

What's next?

Important projects planned for the coming months:

■ TMA Research Grant and Fellowship Program. The Myositis Association's third call for research applications has begun, with awards to be decided and announced in January 2005.

■ s-IBM Conference focused on potential treatments to occur in January 2005. Conference is limited to physicians and researchers by invitation only.

■ *"Myositis and me: a family guide to juvenile dermatomyositis and other inflammatory myopathies"* is a one-of-a-kind book TMA is producing on juvenile forms of myositis (JM). This resource for families and physicians will be printed early in 2005.

■ Accredo Therapeutics, a national network of pharmacies providing IVIG therapy to patients in their homes, has agreed to be the KIT Support Group Supporter for the next year. As KIT Supporter, Accredo Therapeutics will be providing financial support to help defray some of the costs of operating the 65 support groups TMA has worldwide. Accredo Therapeutics will also make available speakers and other resources to the support groups to educate those with myositis about the potential benefits of IVIG therapy.

See *What's next*, page 3

The long-term care challenge

Thomas Day found out about long-term care firsthand, caring for his parents, his in-laws and then finding that he had an immune demyelinating neuropathy shortly after he purchased his own long-term care policy. The dilemma of those who find themselves with a diagnosis and no possibility of private insurance is of great interest to him, and he's set up a web site as a resource. In addition to several degrees, Day holds a Certified Eldercare Advisor (CEA) designation from the National Council for Long Term Care Planning.

Through Day's web site, www.longtermcarelink.net, he wants to let everyone know exactly what they can expect from existing programs. Day has counseled people with inclusion-body myositis, polymyositis and dermatomyositis, and he told us in an interview that, to his knowledge, there is no insurance company that will insure people who have been diagnosed with autoimmune disease, with some exceptions for mild rheumatoid arthritis and fibromyalgia. That statement is reinforced by the experiences of TMA members, who find that the conversation about insurance stops where the diagnosis begins. Day said that myositis patients can expect some long-term care assistance from public programs.

What can you expect from Medicare?

The answer to this question changes frequently as the system is perpetually tweaked. But for now, these are the options covered:

Skilled nursing facility:

Medicare is only applicable to those 65 years and older, or those qualifying for coverage due to disability. It will pay in full 20 days of skilled nursing care, followed by a portion of 80 additional days. To qualify for this benefit, you must have stayed in the hospital for three full days, have a need for skilled care, and have a doctor's orders for this care.

Home health care: For home health, there are similar provisions – you must have the need and a doctor's orders under a "plan of care." You must also be homebound, defined as being difficult for you to be away from home during a particular time. Home health benefits can include personal aides, social services and others. "Prior to 1997," says Day, "Medicare payments were very helpful in allowing long-term care recipients to stay at home and avoid institutions. But, Medicare was never intended to pay for chronic, long-term home care."

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Dear Reader:

This issue of *The Outlook* marks a special beginning for The Myositis Association. It contains a summary of the preliminary findings of a researcher, Dr. Sabine Krause of Germany, being funded through a TMA fellowship. Now that the TMA research program is fully underway, with a dozen grants and fellowships awarded, we will be using *The Outlook* and other TMA special publications to inform you of the progress being made by our researchers. I think you will find Dr. Krause's report interesting and easy to comprehend.

The very complex and challenging issue of long-term insurance in the United States is also addressed within. There are insights into the intricacies of providing and paying for long-term care in the 21st Century. We have also included some helpful hints to allow you to find your way through the maze of public health programs currently available to those needing skilled nursing care or home health care.

Lastly, we have a summary of the report Dr. Fred Miller provided to the 70 parents and children who attended TMA's first-ever Juvenile Myositis Conference last May. Dr. Miller discussed the areas of research and treatment that hold promise for advances in the care of those with myositis.

Your thoughts and suggestions are always welcome. Please feel free to contact us at tma@myositis.org or by mail.

Enjoy!

Yours truly,

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

Bob Goldberg
Executive Director

The opinions expressed in this newsletter are not necessarily those of The Myositis Association. We do not endorse any product or treatment we report. It is our intent to keep you informed. We ask that you always check any treatment with your physician. Copyright 2004 by TMA, Inc.

Long-term care,

Continued from cover

In 1997, it implemented a system to reestablish the original intent for Medicare to cover only acute-care needs. Under the Prospective Payment System, Day says on his web site, a health agency is only reimbursed per patient for each 60-day episode. There are provisions in place to discontinue reimbursement if the patient recovers early, or to extend payment if the condition worsens. Medicare is not a resource for chronic, non-improving, homebound individuals. Recently, with pressure from home health agencies, Congress passed legislation to restore some funding to home care.

What does Medicaid have to offer?

Medicaid was established to help low-income families, people on Supplemental Security Income (SSI), and those with excessive medical bills. Though it's a federal program, states have flexibility in designing their own Medicaid programs. However, all states must offer certain services, including skilled nursing and home health services.

Skilled nursing facility:

Government spending on Medicaid has risen quickly, prompting Congress to cut back. Congress targeted long-term care, the fastest growing segment of expenses. To qualify for skilled nursing care, Medicaid recipients must be receiving SSI or have no more than \$2,000 in resources (or \$3,000 for couples in need of care). Special rules allow people over age 65 and disabled people who are in nursing homes or who are receiving waivers but not receiving SSI to meet alternate income tests. The exact rules vary from state to state.

Medicaid community waiver: A certain number of individuals may qualify for Medicaid Home Based and Community Service (HBCS) waivers. These waivers allow for home care, assisted living and similar

services in place of skilled nursing care. According to Day's web site, federal rules require that waiver participants meet state Medicaid level of care eligibility rules for nursing homes and that the cost for waivers not exceed equivalent nursing home costs. These waivers are not readily available, and Day cites four reasons for this:

- The number of people allowed to participate is low, limiting access to these services.
- States often create tougher financial eligibility rules for community care than for nursing home care.
- Since people are required to meet nursing home level of care eligibility rules and costs can't exceed those of nursing home care, many states find it more cost effective to use a nursing home rather than community care.
- Medicaid reimburses room and board for those in skilled nursing facilities; reimbursement for community services covers only the home care. "Most states recognize this dilemma," says Day, "and allow the beneficiary as well as a spouse to retain some income to pay for room and board. However, allowances are either too small or lacking in some states. This forces many who could rely on waivers to go to a nursing home instead."

A 1999 Supreme Court case (Olmstead) will impact the availability of community services through Medicaid, says Day. This decision mandates that care for the disabled under the Americans with Disabilities Act be provided in the most suitable setting, regardless of cost.

On the horizon

Congress is increasingly looking at the plight of family caregivers and the burden of the aging population to society, says Day. The "Partnership Plan," now a pilot project in New York, Connecticut, Indiana and California, encourages people to buy

long-term care insurance by offering Medicaid to those with long-term care insurance after the terms of the insurance expires, provided that the private payer has footed the bill for at least three years of nursing home care or six years of home care. More relevant to families of people with myositis is a new Medicaid regulation that allows parents to transfer their home to any child who has provided two years of care in that home prior to the parent receiving Medicaid benefits. And there are various tax credits for family caregivers, usually income-based, says Day.

What you can do

In progressive states like Oregon, 80 percent of the Medicaid payments go for care provided in the home, Day says, and it appears to be the mood of Congress to encourage in-home care as a substitute for nursing home care. Day encourages caregivers to educate themselves about the policies of their state and to work for federal legislation that increases the number of waivers for home care, thus easing the burden of caregivers who want to keep their loved ones at home.

Contact Thomas Day at (801) 298-8676 or tom@careutah.com.



What's next,

Continued from cover

This contribution will relieve some of the financial burden now borne by volunteer leaders of the KITs. TMA is very grateful for the ongoing support from Accredo Therapeutics and the long-term relationship the company has had with TMA in helping myositis patients and their caregivers. Additional information about Accredo Therapeutics can be found by clicking on the Accredo Therapeutics logo on the KIT page of the TMA web site <http://www.myositis.org/community/KIT.cfm>.



ALTERNATIVES TO TRADITIONAL PAIN RELIEF

Though not all of you experience pain, those who do feel debilitated, sidelined due to the constant throbbing or aching. Hurting often leads many people to be inactive and, if working, unproductive. Pain can be a signal that your body needs rest, especially if you've overdone it. But it can also keep you from doing things that'll help - exercising to your ability, socializing with family and friends, and simply going about your daily routine. Getting your pain under control helps both physically and emotionally.

If your medicine cabinet is already overflowing, you may not welcome more painkillers. Researchers, family physicians and the patient population are examining alternative ways to control pain by relaxation and other complementary techniques in addition to conventional pain medicine.

Start with the basics

Exercise, diet and sleep. Mayo Clinic specialists encourage everyone with a chronic disease to pay close attention to these three most basic elements of health. On the Mayo Clinic web site (www.mayoclinic.com), specialists discuss different ways to deal with pain: exercise, medicines and stress management. They've found that regular exercise improves sleep and gives chronically ill patients more energy to cope with their pain.

Another important factor in pain is stress, especially how you respond to stress in your own life. Since pain and stress go hand in hand, pain makes you less able to handle the stress of everyday life. Common hassles turn into major obstacles. Stress may also cause you to do things that intensify your pain, such as tightening your muscles or hunching your shoulders. You can control some of the factors that trigger your stress; others are not so easy to control. Meditation, massage, yoga and deep breathing, along with other mind-

body therapies, help you relax by physical release of tension and by drawing your focus somewhere other than on your pain.

Relaxation therapies

Many of you have already turned to relaxation techniques and have found that they promote physical fitness along with alleviating stress and anxiety. University of Arizona researchers studied exercise, education and behavioral modification in dealing with the pain and stress of rheumatic diseases. They found that therapies such as Tai Chi and meditation, in combination with conventional medicines, benefited arthritis patients.

Most health clubs, YMCAs, and community programs offer some type of low-impact or alternative exercises: yoga, Tai Chi, meditation, massage, and many others. These programs combine physical exercises with techniques that help your mind heal your body and manage pain.

Tai Chi

Several studies have looked at Tai Chi, an ancient Chinese mind-body exercise, as an adjunct therapy for arthritis, fibromyalgia and similar conditions. One group in Savannah, Georgia, found that fibromyalgia symptoms improved significantly after completing Tai Chi classes. A Boston study showed that Tai Chi appears to have physiological and psychosocial benefits; and other studies note that Tai Chi reduces the risk of falls in the elderly population by promoting balance.

Tai Chi is often called "meditation in motion" because

of its gentle, rhythmic movements. In Tai Chi, the focus is on conscious breathing and inner calm. Once you learn the moves, you can do them at home.

Touch therapies

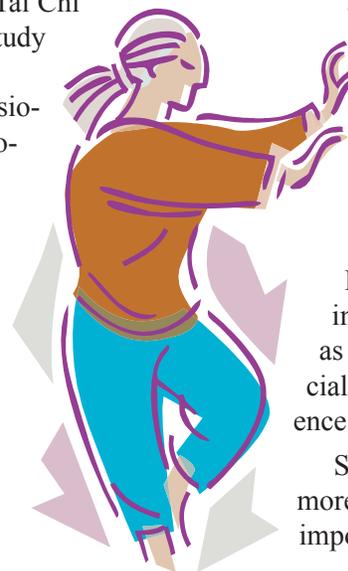
For Harriet Riendeau (DM), massage therapy was great at helping her mind quiet down, while she also reaped the benefits of touch. (See *Taking control of her pain*, page 5.) Touch therapies are all growing in popularity, and you'll find a variety of techniques. LaStone therapy alternates warm and cool stones for a unique and spiritual massage experience. In shiatsu, therapists use overhead bars to balance themselves and direct the right amount of pressure during the massage, a technique that's especially good for large men.

Mary Jane Aswegan, RN, CCRN, CHTP, whose adult daughter Stephanie has dermatomyositis, is a certified practitioner in Healing Touch. "On a regular basis," she said, "I do a full treatment with her on the massage table where I connect all the

major and minor energy centers (chakras) and do a full body magnetic clearing." She admits it's difficult to describe without a visual. She demonstrated certain techniques at this year's Annual Conference.

Many of the basic principles in Healing Touch are the same as other touch therapies, especially the belief that you influence your own healing.

Some types are only offered in more specialized centers. It's important that you let your thera-



pist know exactly how myositis affects your muscles. If you don't know where to start, ask your doctor to recommend a therapist for you. There are therapists who specialize in working with people with chronic muscle disease.



Putting it all together

Harriet uses Tai Chi, meditation and massage, along with traditional therapies, to treat her dermatomyositis and move her focus away from her pain. "The Tai Chi actually started as Ai Chi (same thing but in the water)," she said. "It was fabulous." The young mother of three who taught Harriet also read positive affirmations at the end of the lesson while the patients floated in the pool. This guided form of meditation encourages "present mindfulness," a form of meditation that serves to slow the mind down by focusing on the present rather than past or future.

As you balance low-impact exercises, pain medicines, relaxation therapies, or a combination of these, you'll become more aware of how your mind and body interact to regulate your physical and emotional stress.

Resources:

American Academy of Pain Medicine: www.painmed.org

American Chronic Pain Association: www.theacpa.org; P.O. Box 850, Rocklin, CA 95677; 1-800-533-3231 [Support groups meet in the US, Canada, Great Britain, and other countries.]

American Pain Foundation: www.painfoundation.org; 1-888-615-7246

American Pain Society: www.ampainsoc.org; American Pain Society, 4700 W. Lake Ave., Glenview, IL 60025; 847-375-4715

Mayo Clinic: www.mayoclinic.com



Taking control of her pain

Harriet Riendeau is a registered, licensed dietician. With her background in nutrition, she quickly learned how what she eats and the way she thinks affect her dermatomyositis. She decided to take control of both.

"I do have good social support," she said, "which allowed me to keep perspective. I had to figure out what else I could do to help myself. I did not like having to use morphine sulfate for a few years for pain management." She found out about a pain management course and signed up.

Meeting at an outpatient clinic at Dartmouth-Hitchcock in Lebanon, New Hampshire, the class learned to measure and describe the pain they felt then to effectively communicate this to their doctors and families. (See *Rate your pain*.) This course taught Harriet to listen to her body.

Her therapist pointed out that working too hard to get things "just right" triggers more pain and fatigue than just doing what you can, even if it's not up to your previous standards. The therapist went on to explain that it's okay to let chores go unfinished if finishing a job will intensify her pain. "That is what became unacceptable," said Harriet, "allowing the pain to escalate when I could do something to prevent that."

She included Tai Chi and meditation in her therapy. These relaxation techniques focused her thoughts on the present, rather than thoughts of the past or future. Through her courses and self-realizations, Harriet has found a way to deal with her pain. She readily shares her methods with others but doesn't expect her routine to work for everyone: "There are lots of paths to get to the same place."

Editor's Note: Harriet presented at the 2004 Annual Conference in Las Vegas, sharing her thoughts on meditation and Tai Chi.



RATE YOUR PAIN

Pain is mild, moderate or severe; a dull, throbbing ache or a sharp, shooting pain. No diagnostic tools can accurately measure pain - only you can explain how you feel. It's not always easy managing pain, says Margaret Caudill, MD, PhD, adjunct associate professor of anesthesiology at Dartmouth Medical School. Dr. Caudill developed a program to manage chronic pain, and describes it in her book, "Managing Pain Before It Manages You" (Guilford Press, 2002).

Describing your pain

Keep a journal to record your pain three times each day, paying attention both to physical pain and your emotional response to it:

- 1 Rate your physical pain on a scale from 1 to 10, with lower numbers representing no painful physical sensation; 4 to 5, uncomfortable, moderate pain; and higher numbers, intense, unbearable pain. Average your three daily ratings.
- 2 Describe how the pain feels - sharp, burning, aching, dull, tight.
- 3 Measure your emotions, with 0 showing no negative emotional response and 10 indicating severe depression or anxiety. Again, average the three numbers.
- 4 Explain your emotions - frustrated, angry, indifferent, sad.
- 5 Record what you were doing at the time you rated your pain and what you did to help.

After you do this for a while, you'll notice patterns, Caudill says. Look for any variations from one day to the next, and decide what may have caused any changes.

Keeping these records will allow you to understand your pain and perhaps point you to ways to help yourself manage it. It will also give you tools to communicate with your doctor more clearly and effectively.

THE FUTURE OF MYOSITIS TREATMENT

Dr. Fred Miller says he's optimistic about the future of myositis treatment for several reasons. Miller, a TMA board member and the chief of the Environmental Autoimmunity Group at the National Institutes of Health, spoke about progress in research and collaboration at the Juvenile Myositis Conference in May. "This is an exciting time to be a rheumatologist and someone concerned about autoimmune disease," he said. His reasons? First, there have been advances in understanding basic biology and immunology in research labs all over the world. There's also a new understanding of the possible causes of myositis and other autoimmune diseases, increased collaboration between scientists, substantial research support by TMA and other groups, and the likely benefit for myositis patients from drugs developed and tested on much larger disease groups, particularly rheumatoid arthritis.

In order to find new, effective treatments, scientists need to better understand the processes that lead to and sustain myositis, Miller said. Scientists first need to test the new drugs in animal models for safety, prove they work in animals as well as in the laboratory, and then confirm they're safe and effective for people.

The audience at the JM Conference in Bethesda followed Miller through a condensed explanation of immunology. The immune system is our defense against infection, and many cell types in many parts of the body help in this process. These immune system cells sometimes turn against us to attack our own tissues. We call that process – attack of our own tissue by immune system cells – autoimmune disease. Five distinct treatments are now under study for use in autoimmune diseases, including a couple that are approved for rheumatoid arthritis and are being prescribed for myositis

patients. Dr. Miller warns that these are experimental treatments for myositis, so it's not yet known whether they will effectively treat the disease. Therefore, they should only be used by doctors who have experience with them. Future, better treatments for myositis will probably come from the following treatments, Miller said.

FUTURE TREATMENTS

Anti-TNF agents

Tumor necrosis factor (TNF) has been implicated in the inflammation process as part of the body's response to a perceived threat. Three different agents that are considered anti-TNF are now licensed to treat rheumatoid arthritis: etanercept (Enbrel); infliximab (Remicade); and adalimumab (Humira). These agents block inflammation by blocking TNF action. Doctors using the drugs privately in small studies have found that some myositis patients respond well to these drugs. Since they suppress some of the body's responses that protect us from infection, they make patients more susceptible to infections, especially tuberculosis, and there are some reactions to the injection itself. Larger trials of these drugs are now underway.

Anti-B lymphocyte agents

B lymphocytes or B cells are the immune system cells that produce antibodies, with the help of T cells. B cells are found mainly in the spleen, blood and lymph nodes. Under the microscope, these antibodies appear Y shaped and can be made to bind to almost any structure or protein to block its function. Anti-B cell agents block inflammation by killing B cells. Dr. Miller said that one agent, rituximab (Rituxan), is now licensed to treat B cell lymphoma. Like the anti-TNF agents, the anti-B cell agents can cause allergic reactions and can make

people more susceptible to infections. In small studies, both in rheumatoid arthritis and myositis, there are informal reports of some improvement in some patients, and these agents continue to be studied.

Anti-T cell agents

Anti-T cell agents block inflammation by blocking T cell functions. There are presently no such agents licensed to block T cells, but there are studies of Campath 1H, a monoclonal antibody that binds to and blocks T cell function. Most likely, side effects of the anti-T cell agents would include the same kinds of allergic reactions to infusions and infections.

Anti-complement agents

Anti-complement agents can block inflammation by blocking complement functions. Complement is a series of proteins in the blood with an important role in protecting us from infection. In some autoimmune disease, the activation of complement results in inflammation and the killing of "good" cells. There's one agent, eculizumab, now being studied to block a complement named C-5, and a small Phase I study in adult myositis suggested safety and no deterioration in patients. Like other agents, there's increased risk of allergic reaction to infection and also injection.

Autologous stem cell treatment

Researchers noted that people with both rheumatoid arthritis and cancer who had their immune systems destroyed by radiation and high doses of chemotherapy were cured of both the cancer and the arthritis. When the



Continued on next page

immune system was restored, the immune disease did not reoccur. A very small number of myositis patients have been treated this way. Of them, a case of juvenile myositis survived with no reoccurrence.

NEED FOR MORE RESEARCH

Dr. Miller noted that there are really no approved therapies for myositis – everything used today to treat it is an off-label use, including prednisone and methotrexate. “It’s rare, and we’re far-flung,” Miller said. “We’re just not capturing all the information we should be.” Miller noted the encouraging trend of researchers from different disciplines meeting together and agreeing on definitions for disease improvement to measure progress against myositis.

What can you do to promote myositis research? Miller advised the audience to work with TMA, to educate family and friends, and to participate in research, including enrolling in a trial if appropriate. “We need new treatments,” Miller said. “We’re still several years from the results we want to see.” Why is this, when there are promising studies in process, asked several audience members.

Miller pointed to there not being a lot of incentive for research into treatments that will benefit a small group with a disease such as myositis. With continued progress toward international cooperation, such as the recent agreement among scientists on guidelines for measuring improvement, there is hope for better monitoring of the disease and the impact of various treatments, he said.



Surface cells hold clues to effective gene therapy for myositis

Sabine Krause, MD, PhD, of the Friedrich Bauer Institute at the University of Munich, Germany, was chosen by TMA as one of its first grantees in 2002. Dr. Krause has been interested in immunology for many years. “Along with the brain,” Dr. Krause says, “the immune system holds the most challenging mysteries.” She notes that though immunology is one of the busiest fields of research today, autoimmunity is still far from being fully understood. Understanding how the immune system goes wrong will help in figuring out how patients can strengthen their own ability to overcome the disease, Dr. Krause says. Her goals for her myositis research are:

- to minimize the side effects of therapy,
- to increase efficiency,
- to develop treatments that target only the disease and not the whole immune system.

Dr. Krause is studying muscle fibers, the targets attacked by the immune system in inflammatory myopathies. Molecules on the surface of our muscle cells communicate with the molecules on the surface of our immune cells, somehow encouraging or discouraging immune system intervention. The molecule labeled HLA-G on the surface of our cells prevents attack by natural killer cells, and when it’s transferred into muscle cells in the culture dish, it helps the cells resist death from certain deadly T cells and other cells that help T cells. Dr. Krause is studying whether gene therapy in inflamed muscle tissue might help prevent more damage from autoimmune attack. Interestingly, she says, it only takes a very small amount of HLA-G-positive cells to inhibit the T cells significantly in a large group of muscle target cells. This leads her to believe that low dose or localized gene therapy might be a future treatment option.

A healthy immune response

depends on how cells interact, and how they regulate the activation of other cells. T cells bind to foreign protein pieces (antigens) that are on the cell surface when, for example, the cell is infected by a virus. But this simple binding is not enough to activate the immune system. For the T cell to really respond to the antigen, it needs a second signal, which could be binding to another surface molecule on the presenting cell. Then the T cell recognizes the second signal. Krause’s research will show that a molecule called B7-H1 is a strong inhibitor of T cell activation. In muscle biopsies from patients with polymyositis, dermatomyositis and inclusion-body myositis, B7-H1 was predominantly found in the areas of strongest inflammation. This provides evidence that the muscle is trying to protect itself, and might lead to a new approach to treatment.

As we know, the disease process that leads to inclusion-body myositis is poorly understood, Krause says. Patients in a certain group of hereditary inclusion-body myositis patients carry mutations in a gene called GNE, an enzyme essential for cell development. GNE may affect protein folding, cell-to-cell contact and cellular signalling. Krause and others have developed a way to see GNE within the cell in different locations in a dynamic pattern, the first time this has been achieved. Pinpointing GNE functions will promote our understanding of hereditary IBM, and might also improve our understanding of the more common sporadic form of IBM.

Dr. Krause’s research provides further insights into the immunobiology of muscle tissue. The findings suggest that engineering muscle cell surface molecules might become a future treatment for fighting autoimmunity in muscle cells.



SUNLIGHT SUSPECTED

International collaboration has already revealed some very interesting facts about who gets dermatomyositis: In a study of 1,000 patients worldwide (90% adult), researchers found virtually no DM in Iceland or Scotland and found that DM was the predominant form of myositis found in Belize and India. "You can pretty well predict how myositis patients will break down between PM and DM groups by the amount of ultraviolet light where they live," Dr. Fred Miller said.

Could sunlight itself be the trigger? "The evidence points to this," Miller said. "And all forms of myositis peak in the summer."



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Accredo Therapeutics, the country's most extensive network of pharmacies dedicated to the treatment of disorders treated with IVIG therapy, is proud to **SPONSOR** the **Keeping in Touch (KIT) Support Network**.



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