

Index to OutLook 2004

Many of you have requested a yearly index to our quarterly print magazine. If you need an issue to complete your set, email tma@myositis.org.

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Past struggles equip us for change and growth

We're all on a journey, and change is our constant companion, said Laury Goolsby, PhD. Dr. Goolsby is a clinical psychologist who was on TMA's founding board of directors. She spoke at the 2004 Annual Conference about the importance of tapping into your ability to adapt when facing a chronic illness. We've got the skills, she said: life has forced all of us to change before. "The good news is that many of the ways you have coped with changes in the past can be used to cope with the challenges of having a chronic illness," she said. While we may have fumbled and stumbled through change, we're still here and that means somehow we've managed to cope before and we can again.

Certainly, myositis is a change that wasn't invited or sought after, but it has the same demands as other changes, Goolsby said. Using the letters of "Change" as the key, Goolsby talked about what change really means.

C in change stands for...

Challenge: anything that puts demands on us, or requires special effort or dedication.

Courage: facing and dealing with a difficult or painful situation despite fear, sadness or other reactions.

Creative problem solving: thinking outside the box, discovering new ways of approaching the situation.

Coping: willingness to use old skills and develop new ones.

Communication: share with and learn from others. Goolsby said it's not necessary to make this journey alone, nor is there any need to reinvent the wheel.

H in change stands for...

Hope: not hopelessness, not helplessness. You will experience helplessness and feelings of hopelessness as you live with chronic illness, Goolsby said. Remember that even if there is no cure close at hand, we can still hope for medical advances. Goolsby cited the tremendous advances in research and treatments in the 11 years that have passed since her first involvement with TMA. In the meantime, you can reasonably hope for a quality of life worth living; hope for decreased discomfort; hope for maintaining self-worth; hope for meaningful relationships.

Healing: comes in many forms. We find ourselves in need of healing physically, emotionally, spiritually, Goolsby said. If you get fixated only on physical healing, you won't live well with chronic illness. You have a lot more control at your own individual level over your emotional, social and spiritual well-being. Do what you can for your physical well-being, and take control where you can.

Humor: try to maintain a good sense

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Dear TMA member:

This past year has been a year of many "firsts" for The Myositis Association - the first-ever conference devoted exclusively to juvenile myositis; preparation for the first-ever international s-IBM Conference; writing of the first-ever book devoted entirely to juvenile myositis; the first time TMA's Annual Conference had 300 attendees; etc.

While we are proud of these achievements, they are not important in and of themselves. Their true value lies in how much of a difference they will make in the lives of you and our other members. We hope that they will lead to significant differences and will bring us closer to better treatments and, ultimately, a cure for myositis.

We have also placed more emphasis this year on the importance of caregivers in the lives of our members and have tried to give more recognition to the others who assist you, providing the physical and emotional support so necessary for coping with this disease.

This issue of *OutLook* covers some of these topics as they were presented at the Annual Conference. The special Treatment Issue of *OutLook Extra* that you will receive soon covers the medical and research topics discussed at the Annual Conference.

Please let us know if there are other subjects you would like to see covered in our publications, at the Annual Conference, and as part of the other conferences TMA will be holding in 2005.

We are looking forward to an exciting year of accomplishment and other "firsts" in 2005.

Best wishes to you and your family for a happy and safe holiday season and New Year!

A handwritten signature in black ink, appearing to read "Bob Goldberg". The signature is fluid and cursive.

Bob Goldberg
Executive Director

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Change and growth,

Continued from cover

of humor, Goolsby said. Finding humor in a painful situation can be very helpful. Don't take either yourself or your situation so seriously.

A in change stands for...

Acknowledgement of current circumstances: facts are facts. You and your life are moving in a new direction, and there are new limitations in your life.

Acceptance: reality is what it is whether I like it or not. Acceptance is not giving up but facing head on the reality of your circumstances. Acceptance is not an admission of defeat or failure nor is it a place you arrive at and stay. Acceptance is an ongoing process.

Adaptation: adjusting to new or changed circumstances and developing flexibility.

Ask for help: if you find yourself reluctant to do this, ask yourself how you would react if someone asked you for the same kind of help. Would you think less of that person?

Ability not disability: ability is the power, willingness and skill to do something, but disability is something that restricts and limits you. You are not without the power and willingness to develop the skills to put quality and meaning in your life.

N in change stands for...

Never define yourself as your illness: you are not your illness, you are a person who has developed and lives with a chronic illness. Avoid living the role of the victim.

New: letting go of the old - and your old ways - and creating a new you with new ways.

Nothing is forever: learn to take one day at a time.

G in change stands for...

Get active and get involved

Gather support and information wherever you can

Grief: identify what you've lost and grieve for those losses, but resist staying there.

E in change stands for...

Emotional realities: acknowledge and express the emotions you are experiencing rather than minimize, repress or deny them. All your emotions need is acknowledgement and validation.

Endurance: remember life is a journey, not a destination.



Patients face their disease with courage and optimism

Posts from the TMA bulletin board offer patients' perspectives

Look for humor and pleasure where we find them

Recently, I read a quote from a person who said, "I'm going to be in a wheelchair whether I'm happy or depressed. I choose to be happy wherever I am because it's a lot more fun."

We can control our autonomy and say no when we feel too tired or too sick. We can ask for help when we need it. We can continue to do the things for ourselves that we are still able. We can tell visitors when it's time for them to leave because we need a rest or have something else we need to do.

Myositis and most serious illnesses demand so much from us. I don't mean don't ever get angry or feel frustrated. We're going to feel depressed and discouraged sometimes. We're going to feel the unfairness of being struck by illness.



Sometimes we need to grieve all of those losses. We're going to run into insensitive people. Just seems to me that we should take as much control as we can, letting remarks that may seem insensitive roll right off, and looking for humor and pleasure wherever we find them.

When my doctor challenged me "don't be your disease," it was an emotional revelation for me. It takes energy to engage in those negative feelings that can be channeled in other, more positive directions.

It's a cliché but true, that things could always be worse and it's important to focus on the positives in our lives.

Tenayahh/PM

Ready to make the best of it

Since I've had PM, I've known that a big shift in my thinking was necessary in order for me to successfully cope with this illness, but I've only recently had the wherewithal to actively work at making those changes! It really takes stepping back from the illness a bit and reassessing things in order to be successful - I was in denial that I was even ill. It took a while for that to sink in. But now, I think I've pretty much accepted it, and I'm ready to make the best of it.

Mariuca/PM

Having DM certainly hones your priorities

Many things in my life have changed but I am still here and don't spend most of my days curled up in a sodden lump of misery on the sofa. I have been on a tour of the British Riviera two years ago, a cruise to Alaska last fall and I am going on one to New England and Canada. My husband and I are doing things now that we only talked about before. Having DM certainly hones your priorities. Have pills will travel.

Mary P/DM

Grassroots efforts: advocating for yourself and your children

What is grassroots advocacy?

"Grassroots" is a way to describe the most basic, fundamental level, and is often used in connection with advocacy. "It's you as an individual giving a voice to an idea or a disease that needs to have a voice," says Harris Teller, PhD, who has IBM and is a patient advocate and long-time member of The Myositis Association. He spoke on advocacy at the Annual Conference.

Grassroots advocacy can be informal, like teaching your neighbors or child's classmates about myositis; or formal, like meeting with Senate and House representatives to encourage funding for autoimmune diseases.

You know what it's like to live with myositis on a daily basis better than anyone else, says Teller. Use this knowledge to your advantage. Educate others, even your own doctors, nurses and therapists.

Start on a more personal level.

When an obstacle makes it difficult for his wheelchair to pass by, Harris talks to store managers, asking them what they would do in his situation. This is an opportunity to teach, and people tend to listen when you explain things in an informative, friendly way. Every time you communicate a problem to a manager, he says, you're helping the next person. This informal advocacy may bring new contacts that can lead to opportunities to educate more and more people.

Broaden your scope. "In order to be successful as a grassroots advocate," Teller says, "you need to know everything you can." If you have IBM, learn more about polymyositis and dermatomyositis as well, including both the adult and childhood forms. Develop a clear, focused statement about myositis in general. It may help to use a more familiar

condition or analogy to illustrate your point. "Your statement should help the average layperson develop a mental picture of your condition," he says.

Example: Talking to a group of elementary school students, Shari Weber, whose son has JDM, asked the group to raise their hands and hold them up. As their arms began to tire and ache, she asked them to think about how their shoulder muscles felt (sore, achy, tired). She explained that this is how her son felt in his whole body even without holding his arms up. This simple demonstration helped them understand a little more about how sore and tired a child with JDM feels throughout the day.

Filling in the GAP: developing a Grassroots Advocacy Plan

Why advocate? The goal of advocacy is to educate and influence local representatives, especially those who deal with funding decisions, Teller says: "We need to make sure decision makers know what myositis is, how it affects individuals, how it affects their lives, how they can help us." To do this, find out what's already being done in your area then contact others to help. *Keep In Touch* support groups around the country have embarked on grassroots campaigns from walkathons and bake sales to a benefit shopping day at Macy's. Some events take only a handful of dedicated people, while others require a larger group of volunteers.

If you're spearheading an event or a visit to your representative's office, knowing how to effectively work with volunteers is key. Assign people to tasks they'll feel most comfortable doing, Teller says: "In my experience, people are willing to do just about anything in the end - they just need to carve out their niche at beginning."

To develop your own Grassroots

Advocacy Plan, consider these questions:

■ Who is your audience?

Lawmakers, doctors, nurses, pharmacists, or another group? Make a list of individuals or groups to contact.

■ **What do you think they need to know?** Gather materials appropriate to your audience to distribute when speaking to them. Contact TMA or go online to, www.myositis.org.

■ **What different jobs will there be as your event unfolds?** Which volunteers best match each particular duty? Match volunteers to the jobs they'll enjoy - then they're most likely to get the job done.

Once you outline who your audience is and what they need to know, write down the personal side of your myositis story. Include your diagnosis and symptoms, treatments you're receiving or have received in the past, challenges you face daily, and what is currently known about myositis. Remember that lawmakers and assistants may have only a short time to meet, so keep your points relevant and concise. Keep them focused on the issues that have solutions that are achievable with their help.

Don't stop there

Whether your team is visiting a local representative or talking to a group of medical professionals, be sure to follow up. Call your representatives about a month after the meeting to see if they need additional information. Follow up with a letter of thanks to anyone you meet, and be sure to include the name of a local contact as well as TMA's office and web addresses.

TMA has put together sample letters as well as links to your local and state representatives. Visit the web site or call for more information.



Empowering patients to manage chronic disease

Janet Austin, PhD, Director of the Office of Communications and Public Liaison at the National Institutes of Health (NIH), provides information to help people manage their conditions every day. This job is close to her heart.

When she was 16, she woke up one morning unable to make a fist. Her father assumed she had sprained her wrist trying out for majorette at school. This went away, but a few months later, she couldn't grip with either hand. She soon learned firsthand about living with a chronic illness - rheumatoid arthritis (RA). For three years, she took 16 pills a day until, at 19, she decided she'd had enough. Quitting her medicines, she experienced one of the most unbelievable flares of her life, she said. Luckily, she had access to specialty care at the Arthritis Center in Birmingham, Alabama, a center funded primarily by NIH.

Over time, Austin's condition improved to the point where she was able to work full time and return to school, earning her doctorate. Her experiences taught her a few things: to learn what you can do for yourself; to be patient; to believe tomorrow is going to be better. Disease is a part of your life, but it's not your whole life, so don't let it take over, she said. If you have a positive outlook and attitude, people aren't looking at your disease but at other things. She learns a great deal from children she sees: "There's something about growing up with a chronic illness. They have such a stoic attitude about it; they're so strong."

Through her position at NIH, Austin publicizes information important for those affected by chronic diseases, from clinical trials to newly released research findings. At the Annual Conference, she presented her thoughts on dealing with chronic illness and how you can help yourself through knowledge and participation.

Managing your myositis

There's more to managing your condition than remembering to take your medicines, she said. It's your responsibility as someone with a chronic illness to learn as much as you can and to ask questions.

Keep a written record

One of the best ways to be a better advocate for yourself is to document everything. If you make a phone call to the doctor's office, make a note of the date, time, people you talked to and what was said, especially if someone promised a reply. For doctor's appointments, keep follow-up notes so you'll remember what happened during your visit.

Months may pass between doctor's visits, so when doctors ask how you're doing, you may want to rehash the entire period since your last visit. Prepare yourself before the visit, Austin said. What are your five most critical concerns? Write these down to discuss with your doctor during the appointment, and then remember to update your own journal, writing down your impressions of the day, what the doctor said during the appointment, and who was most helpful during your visit. This last bit of information may come in quite handy if you need someone to help down the road, she said.

Find information online

To learn more from the Internet, know where to look. There are many different sources of information, including government and association web sites. (See *Resources*, page 7.) Government sources, like the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), make sure they have the most accurate, up-to-date information available. NIAMS updates its health information at least every three years, reviewing the most recent research

and enlisting experts to review new material made available to the public. The goal is to provide valuable information to the public and to add to the information available from voluntary organizations like TMA.

Dr. Austin leads a team that writes medical information in plain language for the public. Researchers share their findings with other researchers primarily through presentations at professional conferences and articles published in medical journals. To share the research information with the public, NIAMS and other institutes at NIH write science updates, press releases, brochures, booklets, and other publications.

Recognize challenge, maintain hope

Finding support and good medical information are basic to self-advocacy, said Austin, and they link to another important ingredient: hope. With the National Bone and Joint Decade Proclamation, the President declared 2002-2011 National Bone and Joint Decade, calling upon the public and medical community to do their part in creating awareness and pursuing research. This signals a national commitment to improve the quality of life for people with musculoskeletal conditions and outlines new steps to advance this cause through research, prevention, and education. It envisions health professionals working together at international, national, regional, and local levels so that no one lives with daily musculoskeletal pain or discomfort.



Resources related to information and advocacy can be found on page 7. If you have additional tips or resources to share, please email tma@myositis.org.

Focus on research: tribal patterns of illness may lead to understanding of juvenile myositis

The Apache, Cherokee, Cheyenne, Chickasaw, Choctaw, Creek, Pawnee and Seminole nations call Oklahoma home. They're just a few of the 67 nations who live here, mostly in rural enclaves, making up the largest number of Native Americans in any state. The Apache Chief Geronimo is buried here, and you can't go far in any direction without finding traces of the culture and history that once dominated the Great Plains. Each group is very different, but they continue to hold some values in common: respect and love for nature, an emphasis on the spiritual, and a history of believing in the integration of physical and spiritual health.

When Dr. James Jarvis came to Oklahoma to work at the University of Oklahoma College of Medicine, he learned about the Great Plains people as he worked among them in the children's clinic. They are not in reservations, he said, but they are mostly a rural people, living in sparsely populated areas in the rugged and often difficult landscape. "American Indians are the youngest and poorest population in our country," he said. The scars remaining from the loss of their native lands and traditions are still very real, he said, and to many the traumas of the mid-19th century invasion of settlers seem very near.

The Great Plains people have the same health concerns as the general population, but often at higher rates. This is true of heart disease and diabetes, and also of autoimmune diseases. Researchers found that Native Americans suffer from rheumatic diseases at five to seven times the rate of the general population. The work of Dr. Jarvis at the Children's Physicians Arthritis Center at the OU College of Medicine led him to wonder if children were also being affected at rates greater than the general population. "It was glaringly obvious within my

first six months," he said. "In one afternoon, I saw three Native children with JM in the same afternoon, and they were all from one tribe." His assistant, who knew the patients, told him that all three children were related.

Dr. Jarvis became fascinated with the high rate of JM, and he applied for and received a TMA grant for his continuing studies. Based both on his experience in the clinic and reviewing the Indian Health Service records, Jarvis estimates that the prevalence rate of JM in Native American children may be two to three times higher than that seen in Caucasian children. This increased prevalence rate is not seen in all tribes, he said: The highest rates are seen in a single tribe living on the southern Great Plains. Jarvis's studies have shown that, when JM occurs in Native American children, it usually occurs in families that have multiple family members affected with other rheumatic diseases, such as systemic lupus and juvenile rheumatoid arthritis, or even other distant relatives with JM. In interviewing immediate families and extended families, he found that systemic lupus was especially common in the families of children with JM; so far, he hasn't found an increased instance of adult forms of myositis.

These findings are important, he said, because familial cases of JM are extraordinarily rare. Investigators have known for some time that there is a genetic component to JM, but finding it has been difficult because of the rarity of more than one case of JM in families. Research funding

from The Myositis Association allows Dr. Jarvis to engage in more in-depth studies of existing Native American families and identify new families in the Native

American population,

Jarvis said:

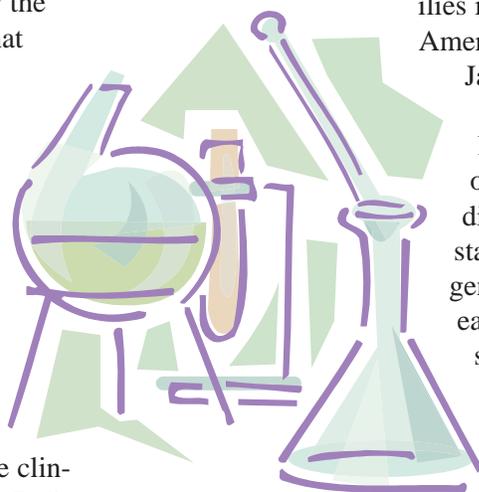
"Understanding how JM relates to other rheumatic diseases, understanding the complex genetics of this disease, and understanding how the illness affects people of different ethnic groups will allow us to understand better what causes JM and develop therapies that will be more effective with fewer side effects."

Does JM seem any different or require different treatment in his Native American children? "Too early to tell," Jarvis said. "My impression is that the myositis is just a bit more tenacious than what we see in the Caucasian population, but let's face it, JM is a challenging disease no matter what color your skin is."

■ ■ ■

Early settlers benefited from traditional Indian healing

People anxious to avoid the side effects of today's powerful drugs may want to consider the plight of the 18th century settler. Many scientific minds of the day objected to what they called the "heroic" methods of modern European medicine, which included bleeding, amputation and other extreme measures. In contrast, the herbal medicine practiced along with the spiritual healing practices of the Plains Indians seemed advanced.



Native herbologists understood the medicinal properties of herbs. Some doctors worked to help those they considered sick at heart, and others used rituals, symbols, dreams, prayers and hands-on methods of healing. There were surgeons who set plasters with feathers and stitched wounds using human hair as their thread. They used thousands of plant-based drugs that greatly enriched the pharmacopoeia of the world, including natural cures for malaria, scurvy and constipation. They introduced the world to petroleum jelly, extracted the acid that forms the basis for aspirin, and prescribed periods of rest and reflection alternated with grueling work of survival.

Dr. Jarvis and others who work with Native Americans on the Plains and in other communities have written about the importance of respect for traditional healing methods and other aspects of Native American culture for physicians and nurses at tribal clinics. One study done by a group of tribal nurses found that many of the patients didn't understand that they would have a few minutes with a doctor or nurse: their shamans spent days or weeks with a sick person, serving one person at a time until they saw signs of healing. Another study showed that a number of patients were treated by both a physician and a shaman at the same time without telling either about the other. Dr. Jarvis and other physicians working with Native American children hope that increased understanding of the dynamics of the extended families will help in their work with children with complex, chronic, serious disease.



Resources for information and advocacy

The following are useful sites recommended by Harris Teller and Janet Austin for understanding your disease and publicizing it in the wider community.

[National Institutes of Health: a wealth of information](#)

The National Institutes of Health (NIH), a part of the U.S. Department of Health and Human Services, is the primary federal agency for conducting and supporting medical research. NIH provides leadership and financial support to researchers in every state and throughout the world. Many important health and medical discoveries of the last century came from research supported by the NIH, Dr. Austin said. Two valuable sources of information online from NIH are MedlinePlus and ClinicalTrials.gov.

MedlinePlus is the NIH National Library of Medicine's consumer-friendly web site for health information. In addition to the extensive health topics section, MedlinePlus features information about thousands of prescription and over-the-counter drugs, an illustrated medical encyclopedia, a medical dictionary, directories of hospitals and health professionals, and more. Consumer Reports has said that MedlinePlus is the best place to find health information online.

ClinicalTrials.gov contains current information about federally and privately supported clinical research using human volunteers. It is an easy-to-use system that lets you search for clinical trials using the name of a health condition (myositis), the location of a study, or the study sponsor. ClinicalTrials.gov also provides information about a trial's purpose, tells who may participate, and gives phone numbers to call for more details.

A site under construction by search engine giant Google responds to the search parameters you enter by rating research and review articles in

the PubMed database and sorting them by the number of times other researchers have quoted them. This is a new way of approaching scholarly articles which are better rated according to respect shown by other researchers than by general popularity as measured by Internet hits. Go to www.scholar.google.com to find papers and published articles on myositis.

[Check out these sites:](#)

ClinicalTrials.gov: www.clinicaltrials.gov

MedlinePlus: <http://medlineplus.gov>

National Bone and Joint Decade Proclamation: <http://www.whitehouse.gov/news/releases/2002/03/20020325-5.html>

National Institutes of Health (NIH): www.nih.gov

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS): www.niams.nih.gov

[Advocacy Resources:](#)

The Myositis Association: www.myositis.org; 800-821-7356

Find out more about your elected officials: www.vote-smart.org; 1-888-VOTE-SMART (1-888-868-3762)

Find your state Senator: www.senate.gov; 202-224-3121

Find your U.S. Representative: www.House.gov (click on "House directory" on the left menu bar); 202-224-3121

The official site of the White House: www.whitehouse.gov; 202-456-1414

THOMAS Legislative Information on the Internet (Library of Congress): <http://thomas.loc.gov>; 202-707-5000

National Institutes of Health: www.nih.gov; 301-496-4466



Upcoming Events

JM family event
Boston, MA
December 19, 2004

For families in MA, NY, CT, NH, RI, ME and VT. More events are being planned in different cities across the country. Let us know if you're interested in helping organize or host a JM family event near you.

Conference on s-IBM:
Frontiers of Research
Potentially Relevant to
Treatment
San Diego, CA
January 26-29, 2005
By invitation only.



Best Wishes
for a Safe and Happy
Holiday Season!

Corporate Sponsor: In addition to the previously announced corporate supporters of TMA's 2004 Annual Conference, Baxter Healthcare joined the other sponsors with a recent financial donation.



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