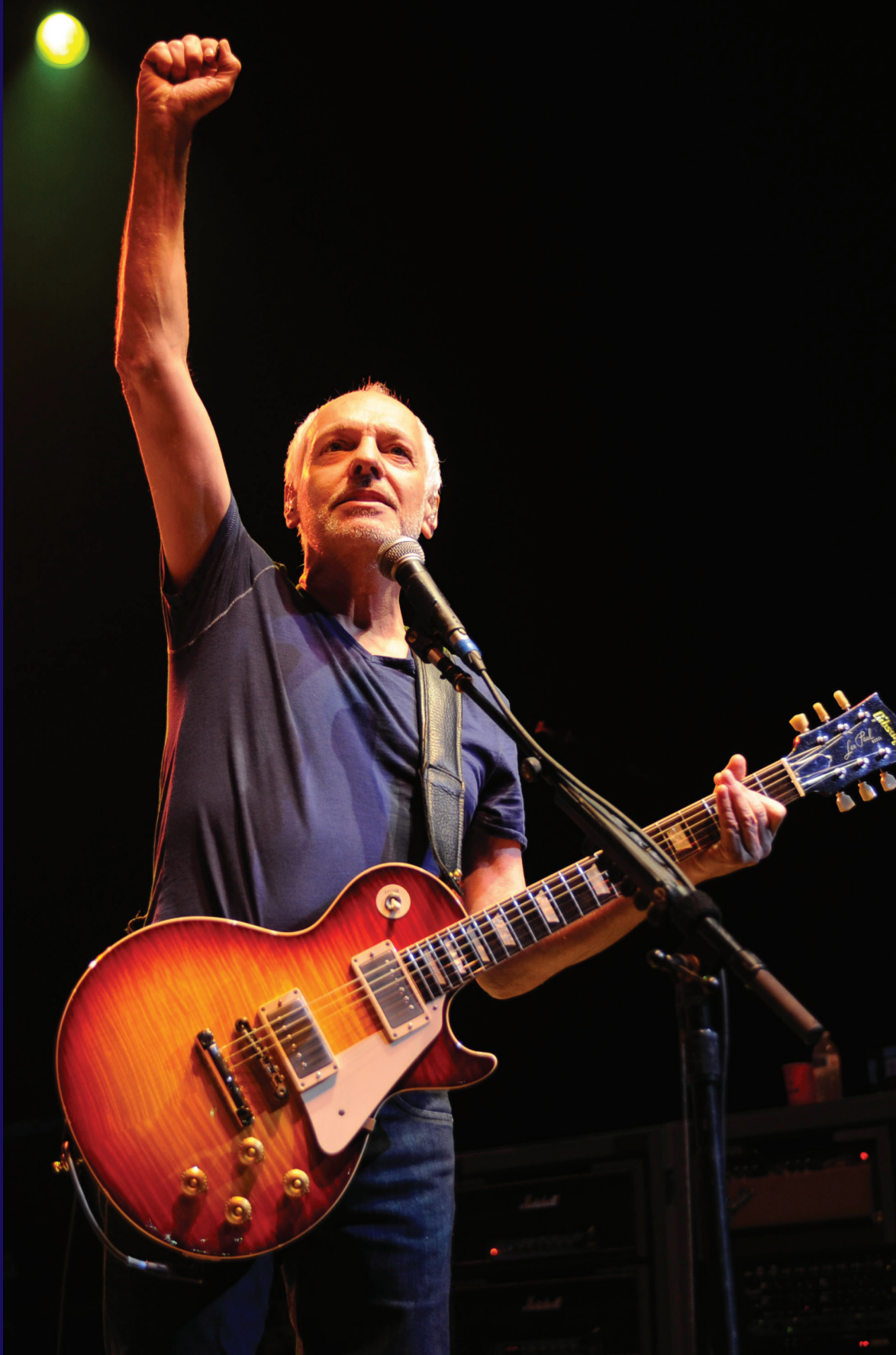


THE OUTLOOK



THE MYOSITIS ASSOCIATION

WINTER 2020
Quarterly Newsletter



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THE OUTLOOK

A quarterly publication of The Myositis Association

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**TMA’s vision is a world
without myositis**

**TMA’s mission is to improve
the lives of persons affected
by myositis, fund innovative
research, and increase myositis
awareness and advocacy**

Cover photo courtesy Peter Frampton

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Executive Director, who we hope will be penning the next Director note in this very space. Rather than being held back by COVID-imposed challenges, we at TMA are remaining agile, continuing all operations while also finding new ways to support you, the members, even better.

In September, we held the TMA Annual Patient Conference virtually for the first time. More than 600 registrants, by far the most attendees ever, participated in new webinars and interacted directly with each other, our small army of outstanding myositis physicians, and our generous sponsors and exhibitors. Moving into the future, we will continue in-person events for human interaction, as well as virtual events to increase global connections and include those who can't travel (and combinations of both of the above!)

You'll see more of rock legend and myositis patient Peter Frampton in these pages. He opened our conference in September, and TMA had the privilege of nominating him for the NORD Rare Impact Award that he accepted in October. He also just published his memoir, "Do You Feel Like I Do," reviewed here, back page.

Above all, TMA is renewing our commitment to you, our members. Whether you are a patient, family member, care partner, physician, or sponsor, you are the most important thing to TMA. We're focused on our correspondence with you and listening to your situation and needs. Just one initiative we're launching is expanding support meetings into the virtual world. In addition to geographically based in-person support groups, new and expanded virtual meetings will bring together members with common interests and needs from all over the world. This will increase the number of programs like Women of Color, and form new groups of members who may previously have felt isolated.

As a patient myself, I wish you the happiest of holidays! All of us are going to make it through this time of change, and keep fighting as myositis warriors.

Chris Dotur

Interim Administrator, TMA

Tell me—have your circumstances changed at all this year? Of course they have! None of us can say we are in the same circumstances as this time in 2019. Whether it's your health, family, job, finances, or otherwise: if nothing else, each of us has had major areas of our lives upended by COVID-19.

It's not whether there's been change, or whether you're encountering challenges. The question is what are you going to do about it?

Challenging change is no different at TMA. I'm writing to you as our Interim Administrator, as TMA is chest-deep in the process of hiring our new

TMA Virtual Annual Patient Conference: Some highlights

The Virtual Annual Patient Conference made myositis experts available to those not able to travel to in-person conferences, and became our biggest conference yet. In this issue of the Outlook, we hope to give you key points from some of the sessions. To see them in their entirety, please register for the Conference after-the-event at www.myositis.org, where you'll find videos of the sessions until the end of the year.

For the exercises that follow, Alexanderson recommends starting at 2 or 3 on the scale, repeating the series of repetitions twice daily for two weeks, and continuing with repetitions, gradually increasing them until you reach "Heavy," or No. 5. After 16 weeks, re-assess your exercise program with the help of your physical therapist.

Exercise is your friend

There's a small number of IBM patients who find that exercise doesn't have an impact on disease progression, said Helene Alexanderson, but most find it helpful in retaining strength and flexibility, and delaying further weakening of the muscles. And some—those with less muscle damage—can actually see improvement in their strength over time.

Dr. Alexanderson is an associate professor and physical therapist at the Karolinska University in Stockholm, and a long-time researcher into exercises for people with myositis. She's found many reasons, in addition to increasing muscle strength, why people with advanced disease should establish and continue an exercise program, she said. Exercise positively affects your understanding, improves your mood, and reduces your chance of diabetes, cancer and heart disease.

Alexanderson has designed a number of different exercise programs for myositis patients, and has presented often at TMA Conferences. In this particular session she specifically counsels those with advanced IBM. She defines "advanced" by limited ability: being able to walk only a few steps indoors or outdoors using an assistive device, for instance; or using a wheelchair or support from a care partner.

When Alexanderson recommends a rubber band for exercise, she doesn't mean the kind that comes around

your broccoli at the grocery store. She's referring to therapeutic rubber bands used by physical therapists. They're often available at pharmacies, sporting goods stores and online.

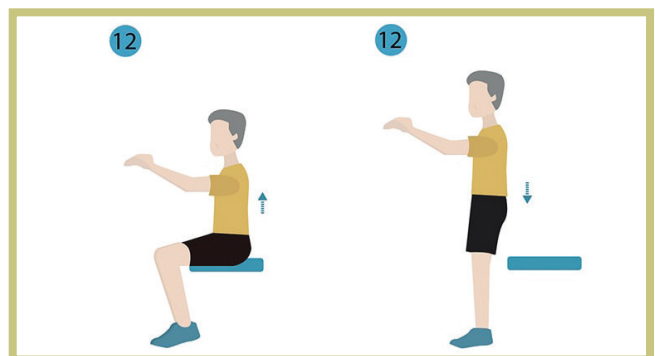
Alexanderson's overall advice

"Try to do something every day," she said. "Better to have shorter sessions and have them more often."

She offered some guidelines to establish a consistent exercise program:

- ✚ Adapt exercises to your functional ability and strength.
- ✚ Remember that a little muscle soreness is normal, but more severe aches and pains a signal to dial it back.
- ✚ Rest after an exercise session before walking to reduce falls.
- ✚ Remember to train your balance.
- ✚ Remember to stretch.
- ✚ Exercise should be enjoyable!

Practice makes perfect



Practice getting up and down from a chair any way you can.

If you have IBM, you know how frustrating it can be just to pull your own weight up, once seated. A simple exercise designed to help with this is just to do it, over and over again. Alexanderson recommends finding a chair that's adjustable in height, if possible. Put it against the wall and place a table in front of you for safety. Sit down and then stand up several times. If possible, try to do it without using your arms but if it's not possible, "just do it however you can," Alexanderson said. "You may need your arms for support."

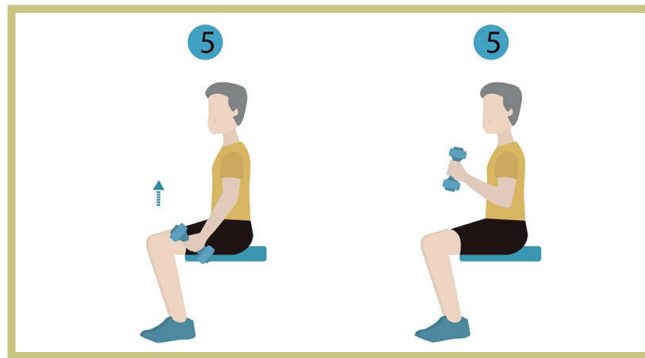
Also practice the act of sitting down. It's easier, she said, than standing up, as the muscles involved are lengthening rather than contracting. You'll strengthen your muscles sitting down if you control the speed, resisting gravity in the process. Alexanderson said a rubber band around your knees will help stabilize them.

Move your wrist and finger flexors

Keeping wrist and finger flexors as strong as possible is very important for IBM patients, Alexanderson said. To exercise them, you can use a rubber band or a free weight. Sit down with your arm supported on your thigh with the palm facing up. If you're using a rubber band, anchor it with your foot. Bend your wrist up while keeping your arm tightly against your thigh. Change sides and repeat the exercise.

Repeat this exercise until you reach a low intensity level in twice-a-day sessions for two weeks, then add repetitions twice a day until you've reached a level of moderate exertion. Change sides and repeat. Continue for weeks 3 to 16 until you reach heavy exertion.

Pump up those biceps



Biceps, usually not affected by IBM, can be strengthened by exercise.

Biceps are not so severely affected in IBM, Alexanderson said, so it will be easier to see progress.

Start by standing up or sitting down with your arms at your sides. Hold a rubber band in your hand with the other end under your foot. Lift one hand up to the shoulder, keeping the elbow held against your torso. Release the arm slowly, keeping it close to your side. Repeat on the other side. This can also be done very satisfactorily with free weights, Alexanderson said, or—in cases of advanced weakness—using just the weight of the arm and gravity. Your care partner can help guide the movement or put some resistance on the arm when you extend your elbow. Repeat as recommended above.

For those with extremely limited strength or mobility, Alexanderson gives a few ideas for exercises that can be done in bed, or in a chair or a wheelchair.

Try the clam: The abductors are well-preserved in IBM, so give them a workout. Lay on your side, feet together, and lift and lower your upper knee.

It's helpful to know how to rate the intensity of your exercise before you begin, so you can follow Dr. Alexanderson's instructions for measuring exertion.

Borg scale

0 - no exertion

1 - very light

2 - light

3 - moderate

4 - somewhat heavy

5 - heavy

6, 7, 8, 9 - progressively heavier

10 - almost maximal

Test your balance: Sitting down, transfer weight from side to side or forward and backwards. Your care partner can stand near you for support and give a slight push in different directions. Standing up, shift your weight from side to side, forwards and backwards.

Stretch and twist: Lying on your back, bend your knees and, keeping them together, move them from one side to other, while keeping your back, head and neck stable.

For swallowing: “We don't know much about the strength and function of breathing muscles,” Alexanderson said, but there are anecdotal reports that taking systematic deeper breaths can help. There are some vocal exercises that also help, such as saying “KPFS” or “SSSSSSSS,” and then relaxing the muscles.

What if it hurts?

Exercise itself can relieve pain, Alexanderson said, because it relieves the stiffness caused by inactivity. Talk to your doctor about pharmaceutical solutions, and also ask about a TENS (transcutaneous electrical nerve stimulation) unit, acupuncture, or massage.

Just have fun!

Peter Frampton notes that he's still able to play his guitar because he does it continuously. TMA members report they play instruments, knit, crochet, draw, paint, and knead bread dough to continue to exercise their fingers.

Another fun exercise, also practiced by Frampton, benefits throat and face muscles: “Sing,” said Alexanderson. “It's good exercise, too.”

Plan ahead for a comfortable, functional home

There's a few ways you can think about preparing your home for advanced stages of myositis, said Chris Dotur. Chris is TMA's interim director, and he has a rare form of IBM, a kind that can be inherited, so he knows something about what to expect. His father, Jeff, had the same form and joined TMA at its start in 1993.

Whatever your preferences, we all have the same goal, Chris said: to make your home safe and barrier-free, useable for you to live your life.

How you do it and what you do is completely up to you. "Don't worry about the ADA regulations that govern public spaces, not private homes," he said. "No one will be banging at your door to see if you're in compliance."

Three basic approaches:

- ✚ If your home presents insurmountable logistical challenges, you may have to move.
- ✚ You may value efficiency to the point where you don't care what your home looks like, so long as it functions well.
- ✚ You may value the appearance of your home and choose to add accessibility in ways that keep it pleasing to the eye.

"No one way is the only way," Chris said. He chose the third option, which became obvious as he invited attendees at TMA's Annual Patient Conference to tour his comfortable home near Anchorage. The entire tour, which is available with registration for the Conference, demonstrates plenty of practical ideas for those anticipating future needs.

A few main points, shared by Chris as he walked through the tour:

Make changes before you need them. It takes a while to interview contractors, choose one, get on the schedule and arrange financing, so figure out what you need in advance.

Say goodbye to tripping hazards. Yes, rugs can be beautiful, warm and comforting, but eventually they'll have to go. Start figuring out how to replace carpeting with alternative flooring and remove doorway thresholds that are tripping hazards for walking, or obstacles to your power chair.



Start looking at portable ramps. "Even if you live in Kansas, there will be inclines," Chris said. To achieve a rise of one inch, plan for a foot of ramp. "You can shorten the length, but it will make it steeper." Make sure in advance that the slant of the ramp is one that a power chair can handle.

Prepare for ups and downs. There are several ways to propel yourself between floors. For small vertical distances, such as a small step down into a garage, you can consider a platform lift. You'll find stair lifts for longer stairs that can be installed even on curved staircases. A more expensive option is an elevator, and Chris likes the models that are built with the motor on top, so there's no separate engine room. The way space is laid out in your home might determine the best place for an elevator to land: for instance, when Chris installs an elevator, he'll land in the master bedroom, which will then give him access to other upstairs rooms.

Stay horizontally mobile. Hoyer lifts and other models fit into overhead ceiling tracks and are helpful for those who can no longer bear their own weight. Lifts propel you within a room, including bathrooms.

Speaking of bathrooms. Chris added to his presentation by showing bathroom videos made by a couple of IBM patients with some really good ideas, like using smaller tiles for better traction, control knobs that can be bumped rather than grasped, incorporating a seat in the shower, sinks with wheelchair space underneath, walls strong enough to support grab bars, and counters and toilets at convenient heights.

Via video, IBM patient Wayne Mortensen showed his walk-in bathtub, a device that helps soothe sore muscles, and his closet, which has racks that pull down to wheelchair level.

Find funding. If you're a veteran, start with the Veteran's administration. "Any VSO (Veterans Service Organization) should be able to help you," Chris said. Start by looking for ones in your own locality. There are other resources, too. Chris showed a screen shot of resources for those with disabilities in Alaska and there were pages of them, so be aware that help in your

locality is different but will be available. Another source Chris likes is homemods.org, compiled by the Leonard Davis School of Gerontology. This site has dozens of ideas for everyday life for those with disabilities, including home modification for low-income people, reputable contractors for home modification, ideas for caregivers, and guaranteed loan programs for seniors.

There may not be one place where you can find financing, Chris said, but don't give up: "You may find small sources of help in several places, but it all adds up."



More help for those with advanced disease

Because TMA's 2020 Annual Patient Conference is virtual, we have included many sessions of interest to those unable to join us for in-person events. Besides finding the entire exercise and home tour

sessions, summarized above, you'll find the following presentations for advanced myositis, and we'll also present them in future editions of the Outlook. They're all available under "Agenda." Click on the day they were originally presented.

Spoon theory - how to pace yourself and manage your expectations

Inclusion body myositis update

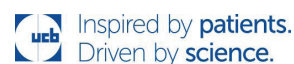
Mindfulness and social isolation in advanced disease state

Medical management for advanced myositis

Introduction to supportive tools and assistive devices

Advanced care planning - medical directives, aging in place

Conference sessions will be available until the end of the year. Find them and register at www.myositis.org.



Thanks to the Annual Patient Conference sponsors and to the Rita B. Lamere Foundation for their continued support.

‘Hints & Hacks’ show the creative spirit of the myositis community

Who knows more about the distinctive challenges inspired by a myositis diagnosis than those with the very same diagnosis and the very same challenges? The “Hints & Hacks” contributed by TMA members at the 2020 Virtual Annual Patient Conference were elevated by the generosity and knowledge of the people who took the time to post them.

Some were elaborate, high-tech and dazzling. Others were simple and homey, or new uses for ordinary objects. Whatever their level of complexity, they all solved real problems that myositis patients face every day. We are glad to share some of them here with you.



Kim Radowiecki uses everyday items to fashion useful accessories.

Everyday genius

Kim Radowiecki, an IBM patient from Connecticut, probably said it best: “The relentless progression of this disease requires continual modification of utensils, assistive devices, and living areas.” She said she tries to catch issues very early, or even anticipate them, before they become obstacles as her disease progresses.

Kim’s an everyday genius at creating modifications from materials on hand, she said, “It’s difficult and expensive to find and order things off-the-shelf to suit our needs.” Because she knows figuring out everything for yourself can be exhausting, she’s happy to share her hacks.

The evolution of Kim’s walker

Kim’s walker has become a focus of her ingenuity, and she’s decked it out gradually with bells and whistles that increase its functionality in her home and outside, all with materials that required no investment. Even her initial investment was minimal: almost a decade ago, she bought a used walker because she liked its compact construction.

Some of her thrifty modifications:

- ✚ She attached an over-the-door hook for hanging her grabber, and used her son’s old Bible bag to carry a no-drip coffee mug, paper napkins, and a headlight. She’s shifted items around and added essential items, and the former Bible bag now holds tongs, a back scratcher, paper towels, a mini flashlight, and a bullhorn.
- ✚ She added a plexiglass walker tray, and found a clementine box to increase height for carrying food and other things. The box is perforated with “bowling ball” finger holes, is easily removable when the seat is needed, and can be flipped to carry items in danger of tottering or tipping. She used an under-the-seat bag from another walker to hold her exercise equipment.
- ✚ She repurposed a jersey belt to serve as a footrest, and a buttoned bag, a gift, to hold napkins and tissue.
- ✚ She hung a headlight and Bluetooth™ headset at the left side of the walker, along with a new iPhone, lint roller and pen (all attached to lanyards). She hung a mask to the right. She stacked another clementine box on the original for increased carrying height. She found that she can no longer use the walker to sit unless she uses a high cushion, but the walker itself is essential for her mobility.



Kim’s walker has evolved over the years into an all-purpose carryall.



Shawna Nielsen, who runs the “Myositis Ramblers” and “PM/DM” Facebook groups with her knowledgeable crew, sets off on her strolls outside with trekking poles, as does TMA Board Member Dave Mochel, who recommends the Leki version; and M.J. Smith, who prefers a collapsible version made of carbon fiber, and uses assorted bottoms depending on the terrain.

Shawna also likes the simple comfort of warmth provided by an electric blanket while she watches television. “It’s like a warm bath without having to get wet,” she said. Shawna has more advice, and has become an expert in emergency preparedness. See how she stays one jump ahead of the forest fires that plague her neighborhood, page 12.

In these days of compulsive COVID de-cluttering, we liked the clever solution for wayward canes (which can topple and trip you, and just plain get in the way) provided by care partner **Julina Smith**, who corrals the walking aids used by husband Alex, an IBM patient, using sturdy broom holders in different rooms of their home near Indianapolis. Julina said she first put the holders at doors, then added them wherever she saw canes leaning and potentially falling down. She’s not through yet, Julina said: if a stray cane appears somewhere a couple of times, there’s likely to be a broom holder nearby shortly. She likes the self-stick broom holders made by Command.



Julina Smith uses broom holders to corral unruly canes.



Small appliances on felt pads can be pulled easily to the front of the counter.

Patty Meyer found that kitchen appliances with rubber feet were hard to drag from the back of the counter to the front where she could use them, so she makes sure the small appliances in her kitchen are resting on felt pads.

Barbara Smith uses her sewing talents to make masks for those in her neighborhood who need them, and has also designed and sewn a lovely phone caddy that she can loop around her neck. She said she made it when she realized she was unable to get up from a fall by herself. At first, she only wore it outside when she walked in her Port Orchard, Washington, neighborhood, but she says it’s now an accessory that’s part of her everyday wardrobe whenever she’s alone. She describes it as “a pocket on a strap.” The strap goes around my neck and is long enough to wear hanging in front or cross body style,” she said. She’s added a flap at the top secured by Velcro®, so the phone won’t fall out if she falls.



Barbara Smith sews “portable pockets” for her phone.



Babette Reeves prepares rice and other grains ahead when she's feeling strong.

Babette Reeves has learned to avoid hours in the kitchen when she's feeling tired and weak. Babette makes huge batches of rice on her good days and portions them out in serving sizes. She pops them in the freezer, then adds some chopped vegetables, microwaves for 30 seconds and there's dinner! She likes to experiment with different sauces for her no-fuss stir-fry. Preparing the most time-consuming part of the meal (it could also be potatoes or another grain) ahead when you have a lot of energy is the key, Babette said. She adds that recipes aren't necessary, but those who want to vary this easy meal can find plenty of ideas under recipes for "Buddha Bowls." Babette, lives in Winchester, Oregon. Another energy-saving tip: Babette uses a rice cooker, which needs no tending.

Tired of having her phone fall from her grip, **Melati Marlene Shinazy** found one that loops over her finger from [**activehands.com**](https://www.activehands.com).



Back finger loops help secure phone.



Rubber treads prevent slipping.

Elisa Glass finds that slippers are too slippery, so she prefers thick socks with rubber treads on the bottom when she's feeling chilly at home.

Strong women educate, support, advocate



Holly Jones

"Let's help the next woman behind me."

Holly Jones was a student, a hardworking teenager who had two jobs and went to school full time. She never slowed down: she went from class to Target,

then back out again later to work at Old Navy.

Sure, she felt tired, but who wouldn't, with her schedule? She fell a couple of times on the salesroom floor and couldn't seem to get up, and she found herself short of breath. "There were all these weird things," she said.

She visited her pediatrician, who worried about cancer or lupus, but there were no indications. She struggled on as best she could with her jobs and classes. She developed strategies for seeming normal. "In school, I'd stay at my desk until everyone left," she said. "Then I'd get myself to the door however I could."

She convinced herself she was just exhausted, so those around her believed it, too. That all changed one day when, getting ready for work at Target, she totally collapsed. She couldn't grip the steering wheel, turn the keys in the car, or even walk. Her mother rushed her to the Emergency Room, where a biopsy confirmed she had polymyositis and interstitial lung disease.

Sixteen years later, Holly's challenges remain. After years of prednisone and first methotrexate and then Imuran, she's in remission from her myositis but has found her lung disease has progressed to severe pulmonary hypertension. Weakness and difficulty breathing will always be with her. She has two young daughters, and over the years has figured out dozens of different ways to be there for them despite her illness.

Where Holly's concerned, don't confuse muscle weakness with lack of mental energy, focus or determination. Holly leads the TMA Houston support group, is the host of two myositis-related Facebook

groups, has a YouTube channel and a Facebook talk show, "Krazy N Christian." She believes her hard work will have future impact on improving treatments and finding a cure: "We might not be able to cure me, but let's help the next woman behind me," she said.

Holly is serious about her work with TMA's "Women of Color" Council (see page 13). Since her strong Christian faith comforted her during the darkest times, she wants to reach other women of color with a strong church background. "Without faith, and without the support of people who understand, there's a danger you'll get depressed and discouraged," she said. "In my family, church helps us stay strong. In fact, my mother asked for prayers from our pastor before she even helped me find a specialist."

Another passion dear to her heart: helping women like herself understand that their disease need not keep them from being good mothers. "If you're too weak to hold your toddler, sit down and ask the child to come to you and climb on your lap," she said. "There's always a way."



Rakhi Batra

"Just so important to keep moving."

It was always important to her to keep fit, through Zumba, hot yoga, weight training and participating in many walks, but when Rakhi Batra

discovered running eight years ago, she knew she'd found her place. Running gave her a high level of fitness, introduced her to like-minded people, and calmed her nerves and stress level.

Last year, Rakhi had plenty to be anxious about: her father, 79, had unexplained falls and weight loss. He was going in and out of the hospital and rehab centers for most of the year. The ordeal was worrisome for the whole family, and at one point, while hospitalized, his heart stopped.

Nothing explained his mysterious falls, though, until 2019, when he was diagnosed with IBM. He lost weight, had trouble swallowing, became bedridden and died in March 2020. After the ceremony—confined to four people because of COVID-19—Rakhi learned that her uncle and mother had found The Myositis Association.

Through TMA, Rakhi trained to become a “Myositis Maven,” and promised to organize a couple of myositis-related events in her San Diego community. It was natural that her choice had to do with running, and she knew hosting a virtual run would allow her to reach runners all over the world. Her campaign, named “Keep Moving” is looking for 250 runners. Actually, she said, you don’t have to run. You can walk, stroll, jog, hop or sprint to help her reach her goal. Find the details here: <https://badassrunners.com/collections/virtual-races/products/keep-moving-virtual-charity-race>

“It’s just so important to keep moving,” said Rakhi, a public health administrator. She’s kept moving through worry, uncertainty, grief, and mourning made more difficult by the pandemic. Please join her by visiting the link above or emailing TMA.



Shawna Nielsen

“Plan, pack and don’t panic.”

Those with chronic disease are constantly looking ahead in anticipation of unexpected challenges and, as a consequence, become better organized than the rest of

the world. But most of us are amateurs, mere rookies compared to Shawna Nielsen, who can flat out get her family from asleep in bed to out the door with everything important before you can say “the fire’s coming.”

Shawna, who has dermatomyositis, has a system that’s always improving as she learns from experience. She has evacuated from her Santa Rosa home several times and has gone to bed expecting evacuation several more times. Her most recent sudden departure was in September, when forest fires swept along a ridge top and down into her neighborhood, burning structures just a few houses away from her family’s home.

Shawna could teach an international course in emergency preparedness. In fact, you could say she does. A nurse by training, she runs the DM/PM patient group and the “Myositis Ramblers” support group, answering questions about everything from how to talk to your doctor to how to make sure you can find what you need after you’re displaced in an emergency. She has more tips and checklists than we can mention here, but below are some we found particularly ingenious:

Have extra medication. Don’t wait until the flames are licking at your door or the flood waters rising before talking to your doctor about an emergency supply of medication, crucial pharmaceuticals you’ll need as replacements if you’re cut off from your regular source or lose it in flight. “It’s especially important with prednisone, which you just can’t stop abruptly,” Shawna said. You’ll also want to discuss with your doctor how to adjust the dose if you’ve had to expend an unusual amount of energy or deal with a catastrophe.

- ✎ Know where you’re going. Shawna suggests choosing the family or public accommodation that’s as close as possible while still being safe, and notifying them in advance. “None of us with myositis do well in a long car ride,” she said. “I know I don’t.”
- ✎ Be travel ready. Shawna has some things always at the ready, regardless of the whether there’s an emergency or not. There are extra masks, gloves, and hand sanitizer in every glove compartment, important papers packed and easy to grab, essentials in rolling suitcases for every family member. “Make sure to take the title to the car you leave behind, as well as proof of purchase for valuables you don’t carry with you,” she said. “If they’re damaged or destroyed, you’ll have to prove their value.”
- ✎ Don’t forget the pets. During fire season, Shawna closes the cat and its crate in the room with her son, so he can quickly coax the cat into the crate without looking all over the house either. Extra pet food, leashes, papers and dishes are in a rolling suitcase, ready to load.
- ✎ Non-essentials can be essential. Shawna figures she can go for three days or so with whatever is available to her, as long as she has medication and aids. After that, she says, “You really need your comfort items. One of mine is Twinings black tea, and I have certain pillows and blankets. So have these kinds of things in your plan, too.”
- ✎ Keep up with the times. Should you need to restock, with tea or pillows or just some favorite snacks that comfort your family, Shawna suggests you become comfortable ordering from a regional or national source online. “Then you can have missing items at your door in a day,” she says. “In an emergency is not the time to take yourself to a big box store.”

To find out more or to join one of Shawna’s groups, email tma@myositis.org.

Elite council ready to help women of color

Statistics tell a depressing story for women of color who have myositis, including younger diagnosis, greater prevalence, higher mortality, more lung involvement, and skin signs unfamiliar to many doctors.

But statistics don't tell the whole story. There's a powerful coalition of women of color who have lived the reality of life with myositis. They've experienced it all: the alarming and mysterious first symptoms, the fear at diagnosis, the depression, isolation, confusion and loneliness. Despite all the challenges, the remarkable women on the council have come to an understanding that their lives may not be what they expected but can still be great.

TMA's Women of Color Council has a mission to provide support and information to women of color who find themselves with a disease likely to be completely unfamiliar to them and their families.



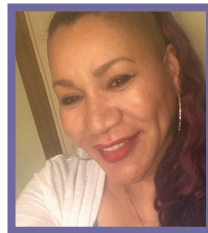
Holly Jones



Cynthia Imana



Donna Barr



Elisa Glass



Kaniah Gunter

Five of them, Holly Jones, Kaniah Gunter, Cynthia Imana, Elisa Glass and Donna Barr, took part in a panel discussion at TMA's Virtual Annual Patient Conference in September, moderated by TMA program chair, Laurie Boyer. Their words contain many messages of hope for all women of color, all women, all people.

A few key points from the Women of Color Council:

- ✚ **Life continues. You get stronger.** That's what you don't know in the long days following your diagnosis, said Cynthia Imana. Part of what helps you have hope in your future is finding people who have been through the same things. "I went for three years without reaching out to anyone," she said. "I was shy, but now I am passionate about this."
- ✚ **Encourage, educate, empower.** That's what Holly Jones does every day of her life. "I'll sit in the back of the church with you and hold your hand until you have the strength to get to the front." She's talking not only about the importance of faith, but about the importance of meeting people where they are, until they have the tools to help themselves.
- ✚ **Put yourself in the driver's seat.** Donna did that literally when she jumped in (more like hobbled to, she said) her car and drove to TMA's office in Alexandria. But she also means it in its other sense. "You have a team," she said, "but it's up to you to be your own advocate."
- ✚ **Educate your doctor.** You have plenty of knowledge about your own rare disease, said Elisa Glass. She suggests monitoring your symptoms with the "myositis tracker" to provide accurate insight into your progress, and discussing what you've learned about treatment from sources like TMA. "And yes, we can fire our doctors," she said. "Find someone who listens to you."
- ✚ **Pay attention to your overall health.** Kaniah Gunter uses a holistic approach to dealing with her disease. "You can't just keep asking, 'Why me? Why now?'" she said. Kaniah, a nutritional health coach, advocates small steps towards improving your diet. She urges people to take their disease one day at a time. "That's your power," she said.

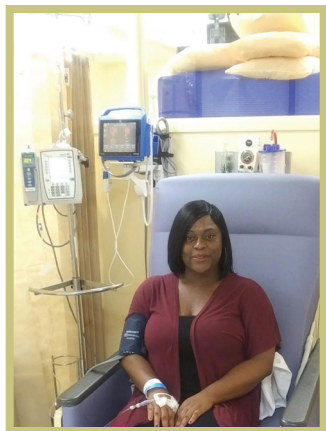
Find out more

See stories about Kaniah, page 14, and Holly, page 11.

Get information about myositis specific to women of color, register for the Virtual Annual Conference to watch the whole session at myositis.org, or get in touch with one of the council members by emailing TMA@myositis.org.

Help those who need IG Therapy

By Linda Kobert



Kaniah Gunter receiving and infusion

Kaniah Gunter's myositis journey has not been easy. Diagnosed with dermatomyositis and overlapping scleroderma in 2007, she struggled to find adequate treatment for years. During that time, she wasn't able to play with her children or dress herself, and she lost nearly 60 pounds because she couldn't swallow.

"I was losing myself," Kaniah says. "I was

unrecognizable. I had two stomach ulcers from the prednisone. I was taking heavy narcotics because of the pain. I was on methotrexate, too. We tried a whole lot of things. It was a challenge."

In 2011, she was referred to the Myositis Center at Johns Hopkins in Baltimore where Dr. Lisa Christopher-Stine recommended a new treatment plan that included intravenous immune globulin (IVIg) therapy. Since then, Kaniah's condition has improved significantly.

She no longer uses prednisone or pain meds and no longer needs a caregiver to help her make it through the day. And while she still needs to be careful not to overdo it, now she can walk a couple miles most days and loves family time with her kids, singing, dancing, and movies with popcorn.

"IVIg has worked wonders for me," says Kaniah, who serves as a member of the TMA Women of Color Advisory Committee.

Last year, however, the US experienced a significant shortage of immune globulin (IG) products due to manufacturing challenges and increased demand. Kaniah's IVIg therapy was cut off for three months, and she panicked. Now we are potentially facing another serious IG shortage because plasma donations have fallen in recent months as a result of COVID-19 restrictions.

What is Immune Globulin?

Immune globulin therapy is a godsend for many who live with myositis diseases and other autoimmune diseases. The only way to make it is with donated human plasma. It can take up to 250 plasma donations to provide enough IG to treat one myositis patient for one year.

How Can You Help?

A number of Kaniah's family members are plasma donors. Originally, they chose to donate because it gave them a little extra cash each week. Kaniah encourages other myositis patients to talk to friends and family members about donating this precious gift. In order to donate, individuals must meet strict eligibility criteria that includes passing a health screening.

To be sure your plasma is used to make IG and other plasma-based products, plasma must be donated at a certified plasma donation center operated by a manufacturer. Plasma donated at a blood bank or hospital is not used for these products.

"We don't always appreciate the things that are right in front of us," Kaniah says. "We take them for granted until they aren't there anymore. Just to have my medication, to know that it brings life to me and I'm able to do the normal things that I love doing, that's important. So, I'm hoping and praying a shortage will not happen again."

How can you help?

- ✚ If you are healthy, over the age of 18, and weigh more than 110 pounds, consider becoming a committed plasma donor.
- ✚ Be sure to donate at a certified plasma donation center and spread the word on your social media platforms about the need for plasma donation and what it means to you as a person who depends on IG therapy.
- ✚ Find more information at [DonatingPlasma.org](https://www.donatingplasma.org).

*Linda Kobert, RN, MSN is Director of Patient and Provider Relations for **CSI Pharmacy**, a specialty pharmacy providing home IG therapy to patients with rare diseases. She is the former Director of Research and Communications for The Myositis Association.*



How can www.myositis.org help you?

Please **visit our website www.myositis.org** to find information on topics of interest to myositis patients and caregivers. Some quick links:

We have dozens of pages of **basic information about myositis: www.myositis.org/about-myositis/**



We can help you find a support group, either virtual or in your area: **www.myositis.org/patient-support/support-groups/find-support-group/**. If there's no support group near you, **we'll help you form one. (tma@myositis.org)**



We have hundreds of videos, newsletters, presentations, podcasts, webinars, live discussions, published research, patient stories, and tools for disease management in the **Myositis Library. (www.myositis.org/myositis-library/)**



We can help you find a doctor: On our website (**www.myositis.org/patient-support/find-doctor/**); By **emailing TMA (tma@myositis.org)**; By asking on **TMA's Facebook page (<https://www.facebook.com/Myositis>)**; Or by finding the **support group in your area www.myositis.org/patient-support/support-groups/find-support-group/** and asking the members.



Support for Patients with Myositis

Soleo Health is an innovative, national provider of home and alternate-site specialty infusion services.

Our interdisciplinary team of pharmacists and registered nurses provides exceptional care through comprehensive therapy management programs.

The Soleo Health Difference

- Timely insurance benefit verification, authorization and start of care
- Dedicated local teams with 24/7 access to experienced pharmacists and registered nurses
- Individualized patient care plans; comprehensive patient and caregiver education and support
- Flexible scheduling of services based upon patient's availability and preferred site of care (home, ambulatory infusion suite or physician office)
- Extensive, local and national nursing coverage to accommodate patients throughout the U.S.
- Patient advocacy including education on manufacturer copay assistance



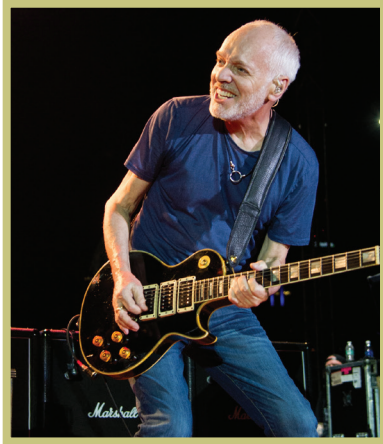
*2019 SoleMetrics® data

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www.soleohealth.com



Peter Frampton: Guitar hero and our hero



Peter Frampton was born at a time when Europe was recovering from World War II. He shows great empathy for his parents who, he said, had each seen plenty of horrors during the war. He grew up with David Bowie (then David Jones) and reveals

that the multitalented Bowie was a gifted artist as well as an amazing musician.

Frampton burst onto the music scene as a full-fledged prodigy, became a respected working musician as a teenager, co-founded Humble Pie, recorded four solo studio albums and, at 26, released one of the best-selling live albums of all time, “Frampton Comes Alive.”

He’s had plenty of ups and downs since that 1976 concert album, and he chronicles many of them in “Do You Feel Like I Do,” the memoir he wrote with Alan Light. He hung around with other rock idols of the time, but said that meeting any Beatle was on a different level. He was a rock idol himself, but looking back, he wishes he had known enough to resist the industry’s push to make him into a heartthrob. He also felt rushed into trying to duplicate the success of “Frampton Comes Alive” before he was ready. “I should have used the word ‘no’ a lot more,” he said.

It wasn’t only his amazing guitar skills that put him into the most exalted musical company of his day. Frampton was a loyal and supportive friend, a seriously hard worker who could talk for hours with other major guitar players about gear, chords and obscure musicians most of us have never heard of. Although he talks honestly about the drugs, alcohol, addiction and depression that swirled around them all, the book does not descend into tabloid-style accusations. He’s quick to praise and slow to blame.

His career plummeted and there was plenty of drama involving pain, addiction, women (he had three wives) and although he deplores the bad advice and bad practices that affected his career, his approach to life is basically easygoing and tolerant, generous to most of those who came before. All three of his wives came to see him on his farewell tour.

Despite all the trappings and pitfalls of rock stardom, at heart Frampton remains a serious musician, with the talent and perseverance that began with the childhood Christmas present of a guitar and continues to this day. Frampton says he handled fame well at times, not so well at others, but through it all has learned and changed. That’s been his approach to dealing with inclusion body myositis as well. His initial alarming symptoms, his diagnosis, his farewell tour, cut short by COVID-19: it’s all chronicled in his memoir with humility and grace. In the final chapter of the book, Frampton talks about his uncertain future and the importance of what he’s doing to advance research. He also talks of meeting fellow IBM patients as he toured the country, including one man who credits Frampton for a successful diagnosis.

Frampton’s honesty about his disease on the tour, in his book and in the many interviews promoting it has done a great deal to educate the world about myositis. For his work, TMA nominated him for NORDs “Rare impact award,” which he accepted in October. Now, he says in his memoir, his fingers don’t always do what he tells them, but he’s not going to dwell on what might be around the corner. “I’ve always managed to stay optimistic,” he writes. “There’s always a reason to hold out hope.”

Buy Peter Frampton’s Book, “Do You Feel Like I Do?” at www.peterframptonbooks.com or wherever books are sold.

