THE MYOSITIS ASSOCIATION

# MYONews & Updates

April 2022 | Issue Four

## Upcoming Events

See what's happening this month

Stay Active in April

TMA Nationwide Myositis Support Group Meeting

TMA Myositis Family Podcast

Father Stu Movie Trailer

April Ask the Doc Series

April Empowerment Clinic: Living with Multiple Diagnoses & Illnesss

Myositis Awareness Month Virtual Summit

International Annual Patient Conference

## TMA Fundraising Corner

**Dr. Victoria Werth** is a Professor of Dermatology and Medicine at the University of Pennsylvania School of Medicine and Chief of the Division of Dermatology at the Philadelphia Veterans Administration Hospital. Dr. Werth earned her medical degree from Johns Hopkins University School of Medicine in Baltimore, Maryland. She completed a residency in internal medicine at Northwestern Memorial Hospital in Chicago, Illinois, and dermatology residency and immunodermatology fellowship at New York University School of Medicine in New York. She joined the faculty at the University of Pennsylvania in 1989 and has developed an internationally recognized program in autoimmune skin diseases.

She is a co-founder of the Rheumatologic Dermatology Society and previous president of the group. She is co-founder of the Medical Dermatology Society, and a recipient of their

### Fundraising Campaign - Running for Research

Danny Botiel created the "Running for Research" campaign to support his wife Meggie and raise awareness about Polymyositis.

Danny completed a 48-mile run challenge in which he ran 4 miles every 4 hours for 48 hours. He slept about 6 hours throughout the 2-days and completed the challenge at 3:30pm on Sunday, March 6th after starting on Friday, March 4th at 7pm. Danny averaged 9 miles a minute and felt pretty good most of the time!

In two days, his campaign received about 100 donations and he raised $14,325. By creating this campaign, Danny was able to help educate his community about Polymyositis and raise funds along the way.

CLICK HERE TO LEARN MORE ABOUT "RUNNING FOR RESEARCH"

## Community Hints & Hacks

Gadget of the Month: A Grab Bar is the best 25 bucks you will spend. Shop for what suits you best, but here is an option with 5 stars.

lifetime achievement award. She initiated the combined internal medicine/dermatology residency program in the U.S., which has successfully trained prominent leaders in complex medical dermatology. She has a longstanding interest in clinical and translational research pertaining to dermatomyositis, with a focus on improving the treatment and outcomes. She has developed and validated disease severity tools now used in many international trials in dermatomyositis, with a goal to advancing evidence for current and new therapeutics targeting these diseases. Her laboratory studies include studies of mediators of inflammation in dermatomyositis, and understanding mechanism for dampening immune responses. Recent clinical studies have examined mechanistic effects of therapeutics in dermatomyositis. Her work has been funded by the Dermatology Foundation, NIH, DOD, the VA, numerous autoimmune disease foundations, and industry.

Dr. Werth is also a member of TMA's Medical Advisory Board.

REGISTER FOR APRIL ASK THE DOC

SUBMIT GENERAL QUESTIONS

**Dr. Aggarwal** is a professor of medicine at University of Pittsburgh and medical director of Arthritis and Autoimmunity Center at University of Pittsburgh Medical Center. He is

CLICK HERE FOR MORE PRODUCT INFORMATION

## Affinity Group Meetings

REGISTER FOR MILITARY VETERANS AFFINITY GROUP

REGISTER FOR CAREGIVER AFFINITY GROUP

the co-director of UPMC Myositis Center. His research and clinical areas of interest are clinical and translational research in inflammatory muscle diseases (myositis) and associated interstitial lung disease. He is the chair of the medical advisory board of The Myositis Association (TMA) as well as past-chair of the scientific committee of IMACS, which are the largest patient and physician groups working in the field of myositis, respectively.

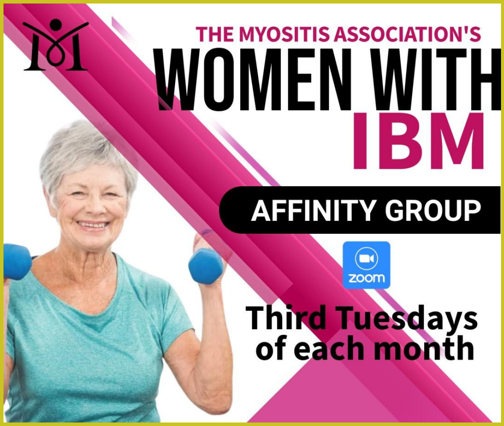
He is an established independent clinical investigator with significant funding from NIH, foundations and industry and currently leading several collaborations internationally with other key leaders in the world. He has maintained an extremetly high publication record and recieved national and international recognition of his work. He continues to be a leader in disease criteria and outcomes measures in myositis as well as in clinical trials of novel therapeutic agents for myositis. He is currently the prinicipal investigator or member of the steering committee for several international phase 2/3 clinical trials in the area of myositis and associated ILD. Dr. Aggarwal is also mentoring future generation of rheumatologist with great success and attracting younger rheumatologist towards myositis research for the advancement of the field. Dr. Aggarwal lectures at various international conferences and promotes patient education through his YouTube channel.

**Dr. Daniela Ghetie** is an Assistant Professor of Medicine in the Division of Arthritis and Rheumatic Diseases in the School of Medicine at the Oregon Health and Science University in Portland, Oregon. She enjoys taking care of general rheumatology patients. Her particular interest includes vasculitis, inflammatory myositis, and interstitial lung disease (ILD). She opened the myositis clinic together with OHSU Neurology and sees patients in that clinic held at CHH.

She has clinical and research interests in this group of disorders and through her fellowship she has been involved in maintaining the clinical research database in vasculitis and she is currently creating a myositis database and establishing the ground for future research in

**REGISTER FOR OUR NEW VIRTUAL AFFINITY GROUP IN SPANISH - ADELANTE!**

**REGISTER FOR WOMEN OF COLOR AFFINITY GROUP**



**REGISTER FOR WOMEN WITH IBM AFFINITY GROUP**

the field.

**REGISTER FOR APRIL EMPOWERMENT CLINIC**

**SUBMIT GENERAL QUESTIONS**

**GET READY TO FUN FIT FLEX! STAY TUNED AS WE RELEASE MORE INFORMATION THIS MONTH!**

## A Focus on THE FUTURE

THE MYOSITIS ASSOCIATION
INTERNATIONAL ANNUAL
PATIENT CONFERENCE

A Focus on
THE FUTURE

SEPTEMBER 8 - 11, 2022
CARIBE ROYALE RESORT
8101 WORLD CENTER DRIVE ORLANDO, FLORIDA

**IN PERSON ATTENDANCE**

***Full Conference Experience***

Welcome and Keynote Address
Meet The Board of Directors
Conference Introductory Breakouts
Getting Acquainted Sessions
Friday and Sunday Early Bird Sessions
Thursday – Sunday Workshop Sessions
Medical Advisory Board Town Hall
Q/A with Medical Advisory Board Breakouts
Attendee Welcome Reception (Wine & Cheese)
Bingo After Dark! Event
Orlando FUN FIT FLEX Event
Access to Sponsors and Exhibitors
Prizes and Awards
TMA Support Group Highlights
Breakfasts and Lunches Included
TMA Community Networking
Access to Recordings of All Sessions Post Conference

**Conference Registration:**
Early Bird Registration **$225**/person through 5/31
Registration **$260** /person through 7/31
Registration **$295**/person after 8/1

**VIRTUAL PARTICIPATION**

***Friday and Saturday Conference Streaming of Select Workshops and General Sessions***

Three Friday Workshop Sessions Live Streamed
Virtual Streaming of Orlando FUN FIT FLEX
Medical Advisory Board Town Hall Live Streamed
Q/A with Medical Advisory Board Live Streamed
One Saturday Workshop Session Live Streamed
TMA Community Networking via Remo Platform
Access to Recordings of All Sessions Post Conference

**Conference Registration:**
**$75**/Household

Join Us!

www.myositis.org

CLICK HERE TO REGISTER

## TMA Spotlight

TMA Affinity Groups are all about connection!
TMA's Women of Color group member Monika

Davis recently showed up to support Shinese Larkin's treatment. If not for the TMA group, they wouldn't know each other. Although affinity groups are virtual and have members from all over the world, there is still a chance you will meet someone who lives close enough to you to visit!

Recently in our TMA Caregiver affinity group, two men found out they live within ten minutes of each other and their wives both have IBM. They have since become fast friends, sharing weekly visits to each other's homes and out to lunch. Both caregivers and patients benefit. Connect with a group today!

## The Myositis Association

April is a busy month at The Myositis Association! We continue our monthly webinar series with Ask the Doc showcasing Dermatologist Dr. Victoria Werth and an Empowerment Clinic about having living with multiple diagnoses & illnesses showcasing Dr. Daniela Ghetie and Dr. Rohit Aggarwal. We are also looking forward to the April 13th movie premier of Father Stu, a film about a boxer turned priest turned myositis patient. You can view the trailer here:

If watching a movie about someone with IBM isn't enough, we have attached an IBM Reading List for you. Thanks to Prof. Merrilee Needham, Kelly Beer and the Myositis Discovery Programme, Perth, Australia for the list!

We are also gearing up for Myositis Awareness Month in May! May 1 st is **Myositis Family Day** – celebrate the people in your support network (whether they be family, friends, neighbors, or basically anyone who has helped you along your journey)! Choose to celebrate in any way you'd like – host a cookout, have a picnic, take a walk or go for a scenic drive together, reach out to your support group, stay home and write thank you cards, post a selfie on social media – there are so many ways to connect with those in your support network!

In preparation for Myositis Family Day, please email pictures of the people in your support network to rachel@myositis.org. We will showcase you in a video montage during our kickoff webinar!

In other news, we are actively recruiting support group leaders and co-leaders. We provide training and the time commitment is a couple of hours per month depending on how often you would like to meet. Gail Woods, the group leader for TMA Philadelphia said it best:

*"Having the opportunity to connect is the reason I stepped in to lead and the reason I*

*continue. It doesn't take much time out of my schedule to be a support group leader, and it is a constant reminder that I am not alone. There is such comfort in that."*

If you are interested in helping others by becoming a support or affinity group leader, please email **Rachel@myositis.org** to get started!