The CMTA raised over $45,000 for its research fund, exceeding the first-year goal of the Armington Challenge by more than $20,000. This tremendous response is a clear indication by our membership that research is our highest priority. It also bodes well as we enter year two of the three-year $75,000 challenge grant.

Heralded at its inception as a means for elevating fundraising efforts and accelerating research activities, the Armington grant is fulfilling those objectives. The CMTA partnership with the Armington family could not have come at a better time for the organization or in the history of medical research. The Medical Advisory Board recently convened at the American Neurological Association meeting to discuss plans for the Third International Conference on CMT Disorders to be held in October 1998 in Montreal, Canada. The conference will be a landmark summit for disparate world experts to interact and exchange ideas.

Dr. Michael Shy, recipient of the first Armington research grant (to be detailed in the winter issue of the newsletter) and one of the conference organizers, expressed his optimism: “I believe the recent advances in the understanding of Charcot-Marie-Tooth disease make it the most exciting field of neurology today. In no other disorder, or group of disorders, are the molecular abnormalities causing the disease, the pathogenic mechanisms of how these genetic mutations cause the disease, and the therapeutic approaches to treat the disease being worked on with such vigor.”

With funding from the challenge grant, the CMTA will aggressively launch new research initiatives in preparation for the International Conference. The importance and timing of the Armington gift cannot be overstated. In recognition of the family’s leadership, the CMTA invited Elizabeth Reardon, daughter of theArmingtons, to become an ex-officio member of the research committee of the board. In a message to the board, President Diane Freaney expressed her personal gratitude by saying, “The CMTA has always emphasized the need to support research, but the Armington Challenge has created a real sense of urgency for our efforts.”

“I believe the recent advances in the understanding of Charcot-Marie-Tooth disease make it the most exciting field of neurology today. In no other disorder, or group of disorders, are the molecular abnormalities causing the disease, the pathogenic mechanisms of how these genetic mutations cause the disease, and the therapeutic approaches to treat the disease being worked on with such vigor.”

—Dr. Michael Shy, recipient of the first Armington research grant
This year the CMTA made numerous advances in the areas of networking with members, improving communications, educating ourselves and the medical community, strengthening our board, supporting research, and most especially, fundraising.

I was very pleased to have met with so many of you this year. And with each encounter, I was struck by the strength and positive attitudes of our members. One person told me that people with CMT are overachievers. That certainly describes the people that I have met.

Many members come from large supportive families who keep in touch through newsletters and reunions. They focus on their abilities and maintain very active lives—golf, tennis, scuba diving, and hunting are just some of their numerous pursuits. Though not always the best, they are certainly the most determined. They are interested in exercise, diet, vitamins, and other programs to maintain and improve their health. Many members connect with one another through support groups, e-mail, and telephone referrals.

Our members worry about future generations and the progress toward finding a cure. At the same time, they want to know what the health care profession is doing to make their lives easier now. They can live with the inconveniences (aching braces, falling, frequent pain), but do not believe them to be inevitable. They are concerned about insurance and health care in this country and the actual and potential level of the care they receive.

We added a record number of new members this year, many of whom contacted us through the Internet and e-mail. Additionally, our board has expanded to sixteen, including four new members: Joe Beernink, Computer Manager, Westminster, Colorado; David Grachek, Executive Search Consultant, Jacksonville, Florida; Krista Hall, Registered Nurse, New Market, Maryland; and Loren Miller, Accountant, Seattle, Washington. We are excited to begin working with our new board members and look forward to harnessing their energy and enthusiasm.

The CMTA organized two Patient/Family Conferences this fall, one in Delaware and one in Connecticut. We did not anticipate that both conferences would be sold out; future conferences will be held in larger facilities. Conference attendees enjoyed meeting other people with CMT and learning more about the genetics and treatment of the disease.

The Third International Conference on Charcot-Marie-Tooth Disorders will be held in October 1998 in Montreal, Canada. The CMTA Medical Advisory Board met in October at the American Neurological Association meeting to begin planning the conference. Dr. Robert Lovelace, MAB Chairman, began the meeting by saying, “We’ve really made incredible progress in our understanding [of CMT] and there are few other areas [in neurology] that have come forward so rapidly.”

Dr. Michael Shy, drafter of the preliminary conference agenda, will place special emphasis on integrating the different areas of research into
the same sessions. For instance, rather than having investigators at separate sessions, neurophysiology, pathology and genetics will be incorporated into common sessions.

After listening to the impressive agenda, Dr. Walter Bradley commented that “...[the conference] is two years away and some of [the agenda] will be old hat by then...” All agreed to maintain some flexibility within the agenda for leading issues at the time of the conference.

Fundraising has been taken to a new level, in large part because of the extraordinary generosity of the Armington family. The Evenor Armington Foundation initiated a three-year research challenge grant of $75,000. Our members responded to the challenge and contributed over $45,000 in the first year. This enabled the CMTA to award two major fellowships during the year and to budget for two more in 1997.

Dr. Peter Denton is currently using his grant at Duke University, Durham, North Carolina, to investigate the gene locations for CMT Type II. In January, Dr. Michael Shy’s study at Wayne State University in Detroit, Michigan will be directed toward the development of an animal model for CMT Type IA (the P0 knockout mouse), with the ultimate goal being possible gene therapy for the disorder.

Through the generosity of a board member, Steve Khosrova, and a matching gift from Salomon Brothers, we also will award three summer fellowships in 1997. The first grant will be named the Caroline Redell Memorial Fellowship after the convener of the first CMT support group. The other two will be named The Salomon Foundation Charcot-Marie-Tooth Summer Research Fellowships.

The year 1996 was a very successful one, but we still have many challenges ahead. Charcot-Marie-Tooth disease does not have name recognition and there is no cure. In 1997, we hope to make substantial progress toward these goals.

Thank you all for your incredible generosity and continued support of the CMTA.

Diane Freaney
President
Dr. Harold Marks hosted the conference at the A.I.duPont Institute in Wilmington, Delaware, on September 21, 1996. More than 150 people filled the auditorium to hear presentations on CMT in the pediatric population, orthopaedic considerations, genetic research, and selecting shoes (“How to Find the Right Shoe,” page 12) and orthotic devices. Survey responses were positive and offered suggestions for improvement. Attendees were anxious for the next conference and pleased with the very personable approach of the presenters.

Dr. Jonathan Goldstein hosted the conference at the Gaylord Rehabilitation Hospital, Wallingford, Connecticut, on October 19, 1996. Again, despite a tremendous rainstorm that swept the East coast, the auditorium was filled to capacity with over 150 attendees. For the first time, the CMTA, assisted by the Westchester County, New York, support group, hosted a hospitality suite on the Friday night preceding the conference. Approximately 25 people met and discussed various concerns including surgery, custom shoes, motorized scooters, support group formation, and the problems of CMT in the adolescent population.

Saturday’s conference included a presentation on an electrical stimulation study conducted at Gaylord (“Electrical Stimulation Strength Increase...” abstracted on page 5) and others on physical therapy, orthotics, and physiatry. One of the attendees expressed interest in starting a support group at Gaylord; information about that group will be available in the spring.

Tapes of the Patient/Family Conference on CMT at the A.I. duPont Institute on September 19, 1996 are now available. The tapes feature presentations on CMTA and children, physical therapy (including finding shoes to fit), genetics, orthotics and orthopaedic surgery. The tapes were professionally filmed and edited and offer a comprehensive overview of CMT and its treatments. The two tapes run approximately three hours and are $25 for members of the CMTA, $40 for non-members.
Publication Abstract

Electrical Stimulation Test Results in Charcot-Marie-Tooth Diseases

Francis X. Palermo, MD (Gaylord Rehabilitation Center, New Haven, CT)

Charcot-Marie-Tooth creates a profound conduction slowing (Type I), distal extremity weakness, and more proximal weakness. The muscle fibers atrophy because of lack of motor axon input rather than intrinsic muscle pathology. Conversely, the lack of muscle fiber activation fails to provide the axon with needed growth factors. Electrical stimulation applied to the motor points of atrophic muscles should activate nerve and muscle and thus reverse some atrophy.

Isometric stimulation was not tolerated. Brief trains simulating walking or cycling patterns (200–400 msec) were well tolerated and were able to create repetitive muscle contractions. In this study, nine patients with CMT I and two patients with CMT II were evaluated with isokinetic torque systems (Lido and Biotex).

The muscle groups that were able to create minimal torque output were tested before and after three to four months of five days per week stimulation, intensity 105 to 125 mA. First-month stimulation time was 20 min and thereafter increased to 40 min five days a week. Trains of 400 msec of 50-Hz pulses with 50-µsec duration were applied each second to the knee or ankle flexors and extensors in a reciprocal fashion.

Visual analogue scales (VAS) were used to evaluate subjects’ sense of balance and fatigue before and after. Ten of the 11 subjects demonstrated large percentage torque and endurance (work) increases in either the ankle dorsi-flexor/plantar-flexor pairs or the knee extensor/flexor muscle groups. Torque improvements were most notable in the ant.tib. (50% to 300% through 30 degrees) (n=4) and knee extensors (30% to 125% through 60 degrees)(n=6). Work output increased over 200% in eight of 10 subjects.

Eight subjects noted an improvement on the VAS in fatigue. Seven noted an improvement in balance. One subject was unable to obtain a contraction and did not show strength gains. Patients with CMT can benefit from brief repetitive patterned stimulation in both quantitative strength (torque) and endurance (work) and can improve their sense of balance.

Editor’s note: Although this abstract is technical in nature, patients interested in pursuing electrical stimulation as a treatment should show this to their physiatrist. Dr. Palermo can be contacted at the Gaylord Rehabilitation Center (1-203-624-3140) for more information.

We’re Networking...

CMTA Board members and staff attended the American Neurological Association meeting, the American Podiatric Medical Association meeting and the annual meeting of the National Organization for Rare Disorders. All three conferences resulted in increased awareness of CMT and the work of the CMTA. Highlights from each will appear in subsequent newsletters.
RESEARCH NEWS

3,4-Diaminopyridine Treatment Ineffective
by Louise Smith

Dr. James Russell, Anthony Windebank, and C. Michel Harper, Jr. conducted a study at the Mayo Clinic on the use of 3,4-diaminopyridine (3,4-DAP) for the treatment of chronic stable demyelinating disorders. Diana Eline published her experiences as a study participant in The CMTA Report, Summer, 1993 (“The Mayo Clinic Dynamine Study: A Personal Account”). Unfortunately, this drug treatment is not effective in treating CMT Type I.

Provided here is a summary of the study findings to help readers better understand what testing entails. CMT Type I causes demyelination of the nerve. The potassium (K+) channels located under the myelin at the nerve’s nodal regions are involved in the generation of the nerve’s resting potential, the prevention of nerve reexcitation, and the stabilization of nerve firing after the event. As the K+ channels become exposed, repolarization is impaired. The drug 4-aminopyridine (4-AP) has been shown in animal studies to block K+ channels and to improve nerve conduction in regions of nerve demyelination. In addition, aminopyridines enhance neuromuscular transmission at the junction between the nerve and the muscle. The use of aminopyridines also has been tested as a potential treatment for multiple sclerosis.

Of the 34 adults participating in the Mayo Clinic study, 27 had CMT Type I. Participants were given either 3,4-DAP or a placebo during the first four days. During the next five days, no treatment was given to allow the drug to wash out of their systems. During the subsequent four days, those who had been given 3,4-DAP were given a placebo, and those who had been given a placebo during the first week were given 3,4-DAP. In this double-blind crossover study, it was unknown to both the participants and the investigators until after the tests were completed during which period the 3,4-DAP was administered.

The 3,4-DAP pill was administered four times a day. The pill dosage was gradually increased from 5 mg four times a day for the first day to 10 mg for the second day, to 20 mg for the third and fourth days. The tests were performed both before treatment and 1 to 2 hours after the final administration when the drug is most prevalent in the blood stream.

A series of tests was conducted to measure isometric muscle strength, sensory ability (pin-prick, vibration, cold, etc.), and electrophysiology. The nerve conduction studies measured the distal, median, ulnar, and peroneal compound muscle action potential; the median and ulnar sensory nerve action potential; and the motor and nerve conduction velocities.

None of the series of tests showed a statistically significant change with the treatment of 3,4-DAP. A mild facial tingling sensation was experienced by 71% of the participants, and 35% experienced mild light-headedness.


Sunshine Foundation Seeks Referrals

The Sunshine Foundation is a nonprofit children’s charity that grants dreams and wishes to chronically ill children. The majority of the dreams they answer are to visit Disney World and other attractions in central Florida. The Sunshine Foundation now has a Dream Village 15 minutes from Disney World on a 21-acre site in Loughman, Florida.

When Sunshine answers a child’s dream to go to Disney World, they assume all the costs that are accrued by such a trip. They provide air travel, accommodations for a five-day/four-night stay at the Dream Village, transportation during their stay, expense money, and admission tickets to Universal studios, Disney World, and Sea World.

The CMTA can refer any child that would benefit from the program. Several criteria must be met:

1. The child must be between the ages of 3 and 21.
2. The child must be chronically ill, terminally ill, or physically impaired.
3. The child’s family must be financially unable to do this on their own.
4. The child must not have received a prior wish from this or any other wish foundation.

To be considered, please send the child’s name, age and a brief history of his or her diagnosis with the parents’ names and address to the CMTA. The Sunshine Foundation will mail out the required paperwork and when the application is completed, the board of directors of the Sunshine Foundation will make the final decision.
Call for Participants

Editor’s Note: Michael Shy, MD, at Wayne State University in Detroit, Michigan, explains the study he and his colleagues are undertaking and the need they have for subjects.

We see CMT patients in the context of our multidisciplinary neuromuscular clinic at the Wayne State University School of Medicine. The goal of the clinic is to provide the highest care possible to patients with neuromuscular disease, in particular to those with CMT. We also provide genetic counseling and, when necessary, genetic testing for the various forms of the disease. Both myself and Dr. Richard Lewis have specific training in the care of patients with diseases of the peripheral nerve. The clinic employs two neurogeneticists, Dr. James Garbern and Dr. John Kamholz, a physiatrist, Dr. Steven Hinderer, as well as specialists in pulmonary disease, nutrition, and psychiatric counseling.

We are interested in developing clinical trials in patients with CMT1A similar to the type of trials being conducted in patients with diabetic peripheral neuropathy or, for example, Lou Gehrig’s disease. As you may know, the mechanisms of how these disorders cause neuropathy are not well understood. However, the recent discovery of various growth factors for nerve cells and the ability by molecular biological techniques to mass produce these growth factors have made the growth factors attractive candidates to promote regeneration of damaged nerves in various forms of peripheral nerve disease. Although CMT1A is, of course, caused by genetic abnormalities in Schwann cells, which ensheathe peripheral nerves, there is emerging evidence that much of the weakness in patients occurs following degeneration of the nerve after the Schwann cell damage.

Prior to trying their growth factors on patients with CMT, biotech companies need to know if they can measure beneficial effects of the compounds in a defined time period, for example, a year. This is potentially a problem with CMT1A patients, who may show little outward change in a year’s time. Therefore, we have been asked by the 17-university medical center organization of which we are a member (The Peripheral Neuropathy Clinical Trials Group) to develop methodology for evaluating progressive weakness in CMT patients so that they can be followed in clinical trials. We plan to evaluate patients by clinical exam, quantitative motor testing, quantitative sensory testing and what is called motor unit analysis. None of this testing involves needle EMG. The exam and the quantitative motor and sensory testing are completely painless. The motor unit analysis involves some mild “shocks” such as occur in nerve condition velocity testing. Because we are not certain which ages are best to study, we are especially seeking patients who have three generations of family members to test. Because we need to know precisely the disease we are hoping to treat, we need patients who have genetically defined CMT1A. If patients do not as yet have genetic diagnosis, we can help perform these through our clinic. Our tentative plan is to evaluate patients a total of three times in one year.

We currently have no financial support for this project so that we cannot pay patients or pay for travel to our clinic. However, because we feel these evaluations are worthwhile, we will not charge patients more than their insurance will cover for any of the evaluations.

Please call Izabella at 313-577-1689 to schedule an appointment or for more information.

—Michael Shy, MD, Associate Professor of Neurology and Molecular Medicine, Wayne State University, Detroit, MI, French Gene Research

GREAT NEWS!
The first Evenor Armington Research Grant recipient has been chosen. Dr. Michael Shy, a researcher and clinician at Wayne State University in Detroit, Michigan and a member of the CMTA’s Medical Advisory Board will receive the grant, effective January 1, 1997. Details of his study will be announced in the winter newsletter.

Also, the Third International Conference on Charcot-Marie-Tooth Disorders will be in October 1998 in Montreal, Canada.
INDEPENDENT AUDITOR’S REPORT

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

We have audited the accompanying statement of financial position of Charcot-Marie-Tooth Association (a Pennsylvania nonprofit corporation) as of June 30, 1996, 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 audits.

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, 1996, and the changes in its net assets and its cash flows for the year then ended, in conformity with generally accepted accounting principles.

August 26, 1996

STATEMENTS OF FINANCIAL POSITION
JUNE 30, 1996 WITH COMPARATIVE TOTALS FOR 1995

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>1996</th>
<th>1995</th>
</tr>
</thead>
<tbody>
<tr>
<td>CURRENT ASSETS</td>
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<td></td>
</tr>
<tr>
<td>Cash</td>
<td>$136,460</td>
<td>$115,378</td>
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<tr>
<td>Accounts receivable—grant</td>
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<td>25,000</td>
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<td>EQUIPMENT—Net of accumulated depreciation of $6,189 and $4,357</td>
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<td>2,065</td>
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<tr>
<td>TOTAL ASSETS</td>
<td>$166,829</td>
<td>$117,608</td>
</tr>
</tbody>
</table>

| LIABILITIES AND NET ASSETS | | |
| CURRENT LIABILITIES | | |
| Accounts payable | $ 3,104 | $ 2,066 |
| Accrued expenses | 250 | 427 |
| TOTAL LIABILITIES | 3,354 | 2,493 |

| NET ASSETS | | |
| UNRESTRICTED | | |
| Operations | 92,410 | 80,937 |
| Board designated for research grants and education | 14,179 | 14,179 |
| TOTAL UNRESTRICTED | 106,589 | 95,116 |
| TEMPORARILY RESTRICTED— For research grants and education | 56,886 | 19,999 |
| | 163,475 | 115,115 |
| TOTAL LIABILITIES AND NET ASSETS | $166,829 | $117,608 |

STATEMENTS OF CASH FLOWS
JUNE 30, 1996 WITH COMPARATIVE TOTALS FOR 1995

| CASH FLOWS FROM OPERATING ACTIVITIES | 1996 | 1995 |
| Change in net assets | 46,360 | 12,468 |
| Adjustments to reconcile change in net assets to net cash provided by operating activities | | |
| Depreciation | 1,832 | 1,285 |
| Increase in Accounts receivable - grants | (25,000) | - |
| Other assets | (100) | - |
| Increase (decrease) in Accounts payable | 1,038 | (157) |
| Accrued expenses | (177) | 177 |
| Net cash provided by operating activities | 25,953 | 13,773 |

| CASH FLOWS FROM INVESTING ACTIVITIES | 1996 | 1995 |
| Purchase of property and equipment | (4,871) | - |
| NET INCREASE IN CASH | 21,082 | 13,773 |
| CASH - BEGINNING OF YEAR | 115,378 | 101,605 |
| CASH - END OF YEAR | $136,460 | $115,378 |

The accompanying notes are an integral part of these financial statements.
STATEMENT OF ACTIVITIES
YEAR ENDED JUNE 30, 1996
WITH COMPARATIVE TOTALS FOR 1995

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<tr>
<th></th>
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<th>TEMPORARILY</th>
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<td>104</td>
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<td></td>
<td>133,670</td>
<td>71,887</td>
<td>205,557</td>
<td>110,936</td>
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<td>NET ASSETS RELEASED FROM RESTRICTIONS</td>
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<td>Satisfaction of program restrictions</td>
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<td>36,887</td>
<td>205,557</td>
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EXPENSES

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<td>Program services</td>
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<td>TOTAL EXPENSES</td>
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CHANGE IN NET ASSETS

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<td></td>
<td>11,473</td>
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NET ASSETS - BEGINNING OF YEAR

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<td>95,116</td>
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NET ASSETS - END OF YEAR

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<th></th>
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<tr>
<td></td>
<td>$106,589</td>
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STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED JUNE 30, 1996
WITH COMPARATIVE TOTALS FOR 1995

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<tr>
<th></th>
<th>1996</th>
<th>1995</th>
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<tr>
<td>Total functional expenses - 1996</td>
<td>$154,074</td>
<td>$157,197</td>
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</tr>
<tr>
<td>Total functional expenses - 1995</td>
<td>$95,288</td>
<td>$88,468</td>
<td></td>
</tr>
</tbody>
</table>

NOTES (cont’d.)

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

In Kind Contributions
Volunteers have donated their time to the organization’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. The value of these assets is not considered material and is therefore not reflected in the Association’s funds.

2. CONCENTRATION OF CREDIT RISK
The Association maintains a cash account balance at a bank located in Philadelphia, PA. The total of these balances are insured by the Federal Deposit Insurance Corporation up to $100,000. During the year, the Association may have a cash balance in its financial institution in excess of the limit. At June 30, 1996, there was no uninsured amount. The Association also maintains uninsured money market cash balances at a financial institution located in Philadelphia, PA. At June 30, 1996, the uninsured balance at this financial institution was approximately $130,000.

3. CONDITIONAL PROMISE TO GIVE
A private foundation has authorized a grant of $75,000 with $25,000 authorized at June 30, 1996. The remaining $50,000 will be paid over the next two years. The annual contribution of $25,000 is contingent upon the Association’s ability to match this amount from the general public. The $50,000 remaining balance of the contribution is not recorded in the current year, but will be recorded as the Association meets the matching requirement each year.

The accompanying notes are an integral part of these financial statements.
Anyone who has a hectic work schedule and an active life takes time out to think about what they would do if they could find more free time. My passions are hunting, fishing, and enjoying the great outdoors.

This past August, I was fortunate enough to experience the outdoor adventure of a lifetime: an African safari. Two friends and I spent two weeks hunting big game animals in the country of Namibia.

Before I continue with my adventure, let me digress and quickly tell you about my CMT. I was diagnosed when I was 13 years old. I have one brother with the disease. We have the X-linked variety with no other relatives showing any signs or symptoms. I was always athletically active despite my CMT. Before high school ended, it became necessary for me to wear braces. I wear rigid AFO's on both legs that can cause unique shoe and boot fitting problems. Hiking and hunting require different shoes and boots, and modifications to fit the braces are necessary. I have always felt the benefits of my outdoor activities outweighed temporary discomfort and distress.

Now back to Africa. The plane ride was extremely long, 15 and a half hours going; 18 hours coming back. We flew from New York to Johannesburg and then to Windhoek, Namibia. Requesting an aisle bulk-head seat near the rest rooms paid great dividends, as I was able to remove my braces during the flight and still get around. Once in Namibia, our safari outfitters picked us up at the airport. We had a four-hour jeep ride out into the African bush. The area we hunted in was the Western Kalahari Desert, which was extremely dry with very sparse, but rugged, vegetation. Our accommodations were quite civilized, with beds, showers, and drinkable water. The entire outfitter staff was extremely hospitable and very entertaining.

Large expanses of open area with several small rocky mountains and rocky high ground were typical. Our hunting was mainly done on foot, after enduring long, open-air jeep rides to get to specific areas. Surprisingly, my feet did very well. The only medical problem I encountered was a cracked rib that only hurt when I laughed.

The hunting was terrific and the photographic opportunities were superb. To properly hunt and photograph undisturbed animals in the wild requires long hours of walking and stalking. Often we needed to climb up on the high, rocky outcroppings to use binoculars to find the small herds of animals. Although I was usually last up the hill, I always made it and the rewards were worth the discomfort.

If any individual with CMT has the desire to participate in adventurous activities, they can fulfill their dreams with detailed planning. Choosing the right outfitter and circumstances with the right physical conditions, along with being honest about your abilities (to your outfitter and yourself), should allow you to enjoy all the adventures you choose to undertake.

The experience in Africa was truly wonderful. Without reservation, I am planning a second trip, hopefully in the not-too-distant future.
Member Starts Golf Group

Andora Peddrick, a CMTA member from Blue Bell, Pennsylvania, is interested in starting a golf group. Possible activities would include group outings, weekend golf trips, and exchanges of ideas and news about special equipment and beneficial instruction.

Andora started playing golf about a year ago in an effort to stay active and to share a love of her husband’s. Diagnosed in her 30s, she has been a teacher and has managed a hotel in the Caribbean, a video store, and a restaurant. Andora has been a lap swimmer for years and started golfing after attending a clinic for the disabled at the Bryn Mawr Rehabilitation Hospital.

Her husband has designed and patented a golf glove which has improved her grip and overall game.

Regardless of ability, CMTA members, families, or friends are invited to call Andora at 215-641-1806 to join the new golf group.

Members outside of Pennsylvania might follow Andora’s lead by initiating similar sport/recreation activities as well.

GIFTS WERE MADE TO CMTA IN MEMORY OF

- Ralph H. Binford
  Marilyn Dodge
- Anne Bernstein
  William Bernstein
- Mr. & Mrs. A.A. Carlson
  Jeanne Corbin
- Edward Coogan
  Kay Flynn
- Ruth B. Davidson
  Jean B. Waldron
- Martin Edelheit
  Ruth Edelheit
- William Feather
  Mrs. Samuel T. Hubbard
- Dr. Milton Greenberg
  Marilyn Prashker
- Kevin Healy
  Robert & Ann Healy
- Sophie Jacobson Adler
  Ruth Edelheit
- Nellie Nan Kelley
  Laurel Financial Group
  Karen Cooper Burkett
  Mark & Wynola Shultz
  Apryl Chidiac
- Fraternal Order of Eagles
  Cooper Brothers
  Mr. & Mrs. Joe Moore
  Barbara & Jay Feuer
  Carrie Robbins
  Girl Scout Troop #1909
- Alfred T. Marks
  Mr. & Mrs. Paul Magnani
  Unibase Direct, Inc.
- James Palmer
  Irene Palmer
  Armond & Alberta Rist
  Bob G. Kester
  Dan & Beverly Rezende
  Family
  Geraldine M. Solari
  Katherine DeAbrary
  Elvira Pedevilla
  Denny & Arlene Bertelsman
  Helen L. George
- Rebecca Sand
  Rose Freed
  Helen Stanton
- Victoria Smith
  Terry Light, M.D.
- Sheldon Thomas
  Mrs. H.C. Lewis
- W. J. Van Huss
  Harris Methodist H.E.B
- Richard F. Walker
  Greg Walker
  Chris Gilchrist
  David B. Wood
  Patricia A. Fitzsimmons
  John & Janet Buttgereit
  and Girls
  George & Edith Rist
  Charles & Vinnie Turner
  Mr. & Mrs. Edward
  Gianolini
  Roberta Oswald
  Ruth Records
  Susan Neal
- Dorothy Williams
  Joan Martucci
  The Grammes Family
  Patricia Weldon
  Mrs. Alois Gutekunst
  Ms. Suzanne Gutekunst
  Bell & Howell Co.
  Employees
  Alois Gutekunst’s
  Co-Workers
  Mrs. Lois Kesack

GIFTS WERE MADE TO CMTA IN HONOR OF

- Barbara Bernstein’s 70th Birthday
  Bernie & Dubby Bernstein
- Gail Gadd’s Birthday
  Roy C. Gadd
- Paul Gomez
  Kay Flynn
- Emily & Bob Louer’s Anniversary
  Mr. & Mrs. Arthur B. Mayers
  Susan Louer
- Donald LeFurge
  His Family
  Donna Spears
  Russell Le Furge
  Dale Le Furge
  Rita Morgan
- Charles T. Lynch
  Helen K. Lynch
- Ms. Janet Smith
  International Library Systems
- Alex Segal’s Birthday
  Helen Segal
- Faustino & Maria Velazquez
  Leonor Deetjen
- Mrs. Ruth Wendkos’ Successful Surgery
  Selma Rothstein
  Estelle C. Bandler
- Hart Wurzburg’s 75th Birthday
  Jane Logan
  Fred & Ann Ullman
  Floraloise A. Goodkind
How to Find the Right Shoe

From a presentation by Maureen Donohoe at the duPont Conference, Wilmington, Delaware

With Charcot-Marie-Tooth, one tends to have a stiff, high-arched foot. One will weight-bear with more on the outside surface of the foot in a supinated position. It is not uncommon to have hammer toes.

The “upper” or top of the shoe should be made of a material that allows the shoe to “breathe,” such as leather, synthetic leather, or a mesh. It should be flexible and have a wide toe box.

The “insole” or the sock liner should be easily removable to allow for an orthosis. The “midsole” or the layer between the sole and the shoe is where the shoe's shock absorption is stored. It should be made of a flexible material such as polyurethane or EVA.

The shape of the shoe should be curved (bean shaped) or semi-curved. Board-lasted shoes look like cardboard inside and are stiffer and good when using an orthosis. Slip-lasted shoes have stitching along the inside of the shoe. This makes the shoe more flexible and is a better choice when not wearing an orthosis. Combination-lasted shoes have a board in the heel for stability and slip last in the front for flexibility. These are difficult to find but not a bad choice with or without an orthotic device.

The “heel counter” is the back of the shoe and should be stiff and snug. It should be deep enough to allow one to wear an orthosis without pistoning the foot out of the shoe. Laces help to hold the foot in the shoe. It is best if there are several lacing options to allow for comfort.

For dress shoes, men need a shoe with a wide toe box and a deep heel counter. Shock-absorbing soles such as crepe are good. If you choose not to use an orthotic device, the shoes can be taken to a shoe repair person to have Reverse Thomas heels put on. Women should avoid high heels. They should look for a shoe that buckles or ties rather than one that slips on. The heel counter should be firm, but the forefoot should be flexible.

Editors note: For more about finding shoes that fit, see page 14, Letters to the Editor.

How to Give to the CMTA...

MAKING A BEQUEST

There are a number of ways of continuing your interests in the Charcot-Marie-Tooth Association through your estate plans. One simple and meaningful way is to include a bequest in your will.

Your attorney can help prepare your will and choose the best wording for your particular circumstances. Following are sample provisions for review by your attorney:

For a Specified Amount

I give and bequeath to the Charcot-Marie-Tooth Association, Upland, Pennsylvania, the sum of _______dollars, to be used as determined by the Board of Directors; (or for research or operations).

For a Percentage of an Estate

I give and bequeath to the Charcot-Marie-Tooth Association, Upland, Pennsylvania, ____% of my estate, after payment of all debts, expenses, and taxes to be used as determined by the Board of Directors; (or for research or operations).

GIFTS OF STOCK

A gift of appreciated stock can save you taxes when you make a donation to the CMTA. For example, if you make a gift of $1,000 using stock that cost you $100, you save $252 in Federal income taxes, so the gift only “costs” you $748.

To make a gift of stock:

For stock held in a brokerage account, send a letter directing your broker to transfer the shares:

______Shares of [name of security]

PaineWebber Inc. DTC # 221
2 Logan Square, 24th Floor, Philadelphia, PA 19103
Attention: Carol Thompson
For credit to the Charcot-Marie-Tooth Association
Account # JH45207-74

For actual stock certificates, send the certificates with a letter to Carol Thompson at Paine Webber Inc. using the above address and account information.

Please send copies of your letter to Pat Dreibelbis at the CMTA, 601 Upland Avenue, Upland, PA 19015 so that we may acknowledge your donation. If you have questions, please call Carol Thompson at 800-523-4144 or Pat at the CMTA office (800-606-2682).
Letters to the Editor:

Type 2 Volunteers Needed for Study

Dear CMTA Report,

For patients diagnosed with CMT Type 2, there is a lab at Duke University working on CMT2. I have this diagnosis. The problem with Type 2 is that the markers appear in different places for different families so there’s no test yet. The researchers weren’t able to use my family info at this time because of the nature of the research at this stage. If you can contribute family/genetic info to this project, you bring the test closer for others, as well.

The man to contact is Jeff Stajich at P.O. Box 2900, Duke University Medical Center. His e-mail is stajich@morgan.mc.duke.edu

Suggestions from Readers

Dear CMTA Report,

As a sufferer of CMT Type II, I take a lot of interest in media reports concerning alternative therapies and vitamin supplements. Just recently an article appeared about carnitine therapy. It was recommended for post-polio sufferers because carnitine deficiency causes fatigue, muscle pain, and muscle weakness. The nutrient is found mainly in red meat and avocado. Polio survivors have less muscle tissue in their affected limbs and a lower capacity to store sufficient carnitine.

I decided to try it and I take 4 grams a day. The results after about 8 weeks were better than I expected. I have a lot more energy; I feel great; and my muscles, especially in my calf are getting bigger. I do not get fatigued like I used to.

I hope you find this information useful.

—R.F. Western Australia

Dear CMTA Report,

I have CMT. I recently had an irregular heartbeat and as a result, started taking magnesium tablets (my magnesium level was low and the tablets were to regulate heartbeat, i.e. muscle contractions.) I’ve noticed fewer leg cramps at night since taking the magnesium. I wonder if others have had a similar experience.

—D.B. Statesville, NC

A Question for Readers

Dear CMTA Report,

I have a problem. I’ve had CMT for some 40 years and until recently have been getting along reasonably well with a cane. It’s one my father bought many years ago when it was fashionable for a gentleman to carry a cane. It is both thin and very light. I now find that I have better support with a forearm crutch, but can’t go more than 25-30 paces without my hand feeling like it’s falling off, causing me to drop the crutch.

Questions: Does anyone else have this problem? Does anyone know of a lighter version of this crutch? If so, could you send me some information on it in care of the CMTA?

—T.R. Virginia Beach, VA

Penpals Wanted

Dear CMTA Report,

I would like to correspond with others (in English, en français, oder auf deutsch). I’m a 29-year old woman with CMT who has overcome much of it through weight-lifting and a use-it-or-lose-it attitude. I was diagnosed at the age of 14 after years of wondering why I couldn’t run like the other kids, and why I was such a klutz.

The best thing I ever did was pay attention to myself instead of the doctors (although doctors now know so much more and are great as guideposts). Instead of being put in a wheelchair like they wanted, I ignored them and continued in the ballet classes I had just started to try to get some coordination. Of course, there are things I couldn’t do, but I loved to dance so much I just couldn’t imagine giving it up for a wheelchair. The disease did get the best of me a lot as a teenager. I was on crutches often.

I couldn’t keep up dance while at college, so I started swimming, using weights, and doing light aerobics (because of fatigue, I couldn’t do high impact). My desire to remain walking without braces, crutches, etc. was so strong that I pushed myself a lot. I have read that people with CMT are not supposed to exercise much because they will burn out their system. Well, I really don’t believe that, especially since it’s now...
been a decade that I’ve been exercising and I’ve been off crutches, etc. for three years.

Recently, a doctor who specializes in CMT (in Montreal) biopsied a nerve from my ankle and compared it with my original biopsy taken when I was 14. Although my EMG and EEG are still weak, the nerve sheath itself looks a lot healthier than it did. He told me to keep up whatever I was doing.

In addition to exercise, I also take lecithin. There are plenty of studies out there on the Net about lecithin and improvement in nerve sheath in people with cerebral palsy. I started taking it when I was 16 after reading initial studies. Now they use it as an accepted treatment for Alzheimer’s disease because they discovered it does slow down, and, in some cases, stop the progression of Alzheimer’s disease. I would love to hear from other people with CMT and about their experiences. I am a translator, living just outside of Montreal.

e-mail address: nickelltrad@autoroute.net

Relief for the Feet

Dear CMTA,

We in Kalamazoo appreciated the recent listing in the newsletter of Okun Bros. Shoe Store, which carries extra-depth shoes. We have had excellent results from another local store that also does custom shoe making. Their address is: Corey’s Bootery, 1016 East Cork Street, Kalamazoo, MI 49001.

—C.L. Kalamazoo, MI

Dear CMTA,

In the past forty years, I have spent a great deal of time and money looking for a pair of shoes that fit me well and feel comfortable. I am a 64-year-old woman who has had surgery three times since 1984.

I have a very short, wide foot with an over-developed arch. One foot is 1 1/2 sizes smaller than the other and rolls to the outside. Add hammer toes and a woman’s sense of vanity...it was quite an order to fill. I have purchased orthopedic shoes, had orthotic inserts made, etc. without success.

In 1987, my daughter found a shoemaker who provided a solution for me and for others. His name is Mr. Andre Feuerman of the Leach-Kale Co., 1261 Broadway, NY, NY 10001, telephone number (212) 683-0571.

Enclosed are photographs of three different pairs of shoes that Andre has made for me. I have had the beige, lace-up shoes for over five years and I wear them for a part of almost every day, particularly when I’m doing a good bit of walking. I call the other two pairs my “dressy shoes.” I have had physicians and orthopedic practitioners tell me these are the finest orthopedic shoes they have ever seen.

There are two caveats: you will need to travel to New York City for your first pair and the shoes are expensive. However, nothing has been of greater help to me. I will be happy to talk with anyone who would like more information. I can be reached through the CMTA.

—Gay Jacobs, Birmingham, AL

Dear CMTA Report:

The following address and telephone number may bring help to someone with a drop foot caused by CMT. This company, Early Winters, offers a catalogue of ski clothing. The ankle brace for the right and left foot is a sturdy and very tightly knit fabric brace with two velcro straps. I wear these; as a result I have fewer stumbles. In fact, when I wear both I do not stumble. I can work in the garden, walk on gravel or stone. The price is $20.00 per brace. My brother, who wears an AFO brace, wears these heavy fabric ones when he wants relief from the heaviness of the plastic.

Here are the company’s address and phone number:

Early Winters, 1 Quality Circle
Kearneysville, WV 25429
1-800-458-4438 (a call will bring a catalogue to anyone who requests it.)

—H.S. Ossian, IN
Following is a list of CMTA contact persons and support group leaders. There are many CMTA support groups, but more groups are needed. The CMTA will help you set up a group in your area. For information about forming a group or being a local contact person, please inform the CMTA by mail, fax 1-610-499-7487, or call the office at 1-610-499-7486. This page will appear in the newsletter whenever space permits.

**CMTA Contacts**

**Alabama/Greater Tennessee Valley**
- Bill Porter
  - 205/386-6579 work
  - 205/876-4181 home

**Arizona**
- Lavin Little
  - 602/516-0539

**California**
- Janice Hagadorn
  - 805/985-7332 after 5
  - (Oxnard/Thousand Oaks)
- Denise Miller
  - 805/251-4537
  - (Canyon County/Saugus)
- Freda K. Brown
  - 707/573-0181
- Denise Miller
  - 805/251-4537
- Robert Kight
  - 410/668-3054

**Massachusetts**
- Wayne Cardillo
  - 413/298-3156
- Donald Hay
  - 617/444-1627 9 am–7 pm
  - (Boston)
- Jim Lawrence
  - 508/460-6928
- Jennifer Brelsford
  - 413/538-9579

**Michigan**
- Robert D. Allard
  - 517/592-5351
- Debbie Clements
  - 616/956-1910
- Suzanne Tarpinian
  - 313/883-1123
- Laurie Vasquez
  - 517/893-4125

**Mississippi**
- Julia Prevost
  - 601/885-6482
- Henry/Brenda Herran
  - 601/885-6503
- Mae Blackledge
  - 601/763-5151

**Minnesota**
- Rosemary Mills
  - 320/567-2156
- Grace Wangaard
  - 612/496-0255

**Missouri**
- Ardish Fetterhoff
  - 816/763-2176
  - voice mail 816/756-2020
- Allan Degenhardt
  - 816/942-1817
- Carol Haislip
  - 314/844-1664
- Lisa Minzer, RN
  - 314/978-0757

**New Hampshire**
- Mary Knightly
  - 603/598-5451

**New Jersey**
- Janet Saleh
  - 908/281-6289
- Linda Muhligh
  - 609/327-4392
- Gary Orson
  - 609/564-9025
  - M–F 9–10 pm & weekends
- Russell Weiss
  - 908/536-6700

**New Mexico**
- Jesse Hostetler
  - 505/536-2890

**New York**
- Joe Ehman
  - 716/442-4123
  - Internet: KOLOB@Multicom.org
  - Lisa Minzer, RN
  - 314/978-0757

**New York (City)**
- Abby Wakefield
  - 212/879-9517
- Bernice Roll
  - 716/564-3585
- Kay Flynn
  - 914/793-4710

**Ohio**
- Roger Emmons
  - 216/286-6485
- Suzanne Lammi
  - 513/339-4312
- Norma Markowitz
  - 215/247-8785

**Oklahoma**
- Leah Holden
  - 405/255-4491

**Oregon**
- Marianne DeStafano-Hill
  - 503/585-3341

**Pennsylvania**
- Dennis Devlin
  - 215/269-2600
- Patricia Zelenowski
  - 717/457-7067
- Camille Walsh
  - 215/747-5321
- Janet Fierst
  - 412/487-0757
- Mary MacMinn
  - 215/322-1073
- Carol Henderson
  - 215/424-1176
- Tony Petre
  - 412/647-8234

**Rhode Island**
- Robert Matteucci
  - 401/647-9154

**Texas**
- Karen Edelson, DPM
  - 214/542-0048
- Camille Walsh
  - 215/747-5321
- Janet Fierst
  - 412/487-0757
- Mary MacMinn
  - 215/322-1073
- Carol Henderson
  - 215/424-1176
- Tony Petre
  - 412/647-8234

**Virginia**
- * Mary Jane King
  - 804/591-0516
- Bernice Roll
  - 716/564-3585
- Bobbey Marberry
  - 816/942-9877

**West Virginia**
- Joe Plant
  - 304/636-7152 after 6 pm
  - (Central)
- Barbara Compton
  - 304/636-5456 24 hrs.

* Denotes support group leader

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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.
What is CMT?

...is the most common inherited neuropathy, 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 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.
...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 the focus of significant genetic research, bringing us closer to answering the CMT enigma.
...Type IA and CMTX can now be diagnosed by a blood test.

The CMTA Report

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

Crozer Mills Enterprise Center
601 Upland Avenue
Upland, PA 19015
1-800-606-CMTA

Forwarding and return postage guaranteed.
Address correction requested.

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.

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