instilled hope. You met people who had had the same disorder for many years, yet looked fine and were leading normal lives. You heard doctors talk about helpful drugs and medical researchers talk about promising new treatments on the horizon.

Yet in spite of the promise of hope, there was no way to learn about the symptoms and possible progression of your disease without becoming frightened. You can't help but fear that what you hear or read about, or what you see— will happen to you.

Or to protect yourself from these fears, you may have avoided attending meetings or reading about your disorder for a long time. You lived with the hope that what you didn't know wouldn't hurt you. But as you got used to your illness, you decided it was now time to learn what you could about your condition— all in search of hope.

### *Hope Keeps You From Giving Up*

More frightening than what you see, hear or read about, is what happens to your own body. As new symptoms emerge, or old symptoms get worse, fear gains

the upper hand. But hope keeps you from giving up and keeps you seeking whatever help is available.

You've heard about ways, other than traditional medicine, to cure diseases of all kinds. Special diets, relaxation and an appropriate balance between exercise and rest are all said to have healing effects. Even if these "holistic approaches" don't heal your disorder directly, they at least could keep your body in the best condition for fighting your illness. In any case, by actively doing something for yourself, you keep hope alive.

You've read that stress predisposes people to diseases of all kinds. There was plenty of stress in your life. You may even blame yourself for having brought on your illness by the stressful life you lived.

You've also read that while stress increases susceptibility to disease, a positive mental attitude has healing powers. It's even been reported that cancers have been helped into remission with psychotherapy and the technique of "visualizing" the cancer away. If it works with cancer, why not with your disease? And if done in conjunction with, and not instead of medical treatment, there certainly is no harm in trying. In any case, doing these kinds of things for yourself inspires hope.

Then, of course, prayer is an eternal source of hope and comfort. The belief in a higher power makes all things possible. You've heard of miracle cures for all kinds of afflictions, why not for yours?

### *Additional Sources Of Hope*

Keeping in mind that the course of your condition is likely to be variable from person to person also keeps hope alive. There are likely to be different types of

## **LETTERS**

**We want to hear from YOU!**

Write us at:

Letters, The NFPMA  
Crozer Mills Enterprise Center  
600 Upland Avenue  
Upland, PA 19015

your disorder which vary in terms of symptoms and progression. So what you see, hear, or read isn't necessarily what you'll get. And although there is still no cure for your illness, there may be helpful medications to treat symptoms as they occur.

And, of course, there is always the hope that in the not too distant future, research will find a cure. Medical research progresses each year. In fact, some of this research may have been brought about by advocacy of NORD, or supported by the organization to which you're a donor.

### *Choices You Have*

When all is said and done, what we all fear most is progression of our disease. Most of us could learn to live with what we have, if we knew it wouldn't get any worse. As it happens, progression of your disorder may be unpredictable and uncertainty is hard to live with. However, we have the choice of living in fear we'll get worse, or living with the hope we'll stay the same, or even get better.

With or without an illness, none of us can predict our future. But if we frighten ourselves by imagining the worst, we undermine our ability to live as fully as possible in the present. On the other hand, keeping involved with purposeful activities and meaningful relationships strengthens us to cope with whatever the future holds.

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### **Attention CMT Patients!**



Dr. James Lupski, of Baylor Medical Center, requests that CMT patients who have a second inherited condition contact him. Please, when you write give the name of the second condition. Also, CMT patients who have a known chromosomal anomaly are asked to contact Dr. Lupski at the NFPMA, Crozer Mills Enterprise Center, 600 Upland Avenue, Upland, PA 19015. (215) 499-7486.

## CMT People

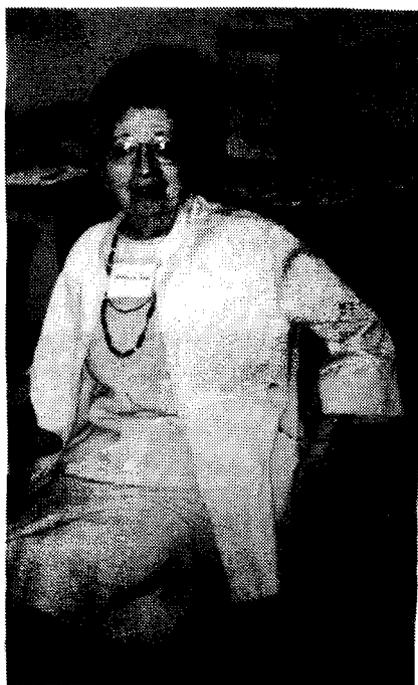
### *The Remarkable Rebecca Sand*

Years ago whenever Rebecca Sand first told people about Charcot-Marie-Tooth disease, she typically got a puzzled look and this reaction: "They'd say 'What? Your tooth hurts?'" she recalls. "And I have to say no, it's a neuromuscular disease."

It's a familiar problem for many CMT patients. But Rebecca came up with a unique solution. Now when people ask her about CMT, she puts an NFPMA brochure in their hand and tells them—sweetly but emphatically—to read it. And people do. It's hard to say no to Rebecca. Since she first learned about the NFPMA four years ago, Rebecca has become a one-woman crusade on behalf of the organization and CMT. She's everything and more an organization needs in a volunteer.

As an expert envelope stuffer, stamper and sorter, she's done countless mailings for the NFPMA. If you're on the mailing list, you've received her handiwork. Single-handedly, she's launched several very successful fund-raising efforts which have raised thousands of much-needed dollars for the foundation. If you're a friend of Rebecca's, you've heard about the good work of the NFPMA. For the last three years she's volunteered to be "model patient" for many orthopedic classes at the Hospital of the University of Pennsylvania. If you're a budding doctor at Penn, you know all about CMT and won't soon forget who told you.

"Rebecca is a tireless, persistent and very creative person," says Karol Hitt, president of the



Rebecca Sand

NFPMA. "She always has projects and ideas for us, and is always looking at and assessing other programs to see how they can be applied to the NFPMA." At an age when some people might be content with the rocking chair, 77-year-old Rebecca just keeps plugging away. "I have to keep busy with something," she says. Rebecca has enjoyed a lifelong commitment to volunteer work. For many years she was an integral part of the local Hadassah, the Jewish women's organization which benefits medical and educational projects in Israel as well as in America. She also worked over the years for MaGee Rehabilitation Hospital in various volunteering capacities.

Rebecca gives her father credit for her interest and commitment to charitable work. "My father used to go door-to-door in our neighborhood collecting for various charities," she recalls. "He had a hard time climbing stairs to get to the door because he had problems with his hands and feet. Looking back on it now, he had CMT, although we didn't know any-

thing about it then. "Anyway, I used to say to him 'Why are you climbing those stairs? You should take it easy, you don't have to do this.' And he would say to me, 'As long as I can walk, I'll do it.'" Much the same can be said about Rebecca.

Born in East Liverpool, Ohio, Rebecca came to Philadelphia in 1925 along with her parents and six siblings. Her father, who immigrated from Russia at the turn of the century, ran dry goods stores in Ohio. "With seven kids to feed we were never rich, but we had what we needed," she says. "Our house was always open to everybody." While in high school Rebecca began to have more and more problems with walking. In 1929 doctors recommended surgery to correct foot problems. It was the first of 12 operations that she would have during her life. Through it all, Rebecca went to school and later to work, first at the Jewish Hospital and then as a bookkeeper with Samuel E. Mandel Co., a small food and produce house in South Philadelphia. She worked there for 35 years during which the company grew into a leading fruit and produce company. Unbelievably, it wasn't until 1969 that a neurologist finally diagnosed her with CMT. "Up until then they told me I just had bad feet or arthritis or whatever," she says. With her diagnosis she determined that two of her brothers also had the disorder, although in a different form.

Although her CMT disabilities made it difficult for her to get around, they never made a dent in her positive outlook on life. "Rebecca had made a wonderful adjustment to the fact that she has CMT," says Karol Hitt. "She

(Continued, next page)

accepted her disability with enormous grace, and because she's accepted it, she can talk about it easily." Rebecca is an active member of the Philadelphia-area CMT support group. Ever the fund-raiser, she typically arrives early to set up a table of goodies for sale, with the proceeds benefiting the group treasury. Moreover, she's always ready to offer encouraging counsel to those who are having difficulty with the disorder.

If all that wasn't enough, Rebecca has also become a champion of handicapped rights in recent years. During a visit to her apartment in Philadelphia's Center City, she proudly shows off letters to various hospitals where changes in seating, access, etc., have been made at her prompting. "It's just something I do because it needs to be done," she says. Doing things that need to be done. That's Rebecca. "She's happiest when she's caring about other people," says Hitt. "The foundation just treasures her; she's a real gem."

*Story by Rex Morgan, Jr.*

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With this issue, *The NFPMA Report* begins a regular column profiling people with CMT. If you would like to tell us about someone you know, please drop us a line. Everyone has an interesting story to share.

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### ATTENTION ←

If you are moving please send your change of address to:

**NFPMA**

Crozer Mills Enterprise Center  
600 Upland Avenue  
Upland, PA 19015

It will help us if you enclose your former mailing label from a previous *NFPMA Report*.



## GADGETS, CATALOGS, & BOOKS

Two excellent clothing catalogs, one for adults and one for children, have come to our attention. The adult catalog features clothing and gadgets for the disabled, and especially for those requiring a scooter or wheelchair. The children's catalog displays very wearable and attractive clothing for children who have special needs.

*For more information about the adult catalog write or call:*

Avenues  
3233 East Mission Oaks Blvd.  
Camarillo, CA 93010  
800/848-2837

*For information concerning the children's catalog write or call:*

Special Clothes  
P.O. Box 4220  
Alexandria, VA 22303  
703/549-2640

Another very comprehensive catalog is ABLEWARE from Maddak, Inc. The products in this catalog range from aids for everyday living and household/work tasks to bowling ball pushers and ping-pong paddle attachments. Individuals may not order directly from the catalog, but if you call and request a catalog and dealer information, one will be sent to you with the name of the nearest dealer. For a catalog call or write:

ABLEWARE / Maddak, Inc., Pequannock, NJ 07440-1993  
phone 800/541-3311

### Books...Books...Books...

*The book based on the proceedings of the NFPMA sponsored Second International Conference on Charcot-Marie-Tooth Disorders is now available. The book, edited by Robert Lovelace, M.D. and Howard Shapiro, Ph.D., is entitled "Charcot-Marie-Tooth Disorders: Pathophysiology, Molecular Genetics, and Therapy". The cost of the book is \$120.00. To order contact:*

Wiley-Liss Publishers  
41 East 11th Street  
New York, NY 10003

"Colleges That Enable: A Guide To Support Services Offered To Physically Disabled Students". This recently published book, by the mother/son team of Prudy and Jason Tweed, describes the types of services provided for physically disabled students at forty colleges. The book categorizes schools based on the level of services offered and the degree of off campus agency assistance in the community. To order send \$10.95 plus \$3.50 for shipping and handling to:

Park Avenue Press  
401 Park Ave.  
Oil City, PA 16301  
or call 814/676-5777

For travel information the following publications and organizations can furnish excellent information:

"Access to the World: A Travel Guide for the Handicapped" by Louise Weiss, Henry Holt & Co., 1986.

"AA Touring Guide for the Disabled by the Automobile Association", Salem House, 1988.

"Travel for the Disabled: A Handbook of Travel Resources and 500 Worldwide Access Guides", by Helen Hecker, RN Twin Peaks Press, j1985.

Society for the Advancement of Travel for the Handicapped (SATH)

26 Court St.  
Brooklyn, NY 11242  
718/858-5483

"Traveling Like Everybody Else: A Practical Guide for Disabled-Travelers", by Jacqueline Freedman and Susan Gersten, Adama Books, 1987.

**ATTENTION CMT  
PATIENTS: STAND UP  
AND BE COUNTED**

Dr. James Lupski's CMT questionnaire appeared in the Spring '89 issue. If you have not filled this out, we urge you to do so now. If more copies for family members are needed, please send a stamped, self-addressed envelope along with your request to:

Karol Hitt/NFPMA  
Crozer Mills Enterprise Center  
600 Upland Avenue  
Upland, PA 19015

Completed forms may be mailed to the same address. Thank you.

**Honorary Gifts**

***In Honor Of***

Virginia Women Golfers  
Mark Willingham  
Perry Sand  
Stephen J. Schafer  
Sophia L. Bradwick  
Sophia L. Bradwick  
Sophia L. Bradwick  
Sophia L. Bradwick  
Louise Perry  
Abraham Firestone  
Randy T. Wells  
R. Gordon Bradwick  
Steven E. Firestone  
William D. Firestone  
Mr. & Mrs. Frank Cruickshank  
Mr. & Mrs. Henry Edredge

***Contributor***

Dorothy O. Hubbard  
Lucie Atkerson  
Beatrice Nelson  
Margaret G. Schafer  
Laura McCann  
Karol Hitt  
Gordon Bradwick  
Faye Bradwick  
Betty Magrosky  
Steven Firestone  
Hudson N. Wells  
Karol B. Hitt  
Ernestine M. Firestone  
Ernestine M. Firestone  
Rebecca C. Brezel  
Douglas Moody

**LETTERS...  
A FORUM FOR NFPMA READERS**

*Dear NFPMA:*

*I am a CMT patient, 49 years old and interested in current and past CMT research. I have attended semi-annual check-ups at the Muscular Dystrophy Clinic for the past three years. So far, the only research they have related is about genetic counseling.*

*I am also interested in any information on medical and/or alternative healing techniques. I have noticed muscle weakness and increased imbalance (while walking) after eating refined sugar and smoked meats.*

*I would appreciate your time in responding to my letter. Thank you.*

*M.M., CA*

Before responding to your letter, I consulted with a doctor well versed in CMT treatment and research. In answer to your question regarding CMT treatment and research, at this time genetic research is receiving the bulk of the funding given by the government and private foundations.

There is a project at the University of Vermont (funded by a federal government grant) which is concerned with the effect of exercise on the person with a neuromuscular disorder. This project was reported upon in the Summer '89 NFPMA Report. The results of this study will also be published in the Newsletter. In addition, there are lipid studies, immune system studies, and autonomic nervous system studies that are being done.

Your observations regarding refined sugar and smoked meats were also discussed. There is some evidence that some CMT patients have trouble utilizing 3 carbon sugars. There is very little work done on this, and there are no dietary guidelines. Current medical opinion is that the CMT patient should follow a well balanced diet and avoid excessive sugar. This should be discussed with your personal physician. He/she should know your unique problems and respond accordingly.

Finally, we know of no alternate healing techniques that have been effective in

treating CMT. Knowledgeable medical personnel who supervise your personal program of physical and occupational therapy will help you to maintain muscle function. They are vitally concerned with your safety and ability to work and perform daily living tasks.

Thank you for your letter.

*The Editors.*

The NFPMA regrets the untimely publication of the Summer '89 and Fall '89 NFPMA Reports. This was due to many circumstances including the moving of the office. Please accept our apologies. It is our intention to publish future newsletters on a set timetable.

## 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) 499-7486.

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

### San Diego, California

Contact: Gary Oleze (619) 792-1427

### San Francisco, California

Contact: David Berger (415) 491-4801  
After 6:00 pm

### Greater Dallas, Texas Area

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

### Parsons, Kansas

Where: Labette Community College  
Parsons, KS  
Contact: Tammy Taylor (316) 421-5268

### Indianapolis, Indiana

Contact: Elaine Donhoffner (317) 841-0241  
Robert Birdwell (317) 352-0235

### Detroit, Michigan

Contact: Marrienne Tarpinian (313) 883-1123

### Chicago, Illinois

Contact: Carol Wilcox (312) 445-2263

### Cleveland, Ohio

Contact: Norma Markowitz (216) 247-8785

### Northern New Jersey

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

Contact: Ann Lee Beyer (201) 391-4624

### Central New Jersey

Where: Princeton Medical Center  
Lambert House  
Classrooms #1&2

Contact: Janet Selah (201) 281-6289

### New York, New York

Where: Rusk Institute of Rehab. Medicine  
Room RR (6th floor Research Wing)  
400 East 34th Street (at First Ave.)

Contact: Linda Goldfarb (212) 496-0001

### Rochester, New York

Contact: Neale Bachmann (716) 554-6644  
Bernice Roll (716) 584-3585

### Boston, Massachusetts

Contact: Eunice Cohen (617) 894-9510

### Delaware Valley, Pennsylvania

Meeting: Holy Redeemer Hospital  
Meadowbrook, PA

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

### Pittsburgh, Pennsylvania

Contact: Garnett McDonald (412) 372-2853

### Tidewater, Virginia Area

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, Georgia

Contact: Molly Howard (404) 253-5632  
Sue Saye (404) 565-5950

### Orlando, Central Florida Area

Contact: Mary Beeler (407) 295-6215  
Meeting: Third Saturday of every other month

### Fort Pierce Area, Florida (Atlantic Coast)

Contact: Dorothy Stefanovich (407) 461-1016

# Attachment G.

## 1989 IN REVIEW

This year has been a year of growth and change for the NFPMA. We continue to add new CMT patients/families to our roster, we moved into a new office, and our educational program was greatly enhanced by our first national conference.

### SOUTH FLORIDA EVENT

The year got off to a great start when Rod and Karen Steele organized a fund-raising event in West Palm Beach, Florida. The party was at the South Florida Science Museum, and we are indebted to the museum for its support and assistance. The theme of the evening was "CMT, The Mystery Disease". As you all know, this is a very apt title for anything connected with this disorder. The featured attrac-



Rod Steele and Pat Pepper

tion was a troupe of actors who performed a "Who-done-it" during the evening. This was great fun with the audience becoming involved in the solving of the "crime". To the lucky detective with the correct solution, USAir awarded two round trip airline tickets to any place in the US that they fly. Among the guests of honor were baseball stars Gary Carter (formerly with the Mets) and Tommy Hutton (formerly with the Yankees, Dodgers and Phillies) and the mayor of West Palm Beach Pat Pepper. Besides wonderful food (all donated by South Florida businesses), the evening included an auction of donated goods. We are very grateful to Rod and  
(continued on page 9)

## 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 hr., 15 min.) rent for \$10, and the double lecture tapes (2 hr., 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, Crozer Mills Enterprise Center, 600 Upland Ave., Upland, PA 19015.

### *I want to be in touch!*

Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone Number: \_\_\_\_\_

#### *Tell us about yourself:*

- |   |   |
|---|---|
| <input type="checkbox"/> CMT Patient          | <input type="checkbox"/> Medical Professional |
| <input type="checkbox"/> Interested Supporter | <input type="checkbox"/> CMT Family Member    |
| <input type="checkbox"/> Other                |   |

*Fill out this form and return it today!*

#### *Please check the appropriate boxes:*

- |   |  |
|---|--|
| <input type="checkbox"/> Put me on the mailing list!                              | <input type="checkbox"/> CMT Genetics - \$10       |
| <input type="checkbox"/> CMT Neurology - \$10                                     | <input type="checkbox"/> Orthopedic Surgery - \$10 |
| <input type="checkbox"/> Physical Therapy - \$10                                  |  |
| <input type="checkbox"/> Physical Therapy/Orthopedic Surgery - \$15 (on one tape) |  |
| <input type="checkbox"/> Neurology/Genetics - \$15 (on one tape)                  |  |

## 1989 IN REVIEW

### WILMINGTON CONFERENCE



Gary Carter and Karen Steele ('89 REVIEW continued from page 8) Karen for the extraordinary job they did. The results were a wonderful party and financial support for the NFPMA.

### CHICAGO MEETINGS

Later in March Dr. Howard Shapiro spoke at a national genetics counselors conference. His speech was about our outreach and support group programs. The same weekend he conducted a half-day CMT conference at Rush-Presbyterian Medical Center. (See Spring '89 NFPMA Report) This was the first time the NFPMA sponsored a meeting in the Midwest.

### ANNUAL BOARD MEETING

In April at the annual Board of Directors meeting the following officers were elected: Karol Hitt, president; Rod Steele, vice-president; Diane Freaney, treasurer; Howard Shapiro, secretary; and Rex Morgan, Jr., assistant-secretary. In addition the board includes George Crohn, Herman Cohen, Ann Beyer, Donald Perrella, William Harra, Robert Lovelace, Lawrence Williams, and Lawrence Wechsler.

In September the NFPMA and the A.I. duPont Institute sponsored a two day educational conference for medical professionals, CMT patients and families. The meetings were at the Institute in Wilmington, DE.. On Friday the target audience was medical professionals. They learned about the diagnosis and treatment of CMT from a variety of experts. (For a complete listing of the participants, see the Spring '89 NFPMA Report.) On Saturday the audience was primarily CMT patients and families. Again, we learned from the experts about the latest in treatment and research. The day also included several workshops which were conducted by interested patients and family members. This reporter would be remiss if I did not tell of the mime workshop done by Steve Gullick. Steve, a professional mime and a CMT patient, entertained and gently taught the attending children. The day ended with a delicious evening meal served at the Institute. Recognition is now given to the food service staff for their contribution to the day. On Sunday support group leaders and interested people met to discuss the support group program. This informal meeting was fun and enlightening. The tone of the whole conference was one of learning, support and companionship. The participants agreed the conference was very worthwhile and urged that it become an annual event. We are deeply indebted to Dr. Harold Marks and the Institute for their support and involvement in the conference. A.I. duPont is a premier children's facility, and we are fortunate that they are

committed to the CMT patient/family community.

### NFPMA OFFICE MOVES

In October the NFPMA office moved into an office center. This now gives us office amenities which we have not had before. Our goal is to provide the CMT patient/family with more information and assistance, in a better organized manner.

### 1990 PLANS

The plans for 1990 include more area conferences. At this writing the cities have not been finalized. The sites depend on funding. If you live in a major metropolitan area and would like a meeting in your area, contact us. We also have plans for an expanded public relations program. We need to let the CMT community know of our existence. There is much to be done on a national level to educate the patient and public about CMT, the most common inherited neuropathy. You as an individual can do much to educate your friends and family about this disorder. The more that is known about CMT by the general public, the more they will support efforts to alleviate it. Finally, we wish you well and hope 1990 will be kind to you and yours.



### 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.

\* Resigned in  
February 1990

## NFPMA MEMORIAL CONTRIBUTIONS

### *In Memory Of*

Dr. Abraham Sand  
 Dr. Abraham Sand  
 Dr. Abraham Sand  
 Dr. Abraham Sand  
 Dr. Arnold Goldman  
 Tillie Giovin  
 Sylvan Shapiro  
 Sylvan Shapiro  
 Zena Cohen  
 Frank Cacckello  
 Wayne E. Hamilton  
 Irving J. Finkelman  
 Irving Finkelman  
 Harris Grossman  
 Harris Grossman  
 Sarah Jo Mitchum  
 Harry Brezel  
 Millard K. Winchell  
 Louise Scarsella  
 John W. Brennan, Jr.  
 Anne Bernstein  
 Virginia B. Lee  
 Jerry Rothman  
 Mathew McNeil  
 Mathew McNeil  
 Mathew McNeil  
 Mathew McNeil  
 Mathew McNeil  
 Mathew McNeil  
 Betty's father  
 Mollye Schwartz

### *by*

Freeman & June Campbell  
 Mr. & Mrs. Mark Sand  
 Alvin & Annerose Walcoff  
 Miriam A. Sand  
 Alvin & Annerose Walcoff  
 Mr. & Mrs. Morris Woolman & family  
 Rebecca Sand  
 Elly Kazin  
 Bessie Pintzuk  
 Dominick Calsolaro  
 Mr. & Mrs. Orville Lecureux  
 Mr. & Mrs. Robert Tissot  
 Harold & Ruth Lauman  
 Mr. & Mrs. George Lauman  
 Mr. & Mrs. Gilbert Logan  
 Mr. & Mrs. Edwin Logan  
 Dr. & Mrs. Richard A. Hogan  
 Ruth Finkelman  
 Mr. & Mrs. Howard Finkelman  
 Julie Leonard  
 Irma Jaffe  
 Alexis McBroom  
 Dr. Karen Edelson  
 Phyllis M. Warren  
 Edward Scarsella  
 Mary Brennan  
 William Bernstein  
 Thomas H. Lee  
 George Young  
 Judy Foster  
 Albert & Dorothy Newton  
 Michael & Natalie Newton  
 Charlie, Joanie & Gertrude Russell  
 Howard Travelpiece  
 Bill Ealy  
 Rebecca Brezel  
 Mr. & Mrs. Michael Schwartz & family

## MORE PROGRESS IN CMT RESEARCH

As reported in the last issue of *The NFPMA Report*, last summer a research team headed by Dr. Jeffrey Vance from Duke University announced that they believed they had found the genetic defect for CMT on chromosome 17.

News of this finding sparked CMT researchers in Texas, Utah and Belgium to check their blood samples for similar DNA markings. So far their work appears to back up Vance's claim and has lead to more extensive genetic mapping of the CMT gene. "There's been a lot of progress over the last few months in terms of narrowing the location on chromosome 17," says Dr. Kenneth Fishbeck, head of the neurology department at the University of Pennsylvania. "Other research groups have confirmed the chromosome 17 location as being probably the most important CMT locus. We're a lot more sure than when the Vance study came out. We've gone from knowing the CMT gene is on chromosome 17 to knowing where it is on chromosome 17."

This encouraging news will hopefully lead to more progress in the identifying and treating the CMT disorder. *The NFPMA Report* will continue to closely monitor the situation.

—Rex Morgan, Jr.

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### *The NFPMA Report*

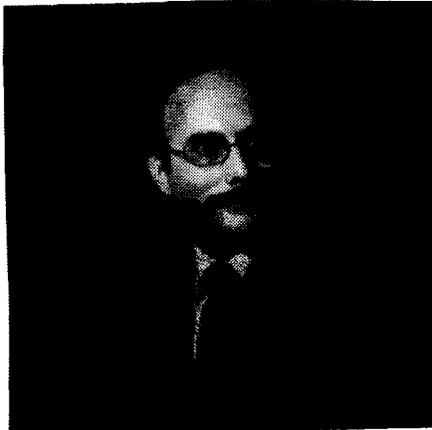
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# NFPMA Founder Howard K. Shapiro to Pursue New Interests

Dr. Howard K. Shapiro, the founder of the NFPMA, has resigned as the Director of Scientific Program of the organization. Dr. Shapiro is leaving to pursue other longstanding interests.



Dr. Howard K. Shapiro

After receiving a doctorate in biochemistry from Bryn Mawr College, Dr. Shapiro worked for several years in CMT research at the University of Pennsylvania Medical School, where he remains an adjunct research associate. While at Penn he perceived the need for an organization devoted solely to Charcot-Marie-Tooth disorders. In 1983, with other interested and dedicated people, the NFPMA was founded. Dr.

Shapiro's perseverance and dedication guided the foundation through those early years.

In 1987 Dr. Shapiro and Dr. Robert Lovelace, of Columbia

University College of Physicians and Surgeons, presided over the Second International Conference on Charcot-Marie-Tooth Disorders. The meeting was at Columbia's conference center in Harriman, NY. It was attended by CMT clinicians and researchers from the United States and 14 foreign countries. A book based on these proceedings, edited by the Drs. Shapiro and Lovelace has been recently published. Dr. Shapiro will continue his association with the NFPMA as a member of the Board of Directors. We thank Dr. Shapiro for his work on behalf of the CMT patients and wish him well in his future endeavors.

α

## NFPMA REMEMBRANCES

Your gift to the NFPMA can honor a living person or the memory of a friend or loved one. Acknowledgment 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, Crozer Mills Enterprise Center, 600 Upland Ave., Upland, PA 19015.*

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## Call for Articles

### ***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. Also, 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:

Summer '89  
Spring '89  
Winter '89  
Fall '88  
Spring/Summer '88  
Winter '88  
Summer/Fall '87  
Spring '87  
Winter '87

Write or call the NFPMA at  
(215) 499-7486

## CMT...

- .....is the most common inherited neurological disease, affecting approximately 125,000 Americans.
- .....is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- .....is slowly progressive, causing deterioration of peripheral nerves which control sensory information and muscle function of the foot/lower leg and hand/forearm.
- .....causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- .....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 scoliosis (curvature of the spine) is sometimes present.
- .....does not affect life expectancy.
- .....has no effective treatment, although physical therapy, occupational therapy and moderate physical activity are beneficial.
- .....is sometimes surgically treated.
- .....is usually inherited in an autosomal dominant pattern, affecting half the children in a family with one CMT parent.
- .....may become worse if certain neurotoxic drugs are taken.

# ***THE NFPMA REPORT***

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