

## Members share ideas for living a full life

Doing something you really enjoy can have a profound effect on your happiness. Whether it's visual—surrounding yourself with art and flowers; audible—listening to pleasing sounds or music; or tactile, holding a grandchild or cuddling a pet, there are many simple ways to enrich your life. The reverse is also true, said Jim Kilpatrick at TMA's 2003 Annual Conference.

Uninviting, depressing music can make a bad situation even worse, he said. Jim, along with several other TMA members, discussed the different ways they've found to remain positive after being diagnosed with myositis.

Music has always been a part of Jim's life, and it took on an even bigger role once he was diagnosed with IBM.

Depending on the type of music you listen to, you can help yourself relax and reduce your anxiety, or the music can make you feel happier and more upbeat.

Mike Shirk learned to paint, using watercolors to express his feelings and creativity. "I've never felt more fulfilled in my life," he said. "Or happier." He has made his scooter work for him by customizing it to hold all of his art supplies.

Marianne Connolly cringed

Continued on page 3

## TMA consolidates offices in DC

After 10 years in Harrisonburg, Virginia, where Betty Curry (TMA's founder) lives, the organization moved all of its operations to Washington, DC on November 25. This move increases TMA's visibility with policymakers, Congress, and members of the research community like the National Institutes of Health, the Food and Drug Administration, and the U.S. Department of Health and Human Services. TMA will continue to provide all the member services and patient support that it has in the past. Along with this move are some changes to the staffing structure of TMA, and current staff members are listed here, along with the information needed to reach them.

TMA established an office in Washington during 2002 and that address is now TMA's national office: 1233 20th Street, NW, Suite 402, Washington DC 20036. TMA's toll-free number is unchanged: 1-800-821-7356. The new direct dial number is 202-887-0088. All general email correspondence to TMA should continue to be sent to [tma@myositis.org](mailto:tma@myositis.org).

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## Message from the Executive Director

Dear Friends,

This issue of *The Outlook* focuses on exercise and the importance of maintaining fitness and strength for those who have myositis. There are practical suggestions as well as advice on how you can avoid overdoing it and damaging your muscles. We think exercise is vital to maintaining your health and ability to func-

tion, and we strongly encourage you to consider the recommendations of the medical experts presented in this issue.

Four other issues of *The Outlook* will follow in 2004 as well as two special editions—one focusing on products that have proven helpful to those with myositis and the other highlighting the latest news in research and treatments for myositis. As we consider the content of these issues, we would like to hear what you would like to see covered. Please send your suggestions to [tma@myositis.org](mailto:tma@myositis.org), call 1-800-821-7356, or mail your suggestions to 1233 20th Street, NW, Suite 402, Washington, DC 20036.

At TMA's 2003 Annual Conference, there were announcements made as to the location and timing of the 2004 Annual Conference. Plans at this time call for the Conference to be held in Las Vegas in either September or October 2004. We are also looking into the possibility of holding a one-day regional conference on the East Coast in the Spring of 2004 as well. Further information regarding the regional conference and Annual Conference will be made available as plans are firmed up.

TMA's relocation of its office to Washington, DC, is now complete. And the replacement of our current information systems with a more fully integrated web-based operation will soon be evident to TMA members—information will be more accessible and easier to use. This transition has required restructuring of our operation and we have appreciated your patience during this period. I believe you will find the changes worthwhile and appreciate the improvements we have made. But as always, your input helps guide us, and I hope you will not hesitate to let us know how we are doing and what we might do differently.

We are here to serve the members of TMA and cannot succeed without your support.

Thank you!

A handwritten signature in black ink that reads "Bob Goldberg". The signature is written in a cursive, flowing style.

Bob Goldberg  
Executive Director

Full lives, continued from front

at the thought of the many side effects of prednisone, especially the weight gain. With the help of her own doctor, who believes that natural methods and medical treatments can go hand in hand, she has eliminated dairy products; increased her protein, fruits and vegetables; and opted for organic foods when possible. (I had to take out a small loan to eat, she said.) She admits it takes discipline, but watching her diet and walking six days a week has helped her outlook.

Many TMA members and friends help others on TMA's online Bulletin Boards by passing on their own experiences and support, interesting information and tidbits, and updates on their own health. This brings them closer to others who live with myositis.

There are many outlets available—reading a good book, watching your favorite movie, or writing your thoughts in a journal or letters to friends and families. You may not be able to exercise physically to the extent you did before, but it's important that you still exercise your mind.



## DM-PM study

NIH is actively recruiting patients with dermatomyositis or polymyositis for a randomized, controlled trial of infliximab (Remicade). The study includes a complete physical screening, treatment, and follow-up with periodic trips to NIH in Bethesda, MD. All expenses, including the drug, are covered except travel for the initial trip to Bethesda.

To find out more, email Dr. Paul Plotz at plotzp@mail.nih.gov.



## Messages from members: Your thoughts on exercise

*Every day, members and friends visit TMA's online Bulletin Boards, sharing ideas, encouraging others, and asking questions. Here are some of your own perspectives on different types of exercise you've tried:*

### Water exercise

When flaring, common knowledge says not to exercise. If not in a flare, appropriate exercise is a plus. Start out real slow and increase the exercise until your body says quit (sore muscles that don't quit after a few hours). After getting started then increase the exercise a little each week or so.

My personal preference is swimming. Good exercise, easy on the joints, and can easily be increased and decreased.

Greg/DM

Water is an excellent medium for exercise. I have been doing aquatics for 6 years; it was 2 years before I could tell it was helping me. Improvement is slow in coming; don't get discouraged if you don't see improvement right away.

Dorris/IBM

### Weight-bearing exercise

Another reason for lifting weights or walking is to help prevent or at least lessen the progression of osteoporosis. Prednisone is notorious for robbing the body of calcium. The exercise must be weight-bearing (your own weight at the very least) so swimming doesn't make a difference in bone density.

What works for me is to do

light exercises (5-pound weights) one day then to rest the next to give the muscles a chance to recover. I do the same with walking every other day. Listen to your body and you'll learn to stop before you hit the wall!

Tenayahh/PM

### Physical therapy

My two cents is to seek out a PT (physical therapist) who is familiar with muscle diseases. I finally did and I now have two exercises to do until my next appointment very gentle. The goal right now is to try and maintain existing strength and flexibility, and improve my core muscle strength if possible.

Doug/PM or IBM



### Yoga

If you have a good yoga teacher, every position has a variation that makes it easier. In my beginning yoga classes, I was one of many that could not come close to most of the positions. But we had an excellent teacher that helped us with all the modifications to make it easier.

If you find the right teacher, it can be just what you need it to be. It also works all your muscles, which is good in myositis, because all your muscles are affected.

Tom/DM



# ADJUST YOUR EXERCISE TO YOUR NEEDS AND ABILITIES

“There’s a tremendous range in designing an effective exercise program,” Dr. Teresa Kaldis told members at the Annual Conference. Dr. Kaldis is the Program Director for Rehabilitation at Houston’s Institute for Rehabilitation and Research and an Assistant Professor at Baylor College of Medicine. “Somewhere between complete bed rest and 24 hours in the gym will be the best level of activity for you!” Dr. Kaldis also discussed skilled therapy, falls, fatigue and contractures in her popular morning session at the Houston gathering in October.

There’s also a lot we don’t know about myositis and exercise, she added. Generally, studies are small and cover short periods of time. One thing has emerged, though, and it’s been consistent throughout the research: most people with myositis experience less disability when they follow an exercise program.

There are long-term benefits as well: exercise increases strength in muscles that aren’t affected, promotes cardiovascular fitness, maintains respiratory health, and gives people a sense of well-being. Michael Harris-Love, a Senior Physical Therapist at the National Institutes of Health, notes that some studies have also shown improved strength in proximal (closer to the body) muscle groups, suggesting that affected muscle groups may benefit from progressive resistance training. “What is less clear,” Harris-Love says, “is how affected muscle fibers respond to strengthening exercise and if strength can be significantly improved in very weak muscle groups.” Part of Harris-Love’s clinical focus is the rehabilitation of people with neuromuscular disease, and he’s been part of the team monitoring Phase

II drug trials for people with myositis. Exercise also helps with sleep, appetite, appearance, and weight control.

“There are cases of patients who have experienced a long flare and then became much, much stronger after exercise,” Dr. Kaldis said. “Generally, we assume that those people were feeling weak because of muscle disuse, which can be reversed in a couple of weeks of prudent exercise.” She’s seen cases where patients have “overworked” and felt weak as a result. Generally, rest and a more realistic exercise program have both helped. Cases where patients feel weak because of permanent muscle damage are more complex, Dr. Kaldis said, although those patients also benefit from a well-designed exercise program. She noted that almost every overview of myositis treatment written in the past few years mentions exercise as an important component. “This was not always true in the past,” she said, mostly because physicians were tied into measuring disease progress by the signs of inflammation monitored by blood tests, which are affected by exercise.

“The most important thing you need to know about exercise is to do it, and to do it regularly,” she said. “Exercise is a daily, ongoing process needed to maintain the strength of everyone, not just myositis patients.” For strengthening, she recommends an individualized program using a variety of muscle contractions.

More and more physicians are prescribing therapy at every level of the disease, Dr. Kaldis said, from assisted exercise even in

intensive care, to the acute rehabilitation unit, to home health therapy administered by a professional who comes to your home, to therapy basically designed by a professional and carried out by the patient. The extent of your weakness and disease activity can help you decide whether you should work with a professional or follow an exercise program of your choice that works for you. “To decide if you’re overdoing it, keep track of your recovery after each exercise session,” she said. “Ideally, you should

recover overnight from each session.”

“These are very important points,” Harris-Love notes. In

his work with myositis patients, he identifies ways in which every patient can exercise to some extent, regardless of the level of the disease. He also encourages patients to learn to monitor their recovery from each exercise session.

For those recovering from an acute flare, or those who are in a stage of the disease with very little mobility, exercise is still important, Dr. Kaldis said. The therapist can help you maintain mobility, beginning with simply being able to move around in the bed better, which will add significantly to your comfort. Other maneuvers aided by the therapist will be balancing and sitting up in bed and on the edge of the bed; and standing, perhaps with the aid of a tilt table with abdominal binder and compression garments or wraps, or with a standing frame or parallel bars.



**Most people with myositis experience less disability when they follow an exercise program.**

More mobile patients – or those who progress after a flare – are taught the best way to use walkers, canes and crutches.

“Standing is especially important because it provides a prolonged stretch of the trunk, legs and ankles,” Dr. Kaldis said. It’s also a very natural weight-bearing activity that strengthens bones and prevents osteoporosis. “More and more devices and programs are being designed to help people stand for some period of time each day.”

If a myositis patient is recovering from a flare, the therapist will then assist the patient with walking, starting with a smooth surface and progressing to an uneven surface like carpet or grass. Next will come ramps, sidewalks and curbs, and stairs with and without handrails. Working with an occupational therapist will help the patient make sure he or she can accomplish the activities of daily living needed for independence. Many patients find that the use of adaptive equipment – even before it’s desperately needed – helps conserve strength. In Dr. Kaldis’s clinic, patients are examined to see if orthotics and splints may help with stability, and are introduced to walkers with seats, brakes and baskets; forearm crutches; and single point canes – all important tools in the myositis rehabilitation arsenal. Other items on the rehabilitation checklist are upper extremity function, hand therapy, cognitive issues and driving rehabilitation.

If a patient needs power-assisted mobility, he’ll be making the choice between a wheelchair and scooter, and be counseled on how best to manage the daily use, control and transportation of the chair or scooter. For those with trouble speaking or swallowing, speech therapy often is of great benefit, as is counseling on food

preparation and eating habits.

If a myositis patient has made a transition to a wheelchair, he or she should be examined regularly for contractures (permanent shortening of the muscles or tendons), and given exercises to prevent them. In cases where mobility is very low, the therapist or caregiver can assist the patient with stretching and range-of-motion exercises. Various kinds of splints, including hand splints, can help with stretching.

How many falls are too many? Dr. Kaldis asked this question and it was clear from the response that everyone had had an experience or two with falling. “Falls in myositis patients happen for a number of reasons, and not just from weakness,” she said. Most people in the class said that they had fallen occasionally before they had myositis but it was getting up from the fall that became so hard. Often it was the significant symptom that led them to seek a diagnosis. “Try to identify the cause of the fall,” Dr. Kaldis said. “Where do they occur? At home, or in the community? Count the near falls as well as the falls.” Proper instruction and therapy can minimize falls, and provide some techniques for avoiding injury and for getting up off the floor. Dr. Kaldis also recommended advising caregivers both in fall prevention and assistance once a fall has taken place. Once again, devices in the home and patient assistance devices like medic alert can add to the safety of the patient.

If fatigue becomes more and more of a problem in the myositis patient, Dr. Kaldis recommends

the patient be examined for other medical issues like drug side effects or related or coincidental illnesses. Depression is always a factor in chronic illness and often causes fatigue. “It’s very likely that you may be doing too little or too much,” she said. “Patients with chronic disease need plenty of activity that takes them into a larger community.” They also need to pace themselves so they don’t overdo it when they have a good day and then suffer for days afterwards. She recommended medications designed to help people with chronic fatigue if all else fails. Once again, exercise can certainly help with the fatigue problem in myositis patients, she said. A quick poll of the attendees revealed that many of the audience had problems with fatigue in hot weather or with exposure to the sun.

Before concluding, Dr. Kaldis noted some other elements to be considered in the myositis rehabilitation scenario:

#### **Pulmonary considerations.**

Lung disease is a possibility and oxygen levels may be low.

**Heart considerations.** Make sure you have a baseline cardiac evaluation.

**Diet.** Weight gain can significantly impact function, and if you do not eat enough protein, your body will go to your muscles to find it.

*Dr. Teresa Kaldis is a board-certified physiatrist and internist. She is an Assistant Professor at Baylor College of Medicine, and an Adjunct Professor at University of Texas Medical School. She sees patients with a wide variety of diagnoses who need functional improvement, including neuromuscular diseases. Dr. Kaldis volunteered her time to speak on exercise to those attending the Annual Conference.*



# IN CHARITIES WE TRUST:

## ADD CHARITABLE TRUSTS TO YOUR ESTATE PLANNING

By Richard L. Bullard III, CPA

What if you could lower your estate taxes, eliminate capital gains tax, claim an income tax deduction and support the work of The Myositis Association with just one estate planning tool? Does this sound too good to be true? Well, believe it or not, you can achieve all four of these goals with a charitable trust. Here's a look at two basic trust types and how you can use each to manage your assets.

### Two charitable trust types

Congress created charitable trusts as a way to help nonprofits like The Myositis Association generate revenue. Trusts come in two forms: charitable lead trusts (CLTs) and charitable remainder trusts (CRTs). Both are formed when you put assets like stock, real estate or cash into the trust. The difference between the two types is the timing of when the charity receives the trust assets.

With a CLT, a charity receives the "lead" interest. It receives payouts periodically throughout the trust's life, typically 10 to 20 years, but dependent on several factors. At the end of the trust's life, the principal goes back to you (this is called a "grantor trust") or to one or more non-charitable beneficiaries, like your children (a "non-grantor trust").

With a CRT the opposite is true. The income beneficiaries — you and your spouse, if you're married, or another non-charitable beneficiary, like your children — receive payouts from the trust for a set period or the rest of their lives. At the end of the trust term, the "remainder" interest (the remaining principal in the trust) passes to the charity.

Trust types are further distinguished by the type of payouts the beneficiaries receive. With a unitrust, the trust assets are revalued each year and the income beneficiary receives a payout equal to a percentage of the trust's current value. With an annuity trust, the trust pays a fixed dollar amount or rate of return based on the initial valuation. The assets are never revalued.

### Ensure retirement income with a CRT

Because they can provide a steady source of income, CRTs are often used to supplement other retirement planning strategies. Ideally, you should set up a CRT during your peak earning years, contributing zero-coupon bonds or non-dividend paying growth stocks. This strategy will help the trust's principal to grow as large as possible before you begin taking payouts.

As an example, let's say Donald Donor has a slightly different concern. He wants assurance that his wife will have the resources to live comfortably if he dies first; but he also wants to give a substantial gift to The Myositis Association. He includes provisions in his will to create a CRT on his death, naming his wife as the income beneficiary and the Association as the remainder beneficiary.

### Save on taxes with a CRT

Another major benefit of CRTs is that you qualify for a charitable income tax deduction the year you create the trust. The IRS determines your deduction by subtracting the expected income stream from the gift made to the trust.

What's left is the current value of the remainder interest that will be

left to The Myositis Association — which is what you deduct. The remainder interest's present value is dependent on criteria such as the type of property you contributed to the trust and the type of charity named as beneficiary.

CRTs are also an ideal way to remove low cost-basis, highly appreciated assets from your estate. If you sold such assets, you would incur capital gains tax of 15% on the increase in value.

(The tax would be higher for assets held a year or less, collectibles and gains attributable to depreciation on real property.) In addition, depending on your state of residence, the gain may subject you to state income tax. By placing the assets in a CRT, the full value transfers to the trust; because its assets will go to a charity, your CRT won't owe any capital gains tax if it sells the property. And because the CRT is outside your estate, there will be no estate taxes on the remainder interest.

Let's say John Retiree bought three lots on Martha's Vineyard in the 1950s, long before it became a hot vacation spot. He paid just \$30,000 for all three properties, and 50 years later that property is valued at \$850,000. Though he was pleased with the return on his investment, John knew the property value would make his estate large enough to be partially taxable on his death. He debated selling the property, investing some of the proceeds and then giving the rest to charity. But then he would have paid capital gains tax. Unless he spent or gave away most of the proceeds, his estate could still be large enough to incur the dreaded death tax.

Instead, he placed the property

into a CRT. The trust sold the lots one by one without incurring capital gains. John received a comfortable payout every month until his death in 2002, and his favorite charitable organization, The Myositis Association, received the remainder of the trust's principal.

### Care for your heirs with a CLT

One CRT disadvantage is that you don't leave assets to your heirs. Unless you're providing for them in other ways, a CRT can make your children and grandchildren extremely unhappy. If this sounds like your family, consider a CLT instead. CLTs let you make charitable gifts now, while leaving an inheritance for your children or other heirs.

Let's say Gwen Giver has made a tidy profit over the years buying, renovating and selling residential property. She wants to leave her money to The Myositis Association but knows her family hopes she will pay for her grandchildren's college educations. So she decides to set up a CLT, which mandates The Myositis Association receive \$20,000 a year for the next 10 years. At the end of the trust's term, the trust assets would be divided equally among her eleven grandchildren, the eldest of whom would be starting college that year.

The year you fund a CLT, you'll owe gift tax (or estate tax if the trust goes into effect on your death) on the projected remainder interest. For instance, say you put \$1 million into a CLT this year and \$300,000 is expected to remain as principal when the trust ends in 20 years. You'll owe gift tax on that \$300,000, but you can offset this with a portion of your \$1 million lifetime gift tax exemption (the amount you can give away during your lifetime free of gift taxes). So, technically, you could fund the trust without paying any tax.

And it gets better. Let's say the

expected \$300,000 grows to a whopping \$3 million during the life of the trust. The children you named as beneficiaries when you set up the CLT will receive the entire principal without being subject to any additional gift or estate taxes.

Unlike CRTs, CLTs aren't income-tax exempt. Trust income is taxed to either the grantor (when the trust assets will revert to you) or the trust (when the assets pass to your heirs). Even though you'll be taxed on the income generated by a grantor trust, this cloud does have a silver lining: You'll also qualify for an immediate income tax charitable deduction. The deduction will be equal to the present value of the income stream the trust will pay to The Myositis Association. For instance, if you leave TMA \$15,000 over the next 15 years, you can take a deduction this year for the present value of that annuity. The deduction amount is a fraction of the transferred amount, the payout percentage, the trust type (annuity or unitrust) and other factors.

With a non-grantor trust, the principal is passed to your heirs. The trust, not you, is taxed on the income this type of trust creates, although the trust is allowed to claim a deduction for the amount transferred to The Myositis Association each year. You can't take an income tax charitable deduction for the distribution made to the Association. However, with non-grantor trusts, you can pass a considerable amount of assets to your heirs with little or no gift or estate tax.

For instance, when Mike Warbucks died in early 2003, his executor followed his wishes and authorized the creation of a charitable lead non-grantor trust naming his three children as beneficiaries. The trust was funded with \$1 million. Assuming a 10-year term, a 5% payout and a growth rate of

10%, the charity he named as beneficiary received \$500,000 in total. The remaining principal had grown to almost \$1.3 million, which his children received free and clear. Furthermore, his estate received a charitable deduction for the present value of the charity's share.

### How to fund your charitable trust

Charitable remainder trusts (CRTs) are ideal ways to dispose of assets that have a low cost basis but high appreciation. A highly appreciated stock that pays no dividend is particularly suited to a CRT. Through this, you'd be able to turn the non-income-producing asset into an income-producing asset and get a charitable deduction in the process. For charitable lead trusts (CLTs), the ideal candidate is an asset that you anticipate will rapidly appreciate. If it does, you will have transferred significant assets to your heirs with potentially little or no gift tax cost. And you'll have helped a charitable cause in the process. You must properly identify these assets to place them in a charitable trust.

The above discussion is general and simplified. The tax benefits and the income, gift, and estate tax impact to the grantors and beneficiaries of each type of trust is obviously dependent on the particular circumstances. Therefore, I recommend that you consult with your tax and financial advisor before proceeding further.

*Richard L. Bullard III is a Certified Public Accountant with thirty-three years public accounting experience working with both business entities and individuals. He spent over ten years as a partner in an international accounting firm. He serves on the Board of Directors of The Myositis Association as Treasurer and Vice-Chair.*



**Start off 2004 right!** Encourage those who you know are concerned about myositis to become members of The Myositis Association. Membership is available for as little as \$15. Or ask them to make a donation to help us find better treatments and ultimately a cure.

**Go to [www.myositis.org](http://www.myositis.org) or call 1-800-821-7356.**



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