



THE MYOSITIS ASSOCIATION

# MYONews & Updates

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September 2022 | Issue Nine

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## Upcoming Events

Some of our support groups are not meeting this month due to the holiday weekend. Please check our [calendar](#) for details and enjoy your Labor Day!

## NEW EPISODE! TMA Myositis Family Podcast

[Sept. 8 - 11 In Person International Annual Patient Conference](#)

[Sept. 9 - 10 Virtual International Annual Patient Conference](#)

[Sept. 10 - Fun Fit Flex Orlando](#)

[Sept. 15 - Ask the Doc Series](#)

[Sept. 27 - Empowerment Clinic: Getting the Most from YOUR TMA Website](#)

## Please Act!

## Medicare Coverage of Seat Elevation and Standing Systems - Public Comments Accepted Through September 14, 2022



The request that Medicare begin funding power seat elevation and standing systems has been in the works for some time.

The Medicare program currently denies coverage for seat elevation and standing systems in power wheelchairs. This means that Medicare beneficiaries with mobility impairments are forced to go without medically necessary wheelchair technology if they are not able to afford the costs out of pocket. The Medicare program is currently reviewing a request to provide coverage for these critical systems.

**If successful, Medicare will recognize**



This year's conference will offer over 25 sessions with our Medical Advisory Board which includes the Townhall and Q & A sessions.

Also meet our Board of Directors and Patient & Family Advisory Council.

**On-Site Registration is AVAILABLE!**

**Can't attend? Register for the online experience!**

Virtual APC Registration



for the first time that these systems are "primarily medical in nature," and, therefore, covered durable medical equipment benefits - not convenience or luxury items for wheelchair users. These systems help wheelchair users carry out important daily activities more independently, such as cooking, eating, and toileting. They also provide numerous health benefits, such as decreased risk of falls or injuries when moving in and out of wheelchairs, improved heart and lung functions, increased bone strength, and improved joint mobility, bladder function, and muscle strength.

**This is extremely important to the myositis community!**

Advocates can send their comments directly to CMS [HERE](#) to support Medicare coverage for power seat elevation and power standing.

**PLEASE ASK EVERYONE YOU KNOW TO SUPPORT THIS EFFORT.**

Medicare must receive individualized comments with your unique voice, *so please use your own words* and explain why you support coverage of seat elevation and standing systems. When commenting, consider the following information to explain your unique story.

**Talking Points for Comments**

**Identify Yourself**

Provide a brief introduction of who you are and why you support this coverage. It's important to provide your specific perspective and explain why YOU are supporting coverage for seat elevation and/or standing systems.

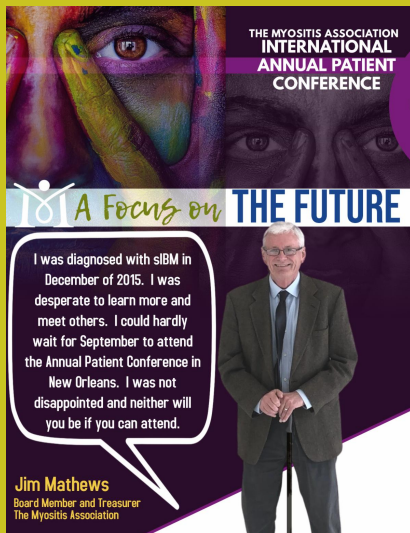
**Express Your Support**

State clearly that you believe Medicare should extend coverage of seat elevation and standing systems in power wheelchairs for Medicare beneficiaries with mobility disabilities.

**Mention the Health Benefits**

Note the numerous health benefits of these systems, especially any benefits that you have experienced or seen.

**Talk About the Functional Benefits**



Please check out TMA's brand new Find A Doctor tool (through a new partnership with MediFind)! If you are looking for a clinician or specialist with documented experience treating the different types of myositis (or to add to your current care team), this could be a great place to start! We are working out some things in the partnership to better feature some of the docs known to TMA, but we are so excited about the availability of this new feature for our patients! If you have any trouble navigating, please

Note the numerous functional benefits of these systems, especially any benefits that you have experienced or seen.

## Conclude

Thank Medicare for the opportunity to submit comments and restate your support for coverage. Encourage Medicare to quickly approve coverage of seat elevation and standing systems to ensure that wheelchair users can access the care they need.

**Make it personal! What you say matters and your unique perspective is important.**

[SUBMIT YOUR COMMENT](#)

**Peter Frampton is supporting The Myositis Association with a raffle for an incredible fan experience!**



**One lucky fan is going to win the Ultimate Peter Frampton Fan Experience to include a 30 minute virtual meeting with Peter Frampton himself!**

Grammy-winning guitarist Peter Frampton is one of the most celebrated artists and guitarists in rock history.

At 16, he was lead singer and guitarist for British band the Herd. At 18, Frampton co-founded one of the first super groups, seminal rock act Humble Pie. After 46 years, Frampton Comes Alive! still remains



reach out to us at  
[tma@myositis.org](mailto:tma@myositis.org).

FIND A DOCTOR

## TMA Fundraising Corner



**ARE YOU  
*ready*  
TO FLEX?**



Holly Jones, Myositis Patient  
National Campaign Ambassador

Many people with myositis find the condition significantly affects their everyday activities and quality of life.

Exercise is a very important part of treatment for all types of myositis. It can help reduce swelling, give more energy, and build up or restore muscle strength.

**FUN FIT FLEX = HOPE & AWARENESS.**  
Join the movement!

[www.funfitflex.org](http://www.funfitflex.org)



Click Here to join the  
**#MYOMOVEMENT**

## Community Tip

Make lifting items easier with  
Armageddon Sports Premium  
Weight Lifting Wrist Hooks Straps  
for Maximum Grip Support!

Shop around for what suits you best  
- here is an option with 4.5 stars.

one of the top-selling live records of all time selling over 17 million worldwide and was inducted into the Grammy Hall of Fame in 2020.

His collaborations in recording sessions and live performances range from such legendary artists as George Harrison, Harry Nilsson, David Bowie, Dion, Hank Marvin, Ringo Starr, B.B. King, Mike McCready & Matt Cameron (Pearl Jam), Buddy Guy, Steve Miller and many others.

He worked closely with Cameron Crowe on his Oscar winning film, *Almost Famous*, as a technical advisor, writing music for the fictional band Stillwater and even making a cameo as Humble Pie's road manager.

In 2007, Peter won a Grammy for Best Pop Instrumental Album for *Fingerprints* and in 2014 was inducted into the Musicians Hall of Fame. Peter received the prestigious Les Paul Innovation Award from NAMM's TEC Awards in 2019.

In 2019, legendary guitarist Peter Frampton revealed that he was diagnosed with Inclusion Body Myositis (IBM). The Myositis Association (TMA) appreciates Mr. Frampton's sharing his story with the public to help raise awareness and his message of inspiration and hope in the face of this progressive, disabling disease of the muscles.

## Now, one lucky person will win the Ultimate Peter Frampton Fan Experience!

### The prize package includes:

- 30 Minute Virtual Meeting with Peter Frampton
- Autographed Copy of Peter's 2020 Book, "Do You Feel Like I Do?"

A Frampton Merchandise Bundle To Include:

- FRAMPTON - CREST PICNIC BLANKET
- AUTOGRAPHED 2019 TOUR PROGRAM
- FRAMPTON - GUITAR T-SHIRT
- FRAMPTON - CREST KOOZIE
- FRAMPTON - GUITAR SOCKS

and a Door Dash Gift Certificate valued at \$50

**Raffle is open through September 10th  
Only!**



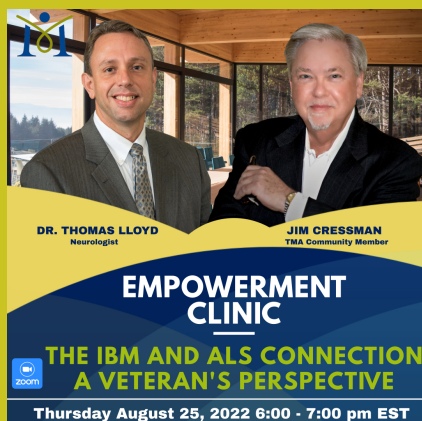


[CLICK HERE FOR MORE  
PRODUCT INFORMATION](#)

Did you miss these previously aired webinars? Click below to view the recordings!



[View Pulmonology Recording](#)



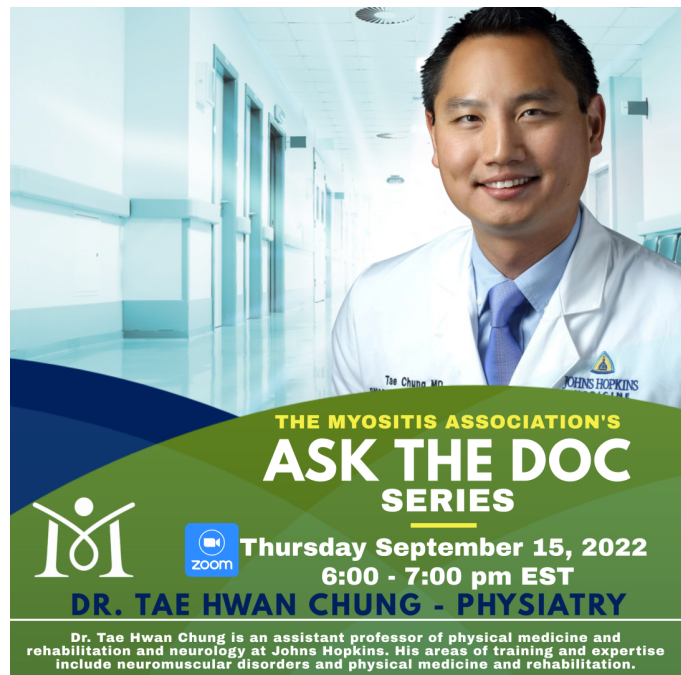
[View Dr. Lloyd Recording](#)

**\*\*SHARE WITH EVERYONE  
YOU KNOW\*\***

*\*All proceeds benefit the mission work of The Myositis Association.*

*Electronic drawing will take place at TMA's Annual Patient Conference on Saturday September 10, 2022. You do not have to be present to win.\**

[Enter the Frampton Raffle](#)



**Dr. Tae Hwan Chung** is an assistant professor of physical medicine and rehabilitation and neurology at Johns Hopkins. His areas of training and expertise include neuromuscular disorders, physical medicine and rehabilitation.

Thanks to his diverse background, Dr. Chung is uniquely positioned to diagnose and treat a variety of neuromuscular conditions and pathology by using electrodiagnostic procedures and immune and rehabilitative treatments. Dr. Chung is particularly interested in rehabilitative treatments and therapeutic exercise for various neuromuscular diseases, such as myositis, peripheral neuropathy and motor neuron diseases.

Dr. Chung runs a multidisciplinary rehabilitation clinic with the Johns Hopkins

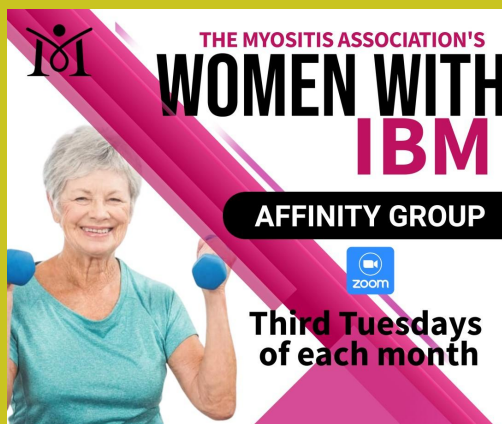
## Affinity Group Meetings



REGISTER FOR FLYING SOLO  
AFFINITY GROUP



REGISTER FOR MILITARY  
VETERANS AFFINITY GROUP

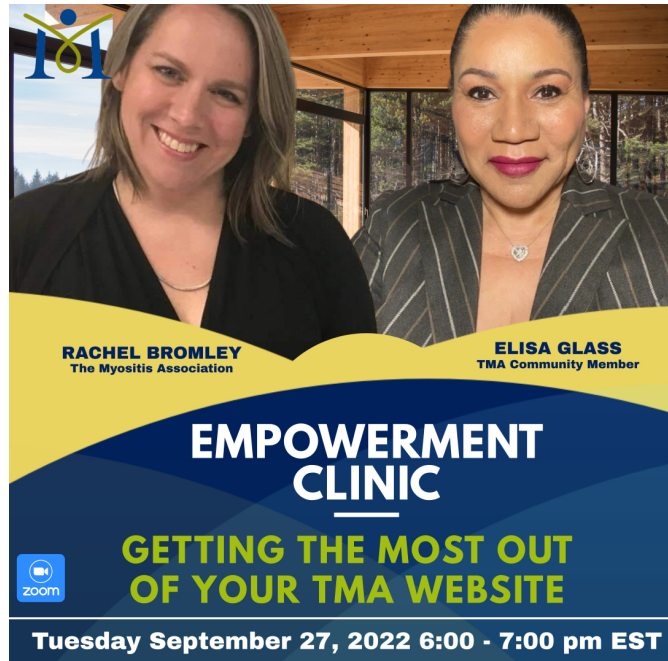


REGISTER FOR WOMEN WITH  
IBM AFFINITY GROUP

neuromuscular rehabilitation team, which he helped develop with physical, occupational and speech therapists, who are dedicated to helping patients with rare neuromuscular diseases.

REGISTER FOR ASK THE DOC

SUBMIT GENERAL QUESTIONS



**Elisa Glass**, a TMA Ambassador, has been living with Dermatomyositis since 2016. Prior to her diagnosis, Elisa was a professor, specializing in the field of Drug and Alcohol abuse. She owned and operated MYTHS, LLC., a retail store which focused on helping members in need, especially the homeless. Elisa is now the Chief Operations Officer for Caridad's Kitchen of Culinary Medicine, An Elizabeth Dole Fellow, Author, Poet and fervent advocate for Myositis.

**Rachel Bromley** is TMA's Senior Manager of Patient Education, Support and Advocacy. She has been a nonprofit executive for ten years, raising awareness and funds for the causes of mental health, domestic violence and sexual assault before transitioning to the rare disease space. She has learned so much from the myositis community since starting her journey with TMA.

The Myositis Association's

# Women of Color

Affinity Group



Third Wednesday of Each Month



REGISTER FOR WOMEN OF  
COLOR AFFINITY GROUP



REGISTER FOR CAREGIVER  
AFFINITY GROUP



REGISTER FOR MEN  
MANAGING MYOSITIS  
AFFINITY GROUP

REGISTER FOR EMPOWERMENT CLINIC

SUBMIT GENERAL QUESTIONS

## FUN FIT FLEX Virtual

If you can't make it to any of our FUN FIT FLEX in-person events, you will be missed!! But, you don't have to MISS OUT!

Consider participating in our virtual experience on Saturday, September 10<sup>th</sup> at 8am. We are ready to host you online!



Click Here to Join FUN FIT FLEX Virtual

Click Here to Register

Click Here to Donate

## FUN FIT FLEX Orlando

Join us on Saturday, September 10th for  
FUN FIT FLEX Orlando

Our FUN FIT FLEX Orlando event has something for everyone. Join us as we celebrate the myositis community through fitness, fun, and festivity! We will have snacks, vendors, fitness demonstrations, and so much more. We hope to see you there.





REGISTER FOR AFFINITY  
GROUP IN SPANISH -  
ADELANTE!



REGISTER FOR RAINBOW  
WARRIORS AFFINITY GROUP



‘Dancing molecules’  
successfully repair severe  
spinal cord injuries



After single injection,  
paralyzed animals regained  
ability to walk within four  
weeks

November 11, 2021 |  
By **Amanda Morris**

Northwestern University researchers have developed a new injectable therapy that harnesses “dancing molecules” to reverse paralysis and repair tissue after severe spinal cord injuries. In a new study, researchers administered a single injection to tissues surrounding the spinal cords of paralyzed mice. Just four weeks later, the animals regained the ability to walk.

### Five key developments

By sending bioactive signals to trigger cells to repair and regenerate, the breakthrough therapy dramatically improved severely injured spinal cords in five key ways:

1. The severed extensions of neurons, called axons, regenerated
2. Scar tissue, which can create a physical barrier to regeneration and repair, significantly diminished
3. Myelin, the insulating layer of axons that is important in transmitting electrical signals efficiently, reformed around cells
4. Functional blood vessels formed to deliver nutrients to cells at the injury site
5. More motor neurons survived

After the therapy performs its function, the materials biodegrade into nutrients for the cells within 12 weeks and then completely disappear from the body without noticeable side effects. This is the first study in which researchers

The Myositis Association  
**Fitness Festival • Fun Walk**

Proceeds support TMA's programs for myositis patients and care partners.



**Saturday  
Sept. 10, 2022  
8:00 am  
Orlando**

Caribe Royale Resort  
8101 World Center Dr, Orlando, FL 32821

**About the event:**

- Non-competitive Walk
- DJ and Music
- Children's Activities
- Fitness Demonstrations
- Health & Wellness Information
- and more...

**TO REGISTER**  
visit [www.funfitflex.org](http://www.funfitflex.org)  
Registration is FREE,  
but participants are  
encouraged to raise funds  
to support the mission.



Sponsorship and vendor opportunities available. Call 800-821-7356.  
[www.funfitflex.org](http://www.funfitflex.org)

You do not need to be registered for the Annual Patient  
Conference to attend FUN FIT FLEX\*

[Click Here to Register](#)

[Click Here to Donate](#)

### Become A FUN FIT FLEX Fundraiser

**START YOUR  
FUNDRAISING TODAY!**

**\$100 GOAL**

1. Step up and show your commitment with your own donation	\$ 5
2. Ask your spouse to match your donation	\$ 5
3. Ask your manager	\$ 10
4. Ask your coworkers (10 x \$5 each)	\$ 50
5. Ask your neighbors / friends (10 x \$3 each)	\$ 30
<b>TOTAL</b>	<b>\$ 100</b>

You've earned a FUN FIT FLEX Event T-Shirt.



controlled the collective motion of molecules through changes in chemical structure to increase a therapeutic's efficacy.

[Read Full Article Here](#)



The staff at TMA  
would like to  
wish you and  
yours a Happy  
Labor Day!

## Thank you to our 2022 FUN FIT FLEX Sponsors



## The Myositis Association

The Myositis Association | 6950 Columbia Gateway Drive, Suite 370, Columbia, MD 21046

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