

## **MYONews & Updates**

## August 2022 | Issue Eight

## **Upcoming Events**

Please check our <u>calendar</u> for our regional support group offerings and more coming this month!

Aug 6 - TMA Nationwide Support Group Meeting

Aug 18 - Ask the Doc Series

Aug 25 - Empowerment Clinic: The IBM and ALS Connection - A Veteran's Perspective

<u>NEW EPISODE! TMA Myositis Family</u> <u>Podcast</u>

**FUN FIT FLEX** 

International Annual Patient Conference





## Dr. Cheilonda Johnson is an Assistant

Professor in the Division of Pulmonary, Allergy, and Critical Care and member of the Interstitial Lung Disease and Sarcoidosis Program at the University of Pennsylvania. Dr. Johnson is an expert translational researcher of interstitial lung disease (ILD) associated with autoimmunity. She is committed to reducing the significant morbidity and mortality associated with autoimmune-ILD. Broadly, her research focuses on the clinical and genetic determinants of autoimmune-ILD and health disparities in patients with ILD.

**Dr. Sonye Danoff** is an Associate Professor of Medicine in the Division of Pulmonary and Critical Care Medicine, Co-Director of the Interstitial Lung Disease Program, and Associate Director of the Myositis Center at

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 reach out to us at tma@myositis.org.

Johns Hopkins University School of Medicine, Baltimore, USA. Her research involves clinical and translational studies of lung fibrosis and autoimmunity.

Dr. Robert Hallowell is a Pulmonary and Critical Care Physician at the Massachusetts General Hospital, where he is the Director of the Interstitial Lung Disease Program and the Pulmonary Ambulatory Clinic. His research focuses on factors that influence outcomes in patients with various types of interstitial lung disease (ILD), particularly those associated with autoantibodies and rheumatologic disorders.

#### **REGISTER FOR ASK THE DOC**

## **FIND A DOCTOR**

#### TMA Fundraising Corner



Awareness building and sustainable fundraising is our best opportunity to increase community knowledge of myositis and fund critical research. Knowing is half the battle!!

Please register at www.funfitflex.org to join the **#MYOMovement** to help us raise awareness and funds to amplify patient voices; to gain a seat at the table to better inform clinical trials and drug development; to secure better resources for our patients; and to ultimately find a cure.

#### SUBMIT GENERAL QUESTIONS



leurologist

## EMPOWERMENT CLINIC

THE IBM AND ALS CONNECTION **I** zoom A VETERAN'S PERSPECTIVE

Thursday August 25, 2022 6:00 - 7:00 pm EST

Dr. Tom Lloyd is Associate Professor of Neurology and Neuroscience at Johns Hopkins University specializing in degenerative diseases of the neuromuscular system including Inclusion Body Myositis (IBM) and Amyotrophic Lateral Sclerosis (ALS). After completing medicine internship and neurology residency at Johns Hopkins Hospital, he performed a postdoctoral fellowship in neuromuscular disorders to gain clinical expertise in muscle and motor neuron diseases. During his fellowship, he read over

#### Click Here to join the #MYOMOVEMENT

## **Community Tip**

Make opening bottles and cans easier with The Extreme Magic Opener. Shop around for what suits you best! Here is an option with 4.5 stars.



### CLICK HERE FOR MORE PRODUCT INFORMATION

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



View Dr. Mammen Recording

300 muscle biopsies, and continues to interpret muscle biopsies as a faculty member. His weekly clinic specializes in Inclusion Body Myositis, and he serves as the director of the Muscular Dystrophy Association clinic and codirector of the Johns Hopkins Myositis Center. He has seen over 200 IBM patients who are enrolled into a large prospective clinical study on IBM, one of the largest such cohorts in the country. He was the site PI for the Novartissponsored clinical trial of Bimagrumab in sporadic Inclusion Body Myositis.

Jim Cressman enlisted in the U.S. Air Force in 1969 and proudly served a very rewarding four years active duty. Three of those years were spent in S.E. Asia during the Vietnam war. After tech school at Keesler, AFB he spent two years at Ubon, Thailand with the 8th TFW and the final year at Udorn, Thailand. After his Air Force career, he traveled extensively as a field engineer throughout Central and South America selling, installing and maintaining large computerized industrial weighing systems. That experience opened the door to several other careers finally settling on a career in financial and investment services. After many years working for one of the largest Wall Street firms, he began his own company in 1992, and retired with his wife, Mary, in 2016.

Just prior to his retirement, Jim began to experience the symptoms of Inclusion Body Myositis. The diagnosis was confirmed in 2015 and resulted in needing to move from their two-story home in the Chicago area to a single story - IBM friendly residence. They chose to relocate to a very scenic area of far western Colorado where they currently reside and thoroughly enjoy the tranquility of country living.

Throughout the journey of dealing with IBM, Jim has read, extensively, some of the articles available from some of the top medical IBM researchers. He now wishes to share this with other veterans in hopes of opening the doorway so they will be able to gain the disability benefits that have been denied for so long by having IBM recognized as a serviceconnected disability. Jim is a very active member in TMA's Military Veterans with Myositis Affinity Group.



#### View Dr. Ernste Recording



View Dr. Goyal Recording

## **Affinity Group Meetings**



REGISTER FOR FLYING SOLO AFFINITY GROUP **REGISTER FOR EMPOWERMENT CLINIC** 

SUBMIT GENERAL QUESTIONS

#### FUN FIT FLEX DMW

On Sunday, July 10th we held our FUN FIT FLEX event in the DMV area and it was EVERYTHING the community needed it to be!

THANK YOU TO ALL INVOLVED! It was an incredible opportunity to build awareness, educate about myositis, focus on fitness and wellness, and was a day for patients, care partners, friends, and family to assemble to celebrate our community's resilience.

WE WERE READY TO FLEX! And, on top of it all, we raised much needed funds for The Myositis Association and our mission.

You can get involved...whether at an in person event, virtually, or even just as a fundraiser/awareness builder. Join our <u>#MYOMovement</u> and visit <u>www.funfitflex.org</u>.





## REGISTER FOR MILITARY VETERANS AFFINITY GROUP



### REGISTER FOR WOMEN WITH IBM AFFINITY GROUP



#### REGISTER FOR WOMEN OF COLOR AFFINITY GROUP









Join us on Saturday, September 10th for



Every participant who raises \$100 or more will



### REGISTER FOR RAINBOW WARRIORS AFFINITY GROUP



## **Call for Auction Items**

Do you have items to donate for auction? Items such as vacation homes, airline miles, gift cards, experiences, home decor, and more do well in auctions. If you have a donation, please email <u>Rachel@myositis.org</u> receive a FUN FIT FLEX Commemorative Event T-Shirt.

Those going above and beyond by raising \$1,000 or more will earn a FUN FIT FLEX Zip Pullover!

We truly appreciate your dedication to help us create awareness and raise funds for people with myositis.



## 2022 International Annual Patient Conference

## THE MYOSITIS ASSOCIATION INTERNATIONAL ANNUAL PATIENT CONFERENCE

# A Focus on THE FUTURE

## **SESSIONS/WORKSHOPS YOU CAN EXPECT AT THE IN PERSON APC!**

**Getting Acquainted Meet The Board Of Directors Fundraising Clinic** Myositis 101 **Research Landscape in Myositis Physical Therapy Considerations Finding Inspiration** Management of Overlap Myositis Meditation Hand Exercises Aquatherapy **Skin Care** Surviving Grief's Stage Two (Anger) **Clinical Overview of Dermatomyositis** Making Better Choices (Health/Wellness) Hints and Hacks (Show and Tell) All About Anti Synthetase Syndrome **Everything You Need to Know About Patient Advocacy** In Sickness and In Health

**Myositis and Swallowing Complimentary Alternative Medicine MSU: From The Heart Advanced Stage Myositis Care Partners and Compassion Fatigue** Update on DM/PM Clinical Trials in **Myositis** Myositis and COVID-19 **Exercise Is Medicine Enrolling In A Clinical Study Reasonable Accommodations While** Working **Cancer and Myositis** Skin and Dermatomyositis Medication and Treatments in Myositis **Research and Clinical Study Design Understanding Genetic Risk Factors** Sing For Your Health! **Energy Preservation Strategies Finding Strength Through Faith** AND MORE! **Blood Flow Restriction IBM Patient Journey** 

## REGISTER FOR APC

The Myositis Association