

The Outlook

SPRING 2015

Quarterly Newsletter

Dietitians whip up a fresh take on nutrition

Easy-to-swallow, easy-to-like meals for those with dysphagia

Right before the winter holidays, two nutritionists took a fresh look at holiday food for those with swallowing difficulties, hoping to offer some of the familiar, traditional tastes of fresh ingredients we all love in easy-to-swallow food, allowing everyone to enjoy family dinners. Their thoughtful and creative reworking of everything from pumpkin pie to turkey and gravy was published in "Practical Gastroenterology" just in time for nutritionists all over the country to share the holiday recipes with clients weary of commercial nutrition products.

Laura Knotts, RDN, is a nutritionist for the Neurology Department at the University of Virginia. She co-authored the article, she said, because she recognized the need for some degree of choice for her clients who had trouble swallowing. Although she works primarily with ALS patients, she also works with inclusion-body myositis (IBM) patients who are seen in the University Hospital with a variety of swallowing challenges: "Some have

the most trouble with liquids that are too thin; others simply can't chew anything solid," she said. "A lot depends

on where in the swallowing process their muscles are the weakest." Knotts said it was important for those with IBM and other forms of myositis to realize that they do not have to be admitted to the hospital in order

to have an evaluation of their dysphagia risks and possible dietary solutions. "You can see a nutritionist as an outpatient," she said. "Ask your doctor to refer you. It's an important step in getting adequate nutrition."

Carole Havrila, RD, CSO, who co-wrote the article with Knotts, points out that people often have a misconception about feeding tubes: "Many of our patients are able to eat some foods,

but meeting all their calorie needs is just too exhausting for them. They don't realize that with a feeding tube, they can still take food by mouth. We always tell them that whatever they CAN swallow, they SHOULD swallow." Havrila works at the Emily Couric Clinical Cancer Center at the University of Virginia Health System. She encourages her clients to make simple meals out of fresh ingredients when they can. "People with chronic diseases and on certain medications are often told to avoid simple sugars," she said. "Others just don't like the chemicals and additives in commercial supplements."

Knotts added another benefit of the creative approach to a varied dysphagia diet: "People with chronic illness often have so few choices," she said. "We like them to at least be able to have a little choice in what they prefer to eat."

Renee' Bricker, a UVA speech pathologist, often does the initial bedside evaluation of patients with muscle disease and other illnesses that make swallowing difficult. "One thing we see a lot is that patients are eating or drinking their meals while laid back in a recliner or tilted back in a wheelchair," she said. "If we can at least get

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Corner Office

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THE MYOSITIS ASSOCIATION

1737 King Street, Suite 600
Alexandria, VA 22314

P: 800-821-7356 E: tma@myositis.org
F: 703-535-6752 W: www.myositis.org

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Editor: Theresa Reynolds Curry

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2015 Looks Promising

Last year was perhaps the best year ever for TMA and those who have to live with myositis. There was more research into myositis last year than ever before, and there is growing interest in myositis among the research community and by pharmaceutical and biotech companies.

We are very pleased with the new initiatives TMA launched in 2014 and are looking forward to continuing to expand our services in 2015.

A series of videos has been added to our website that are dialogues with patients who have myositis. These patients include those who have dermatomyositis, sporadic inclusion-body myositis, hereditary inclusion-body myositis, and polymyositis. These videos detail the experience of patients and how they cope with the challenges of the disease. They can be found under "Learn about Myositis" on the home page (www.myositis.org), and then "TMA Videos."

Last fall, TMA conducted a survey of its members to get feedback on how we are doing and we invited comments about the services TMA provides to its members. The results of this survey are now on TMA's website if you would like to view them. They can be found on TMA's home page at www.myositis.org. At the bottom right, find "About TMA" and look for "2014 Member Survey." The Programs and Services Committee of TMA's Board of Directors will be using the results of the survey to identify areas that can stand improvement. We will keep you informed of changes that are made as a result of the survey.

Awareness of myositis among physicians remains a challenge and TMA now has a unique program underway to educate physicians and medical students about the disease. Learn more about our efforts in this issue of Outlook on page seven.

Speaking of awareness, TMA will be holding a special event in conjunction with the San Francisco Giants' baseball team this year on Sunday, September 20. As you may know, the Giants' TV announcer, Mike Krukow, has inclusion-body myositis. To honor him and inform the public about myositis, the Giants will be holding a special ceremony on September 20 at the ballpark in front of 41,000 fans. This event should generate substantial press coverage and public attention in the San Francisco Bay area.

The following day is National Myositis Awareness Day and we hope you will consider doing something to help bring attention to our disease. Whether it is through your local myositis support group or through your own initiative, we all need to do our part to create greater awareness of myositis.

Together we can make a difference!

Best regards,



Bob Goldberg
Executive Director

Easy meals, from cover

them to sit up straight while they eat, it solves some of the problems." She also coaches patients in other simple steps — taking small bites, eating more slowly — that allow them to retain their ability to eat their favorite foods.

The three swallowing experts gave some pointers on fixing flavorful smoothies at home:

- You don't need to rush out and buy a \$600 blender. Whatever you may have used in the past to mix Margaritas will be fine.
- Put the liquids in first.
- Add any greens with the ice, if you're using ice.
- Vary ingredients: some frozen, some fresh, to get the consistency you need.
- It's good to have at least one thickener, like a banana, avocado or yogurt.
- Add some spices that you especially like.
- Experiment with different sweeteners like honey, maple syrup or agave, or you may find that sweet fruits like bananas make your smoothie sweet enough.
- Smoothies retain the natural bulk and fiber of the vegetables and fruits added, so are a better source of nourishment and calories than juices.

Some smoothie ideas contributed by TMA members with stomach issues are crafted to aid digestion — an issue for those on certain medications — as well as swallowing.

- Eat smaller and more frequent meals.
- Don't over-use protein powders. Better sources of protein include kefir and yogurt, which are fermented dairy products.
- Don't overlook avocados. Just one medium-size avocado contains about 15 grams of fiber, and avocados are easily digested. Avocados add creaminess that makes swallowing easier for many.
- Try some unusual vegetables in your smoothies. Greens are always good, but vary your menu a bit. For instance, red beets are loaded with potassium, magnesium and good fiber. Buy small fresh red beets and steam them, unpeeled, with several inches of the tops left on. Remove the roots and tops and slip the peels off while the beets are still warm.

We've selected a few of Laura's and Carole's recipes that will taste good in any season.

Find more great recipes on page 6.

Smoky Butternut Squash Sauce with Pasta, Beans and Broccoli

- 1/4 cup raw cashews, soaked
- 1 large butternut squash
- 1-2 cups broccoli, finely chopped
- 1 can white beans, drained and rinsed
- 1 package mini shell or macaroni pasta
- 3/4 cup water
- 2 garlic cloves, peeled
- 1 tablespoon lemon juice
- 1/2 teaspoon onion powder
- 1/2 teaspoon smoked paprika
- 1/4 teaspoon chili powder
- 1 teaspoon sea salt
- 1/8 teaspoon liquid smoke

Hot sauce

Place cashews in a small bowl, cover with water. Soak overnight or at least 3-4 hours until soft and plump. Drain, rinse before use. Prepare squash by roasting in the oven at 425 degrees on a baking sheet lined with parchment paper. Drizzle with oil and sprinkle with salt. Roast for 30 – 40 minutes until fork tender. Add cashews, water, garlic, lemon juice, onion powder, paprika, chili powder, beans and 2 cups of cooked squash into a high-speed blender. Blend until smooth. Add salt, liquid smoke and hot sauce to taste, blend again. Cook pasta according to package directions. Steam broccoli until fork tender. Add drained pasta to the pot, pour on desired amount of sauce and stir to combine. Stir in cooked broccoli. Warm over medium heat and serve immediately. Leftover sauce can be stored in an airtight container for up to 1 week in the refrigerator.

Modified from recipe provided by Mary Lou Perry, MS, RD, CDE.

Experts and patients discuss skin care for myositis

It's no secret that those with dermatomyositis (DM) often find their skin symptoms the most troubling part of their disease. One type of DM involves only the skin and is called dermatomyositis sine myositis or, more commonly, amyopathic dermatomyositis, or ADM.

In live discussions sponsored by TMA, dermatologists with a special interest in DM, Drs. Victoria Werth and Ruth Ann Vleugels, fielded questions from TMA members. Below you'll find summaries of the answers to your most common questions, plus some tips that DM patients contributed from their own experience.

Find the complete transcripts of TMA's live discussions on skin care on TMA's website, www.myositis.org. On the home page, go to "Your Myositis Community," then "Live Discussions."

Dr. Victoria Werth is chief of the Division of Dermatology at the Philadelphia Veterans Administration Hospital. She is also a Professor of Dermatology and Medicine at the University of Pennsylvania School of Medicine, an editor for the *Journal of Clinical Rheumatology*, and a former member of TMA's medical advisory board.

Dr. Ruth Ann Vleugels is the Director of the Connective Tissue Disease Clinic at Brigham and Women's Department of Dermatology, Co-Director of the Rheumatology-Dermatology Clinic at Children's Hospital, and an assistant professor in dermatology at Harvard Medical School. She is a member of TMA's medical advisory board.

What can I do about this terrible scalp itch?

Your dermatologist might prescribe a strong topical steroid preparation that penetrates the skin. One example is fluocinolone scalp oil, often sold as "Derma-Smoothie." Since it's greasy, most patients apply it at night and wash their hair in the morning. When your itchy scalp starts to improve, you may want to switch to something less greasy like clobetasol, a lighter topical steroid preparation. Remember that when you use a topical steroid, you should take regular breaks from its use to avoid thinning of the skin. Dr. Vleugels recommends one week on, one week off for the face; two weeks on, one week off for the scalp or body. During the break, you can use a cream like Protopic, with no steroids,

to control inflammation. With these breaks, you can continue the topical steroid use for years.

You may be prescribed systemic medications for itching not controlled by topical treatment (see below). Some members report hard sores on their scalp. You may be scratching your head at night, Dr. Werth notes, and breaking the skin, which forms sores. Nighttime itch can be lessened with Atarax or Zyrtec, both over-the-counter antihistamines that are taken orally.

You recommend: TMA's DM members have had success using coconut oil in their hair at night covered with a shower cap, emu oil, Scalpicin — an over-the-counter medication — and coal tar for itchy scalps. One member with DM described treating her scalp with ointment, then wrapping her hair in wet dressings covered with towels for a peaceful night's sleep. "I looked like a mummy," she said, "but I was able to rest."

I itch all over, whether there's a rash or not

For dry skin, dermatologists often recommend CeraVe cream or plain Vaseline — both preparations with a lot of staying power — after a shower. Make sure to use warm water in the shower or bath, as it is less drying than hot, then pat dry and apply CeraVe cream or Vaseline. You will do better if you make this a daily routine, says Dr. Vleugels, even on those days when your skin is not itchy. Steroid creams and Protopic are topical medications that help your skin as well as your scalp. For those who find Protopic to be effective, but harsh on the skin, Dr. Werth suggests keeping the tube in the refrigerator. "It tends to burn less," she said.



A note from Dr. Vleugels: "Please switch any lotions to creams as creams work much better."

Dr. Werth explains why many people find the itching worse at night: "There are less stimuli distracting you from recognizing the skin symptoms, so it seems much worse."

If you've found your skin improvement is lagging behind your muscle strength, this is very typical, and sometimes called "postmyopathic dermatomyositis." In addition to topical treatment, dermatologists find that some of the same medications used to control muscle weakness also work on skin issues:

- IVIG tends to work well for skin disease, including in patients with tough-to-treat skin disease. Dr. Werth recommends a regimen of IVIG every four weeks when it is helpful.
- Hydroxychloroquine (Plaquenil) is another option that helps the skin in many patients with dermatomyositis.
- Those receiving microphenolate mofetil (Cellcept) often report skin as well as muscle improvement.
- Methotrexate works well for some, not for others.
- Extreme diligence with sun protection often solves skin problems.

You recommend: Freezing an extremely itchy area with ice packs or ice, oatmeal baths, bathing in dead sea salts, aloe vera, Aveeno, lavender oil, mentholated cream.

My hands are itchy, disfigured, cracked or cuticles are ragged and overgrown.

Cuticles take a beating in myositis, according to Dr. Vleugels, who calls this "cuticular hypertrophy." Inflammation in the many tiny blood vessels that loop around in your fingertips may make them look deep red or

even brown. Some patients use Vaseline, vitamin E oil, or eucalyptus oil with natural camphor. She recommends using these preparations under gloves to help with absorption.



Those with the rough, dry fingers of "mechanic's hands" may use a thick layer of Vaseline (thick



like frosting, half a centimeter) under white cotton gloves at night. If the scale is very thick, use urea cream (a 20% urea cream can be obtained over the counter at the pharmacy; your doctor can prescribe a 40% version). This helps to actually reduce the thick scale. Urea cream must also be used in a thick layer under gloves.

Don't cut your ragged cuticles, Dr. Vleugels warns. Best to wait until your fingers improve a bit. Use topical steroids on your hands, and always protect them from the sun. When patients have splits in the fingertips, doctors may use superglue to keep the cracks from breaking open.

You recommend: Silver sulfadiazine cream when cracks get infected, non-latex gloves to wear over vaseline, Vicks Vapor-Rub, zinc ointment.

Supplements

While it's fine to take a multi-vitamin or vitamin D if you're avoiding the sun, some herbal preparations should be avoided, as they make you even more sensitive to the sun. Some "photo-sen-

sitizers" are echinacea and St. John's wort, says Dr. Vleugels.

Dr. Werth recommends avoiding herbal medications that can stimulate the immune system, such as green algae, spirulina, and echinacea.

You recommend: A diet high in fruits and vegetables, especially broccoli and cabbage, flax seed, dark chocolate, berries, turmeric and other antioxidants.

I have calcium deposits that are visible

This tendency, called calcinosis, is one of the most challenging parts of dermatomyositis to treat, says Dr. Vleugels. If calcinosis is spreading, your doctor may revise your whole treatment plan. The best data from the Mayo Clinic notes that surgical removal and a medication called diltiazem, a calcium channel blocker, are the most effective, but neither work or are even possible for everyone. Dr. Werth says cutting the deposits out is not a good approach if your calcinosis is widespread.

What about sun protection?

The sun triggers flares of DM in the skin. We know that the sun can bring inflammatory cells into the skin and also alter skin antigens, says Dr. Werth. It is clear that sunscreen, sun clothing, and sun avoidance are important for those who notice that their skin disease flares when they go in the sun.

Dr. Vleugels prefers physical blockers (sun hats, shirts and cover-ups) as they provide better protection than chemical blocks. If you do use sunscreen, make sure you have a sunscreen with both UVA and UVB protection. You will learn to avoid ingredients in sunscreen that irritate the skin or are too drying.

See Skin care, page 6

Easy meals, from page 3

Curried Butternut Squash and Apple Soup

Laura and Carole point out that any homemade soup or bought soup may be pureed. Soups that work the best are potato soup, split pea, lentil, bean and vegetable soups such as minestrone. You may also consider adding protein powder, dry milk powder, milk or cream, or nut butters when blending for additional protein and creaminess.

- 1 teaspoon extra virgin olive oil
- 1 small onion, large dice, or 1 teaspoon onion powder
- 1 tablespoon Madras curry powder
- 1 tablespoon ginger, freshly grated, or 1 teaspoon dried, ground ginger
- 2 medium butternut squash, peeled, seeded, and cubed
- 2 Granny Smith apples, peeled, cored and cubed
- 4 cups organic vegetable broth
- ¼ - ½ teaspoon salt
- 1 tablespoon peanut or almond butter

Heat oil in a 3 quart saucepan over medium high heat. Sauté onions until golden. Add curry powder and ginger, and stir with onions for about 30 seconds. Add squash and apple, toss until coated with oil and spices. Add 3 cups of broth and bring to a boil. Reduce heat. Simmer until squash and apples are tender. Puree small batches in the blender until smooth and creamy. Blend in nut butter. Add all back to the pot. Add more broth, if soup is too thick. Reheat, taste and adjust seasonings

Adapted by Laura Pole from recipe by Rich LaMarita.

Tofu Chocolate Pudding

- 12 1/3 ounce silken tofu, drained
- 1/4 cup unsweetened cocoa powder
- 1/4 cup water
- 1/2 cup sugar
- 1/2 teaspoon vanilla
- 2 tablespoons nut butter (optional)

Place all ingredients in blender until smooth.

*Recipe from Renee Bricker,
Speech Pathologist, UVA*



Skin care, from page 5

You recommend: Choosing clothing that has a dense weave rather than chemicals to protect you from the sun, carrying an umbrella in the sun, gardening in the first hours of daylight, wide-brimmed hats. One member wrote about Solumbra products (www.Solumbra.com). "This catalog offers sun protection (100+SPF) 'for sun sensitive and sun sensible people.' As a result of the clothes in this catalog I am able to go outside with hats, swim with full covering, and ride in cars."

Resources

If you are looking for a dermatologist for skin problems associated with DM, you will find that there are many dermatologists around the country who specialize in this type of patient. Many are members of the Rheumatologic Dermatology Society (RDS). If you need to find one of these doctors, you can go to www.rheumaderm-society.org and look under "For Patients" at the bottom and then click "Our Physicians." They are listed by state. You can also go on TMA's patient forum to find recommendations from DM patients in your area.

TMA has collected many resources for those with dermatomyositis. You'll find them at the TMA web page www.myositis.org under "Learn about myositis." Researchers are looking for volunteers to join trials. Some are listed on the website's home page under "In the Spotlight." You'll also find published research studies about DM under the "Explore Research" tab, including those funded by TMA.

TMA reaches and teaches physicians

Awareness of myositis among the public is important, but even more important is awareness of the disease among physicians. Many physicians, even those specialists who are likely to treat myositis — neurologists, rheumatologists and dermatologists — may never see a person who has myositis during their entire medical career. There are about 7,000 rare diseases and it is unrealistic for physicians to learn of all rare diseases during medical school and while training for their career.

However, TMA is actively trying to overcome this lack of knowledge about myositis in a number of ways. TMA has an exhibit booth each year at the annual meetings of these specialties where we distribute literature about myositis and inform physicians of the 40+ support groups we have around the U.S. These physician professional meetings are large annual gatherings (each has more than 10,000 physicians attending) and provide an opportunity for TMA to increase awareness of myositis.

These three-day meetings do not allow for in-depth conversations with all those physicians who are not aware of myositis or want to learn more. To provide more substantive education about myositis and to acquaint physicians early in their career with myositis, TMA initiated a "Visiting Professors Series" in 2014. This program invites U.S. and Canadian medical schools to have a member of TMA's Medical Advisory Board provide a lecture and/or Grand Rounds at their school to teach medical students, interns and residents about myositis and how to treat it. This unique program was very well-received in 2014 with nearly 25% of all medical schools asking to participate.

TMA funds the travel, lodging and, in some cases, honorarium, for the members of our Medical Advisory Board to be able to spend a day at these schools teaching others about myositis. The funding for this highly valuable program was provided by Mallinckrodt (formerly Questcor Pharmaceuticals).

TMA is planning to continue this program in 2015 and beyond. We will continue to seek ways to educate the medical and scientific communities about myositis and treatments. We will also continue to find unique vehicles to inform the public about myositis and which medical specialties are most appropriate to treat persons who have myositis.

Our outreach and education efforts will have an impact over time, and we will remain persistent.

TMA has resources for physicians

The Myositis Association has collected materials of interest to myositis specialists and other health professionals on its website at www.myositis.org. Please refer your physician or let TMA know (tma@myositis.org) if he or she would like to receive any of our materials, including our digital newsletter, "Myositis Monitor," and print copies of the newsletter, "The OutLook" for the office. Also on our website, health professionals can find:

- "Myositis: a Physician's Guide to the Inflammatory Myopathies," a primer for diagnosis, treatment, possible complications, and overlap diseases, written by experts.
- A list of our medical advisors, who are available for consultation, and their contact information.
- Disease specific information from peer-reviewed journal articles.
- Materials for distribution, including locations of support groups and brochures.

To find these and other items of interest to those treating myositis patients, refer to "Professional Resources" under "For Health Professionals" on TMA's home page at www.myositis.org.

REMEMBER!

- ✓ To register now for TMA's 2015 Annual Patient Conference - September 10-13 in Orlando.
- ✓ To plan for Myositis Awareness Day - September 21, 2015.
- ✓ To find the support group nearest you: tma@myositis.org.
- ✓ To join a myositis patient trial: www.clinicaltrials.gov.
- ✓ To "like" TMA on Facebook and follow on Twitter.
- ✓ To send suggestions for live discussions, newsletter articles, conference speakers: tma@myositis.org.

For the Caregiver

Partners in care solve problems, find support



Ingenious solution made bed accessible

By Nancy Harber

With this issue we introduce Nancy Harber, who will write a regular column for caregivers. Harber, a registered nurse, is an informal consultant to many struggling with the challenges of myositis. Although her experience was specifically with IBM, many of her solutions will apply to all forms of myositis.

So let's talk about beds. No, no, not the x-rated discussion but the practicality of getting into and out of them. How can such a simple task suddenly become so challenging and difficult?

It's easy, when you have joined the ranks of people with that strange disease, inclusion-body myositis (IBM). My husband, Charlie, (and I) lived with these challenges for 12 years. Fortunately I was a Registered Nurse and understood some of the ins and outs of caregiving, but this disease was new to me. Add to that the fact that Charlie was 6 feet, 5 inches tall, and what a challenge this became!

For the first couple of years, when he started with a cane and then progressed to a walker, we figured it out pretty well. He would walk to the side of our lovely California King-size bed using the walker, lean against the bed and undress, and when he was ready, sit on the side of the bed. Almost from the beginning, lifting his legs up and onto the bed was difficult for him to do, so I was there to help lift them up and we were pretty much set. Getting

up in the morning was an exercise in reverse. I often had to get under his arm, have him pull against the back of my shoulder to get into a sitting position, pull his legs to the side and up he came, to sit on the side of the bed.

It wasn't too long however, until this no longer worked. The bed was just too low for his weak quadriceps to get him onto his feet. Obviously the bed needed to be higher. We explored several options. First was the use of the "risers," available for sale in many medical supply houses and catalogs. These are the hard rubber items, shaped like the orange cones used in the streets to mark off accidents, but smaller. They have a depression in the center of the cone at the top, where the bed caster or leg can fit. We bought a set of 4 of these and tried them. However for a large bed like the California King, we needed more support in the center of the bed. (We later discovered these risers worked pretty well on chairs).

I then decided to purchase a second mattress to pile on top of the one we had, adding another six inches or so. I went to the mattress store and found a very helpful gentleman who understood beds well. He suggested to me that I didn't want another mattress, since that might result in the two mattresses just sliding back and forth. He asked me if I had considered purchasing another set of box springs. He felt they would be more stable and stationary. He was right!

That's what we did and they served us well until more assistance was needed, several years later. There was a big advantage to me having the bed elevated so high. Not only was it easier to help lift Charlie in and out, but also it

was the perfect height to bring my freshly-washed clothes from the dryer to stand and fold them. No bending or lifting required.

There is, of course, a caution. I always knew if I fell out of bed, I could break my hip, but fortunately I am not a restless sleeper and soon got very used to slipping out of bed, leaning against the side. Although Charlie is gone, I have kept the double box springs. Folding clothes is still much easier and I can use the bed to sort papers and other items.

Not a perfect trade-off, but there is still a touch of Pollyanna in me, I guess!

Finding a caregiver

Even when family provides the majority of personal care, there may come a time when an outside caregiver is needed. James Barrow, who has polymyositis, sent us some questions to use during an initial employment

See Partners in care, page 13



Patients tell stories of loss, perseverance and hope

When answering our 2014 Member Survey, many of you requested more stories in *The OutLook* about how people with various forms of myositis have coped with the different stages of their diseases. For several years, we have been offering Andrea Langworthy's candid and humorous reports of her life with IBM. In this issue, we also have accounts by Bill Simeral, who has polymyositis; and Kathryn Nevard, who has dermatomyositis. On page eight, you'll find a glimpse of Nancy Harber's experience as a caregiver.

Please see our new videos at "Learn about Myositis" on the home page (www.myositis.org), under "Patient Stories."

Polymyositis



What surprised me

By Bill Simeral, polymyositis patient

Recently I was asked to write a short article about a single aspect of myositis. I chose to write on "What surprised me about my disease?" I never could have predicted the bizarre course of my disease or my life after getting polymyositis and lupus in 2005. Terrible surprises at first but good ones later on.

The most obvious answer to the question is that I got the disease in the first place. I had been so healthy, fit, and active that I never expected to get a disabling disease, let alone one I had never heard of. Then it was a huge surprise that it could be so severe, unresponsive to treatment, and completely disabling in such a short time. And lastly, the bonus surprise of not being able to swallow six months into the disease and treatment. I knew nothing about dysphagia and didn't know it could be caused by a muscle disease. Dysphagia was tougher to accept and cope with than being completely disabled. That surprised me! At the six month mark things looked dire and my expectations were low.

My condition slowly improved and a ray of hope poked through the clouds of doubt. After only five weeks in a rehabilitation hospital, I was able to stand and walk again. That was a surprise, and not even my therapists expected such rapid progress. I was still a mere shadow of my former physical self but walking and taking care of myself again. Initially, it was doubtful that I would swallow again but

after a lot more therapy my swallowing was restored. What a surprise to enjoy that first meal eating real food, enjoying a glass of red wine, and sipping a cup of coffee.

In the course of three years, I was able to return to an active life again of downhill skiing, golfing, and working out. As the years passed and I continued to work through my physical disabilities, life began to resemble my old, normal life before myositis. That was a surprise. A pleasant one.

During my long physical recovery I made a decision to try and help others afflicted with myositis, lupus, or a disability. I volunteered in a rehabilitation hospital, co-led a TMA KIT support group, and became active in the lupus community. My hope was that my experiences might help others in some way to cope with their disease or disability. That has become a rewarding part of my life since 2006 and I have made many new friends and learned so much from them. They are the bravest and toughest people I know and it is a privilege to know them. This part of my life was a big surprise and has given me new purpose in retirement. My surprises were getting better.

Most of us complain of loss as we age. Couple age with a disabling disease and it is hard to be grateful for what you have. I have learned to be grateful. While life is far from perfect, it is good and purposeful with unexpected rewards. Any early predictions were completely wrong. My journey has been full of surprises. At the ten-year mark I would say that this is the best time of my life and that was totally unexpected. Today I try to remain optimistic and live in the moment. I have no idea what will come next. Tomorrow's surprise: who knows?

Find Bill Simeral's video story at "Learn about Myositis" on the home page (www.myositis.org), under "Patient Stories."

Dermatomyositis



Positive changes made the difference

By Kathryn Nevard

I will never forget the day I was diagnosed with dermatomyositis. My face was covered with a rash, itchy and

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swollen. My doctor prescribed high doses of prednisone and methotrexate. After the first few months, I started losing my hair, and I was continually tired and puffy.

Determined to take my health into my own hands, three months after diagnosis I saw a nutritionist and tested my allergies, to find that I was highly allergic to gluten and wheat. I decided to cut out alcohol, wheat, gluten, caffeine, and sugar from my diet, all foods that can be highly inflammatory; and eat mainly fresh fruit, veggies, and proteins. Within weeks my headaches and joint pain went away, and within months, most of my symptoms disappeared. I was back out biking and practicing yoga, and my skin redness had subsided.

Now, three years later, I know my body better than before I was diagnosed. If I enjoy a glass of wine during the holidays or a slice of chocolate cake, the next day my body will ache or a rash may appear on my face or hands. When I stick to fresh juices, smoothies, and salads, my skin glows.

Making a lifestyle change can be difficult; however, I feel one must reduce inflammation in the gut before we see the effects on the outside. So how do you start this transition?

Here are a few tips that helped me.

- Get your allergies tested: See if you should remove foods from your diet that are hindering your recovery.
- Coconut oil: Cook with it and use it on your skin. It will help soothe your skin and protect against infections.
- Nourish your gut to nourish your skin: There is a reason they say “you are what you eat.” Cook more at home, and know what goes in your food and ultimately your body.
- Invest in a juicer: I purchased my juicer one year after my diagnosis and it was one year too late. Fresh green juice can energize your body and help fight inflammation.
- Take your vitamins: Probiotics, vitamin D, fish oil, folic acid. Find out what your body needs to help recover.
- Take it slow: Having an autoimmune disease is overwhelming. Take time for yourself.
- Hydrate: Nothing helps your skin more than water.

Prescription medication saved my life; however, these small changes at home have given me hope for a healthy and active future.

My advice to you if you are struggling or feeling overwhelmed? Make one positive change a day. Put the alcohol

down, drink more water, or allow Mondays to be your only coffee day. By doing this, at the end of the year you will have made 365 positive changes to get you one step closer to a healthier and happier you.

Trust me, your body will thank you!

Inclusion body myositis



Julia Child and I

By Andrea Langworthy

Last September, I called my primary care clinic and asked a nurse to give a message to my doctor. “Please tell her, regarding the feeding tube,” Andrea Langworthy says, “‘uncle’.”

Relief wrapped its arms around me like a giant hug. I set down the telephone and began to cry. Minutes later, the phone rang. The nurse told me surgery would be the following week. I laughed, wondering if she had the radiology department on speed dial just in case I changed my mind about the feeding tube my doctor had been bringing up the past three years.

When I told my husband about the call, his relief was obvious. “Good,” he said, as he went on to explain my doctor had said there was a chance of losing me if I didn’t have the surgery.

The dysphasia (difficulty swallowing) related to my inclusion-body myositis had gotten worse. Meal times were chewing, coughing and choking sessions. Over and over, I took a tiny bite of food, chewed it into mush, tipped my chin down and gave the morsel a push. It was always a gamble; always touch and go.

Two years ago, with my family around the dining table, I took a breath when I shouldn’t have and the morsel of salmon in my mouth flew to the back of my throat, went down too fast and got stuck. Eventually, it dislodged but not before the reply I’d given my doctor when she first suggested a feeding tube came back to haunt me. “No feeding tube for me,” I had said. “I’d rather go out choking on a piece of salmon.”

That first recommendation came after a barium swallowing test I’d taken. The radiologist must have shared his concern about my weight loss. I assured him I was eating three normal-sized meals a day. It took so long to get the food down, though, and was so much work, I couldn’t bear to force-feed myself in-between meals to add some pounds. He recommended a protein drink like Boost or Ensure. “But

they're full of chemicals," I protested. He said I couldn't afford to worry about that.

Two years passed. I was losing weight at a dangerous pace and a recent bout of pneumonia — the result of aspirating food — had left me extremely weak. My daughter and husband were in the room when my doctor visited and, once more, broached the subject of a feeding tube. I begged for more time. Ninety days. "I can do this," I said, promising to eat more often.

The list of foods I could usually eat safely had dwindled. Breakfast was two applesauce muffins. Lunch, a large bowl of crackers with hummus. Dinner was often hearty chicken and vegetable soup, French bread smeared with olive oil, and Mandarin oranges. Or asparagus and rice alongside chicken or salmon. Each meal took an hour (breakfast) to an hour and a half. After a month, even with a snack or two, instead of gaining weight, I'd lost two pounds.

My cautious eating didn't stop me from aspirating food into my lung last summer. I got pneumonia; the second time in two years. My daughter came to help one weekend. She brought up the feeding tube and suggested I go to a rehab facility to build up my strength. I called my son. "Your sister is not going to let up on this feeding tube and rehabilitation," I said. "I need your support."

An hour later, my children pulled chairs into the bedroom and sat side-by-side facing me. My husband joined them.

This looks like an intervention, I told myself, as I looked across the room. Their grim faces and words of worry didn't sway me. "Just give me 30 days," I said. "One month."

Two weeks later, I knew I couldn't get the job done. Eating had become dangerous. I remembered reading that

people usually don't die from myositis but from falling or choking.

That's when I made the "uncle" call to my doctor's office. Two days later, I couldn't get any food down. The next day, I wasn't able to swallow water. My husband called 9-1-1. The surgery was moved up.

I wasn't sure what to expect. My dad had a feeding tube, also, but I never saw it. I have no idea what it's like under my skin but whatever's there must be connected to the skinny tubing poking out of my abdomen to the left of my navel.

There's a flat, clear, plastic disc to keep it in place and then, more tubing that extends about half a foot. At its end are three different-looking plastic things: one is a tiny receptacle where a skinny syringe of medication can be inserted. Another is a bit larger; cylinder-shaped for a syringe of water or watered-down crushed pills. It's also where the red nozzle connected to the tubing coming from the bag of food is plugged in.

A digital brain is latched onto the five-foot pole the bag hangs from and

the pole spreads out at the bottom with four bouncy legs. The pole can go everywhere I do but the bag can also be hung from a shorter post on my wheelchair. No matter where it's set up. I refer to the entire thing as "Julia Child."

I spent two days in the hospital after the tube was inserted. A staff social worker told me about transitional care places where I could stay to get used to the feeding tube. My husband could be with me and we'd be taught how to put the food in and take care of the entire apparatus.

She spoke highly of one TCU where I would have speech, occupational and physical therapy. When the word, "Sure," came out of my mouth, I was surprised but didn't take it back. A few days later, I was on my way in a medical transport vehicle. My gurney faced the back doors and through the windows I could see my husband and sister following in separate cars. Once again, a warm, fuzzy feeling of overwhelming relief embraced me and held me tight. I was anxious about what was ahead but that will have to be another column.



TMA-supported Research

Adding understanding to myositis causes and treatment

A predictive model of disease outcome in rituximab-treated myositis patients using clinical features, autoantibodies, and serum biomarkers

A team of researchers led by Cynthia Crowson of the Mayo Clinic in Rochester and including two TMA medical advisors set out to see if they could develop models that could predict the success of the drug rituximab (Rituxan) in improving hard-to-treat cases of myositis. They wanted to see how the drug worked if administered early in the disease course (eight weeks) and later (24 weeks). This project, funded by TMA in 2014, has shown in its preliminary reports that it is possible to predict, using clinical observations and blood work, how the drug will change disease activity in certain patients when administered at both the early and later stages.

MYOVISION

The Myositis Association, in conjunction with leading myositis researchers, sent out 9,211 questionnaires between December 2010 and July 2012 to patients with adult and juvenile dermatomyositis (DM, JDM), polymyositis (PM, JPM), inclusion-body myositis (IBM), and other forms of myositis in the US and Canada who had registered with TMA or learned of the survey from other sources. The questionnaire queried demographics, clinical features, environmental exposures, and quality of life. The response rate was 24.2% or 2,209. Researchers re-contacted 1,266 participants to resolve missing and conflicting responses. Some of the findings made possible by MYOVISION were presented at the

2014 meeting of the American Academy of Rheumatologists. The following two summaries are from the nationwide registry.

Epidemiologic and Clinical Features of Patients with Adult and Juvenile Dermatomyositis, Polymyositis and Inclusion-Body Myositis from MYOVISION, a National Myositis Patient Registry

A nationwide registry of myositis patients has been established with similar demographic and clinical features to other myositis cohorts. The results suggest that there is considerable variation in the demographic and comorbidity profiles of patients by myositis subtype. MYOVISION registry data will be useful in further clinical and epidemiological studies. For more information on the demographic information collected, go to TMA's website, www.myositis.org, and find "Published Research" and then click on General Myositis.

Predictors of Myositis Treatments Received and Associated Treatment Responses in MYOVISION, a National Myositis Patient Registry

Researchers concluded that prednisone and methotrexate are the most frequently prescribed medications in DM, PM, IBM and JDM. Patients vary substantially in their assessment of the effectiveness of these and other treatment approaches. For more information on the predictors of myositis treatments and responses collected, go to TMA's website, www.myositis.org, and find "Published Research" and then click on General Myositis.

Resource Utilization in a US-based Sample of Patients with Sporadic Inclusion Body Myositis (sIBM)

The Myositis Association invited those with a confirmed clinical diagnosis of IBM at the 2013 and 2014 Annual Patient Conferences to meet with investigators in order to better characterize the socioeconomic burden of people with sIBM in the United States.

Results of this study, which provides socioeconomic data for the first time in a US-based sample of patients with sIBM, demonstrate a high resource utilization and financial burden experienced by sIBM patients in the United States. For the study's full results, go to TMA's website, www.myositis.org, and find "Published Research" and then click on IBM.

Targeted sequencing and identification of genetic variants in sporadic inclusion-body myositis.

Many IBM patients volunteered to participate in a research study while attending past TMA Annual Patient Conferences. The study, funded by TMA, was recently published in *Neuromuscular Disorders*. Lead researcher Dr. Chris Weihl said the study addressed the fundamental question of why some people develop inclusion-body myositis and others do not. To answer this question, researchers collected DNA from 79 patients with sIBM, looked at the genetic variation within this group and compared it with population controls. The approach was biased in that it only looked at genes associated with clinical syndromes resembling sIBM, Dr. Weihl said. One finding was the identification of rare patients with mutations in genes associated with hereditary muscle diseases, although they

had no clear family history. Whether these mutations caused sIBM in these patients or are risk factors for sIBM remains to be established in larger groups of patients. This study was a critical first step in exploring the complex genetic factors in sIBM patients. Ongoing studies are to perform unbiased genetic sequencing in a similar group of patients to identify genetic factors that may explain risk, prognosis or treatment responsiveness.

Role of RLR innate immunity in initiating and perpetuating dermatomyositis.

Isabel ILLA, MD, PhD. X. Suarez-Calvet, and E. Gallardo of the Neuromuscular Diseases Unit, HSCSP, Barcelona, Spain, were awarded this research grant by TMA in 2014.

Citing recent discoveries that show the importance of innate immunity as a factor in the pathogenesis of inflammatory myopathies, these researchers will describe new immune pathways involved specifically in DM. This will be key to understanding the immunopathogenesis that leads to muscle damage and contribute to the discovery of new specific therapeutic targets that would improve the treatment of these patients. To follow up on research already conducted, X. Suarez-Calvet (co-investigator of the present proposal) received a fellowship grant from TMA for 2015-16. This grant will allow the group to continue developing this work and to start collaboration with the group of Dr. Olivier Benveniste in Paris to develop an animal model of DM with autoantibodies against MDA5. Preliminary research has begun, showing that the morphological pattern differs among MDA5 positive patients and classical DM patients.

Partners in care, from page 8

interview. When his computer was stolen, Barrow learned from experience that not all caregivers are reliable and trustworthy. He went from using an agency at times when he needed help to doing the hiring himself. He points out that the individual employer can legally ask more detailed questions than would be appropriate for a commercial employer.

- **Experience.** Do the applicants have experience? If the experience has been in a long-term care setting, find out if they understand how your situation may be different. Ask if they have experiences with diseases similar to myositis. Because your caregiving needs may change as the disease progresses, you'll need to know about their educational or training backgrounds, especially if skilled nursing needs may arise. Ask if they have CPR and first aid training.
- **Capabilities.** Are they physically capable of providing the type of direct care needed? Are they willing to take the initiative to assist with household duties? Are they likely to be patient and calm when faced with difficult or unexpected circumstances? Ask them for an example of a time when they had to handle a challenging situation. Are they able to work extra hours if needed?

- **Security.** Ask for names, addresses, phone numbers, cell phones and best time of day to be contacted. Get permission to conduct a criminal background check in all states where applicants have lived. Do they have a reliable means of transportation in order to get to your home promptly each day? If you need the applicant to transport you, conduct a check of driving records with the Motor Vehicle Division and ask for a copy of valid driver's licenses. Where were they last employed? How long were they employed? Why did they leave? Can you contact the employer? Ask for multiple references and be sure to contact those references. Phone is better than email, as people tend to be more honest. Require both personal and professional references.
- **Observe legal procedures.** Find out the requirements for social security contributions, days off, overtime. You can find out the particulars from your local Center for Independent Living. Your Center will also have an appropriate contract form for your use.

You can find other information about finding and hiring a caregiver at your local Center for Independent Living. Find the one closest to you at www.ilru.org.

LEAVING A LEGACY

Fact: TMA received several large bequests in 2014.

Result: TMA will triple its funding for research in 2015 to \$750,000.

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Remember: To consider including TMA as a beneficiary of your estate, a life insurance policy, or an IRA.

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Lisa—28 years old, IG infusion patient
Photographer, favorite subject: her son

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