FALL 2000

The CMTA Report

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A resource for information on Charcot-Marie-Tooth disease (Peroneal Muscular Atrophy or Hereditary Motor Sensory Neuropathy), the most common inherited neuropathy.

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Rain Can't Dampen Success of First Annual Golf Outing

By RICHARD L. SHARPE

Golf event in Sands Point, New York raised over $25,000 for CMT research.

On August 14, 2000, the Charcot-Marie-Tooth Association held its first golf outing at the exclusive Sands Point Golf Club in New York. The event was fully subscribed, with 72 golfers enjoying a full day of activities including brunch, golf, cocktails, and a full buffet dinner. The event, which will be held on an annual basis, raised over $25,000 to be used to further CMT research.

This substantial contribution to CMT research would not have been possible without the generous support of AFA Protective Systems, Inc., the country's oldest central station fire and burglar alarm company. AFA was the exclusive underwriting sponsor for the event, assuming all the basic costs. Thanks to AFA's sponsorship, all ticket proceeds benefitted the CMTA. The CMT Board is very appreciative of the generosity of Robert Kleinman and AFA for the wonderful support of the CMTA.

The day began with the golfers enjoying an excellent brunch prepared by Chef Dominic and then heading out to the course, with 18 foursomes competing for an extensive list of prizes to be awarded for low net, low gross; and individual prizes for longest drive and closest to the pin. Unfortunately the weather did not cooperate, and play had to be suspended after about 4 holes because of thunder and lightning storms in the area. When the weather did not clear after a 1½ hour wait, the golf tournament had to be cancelled, and the outing participants then enjoyed cocktails and a full dinner buffet. During the cocktail and dinner festivities, the names of all the outing attendees were placed in a hat, a

(continued on page 2)

CREATING A SUCCESSFUL FUNDRAISER

The New York area CMTA Golf Outing had all the elements required to assure the success of fundraisers of this type: a generous underwriting sponsor, a challenging and sporty golf course, excellent food, some great prizes, and the support of members of the CMT Association who participated in planning the event, attending the outing on August 14, or providing monetary support.

The planning and implementation of this event required a lot of hard work by the Board members and the result was an almost "perfect" (unfortunately no one can control the weather), outing when measured by the funds raised and the positive response of those attending.

Other CMTA members might wish to consider a golf outing as a means of raising funds to further CMT research. Anyone undertaking such an event would benefit from the lessons learned by the New York organizers. Richard Sharpe, Treasurer (516-656-0681), would be willing to share his expertise in running this event with anyone wishing to call.

The Year in Review

By JACK WALFISH, President

I usually go through the exercise of presenting a report to the Board of Directors for each bi-monthly meeting to keep them informed of the current state of affairs of the organization. This report, however, is triggered by the required Annual Audit, which forces the CMTA staff and me to mine the depths of the computer data, plus our paper records (some of which are in poor condition as a result of last year's flooding), to satisfy the auditor that what we claim is what actually took place. This fiscal year was one of both good news and bad news. You can see that by examining the audit on pages 10–12.

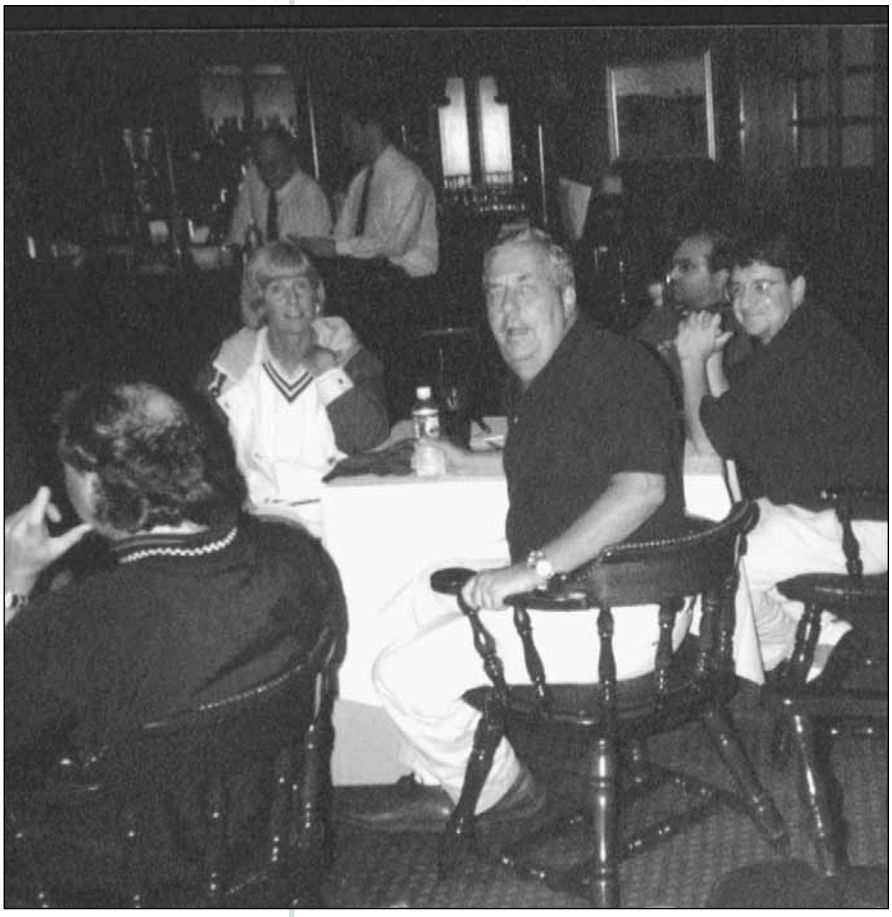
First the bad news. The single, most important event was the flooding caused by Hurricane Floyd and the havoc it played on our office with the destruction of furniture, computers and paper records.

But, like the Phoenix rising from the ashes, many good things have happened as a result of that flood. We were able to quickly replace the computers and retrieve the data from our server, which had been located out of harm's way, so we could continue to operate. Although, as I reflect now, we were operating under rather unbearable conditions. We found a firm that specializes in restoring water-damaged records, but what we have now are far from perfect.

I must pay tribute, here, to the loyalty and dedication of our staff. Without their hard work under extremely harsh conditions, we would not have had the ability to operate, even during the time that the new office was being set up. Our "forced" move to a new, more expensive site has provided more space, more pleasant working conditions, and thereby, better service to our clients.

The fiscal year 2000 has proved, so far, to be a great year for the CMTA in terms of giving. The single largest gift ever, the James Thomas Moore bequest, propelled the research fund to almost $160,000, and we are planning to award a fellowship grant in his honor. We did award

Co-organizer of the Sand Point Golf Tournament, Richard L. Sharpe enjoys the gourmet food with his wife Sheila (opposite) during a rain delay.



GOLF FUNDRAISER

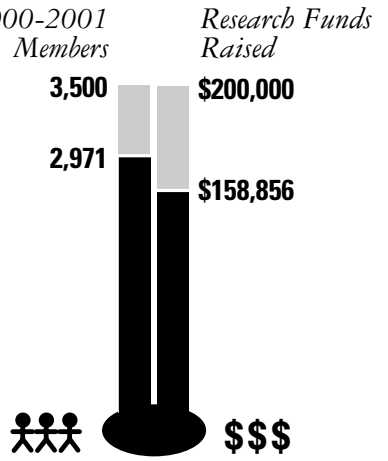
(continued from page 1)

drawing was held, and all the prizes were awarded. The participants were unanimous in their praise of the club facilities, the challenging and sporty golf course, and especially the spectacular food at the brunch and dinner buffets.

CMTA Board members attending the event were Ann Lee Beyer, Chairman, Richard L. Sharpe, Treasurer, and Phyllis Sanders. Additionally, Jeff Beyer, Pam Kleinman, Jamie Kleinman and Sheila Sharpe volunteered their time to assist with registration and monitoring the longest-drive and closest-to-pin contests.

The Board is very grateful to everyone who attended the outing for their monetary support of the CMTA, to many invited guests who could not attend, but provided a donation to the CMTA, and particularly to Robert Kleinman and AFA Protective Systems, the very generous underwriting sponsor. AFA will also be the exclusive underwriting sponsor of the 2001 outing, making another substantial contribution to CMT research possible. With clear skies, and the continuing support of members of the CMT Association, the 2001 golf outing should surpass the success of this year.

Our Fundraising Progress as of September 15, 2000:



three postdoctoral grants of $35,000 each, but did not award the small summer grants, believing that more was gained from the larger, full-year studies. For the calendar year beginning in January of 2001, we will again award the postdoctoral grants.

The long-awaited genetics booklet has been published and is available now from the office. This is the first genetics booklet completely dedicated to a discussion of the inheritance patterns in many of the forms of CMT. This landmark work was written by Karen Krajewski and Anne Greb of Wayne State University. The publication was sponsored in part by Athena Diagnostics, the CMTA, and Wayne State University School of Medicine.

Two patient-family conferences have taken place as of this writing. One was held in August at the University of Utah School of Medicine, Salt Lake City, Utah, and the second one occurred at the University of Pennsylvania School of Medicine in Philadelphia. Family conferences bring together knowledgeable CMT specialists who donate their time to educate and inform persons with CMT and their families about the latest in research and treatment.

We continue to honor our vision and mission by creating awareness of CMT through our home page, our informational packets, our attendance at medical conventions, and the publication of our newsletter. More than ever, we are encouraging, promoting, and supporting research into the cause, treatment, and eventual cure of CMT.

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CMTA MEMBERSHIP/ORDER FORM

Name:_____

Address:_____

_____

Phone Number:_____ Email: _____

Members who are current with their dues are considered "active."
If you are unsure as to whether you are current with your member dues, please call the office at 1-800-606-CMTA.

	QTY	COST	TOTAL
Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians		*active members* $15 ***inactive members* $20**	
Membership Dues		$35	
SPECIAL OFFER FOR ACTIVE MEMBERS ONLY: CMT Facts Series (I-IV)		*active members* $16	
CMT Facts I ☐ English ☐ Spanish		*active members* $3 ***inactive members* $5**	
CMT Facts II ☐ English ☐ Spanish		*active members* $5 ***inactive members* $7**	
CMT Facts III		*active members* $5 ***inactive members* $7**	
CMT Facts IV		*active members* $8 ***inactive members* $10**	
A Guide About Genetics for the CMT Patient ***NEW!*** *No shipping and handling on this item only.*		*active members* $4 ***inactive members* $5**	
VCR Double Tape: duPont Conference		*active members* $25 ***inactive members* $40**	
CMT Informational Brochure ☐ English ☐ Spanish		FREE	*Send Self-Addressed Stamped Envelope*
Physician Referral List: States: _____ _____ _____		FREE	
Letter to Medical Professional with Drug List		FREE	
Contribution to CMT Research *10% will be applied to administrative expenses.*			
Shipping & Handling *Orders under $10 add $1.50, orders over $10 add $3.00*			
TOTAL			

☐ Check payable to the CMTA (US Residents only).
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Mail to the CMTA, 2700 Chestnut Parkway, Chester, PA 19013

A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling, toll-free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.

Getting Educated About Genetic Testing

By VINCENT BERTOLINO, Athena Diagnostics

We live in a very interesting age. Scientists now have the whole human genome decoded, the biomedical equivalent of putting the first man on the moon. The achievement itself does not produce answers, but rather, more questions. It also creates more choices for us to make about our healthcare. These choices usually come to our attention before we have the understanding to make an informed decision. Not understanding the issues in the age of genetic testing can cause decision-making to be compromised, benefits of technology to be unrealized, and new problems to be created.

Physicians have been performing genetic examinations for years in the form of the patient's family history. The added capability of being able to identify who in the family has a particular gene, and to make predictions about one's future health status, improves the physician's diagnostic and prognostic power. It can also become an irrefutable fact forced into the patient's unready psyche.

Since genes are inherited in specific ways, identifying a gene in one individual can make it possible to figure out who else in the family must have the same gene. This can cause problems with family members who may not want to know about their genetic status, yet become involuntarily diagnosed as a result of a relative being tested. Inappropriate application of genetic tests can also cause unnecessary pain in the form of guilt, or change behavior in unconstructive ways.

Denial of insurance coverage on the basis of one's genetic tests can also be a significant concern. This is a complex issue. If your medical chart contains a diagnosis and history of CMT, then you already have genetic information in your life regardless of whether you also get tested. This is true any time a physician takes patient and family history for any disorder (cholesterol, heart disease, cancer, etc.).

The best defense against these perils is education. You can start doing this on your own with publications available from the CMTA, like the recently published *Guide About Genetics for Patients: Charcot-Marie-Tooth Disease*. But don't let this be your only source of information. Talk with your doctors, seek referrals to genetic counselors, and talk with other patients in the support groups about their experiences. Once you have taken the time to educate yourself, you will be better equipped to judge the value and benefit of genetic diagnosis in your case, if any.

The principle benefit of gene testing is establishing the molecular definition of the diagnosis. That is, the physician always makes the diagnosis. The various tests and questions help the doctor narrow the likely candidates until one stands out as the most likely. Going the extra step can confirm the physician's suspicions, and provide the specifics about the underlying cause. This is especially useful when the clinical picture is unclear, or not what you would typically expect.

Without an affected family member who has already been tested, it is impossible to determine which gene is affected. Frequently, the doctor will order a profile of genes on that first individual. Once the specific gene has been identified, it might not be necessary to test any other affected family members. Once again, this is a discussion you would have to have with your physician or genetic counselor.

Some questions you might want to consider:

- How will having a genetic test affect your life, and the lives of those close to you?

Ann Lee Beyer and Karen Krajewski pose before a poster display at the American Academy of Neurologists' Meeting. Karen is the co-author of the new genetics guide for patients with CMT. (See article on facing page.)

- Would you do anything differently if you knew your variant with certainty?
- How would you feel after acquiring the new information?
- Will the knowledge be helpful for your family? What if other family members don't want to know?
- How would it affect your insurability or employability?

Depending on your situation, there may be some specific benefits of testing. A negative result on such a test could remove the family history of CMT from your medical records. This of course assumes that the variant of CMT in your family can be identified by a test. If no affected individuals in your family have been tested, and you are without symptoms, there is no guarantee that you are free from risk, since the family's particular variant may not be detectable. This is why medical professionals who understand genetics always want to start testing with an affected individual before moving on to other family members.

Family planning can benefit from testing. Knowing your variant of CMT with certainty will tell you how the trait is inherited, and under what circumstances it might not be passed on. For instance, if you are a male and your test result is positive for CMTX, and your wife does not have CMT, you can expect that none of your sons will have CMTX, and that all of your daughters will be carriers of CMTX.

Another practical benefit of testing is the avoidance of neurotoxic therapies. A CMT family member, who does not have symptoms, yet requires a therapy that has been clinically documented to be harmful to individuals with CMT, might benefit from testing. The most published example of this is the case of the drug Vincristine. Vincristine is a therapy for various types of cancer. Case reports have documented its devastating effects upon non-symptomatic carriers of CMT. Even deaths have occurred.

These are a few compelling reasons for testing that are medically relevant. Perhaps the most compelling reason is our own personal choice. Do we want to know, or don't we. No one can stop you from exercising that choice, but understand what making the choice means. Take the time to get educated and talk with the specialists. Always bear in mind that the decisions you make about genetic testing will be with you for life.

VISIT OUR HOMEPAGE

at

www.charcot-marie-tooth.org

First CMT-Specific Genetics Booklet Available to CMTA Members

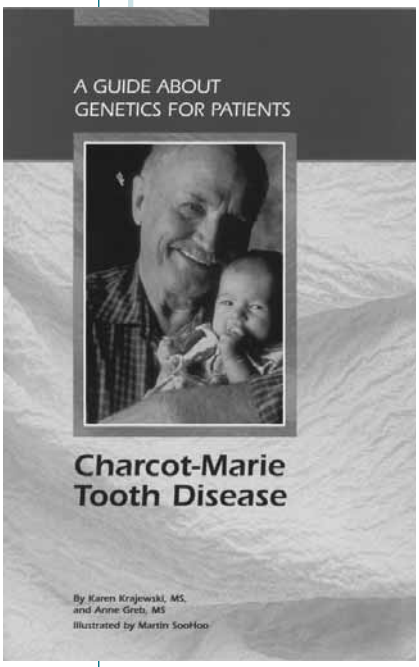
The long-awaited booklet on the genetics of CMT is available from the CMTA for the price of $4 for current members and $5 for non-members. All proceeds from the sale of this booklet will go to fund research to help in the ultimate cure of CMT. The booklet is printed on high-quality glossy paper with approximately twenty pages of information on the disease itself as well as the genetic inheritance patterns. Replete with illustrations, the booklet makes the various inheritance patterns understandable to the lay person.

The booklet is the result of a tremendous effort on the part of Karen Krajewski, MS, Wayne State University, Department of Neurology and Anne Greb, MS, of Wayne State University, Center for Molecular Medicine and Genetics. In addition, Athena Diagnostics, Worcester, MA, generously provided funding to have the booklet published so that CMTA members would have access to this information.

Not only does the booklet explain, in detail, about CMT1A, 1B, CMTX, and HNPP, but it also explains autosomal recessive inheritance patterns. Because the Type 2 variations of CMT have not yet been linked to the causing genes or the specific mutations, those forms are not discussed in detail.

Some commonly asked questions, such as "If someone in my family does not have symptoms of CMT, can he or she have a child with CMT?" or "Why am I the only one in my family with CMT?" are covered in the closing pages of the booklet.

In a compact and easily read format, this little booklet, *A Guide About Genetics for Patients: Charcot-Marie-Tooth Disease*, is a must-have for every patient library. The CMTA is pleased to be able to make this booklet available to our members.



Applying for Social Security Assistance

By PAT DREIBELBIS (With editorial assistance from Phyllis Sanders, Esq.)

The procedure for applying for, and being granted, Social Security disability or insurance has long been a confusing and trying experience. Questions about the likelihood of being approved to receive disability insurance are often addressed to the CMTA Office. Social Security Disability Benefits are available for applicants who are unable to do any kind of work for which they are suited. While speaking with a member of the organization, Lawrence Porterfield, several useful pieces of information were given to me. He was successful in being approved for coverage and he believed that was the result of his having hired a lawyer who was well versed in Social Security's listing of impairments and how to complete the application. In fact, statistics show that people who apply for benefits with professional help have a much greater likelihood of getting benefits than people who apply on their own. I was surprised to learn that many law firms will represent applicants on a contingency fee basis where the lawyer gets paid only if he/she is successful in getting benefits. The fee, then, comes out of the back-due benefits.

Social Security Disability Benefits are available for applicants who are unable to do any kind of work for which they are suited.

Lawrence Porterfield purchased a book which is published by the National Organization

OF INTEREST

Pilot offers a new pen called "Dr. Grip," which is a retractable ballpoint pen that is promoted as being perfect for arthritis sufferers and people with carpal tunnel syndrome. Its unique cushion grip reduces writing stress by up to 40%. The larger barrel makes it easier to hold and CMT patients who have tried it note that it requires less pressure to hold and to write with. The cost is in the $5 range, but it is refillable and ink refills are about $1.

Two New Gene Tests Available

Athena Diagnostics is pleased to announce the addition of two new gene tests: early growth response gene 2 (EGR2), and peripheral myelin protein 22 (PMP22) DNA sequencing. The most common cause of CMT remains the PMP22 duplication, where an extra copy of the PMP22 gene is inherited. CMT may also be caused by mutations within the PMP22 genes in a minority of cases. These patients would not have been detected by the previous duplication test. EGR2, one of the latest CMT genes discovered, also accounts for a minority of patients.

With these two new tests, Athena now offers a total of five tests that analyze mutations affecting four different CMT genes. These tests are the PMP22 (duplication/deletion) DNA testing service for CMT1A and hereditary neuropathy with liability for pressure palsy (HNPP), the PMP22 DNA sequencing testing service for CMT1A, Dejerine-Sottas Syndrome (DSS), and HNPP, the connexin32 DNA sequencing testing service for CMTX, the myelin protein zero DNA sequencing testing service for CMT1B, CMT2E, DSS, and congenital hypomyelination neuropathy (CHN), and finally, the EGR2 DNA sequencing testing service for CMT1D and CHN.

These tests are offered in profiles that address the clinical syndromes as well as those of the individual. Tests and profiles are only available by prescription from your physician. Athena supports the responsible use of genetic tests under the supervision of a knowledgeable physician, and encourages the use of genetic counseling in the education of patients about their testing choices.

—Vincent Bertolino, Athena Diagnostics

of Social Security Claimant's Representatives and is called *The Listing of Impairments*. He very generously donated that book to the office for our reference shelves.

Section 11 is the one specifically related to neurological impairments. Section 11.14 is titled "Peripheral Neuropathies," with disorganization of motor function as described in 11.04B, in spite of prescribed treatment. 11.04B reads: "Significant and persistent disorganization of motor function in two extremities, resulting in sustained disturbance of gross and dexterous movements or gait and station (See 11.00C)." 11.00C reads: "Persistent disorganization of motor function in the form of paresis or paralysis, tremor or other involuntary movements, ataxia and sensory disturbances (any or all of which may be due to cerebral cerebella, brain stem, spinal cord, or peripheral nerve dysfunction) which occur singly or in various combinations, frequently provides the sole or partial basis for decisions in cases of neurological impairment. The assessment of impairment depends on the degree of interference with locomotion and/or interference with the use of fingers, hands, and arms."

Clearly, most CMT patients would seem to qualify for social security insurance based on those descriptions, However, even when it seems clear cut that a person deserves benefits, the Social Security Administration will often deny benefits because a claimant's injury did not prevent him from performing some work. Often it is just a matter of securing medical evidence to support the claim.

CMT patients need their treating doctor to list all the restrictions they have on the application. The doctor needs to answer the following questions in support of the application. How long can the applicant stand and sit without pain? How far can the applicant walk without pain? How many flights of stairs can the applicant ascend or descend without pain? Can the applicant drive a car? Can the applicant use public transportation?

Often a person with severe CMT disease is depressed or has an anxiety disorder. This is a very important factor in determining eligibility. If the applicant is seeing a psychologist or psychiatrist, the applicant must give this information to the Social Security Office.

In the past, the organization has heard numerous horror stories of the number of times a claim has been denied before the person is granted coverage. Hopefully, this information will help applicants and improve the chances of their being approved with the first application.

Upper Body Exercises for Neuropathy

By NORA A. LUSTIG, MA, OTR

These exercises promote strength and flexibility throughout the shoulders, elbows, wrists, and fingers. Perform them slowly, 10 times each, and increase repetitions as you feel ready.

HALLELUJAH

- Stand or sit with arms at sides, elbows straight.
- Bring arms overhead at an angle halfway between side and front.
- Try to keep your shoulder blades back and down while moving.
- Lower arms slowly.

BICEP CURLS

- Sit or stand with arms at side, elbows at waist.
- Bend elbows, bringing hands up to shoulders.
- Lower slowly.

WRIST LIFTS

- Sit or stand with elbows bent halfway.
- Hold a light weight or soup can in each hand with your palms facing down.
- Only moving at your wrists, lift hands up and slowly lower down.
- Repeat exercise with palms facing ceiling.

HAND TENDON GLIDING EXERCISES

A true liberator of the hands: promotes circulation and well-being by "lubricating" the fingers so the tendons glide with more ease and the hands become more flexible. You can do them at the movies or one hand at a time, while you're sitting and talking on the phone, etc. They may look complicated here, but they're really easy.

- Make a finger sign of a duck's beak, thumb open, forefinger separated by 4 inches, hold 3 seconds, release, opening fingers wide toward ceiling in an open-fingered greeting.
- Make a cat's claw, bending fingers and thumb at first joint, hold 3 seconds, release, opening fingers wide toward ceiling.
- Make a closed fist, thumb open and 4 fingertips touching lower palm, hold 3 seconds, release, opening fingers wide toward ceiling.
- Make a tight fist, bending all fingers and thumb tightly toward mid palm, hold 3 seconds, release, opening fingers toward ceiling.

Consult your physician before doing any new exercises.

(Reprinted from The Neuropathy News.*)*

Utah Conference Held Saturday, August 5, 2000

The University of Utah School of Medicine, Department of Neurology, and the Charcot-Marie-Tooth Association co-hosted the first conference in Utah designed for patients with Charcot-Marie-Tooth neuropathy and their families. Over fifty patients, family members, and medical professionals attended the all-day event.

The program ran from 9 AM until 4:30 PM and covered such topics as: "CMT… from A to Z," "Who Were C, M, and T?" "Genetic Issues in CMT," "Orthopedic Issues," "What Exercise Is Right for You?" and "Where to Go When You Need Help."

The presentation on "What Exercise is Right for You?" by Eduard Gappmaier, PT, PhD, stressed the importance of accumulating 30 minutes or more of moderate-intensity physical activity on most, preferably all, days of the week. A report from the Surgeon General has found that "significant health benefits can be obtained by including a moderate amount of physical activity on most, if not all, days of the week. Through a modest increase in daily activity, most Americans can improve their health and quality of life."

What do the experts recommend for patients with CMT?

Slowly progressive regular exercise has benefits, especially when begun early in the disease process.

Some of the presenters at the Utah conference included, left to right, Kevin Flanigan, MD, Victoria Lawson, MD, Mark Bromberg, MD, PhD, Ardith Fetterolf, CMTA Vice President, Patrick Mahoney, LCSW, Eduard Gappmaier, PT, PhD.

Exercise has many benefits for the CMT patient. Experts recommend 30 minutes of moderate physical activity on most days of the week.

It is important to prescribe enough activity to avoid additional weakening from disuse atrophy.

The exercise program should be carefully prescribed and supervised.

The goals of the exercise program according to Dr. Gappmaier are:

- To improve cardiovascular fitness, to prevent premature onset of hypokinetic (underactivity) disease.
- To increase, maintain or slow loss of strength and endurance and prolong function.
- To maintain adequate muscle mass for activities of daily living and occupational and leisure pursuits.
- To prevent or slow development of complications (contractures, disuse atrophy, etc.).

Dr. Gappmeier concluded his presentation by stressing that it is necessary to protect severely weakened muscles and that daily flexibility training and stretching exercises can help prevent contractures, which are much easier to avoid than to correct. Before starting any exercise program, a patient should consult his/her doctor, have his/her exercise supervised by a trained health professional, and be monitored for the first two months. If there is increased fatigue, weakness or pain, the exercise intensity and duration should be decreased. There should be complete recovery after a night's sleep.

Vice-President Ardith Fetterolf represented the CMTA at the conference and presented a brief overview of research and the mission and vision of the organization.

Celebrating Ten Years of the Americans with Disabilities Act

(Editor's note: This article is published with the permission of the Genetic Alliance. It appeared in their July 2000 issue of Alliance Alert.)

On July 26, 1990, the Americans with Disabilities Act (ADA) was signed into law. It was a momentous occasion, the result of years of dedication by people with disabilities and their families, friends and advocates. Twenty-six years after the passage of the Civil Rights Act, people with disabilities were finally guaranteed equal protection from discrimination.

Genetic conditions can cause a wide range of disabilities, affecting individuals and families. Because of the ADA, people with disabilities have the right to equal opportunity and access to employment and certain services. There is no way to quantify the difference this access has made in the lives of people with disabilities, or in the benefit to our society overall.

The 10th anniversary of the Americans with Disabilities Act was celebrated everywhere. From the nation's capital to small towns in every state, people reflected on the difference the ADA has made in their lives and the lives of their loved ones. A "Spirit of the ADA" torch relay was punctuated by celebratory events nationwide. At the FDR Memorial in Washington, DC, "Honoring the Heroes" paid tribute to advocates who worked to ensure the passage of the ADA.

We must also understand the protections provided by the ADA and other disability laws for people with genetic conditions. The ADA specifically prohibits discrimination on the basis of disability in employment, state and local government services, public accommodations, commercial facilities, transportation and telecommunications. The ADA defines disability as a physical or mental impairment that substantially limits one or more major life activities, a history or record of such an impairment, or the perception by others of such an impairment.

Many groups have been leaders in defining issues and policies that affect persons with disabilities. These include, but are not limited to, the US Equal Employment Opportunity Commission, American Association of People with Disabilities, National Council on Disability and the President's Commission on Employment of Adults with Disabilities. These groups and many others work to provide valuable resources for the genetics community as well.

Incredible progress has been made, but challenges still lie ahead. We must be vigilant to ensure that the laws are interpreted broadly enough to cover all aspects of disability discrimination, including mental illness and genetic predispositions. It is not clear that protections offered by the ADA are sufficient to safeguard genetic privacy and prevent discrimination in the workplace based on genetic predispositions.

Genetic conditions that impact mental health may make it difficult to take advantage of ADA protections. The law requires that individuals disclose their health condition before requesting special accommodations. Fear of stigmatization can make this difficult to do. In addition, recent Supreme Court decisions have ruled that the ADA does not cover individuals when their condition can be controlled. For example, a person with the genetic condition bipolar disorder would only be covered by the law when they did not take their medication.

The ADA is a landmark piece of legislation for all persons with disabilities, yet there is still work to be done to ensure that it is used to its full potential to protect people with genetic disabilities. Both the genetics and the disability communities will be working to ensure that this is the case. What unites these communities is the overall goal of quality of life for everyone affected by genetics and disability.

QUESTIONS AND ANSWERS ABOUT IDEA

The National Information Center for Children and Youth with Disabilities has published a second edition of Questions and Answers about IDEA. This publication answers many of the questions families and professionals have about the requirements of the Individuals with Disabilities Education Act. This edition has been revised to reflect IDEA regulations that were released in 1999. First copy is free; additional copies $4.00 each. To order, contact the National Information Center at 800-695-0285 or email nichcy@aed.org.

OF INTEREST

The Exceptional Parent Library is pleased to offer the book *The Complete IEP Guide: How to Advocate Your Special Ed. Child.* It is a comprehensive step-by-step guide through the entire IEP process that provides encouragement and advice, making the complicated process that much easier to navigate and understand. The book is filled with instructions, suggestions, strategies, resources, forms, and much more. The book costs $24.95 and it is listed under item code NL001SE. For a review of the book and a complete listing of the almost 1000 other books and videos in over 50 need-specific categories, just visit the website at eparent.com.

Charcot-Marie-Tooth Association

INDEPENDENT AUDITORS' REPORT

To the Board of Directors
Charcot-Marie-Tooth Association
Chester, Pennsylvania

We have audited the accompanying statement of financial position of Charcot-Marie-Tooth Association (a Pennsylvania nonprofit corporation) as of June 30, 2000, the related statements of activities, cash flows and functional expenses for the year then ended. These financial statements are the responsibility of the Association's management. Our responsibility is to express an opinion on these financial statements based on our audit. The prior-year summarized comparative information has been derived from the Organization's 1999 financial statements and, in our report dated July 30, 1999, we expressed an unqualified opinion on those financial statements.

We conducted our audit in accordance with generally accepted auditing standards. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Charcot-Marie-Tooth Association at June 30, 2000, and the changes in its net assets and its cash flows for the year then ended, in conformity with generally accepted accounting principles.

August 11, 2000

STATEMENT OF FINANCIAL POSITION

JUNE 30, 2000 WITH COMPARATIVE TOTALS FOR JUNE 30, 1999

ASSETS	2000	1999
CURRENT ASSETS		
Cash	$343,403	$132,154
Unconditional promises to give	-	54,250
	343,403	186,404
EQUIPMENT - Net of accumulated depreciation of $11,719	17,746	17,193
OTHER ASSETS	4,523	1,888
TOTAL ASSETS	$365,672	$205,485
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	$ 2,034	$ 6,235
Accrued expenses	578	71
TOTAL LIABILITIES	2,612	6,306
NET ASSETS		
UNRESTRICTED	164,206	81,762
TEMPORARILY RESTRICTED	198,854	117,417
TOTAL NET ASSETS	363,060	199,179
TOTAL LIABILITIES AND NET ASSETS	$365,672	205,485

STATEMENTS OF CASH FLOWS

JUNE 30, 2000 WITH COMPARATIVE TOTALS FOR JUNE 30, 1999

	2000	1999
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	$ 163,881	$(87,083)
Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities		
Depreciation	4,613	5,232
Donated equipment	(1,660)	(4,500)
(Increase) decrease in assets		
Unconditional promises to give	54,250	47,412
Other assets	(2,635)	(261)
Increase (decrease) in liabilities		
Accounts payable and accrued expenses	(3,694)	(4,037)
Accounts payable - research grant	-	(35,000)
Net cash provided by (used in) operating activities	214,755	(78,237)
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchase of property and equipment	(3,506)	-
NET INCREASE (DECREASE) IN CASH	211,249	(78,237)
CASH - BEGINNING OF YEAR	132,154	210,391
CASH - END OF YEAR	343,403	$132,154

The accompanying notes are an integral part of these financial statements. *See page 12.*

Financial Report as of June 30, 2000

STATEMENT OF ACTIVITIES

YEAR ENDED JUNE 30, 2000

(WITH SUMMARIZED FINANCIAL INFORMATION FOR THE YEAR ENDED JUNE 30, 1999)

	2000			
	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL	1999 TOTAL
SUPPORT AND REVENUES				
Contributions	$263,873	$ 197,050	$460,923	$440,685
Interest income	9,550	-	9,550	8,547
Donated equipment	1,660	-	1,660	4,500
	275,083	197,050	472,133	453,732
NET ASSETS RELEASED FROM RESTRICTIONS				
Satisfaction of program restrictions	115,613	(115,613)	-	-
TOTAL SUPPORT AND REVENUES	390,696	81,437	472,133	453,732
EXPENSES				
Program services	253,992	-	253,992	461,013
Management and general	18,690	-	18,690	51,398
Fundraising	35,570	-	35,570	28,404
TOTAL EXPENSES	308,252	-	308,252	540,815
CHANGE IN NET ASSETS	82,444	81,437	163,881	(87,083)
NET ASSETS - BEGINNING OF YEAR	81,762	117,417	199,179	286,262
NET ASSETS - END OF YEAR	$164,206	$ 198,854	$363,060	$199,179

The accompanying notes are an integral part of these financial statements. See page 12.

STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED JUNE 30, 2000

(WITH SUMMARIZED FINANCIAL INFORMATION FOR THE YEAR ENDED JUNE 30, 1999)

	2000				1999
	PROGRAM SERVICES	MANAGEMENT AND GENERAL	FUNDRAISING	TOTAL EXPENSES	TOTAL EXPENSES
Salaries and benefits	$ 32,300	$ 1,855	$22,396	$ 56,551	$111,250
Publications and supplies	45,299	13,920	-	59,219	98,193
Occupancy and office expense	33,805	-	6,439	40,244	21,743
Research fellowships	105,129	-	-	105,129	157,044
Conference expense	28,988	-	-	28,988	138,080
Special event	-	2,915	-	2,915	580
Consulting	4,773	-	-	4,773	1,528
Professional fees	239	-	5,581	5,820	7,165
Depreciation	3,459	-	1,154	4,613	5,232
TOTAL FUNCTIONAL EXPENSES	$253,992	$18,690	$35,570	$308,252	$540,815

The accompanying notes are an integral part of these financial statements. See page 12.

CHARCOT-MARIE-TOOTH ASSOCIATION
NOTES TO FINANCIAL STATEMENTS—JUNE 30, 2000

NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Nature of Operations

The Charcot-Marie-Tooth Association (the Association) was established to create awareness of Charcot-Marie-Tooth (CMT) disorders within the health care community and the general public, and be a leading source of information regarding CMT disorders. The Association encourages, promotes and supports research into the cause, treatment and cure of CMT. The Association also facilitates education and support for persons affected by CMT.

Basis of Presentation

The Association follows Statement of Financial Accounting Standards (SFAS) No. 117, Financial Statements of Not-for-Profit Organizations to prepare its financial statements. Under SFAS No. 117, the Association is required to report information regarding its financial position and activities according to three classes of net assets: unrestricted net assets, temporarily restricted net assets and permanently restricted net assets.

Restricted and Unrestricted Support

The Association follows SFAS No. 116, Accounting for Contributions Received and Contributions Made in recording contributions received. Contributions received are recorded as unrestricted, temporarily restricted, or permanently restricted support, depending on the existence and/or nature of any donor restrictions.

Support that is restricted by the donor is reported as an increase in unrestricted net assets if the restriction expires in the reporting period in which the support is recognized. All other donor-restricted support is reported as an increase in temporarily or permanently restricted net assets, depending on the nature of the restriction. When a restriction expires (that is, when a stipulated time restriction ends or purpose restriction is accomplished), temporarily restricted net assets are reclassified to unrestricted net assets and reported in the Statement of Activities as net assets released from restrictions. There are no permanently restricted funds.

Estimates

The preparation of financial statements in conformity with generally accepted accounting principles requires the use of estimates based on management's knowledge and experience. Accordingly, actual results could differ from those estimates.

Functional Allocation of Expenses

The costs of providing the various programs and other activities have been summarized on a functional basis in the statement of activities. Accordingly, certain costs have been allocated among the programs and supporting services benefitted.

Equipment and Depreciation

Equipment is recorded at cost. Depreciation is provided on a straight-line basis over the estimated useful lives of the assets.

Tax Status

The Association is incorporated in the Commonwealth of Pennsylvania and is exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. The Association is registered as required with the Pennsylvania Bureau of Charitable Organizations.

In-kind Contributions

Volunteers have donated their time to the Association's program and administrative services and its fund raising campaigns. The value of this contributed time is not reflected in these statements since it is not susceptible to objective measurement or valuation.

The Association occasionally receives donations of property and equipment. During the year ended June 30, 2000, the value of donated assets is $1,660 and is reflected in the Association's funds.

Prior Year Comparative Data

The financial statements include certain prior-year summarized comparative information in total but not by net asset class. Such information does not include sufficient detail to constitute a presentation in conformity with generally accepted accounting principles. Accordingly, such information should be read in conjunction with the Association's financial statements for the year ended June 30, 1999, from which the summarized information was derived.

NOTE 2 - CONCENTRATION OF CREDIT RISK

At June 30, 2000, the Company has deposits with major financial institutions which exceed Federal Depository Insurance limits. These financial institutions have strong credit ratings, and management believes that credit risk related to these deposits is minimal.

NOTE 3 - TEMPORARILY RESTRICTED FUND

At June 30, 2000, the temporarily restricted fund had a balance of $198,854 comprised of monies for research grants and education.

NOTE 4 - LEASES

The organization conducts its operations from a facility leased under an operating lease expiring in November of 2002. At June 30, 2000, the organization was obligated under this lease arrangement as follows:

YEARS ENDING JUNE 30,	
2001	$16,300
2002	17,500
2003	7,500
	$41,300

GIFTS WERE MADE TO THE CMTA...

IN MEMORY OF:

Lois B. Basquill
Harry & Ruth Baker
Barbara Hayes
Christopher & Lisa Heyl
Robert D. Johnson
Agnes & Leo Kelly
William & Roberta Meaney

Stuart Beardall
Ben, Sue, Mollie, Zack, Matt & Abby
Pat Brannin
Robert & Barbara Brant
Dave Brinkman
Carolyn Dovel
Tom Gimble
Paul Granetto
Jay Lane
Bob Lieberman
Dave Steensma
Seth Waltman
Shel Young
The Judge Advocate General Women's Club

William P. Brady
Raymond & Naomi Holloway
Glen & Vicki Willesen

Al Feldman
Harriet & Frank Weiss

Shirley Hubbard
Marilyn Fleischer
Robert D. Gordon, Jr
Mr. & Mrs. George Hubbard
Mr. & Mrs. Lawrence Schenck
Mrs. Richard Stafford
John W. Thoman, Jr

John P. Kearney
John F. Ingro
Marie C. McCalmon
Alex & Jerry Sharp

Thomas M. Lowman
Kraft Foods (Dover Plant)

Arnold Neumann
Bernil Neumann

Lisa Pransky
Harriet & Frank Weiss

Robert Sohnen
Belle, Marla & Jason

Arita Stephens
Irene Hill

IN HONOR OF:

Alex DeBate
The Mellinger Family Foundation

Mr. & Mrs. Joe Gelman
Leon Gelman

Karl Heinricks
Virginia Phillips

Sally Mayers' 75th Birthday
Donna Moss
Doris & Tom Weil
Many Other Friends

Miles G. McCollum
Mr. & Mrs. Robert McCollum

MOORE ESTATE MAKES AN ADDITIONAL GIFT

The estate of James Thomas Moore has sent an additional $30,000 to the research fund of the CMTA. Once the final accounting was completed and all of Mr. Moore's outstanding bills were paid, there was an additional $30,000, which his brother, W.C. Moore and his sister, Alice Stout, knew he would have wanted the CMTA to have. In all, this additional gift makes Mr. Moore's bequest to the organization total $129,471.05. Of that sum, $104,603.29 has been dedicated to fund research grants.

CMTA Remembrances

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and 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 CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, 2700 Chestnut Parkway, Chester, PA 19013.

Honorary Gift:
In honor of (person you wish to honor)

_____

Send acknowledgment to:

Name:_____

Address:_____

_____

_____

Occasion (if desired):

☐ Birthday ☐ Holiday ☐ Wedding
☐ Thank You ☐ Anniversary ☐ Other

Memorial Gift:
In memory of (name of deceased)

_____

Send acknowledgment to:

Name:_____

Address:_____

_____

_____

Amount Enclosed: _____

☐ Check Enclosed ☐ VISA ☐ MasterCard

Card #_____

Exp. Date _____

Signature _____

Gift Given By:

Name:_____

Address:_____

_____

Signature Health Golf Outing Nets Funding for CMTA

The first annual Signature Health Center Golf Outing was held on July 24, 2000, at the Pelham Country Club in Pelham Manor, New York. The golf event was hosted by Craig Sanders, President of Signature Health, whose mother, Phyllis Sanders, is on the Board of Directors of the CMTA. He decided to dedicate the profits from the raffle and silent auction to the association to be used to support CMT research.

The event was primarily a golf outing that Signature Health Center organized as a "thank you" to their clients and customers. Mr. Sanders got the idea to hold a silent auction and a raffle of sports memorabilia to help raise money for the CMTA's research fund. Among the donated items for the raffle were autographed Charlie Ward jackets from the New York Knicks, pairs of Mets tickets and Jet tickets donated by Stanley Sanders, a collection of cigars donated by Dr. Ferrato and various golf-related items such as golf bags, a children's golf set and a putter and golf balls donated by the Beyer family.

In addition, money was raised for the CMTA by having various businesses sponsor the tees. Their sponsorship was noted at each tee and the association benefitted from their generosity. Twelve organizations contributed in this manner.

Board Member, Phyllis Sanders, poses with her son, Craig Sanders, who organized and ran the Pelham Country Club Golf event to raise money for CMT research.

The master of ceremonies for the event was Pat Prescott a local radio personality from 101.9 FM. In all, 106 golfers took part and an additional 20 persons attended the dinner reception and awards ceremony. To date, the CMTA has received $8,800 from the fundraiser and more is still expected.

The organization wishes to thank Craig Sanders, President of Signature Health Center, L.L.C., Dave Buckstel, Executive Vice President of Signature, and Celeste Jackson, Event Coordinator, for making this fundraising event a success. The Signature Health Centers hope to make this an annual event.

Volunteers at the Signature Health Golf outing included: (first row) Kay Flynn, Mary Rehm, CMTA Chairman, Ann Lee Beyer; (standing) Stan Kosik, CMTA Board Member Phyllis Sanders, Diane Kosik, and Mel Berry.

Ask the Doctor

Members of the CMTA's Medical Advisory Board answer questions from readers.

Dear Doctor,

Recently, I was standing in my den when my right knee suddenly collapsed. It happened so quickly that I'm not sure if I pitched forward over my foot and then fell backwards, or if I immediately fell backwards. Whichever way it occurred, I severely sprained the top of my right foot. I was wearing my AFOs at the time.

On the assumption that the buckling of my knee was associated with my CMT, I wonder if any of the doctors on your panel have seen this before and have any advice about strengthening certain muscles or any other advice about avoiding that kind of fall.

The Podiatrist Replies:

It is difficult to give an exact answer without examining the individual and accessing the entire limb. However, I will try to answer the question with the information given. Experiencing the knee giving out in a backward direction and hyperextending the foot and ankle is not an uncommon occurrence in people with Charcot-Marie-Tooth Disease. Because of poor proprioception (the ability to feel position) and atrophy of leg muscles, it is difficult for all CMT individuals to maintain good balance. The calf muscle (behind the lower leg) crosses and helps stabilize both the knee and ankle. Because of weakness in this muscle due to CMT, the knee can hyperextend (recuvatum) and cause instability and balance loss. This can cause the individual to fall backwards, thus hyperextending the foot and ankle.

Strengthening exercises usually offer little value due to the muscles' inability to function from CMT. A knee brace can help, but they are bulky and cumbersome to wear especially if one is already wearing AFO bracing. There is no specific treatment for this problem other than being aware that it is present and taking precautions to avoid being injured in the fall. Continued use of a crutch for extra stability would also be recommended.

Re: Ask the Doctor Response in the Summer Issue

I wish to add additional information and clarification to the answer of the question printed in the Summer, 2000 issue of *The CMTA Report*. The question was written concerning surgery to lower the arch of a 50-year-old individual with Charcot-Marie-Tooth Disease. Although I agree completely with exhaustive conservative care, including bracing (AFOs), before surgical consideration, I feel strongly that only surgeons experienced in reconstructive surgery and reconstructive foot surgery should perform these procedures. Although orthopedic surgeons are generally regarded as the experts in bone surgery, not all orthopedic surgeons perform detailed reconstructive foot surgery. Furthermore, they are not the only qualified surgeons that perform these procedures. Board-certified podiatric surgeons trained and experienced in major reconstructive foot surgery are also qualified to perform these operations. In some locations podiatric surgeons are the most qualified to treat individuals with CMT both surgically and non-surgically. It is recommended that one check into the experience level and the number of Charcot-Marie-Tooth Disease patients the surgeon, either orthopedic or podiatric, has taken care of in the past before undertaking this extensive, reconstructive operation.

—William Quinn, DPM

Dear Doctor,

I am a 58-year-old male who has been determined by blood test to have CMT 1A. The extent of my affliction is that I am limited in the amount of walking I can do without "cramping up" and I have some loss of dexterity in my hands. I hold down a semi-sedentary job, and for my age, I guess I could be labeled mildly to moderately affected by CMT. Two years ago, I was diagnosed with asthma and was prescribed an albuterol inhalant. Since I started using the inhalant, my wife and I have noticed the most remarkable thing. I am becoming more muscular, and certain chronic symptoms that had been attributed to my CMT have occurred less frequently.

Is there any medical explanation for these changes or do I just feel better because I can breathe better and am, therefore, more physically active?

The Doctor Replies:

This is very interesting and probably relates to the nitric oxide system and vasodilation. Athletes have noticed such improvement with inhaled β_2-adrenoceptor agonists, but this is not scientifically confirmed. It would be important to get in touch with the patient, and if we can really prove it works and does not merely impose a feeling of well-being, we might have a treatment for axonal fallout and progressive weakness.

CMTA Support Group News

Arkansas - Northwest Area

Libby Bond, Support Group Leader, attended the Neuropathy Association meeting this summer and visited with another leader, Regina Porter of Oregon, at the summer home of Ardith Fetterolf in Noel, MO.

Regina Porter, Regina's Aunt Dottie, and Libby Bond met for an informal "sharing" session in Noel, MO, during the summer.

California - Berkeley Area

The group has a new meeting place at the Albany Library, Masonic and Marin Avenues, Albany, CA. The September meeting featured a report from Kim Snadow and her mother, Julia Myers, on their trip to the Mayo Clinic in Rochester, MN, where it was discovered that Kim has yet another form of CMT. The November meeting will feature the topic, "Accentuate the Positive," where members will discuss exercise, medication, nutritional supplements, medical practitioners, gadgets, gizmos, books, and articles that have helped make CMT a manageable part of their lives.

Kentucky/Southern Indiana/Southern Ohio

Group Leader Bob Budde reports that the November meeting will feature Dr. Greg Pitts, an Occupational Therapist, from the Sports Medicine Clinic in Lexington, KY. In February, the group will discuss some of the emotional aspects of CMT with Dr. William Weitzel, a psychiatrist in private practice in Lexington. Both guests will answer questions and should provide the group with plenty of discussion topics.

New York - Horseheads

The group's quarterly meeting was held on August 17, 2000, at the New York State Electric and Gas Company's Consumer Education Room. Joyce Wasserman and Michael Niedzielski, physical therapists, spoke to us about a new device called "protonics," which has been shown to be helpful with neuromuscular diseases. One of the members, Joel Henderson, was chosen to help them demonstrate the use and results with this device. It provided objective evidence of help with flexibility after Joel did a few exercises with the protonic.

The New York City support group, under the leadership of Dr. David Younger, attracted about twenty attendees, some of whom are pictured here.

New York (Westchester County)/ Connecticut (Fairfield)

Several members of the support group journeyed to the Pelham Country Club to help with the Pelham Golf Outing on July 24, 2000. The participants were Support Group Leader Kay Flynn, members Mary Rehm, Stan Kosik, Diane Kosik, and Mel Berry. These volunteers helped with the silent auction and represented the CMTA at the fundraiser.

Oregon - Willamette Valley/ Pacific NW

The Oregon support group has elected two co-chairmen, Jeanie Porter and Darlene Weston. The group has also changed its meeting place to alternate between the Brooks Assembly of God Church and the Legacy Good Samaritan Hospital in Portland. The group continues to meet on the third Saturday of each month.

CMTA Support Groups

Alabama/Greater Tennessee Valley
Place: ECM Hospital, Florence, AL
Meeting: Quarterly
Contact: William Porter, 205-767-4181

Arkansas—Northwest Area
Place: Harvey and Bernice Jones Center for Families, Springdale
Meeting: 3rd Saturday of each month
Contact: Libby Bond, 501-795-2318
E-mail: charmicoma@netzero.net

California—Berkeley Area
Place: Albany Library, Albany, CA
Meeting: Quarterly
Contact: Ruth Levitan, 510-524-3506
E-mail: rulev@pacbell.net

California—Los Angeles Area
Place: Various locations
Meeting: Quarterly
Contact: Serena Shaffer, 818-841-7763
E-mail: SerenaM71@aol.com

California—Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)
Place: 300 Sovereign Lane, Santa Rosa
Meeting: Quarterly, Saturday, 1 PM
Contact: Freda Brown, 707-573-0181
E-mail: pcmobley@home.com

Colorado—Denver Area
Place: Glory of God Lutheran Church Wheat Ridge
Meeting: Quarterly
Contact: Marilyn Munn Strand, 303-403-8318
E-mail: mmstrand@aol.com

Florida—Boca Raton to Melbourne
Place: Upledger Institute, Palm Beach Gardens
Meeting: Quarterly
Contact: Cynthia Gracey 561-243-0000

Florida—Miami/Ft. Lauderdale
Place: North Broward Medical Center, Pompano Beach, FL
Contact: Al Kent, 954-742-5200 (daytime) or 954-472-3313 (evenings)
E-mail: marbearwld@aol.com

Kentucky/Southern Indiana/ Southern Ohio
Place: Lexington Public Library, Northside Branch
Meeting: Quarterly
Contact: Robert Budde, 859-255-7471

Massachusetts—Boston Area
Place: Lahey-Hitchcock Clinic, Burlington, MA
Meeting: Every other month, the first Tuesday
Contact: David Prince, 978-667-9008
E-mail: baseball@ma.ultranet.com

Michigan—Detroit Area
Place: Beaumont Hospital
Meeting: Three times each year
Contact: Suzanne Tarpinian, 313-883-1123

Michigan—Flint
Place: University of Michigan, Health Services
Meeting: Quarterly
Contact: Debbie Newberger/ Brenda Kehoe, 810-762-3456

Minnesota—Benson
Place: St. Mark's Lutheran Church
Meeting: Quarterly
Contact: Rosemary Mills, 320-567-2156

Mississippi/Louisiana
Place: Clinton Library, Clinton, MS
Meeting: Quarterly
Contact: Betty Aultman, 601-825-5626
Julia Provost, 601-825-6482

Missouri/Eastern Kansas
Place: Mid-America Rehab Hospital, Overland Park, KS
Meeting: First Saturday bi-monthly
Contact: Lee Ann Borberg, 816-229-2614
E-mail: ardi5@aol.com

Missouri—St. Louis Area
Place: St. Louis University Medical Health Ctr.
Meeting: Quarterly
Contact: Carole Haislip, 314-644-1664

New York—New York City
Place: NYU Medical Center/ Rusk Institute
Meeting: Monthly
Contact: Dr. David Younger, 212-535-4314, Fax 212-535-6392

New York—Horseheads
Place: NYSEG Meeting Room, Rt. 17
Meeting: Quarterly
Contact: Angela Piersimoni, 607-562-8823

New York (Westchester County)/ Connecticut (Fairfield)
Place: Blythedale Hospital
Meeting: Monthly, Saturday
Contact: Kay Flynn, 914-793-4710
E-mail: alma622@worldnet.att.net

North Carolina—Archdale/Triad
Place: Archdale Public Library
Meeting: Quarterly
Contact: Ellen (Nora) Burrows, 336-434-2383

North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)
Place: Church of the Reconciliation, Chapel Hill
Meeting: Quarterly
Contact: Susan Salzberg, 919-967-3118 (evenings)

Ohio—Greenville
Place: Church of the Brethren
Meeting: Fourth Thursday, April-October
Contact: Dot Cain, 937-548-3963

Oregon—Willamette Valley/ Pacific NW
Place: Alternates between Brooks Assembly of God Church and Legacy Good Samaritan Hospital, Portland
Meeting: Third Saturday of the month
Contact: Jeanie Porter, 503-591-9412 Darlene Weston, 503-245-8444

Texas—Dallas/Ft. Worth
Place: Harris Methodist HEB Hospital
Contact: Greta Lindsey, 817-281-5190 or Shari Clark, 817-543-2068
E-mail: jdsbclark@webtv.net

WRITE TO US!

Pat Dreibelbis, Editor

The CMTA Report

CMTA

2700 Chestnut Pkwy.

Chester, PA 19013

The CMTA reserves the right to edit letters for space.

Letters to the Editor:

Dear CMTA,

In 1991, a girl was born. She was born with a disease called CMT (Charcot-Marie-Tooth). She couldn't run or jump and she could barely walk. Sadly, this would only get worse. As Stephanie went to preschool, she started to realize that she was different from the other boys and girls. The other kids could run and jump, but she couldn't. The other boys and girls would play tag and Red Rover, but Stephanie couldn't play. When she was a toddler, she had braces fit for her feet, which she still has. Why would God do this to someone? How unfair!

A year later, Stephanie started school. I was there along with many members of her family. We wished her luck and off she went. However, the trouble was just beginning. Over the next couple of years, Stephanie would experience many setbacks and we worried that she might be teased. Luckily, she wasn't, but people did, often, stare. They still do. When you see it happening, you want to say, "Excuse me. Why are you staring? Is there something wrong with you?"

Gina and Stephanie DiCara leave home for a day of school.

It's very distracting and very saddening. She is a young girl stuck in a wheelchair and not some object to stare at. She is a human being who needs your help, not your pity or amusement.

I haven't been with her during the school hours, but I am sure it would be heartbreaking to see her watch while other children get to play. She must be frustrated at not being able to do things that I find so simple, like going to the bathroom alone, but for her, it is an impossible challenge.

Stephanie is now 9. Despite her disorder, she is one of the luckiest people I know. She has what she calls "the racetrack," which is a track made of blacktop material that goes around her house so she can get around easily. She has a very loving family who cares so much for her. Her father, Mark DiCara, works extremely hard so that his daughter can have the state-of-the-art wheelchair and other items that she needs to function well. Her mother, Theresa, and sister, Gina, give her unconditional love. Gina is such a great sister because when Stephanie needs help, Gina knows what to do and where to find whatever is needed to make things better—even if it is just a hug and a kiss.

Stephanie is a beautiful, young and talented girl who is bound for great things. But she needs help from all of you readers. She needs your prayers and thoughts. Just having faith that God will get us through is more than gift enough to her and her family. She is a great person and hopes, one day, to be a pediatrician with her cousin, Jennifer.

The CMTA is a wonderful association because it gets the message out about CMT. This

CMT POSTER FEATURED AT AAN MEETING

Dr. Richard Lewis, Wayne State University, stands by his poster presentation on arm muscle involvement in CMT at the American Academy of Neurology meeting, which was held this year in San Diego, California, in May. The Medical Advisory Board of the CMTA held a luncheon meeting to discuss the updating of Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians *and the current status of CMT research.*

Autosomal Recessive Conference Scheduled in Capri

The Mediterranean Society of Myology organized a workshop on "Autosomal Recessive CMT Disease", held on September 29, 2000. The workshop was a satellite to the MSM Conference held this year in Capri, Italy. The autosomal recessive forms are relatively prevalent in Mediterranean countries, partly as a result of their high consanguinity (intermarriage) rate.

Participants included a number of international experts in CMT and its recessive forms. The aim of the workshop was to review the most recent developments and to attempt to formulate a diagnostic classification of autosomal recessive CMT, based on the clinical and genetic criteria. This classification effort is the work of Dr. Jeffrey Vance of Duke University.

CMTA Board Members Ann Lee Beyer and Ardith Fetterolf attended the meeting as representatives of the CMTA in an effort to forge relationships with some of the European researchers and support groups. They will report on the meetings in a future newsletter.

is a disease that is so complicated and hard to understand, but with the newsletters and the website, it is easier to understand. I give a lot of credit to the CMTA for their hard work and commitment.

—Jennifer Naye, 13,
Cousin of Stephanie DiCara

Dear CMTA,

I want to thank you for the CMTA reports you send me and I'm sorry we don't have any money to send you. My husband makes a limited amount and much of it goes to pay for health insurance.

When I was a child, I had trouble with my feet and everyone would comment on the way I walked. I had trouble finding shoes to wear. I would to the doctor to take the callouses off my feet. I had a burning sensation and a lot of pain, but no one ever mentioned CMT. In 1976, I was in a car accident and the hospital report still did not show any mention of CMT. I know now that the feelings of numbness in my legs and the tingling were from CMT. In 1982, I had my left foot operated on (no mention of CMT) and in 1984, I had my right foot operated on (still no mention of the cause.) In the intervening years, I have had problems with numbness, pain in my chest, ulcers and swelling of my right hand. In 1991, the doctor put me on temporary work disability, but there was still no mention of CMT.

I didn't file for social security disability benefits, but my husband convinced me not to return to work because of the car accident, the CMT problems (still undiagnosed) and the breathing difficulties. So, I stayed home and lost my income. Between 1992 and 1994, I had the little toes of both feet removed because the doctor said I didn't need them and they were burning and causing me pain. Still, CMT was not mentioned.

Finally, in 1996, I took my son to the doctor because of his foot problems, and that's when I found out about CMT. Since then I have had breast cancer and have been on chemotherapy and have had my lymph nodes removed and a mastectomy performed. I've also had radiation. I was never a good sleeper and now I get more tired than ever. I am in pain every day and I feel that all the other problems I've had fight against the CMT.

No one else in my family, except my son, has CMT as far as I know. The doctors around here know little about CMT and I don't come across too badly when they first see me. They don't think I'm too bad until they read about my car accident, my cancer and my operations. I'm hoping you can hook me up with a doctor who knows more about CMT.

—K.S., Sharon Springs, NY

The CMTA Report is published by the Charcot-Marie-Tooth Association, a registered non-profit 501(C)(3) health organization.

The opinions expressed in the newsletter are not necessarily those of the Charcot-Marie-Tooth Association. The material is presented for educational purposes only and is not meant to diagnose or prescribe. While there is no substitute for professional medical care for CMT disorders, these briefs offer current medical opinion that the reader may use to aid and supplement a doctor's treatment.

MEDICAL ALERT:

These drugs are toxic to the peripheral nervous system and can be harmful to the CMT patient.

Adriamycin
Alcohol
Amiodarone
Chloramphenicol
Cisplatin
Dapsone
Diphenylhydantoin (Dilantin)
Disulfiram (Antabuse)
Glutethimide (Doriden)
Gold
Hydralazine (Apresoline)
Isoniazid (INH)
Megadose of vitamin A*
Megadose of vitamin D*
Megadose of vitamin B6* (Pyridoxine)
Metronidazole (Flagyl)
Nitrofurantoin (Furadantin, Macrodantin)
Nitrous oxide (chronic repeated inhalation)
Penicillin (large IV doses only)
Perhexiline (Pexid)
Taxol
Vincristine
Lithium, Misomidazole, and Zoloft can be used *with caution.*

Before taking any medication, please discuss it fully with your doctor for possible side effects.

*A megadose is defined as ten or more times the recommended daily allowance.

What is CMT?

- … is the most common inherited neuropathy, affecting approximately 150,000 Americans.
- … may become worse if certain neurotoxic drugs are taken.
- … can vary greatly in severity, even within the same family.
- … can, in rare instances, cause severe disability.
- … is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- … is slowly progressive, causing deterioration of peripheral nerves that 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 balance, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, and scoliosis (curvature of the spine).
- … 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, which means if one parent has CMT, there is a 50% chance of passing it on to each child.
- … Types 1A, 1B, 1X, and HNPP can now be diagnosed by a blood test.
- … is the focus of significant genetic research, bringing us closer to answering the CMT enigma.

The CMTA *Report*

Information on Charcot-Marie-Tooth Disorders from the Charcot-Marie-Tooth Association

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