



THE MYOSITIS ASSOCIATION®

MAY 1-31, 2024

Myositis Awareness Month



Raising Awareness: Final call for TMA apparel

Now you can wear your awareness all year round with new TMA apparel for Myositis Awareness Month! Shop now, support our mission, and inform members of the public about myositis. We have great gear that defines myositis, encourages individuals living with IBM, and promotes World Myositis Day. Plus, there's a fleece vest and a style just for your furry, feathered, or scaly friends.

But hurry! TMA apparel must be ordered by May 22!

ORDER TODAY

More Magic for Myositis Awareness Month!

Check out all the terrific programming happening this week!

**May 20 Pregúntale al Doctor
- Reumatología, con la Dra.
Francisca Bozán presentado
por TMA Adelante! grupo de
afinidad**

REGISTER TODAY

TMA and
TMA Grupo de Afinidad
de TMA "Adelante"
presenta



**Pregúntale al Doctor, con la Dra. en
Reumatología Francisca Bozán**

Moderated by TMA Affinity Group Co-Leader
Yashira Tirado

Traiga sus preguntas sobre miositis a esta edición especial
en español de Ask The Doc

REGÍSTRESE
HOY

**May 20, 2024
5:30 PM ET**



KANNEBOYINA NAGARAJU, DVM, PHD



DAVID MOCHEL, MD, FACS

**MYOSITIS
RESEARCH
INSIGHTS
WEBINAR**

REGISTER TODAY!

**TUESDAY
MAY 21, 2024
6 PM ET | 3 PM PT**



LEARN ABOUT DR.
NAGARAJU'S MYOSITIS
RESEARCH AND ITS
POTENTIAL IMPACT

**May 21 Myositis Research
Insights Featuring
Kanneboyina Nagaraju, DVM,
PhD**

**Do you use prednisone? You
won't want to miss this
webinar!**

REGISTER TODAY

TMA's Myositis Research Insights webinar series features a distinguished member of the myositis research community who will discuss their research and its impact on the myositis community.

Dr. Kanneboyina Nagaraju (Raju) is an immunologist specializing in autoimmune myositis. His research, in collaboration with Drs. Eric Hoffman and John McCall led to the creation of a new prednisone-like anti-inflammatory drug that eliminates many of the challenging side effects of steroids.

Vamorolone is the first drug approved in both the US and Europe for the treatment of Duchenne muscular dystrophy. Dr. Raju expects myositis to be the next target of clinical trials for vamorolone.

This webinar will be moderated by David Mochel, MD, FACS and Immediate Past Board Chair of TMA.

May 22 Ask the Doc with Dr. Tahseen Mozaffar

REGISTER TODAY



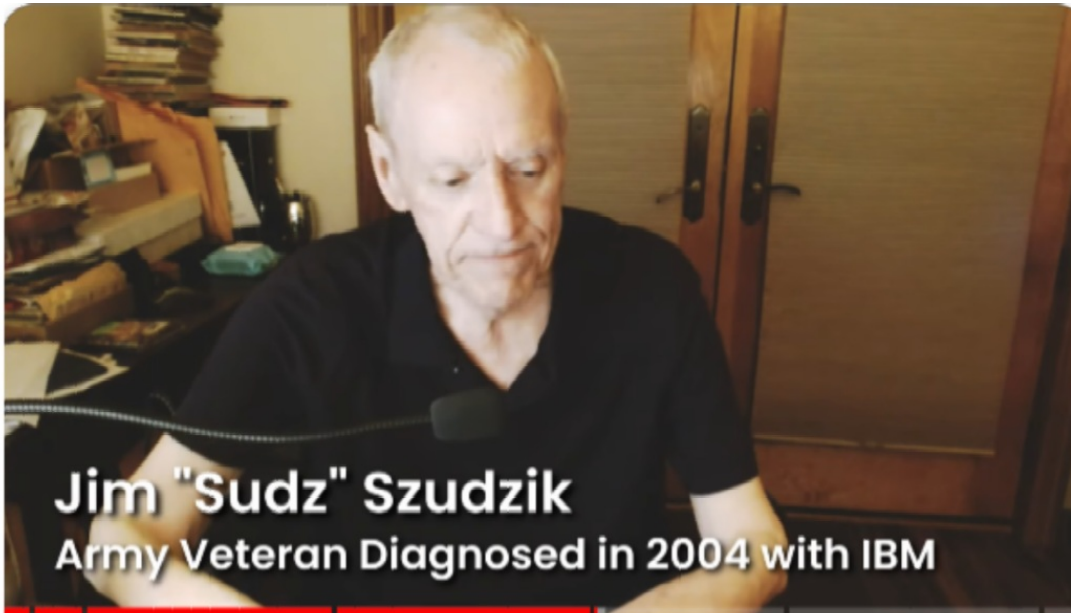
Live Stream of Ask the Doc May 23

In honor of Myositis Awareness Month, TMA is live streaming our "Ask the Doc" program on **Thursday, May 23.**

We will live stream from our [TMA Facebook page](#) while Jemima Albayda, MD, a

rheumatologist at the Johns Hopkins Myositis Center, joins us at the TMA office. **Dr. Albayda will answer your myositis questions from 11 AM - 12 PM ET | 8-9 AM PT.** Submit questions online as you join the Facebook broadcast. No registration is required to view online, simply open our [Facebook page at 11:15 AM.](#)

WATCH LIVE 11 AM MAY 23



Documentary Premiere this May during Myositis Awareness Month!

“Not The Life We Wanted - An Inclusion Body Myositis Documentary” is a compelling new documentary that features veterans and families affected by inclusion body myositis (IBM). The video is a Hill and Ponton production in association with The Myositis Association.

WATCH THE DOCUMENTARY

The TMA blog [“IBM Patients Battle for Veterans Benefits”](#) summarizes the challenges veterans face in obtaining disability benefits from the Veterans Administration. These benefits are crucial as they entitle former service members to comprehensive healthcare, disability compensation, travel allowances for medical appointments, medical equipment, a disability housing grant to adapt their home, stipends for their spouse as a caregiver, and a variety of other assistance.

TMA is calling on the Veterans Benefits Administration at the US Department of Veterans Affairs to determine a presumptive service connection for veterans with IBM. This would mean that if a former service member is diagnosed with IBM, they would automatically receive 100% disability benefits, as it would be presumed that their IBM is directly related to their military service exposure.

TMA members in the US are invited to sign the petition titled “Help Catastrophically Disabled Veterans Get the VA Benefits They Deserve” at

GoPetition. This petition, initiated by volunteers and leaders from the TMA Military Veterans with Myositis Affinity Group, aims to gather signatures to highlight the significance of this issue to the Department of Veterans Affairs.

By signing the petition, you **join other Americans in urging the Veterans Benefits Administration to acknowledge IBM as a service-connected disability and provide assistance to veterans with IBM.** It's important to note that this petition is not associated with any lawsuit; rather, it offers a straightforward way for individuals to express their personal support for IBM veterans and their need for disability coverage.

[SIGN THE IBM VETS PETITION](#)



TMA founder Betty Curry: A force to be reckoned with

During Myositis Awareness Month, TMA honors our founding mother, Betty Curry. Thirty-one years ago from a spare bedroom in her home in Harrisonburg, Virginia, Betty created the organization that would eventually become The Myositis Association.

[READ MORE](#)

Telling Your Story

Myositis Awareness Month is a time to tell the world what it's like to live with this debilitating disease.

This week, TMA member Brianna Childs talks about living with dermatomyositis.

[READ MORE](#)



You too can raise awareness in your community by telling your story. Visit TMA's [Myositis Awareness page](#) for lots of ideas, tips, and tools for spreading the word about myositis.

Back to Basics: Patient and Care Partner Support

When you or a loved one is diagnosed with myositis, you may experience more than just the physical symptoms. Stress, financial and insurance issues, and mental health challenges come along with chronic disease. These challenges are only made worse by living with a rare disease that most people have never heard of.

TMA answers this need by offering a variety of support options.

TMA's Nationwide Myositis Support by Diagnosis Group is new this year. You can **connect with others who understand your new normal and are navigating the same challenges**. It's a reminder that you are not alone. This group meets on the first Saturday of each month and has eight different breakout rooms by diagnosis.

TMA regional support groups are organized on a geographical basis, allowing you to **join with others who may live near you to share mutual support, friendship, and ideas**. Support groups often meet in person, but many also meet virtually, allowing participation from members from any location.

Affinity groups bring together people who share some common interest or affinity in addition to myositis. These groups meet virtually with people from all over the world. Affinity groups provide safe spaces free from judgment where people can feel supported and respected. This is especially important for those who align with marginalized groups.

1x1 Peer support is available for those who need more personal support navigating a challenge. You can discuss specific issues with someone who has been through similar situations. Although at TMA we do not give each other medical advice, this shared experience can provide valuable insights to consider and discuss with your healthcare providers. Please email TMA@myositis.org to get connected.

To participate in these programs, first [join TMA](#) (it's free!). Once you've joined, sign up to attend the [group meeting\(s\)](#) of your choice.

If you are already a member of TMA, simply visit our events calendar to sign up for a meeting or email TMA@myositis.org to get connected to a specific group. To learn more about our patient and care partner support options, visit <https://www.myositis.org/patient-support/support-groups/>.

LEARN MORE

Myositis Awareness Month Resources



[Myositis Awareness
Month Toolkit](#)



[Myositis Awareness
Month Events Calendar](#)



[Myositis Awareness
Month Gear](#)

TMA is able to support people with myositis and their families because of the generosity of individuals who support our work financially. Please [make a gift](#) to TMA to support our impact today!

DONATE TODAY



THE MYOSITIS ASSOCIATION

Connect with us!



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

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