

# 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](http://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.

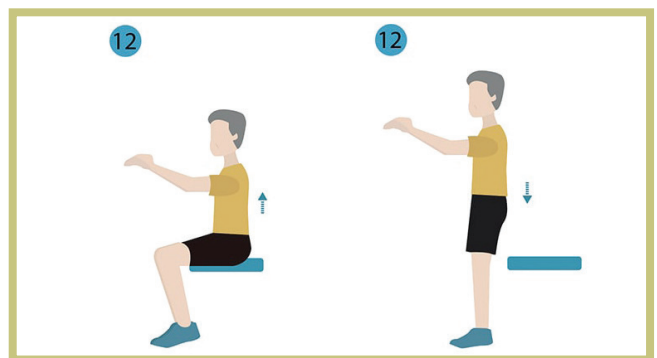
### Alexanderson's overall advice

"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."

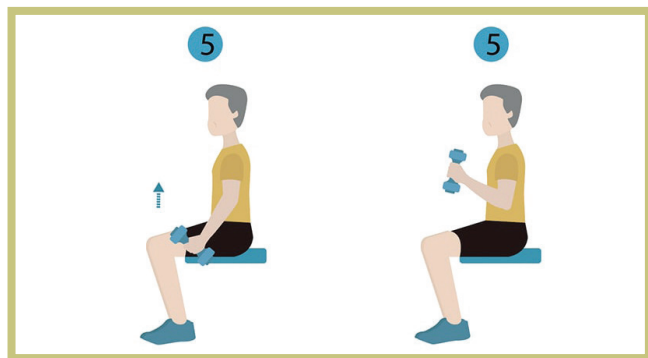
Also practice the act of sitting down. It's easier, she said, than standing up, as the muscles involved are lengthening rather than contracting. You'll strengthen your muscles sitting down if you control the speed, resisting gravity in the process. Alexanderson said a rubber band around your knees will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

### **What if it hurts?**

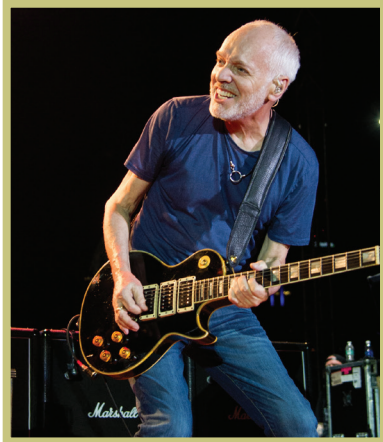
Exercise itself can relieve pain, Alexanderson said, because it relieves the stiffness caused by inactivity. Talk to your doctor about pharmaceutical solutions, and also ask about a TENS (transcutaneous electrical nerve stimulation) unit, acupuncture, or massage.

### **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.”

# 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 multit talented 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](http://www.peterframptonbooks.com) or wherever books are sold.

