

Spring 2021



THE MYOSITIS ASSOCIATION

myositis.org

Official Newsletter of the



**Myositis Support Group
North Texas**

Here for YOU!

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FROM YOUR GROUP LEADERS

Dear Friends,

Who in the world would have, or could have perceived in their wildest dreams when we met in our last meeting in the fall of 2019, that we'd not be able to meet together until the year 2021?!?! We look forward to the time when we can get together again, hopefully at The Summit in Grand Prairie and enjoy the blessings of sharing our journeys with Myositis with one another. More details later!

I'm hopeful this newsletter finds you in a stable place with your health, especially with your own struggle with that which brings us all together, Myositis. How we have missed being together as a group and in many ways, a family. I'm thankful for social media and the way in which it allows to somewhat "keep in touch". Since we've seen you, we've had quite a journey with Sandi, with cardiac issues and pulmonary issues as well. She is now in month seven with a collapsed lung, and we are hopeful to get some resolution to the issue soon as we go and visit the docs at Johns Hopkins, in Baltimore in June.

Our plan is to schedule our next meeting, tentatively set for the second Saturday in November, which is November 13th, and hopefully we can meet in our normal meeting place, but that has not been scheduled with the Summit folks as of this writing. We WILL keep you posted as to those details and certainly hope you'll mark your calendar and "save the date" for this big meeting. We are hopeful to have TMA folks joining us on that day as well. The meeting promises to be a real reunion for us all, and a time to both plan for AND to cherish!



We have some new members of the group, and we welcome them to our family! We look forward to meeting several new-to-the-group folks at our next meeting. Know of someone who needs an invitation? Please let me know.

All the best!

Don and Sandi Parks

2021 International Annual Patient Conference: The Power Of US!

THE MYOSITIS ASSOCIATION
PRESENTS
INTERNATIONAL ANNUAL
PATIENT CONFERENCE

THE
POWER
OF US

SEPTEMBER 10-12, 2021

A VIRTUAL EXPERIENCE

Join The Myositis Association for our 2021 International Annual Patient Conference

“The Power of US!”.

TMA invites you to our 3-day completely virtual experience featuring myositis specialists and expert presenters on everything related to myositis and its treatment. There will be educational workshops, clinical presentations, breakout sessions, networking opportunities, a multi-generational focus, patient and provider recognition, virtual social activities, exhibitors, new conference components, a HUGE TMA Announcement, and much, much more!

We are excited about spending this time focusing on how we are stronger together.

Early Bird Registration (by June 30): \$150
General Registration: \$175



**MAY IS MYOSITIS
AWARENESS MONTH**

a call to action...

VIRTUAL SUMMIT - SATURDAY MAY 22, 2021

MAY 22nd VIRTUAL SUMMIT
go to myositis.org for more information

MEET T.M.A.'S NEW EXECUTIVE DIRECTOR

Chrissy Thornton is the new Executive Director of The Myositis Association, coming to the post in January of this year. Chrissy's background in service to non-profit health-related organizations makes her a great fit for TMA. She has more than twenty years experience in such leadership positions. Chrissy lives in Baltimore where she and her two sons, Jaden and Justin, actively participate in programs that provide support and opportunities for those with few resources. She also has an abiding interest in the arts, is an accomplished choral musician and has traveled the world as a choir member. The North Texas Support Group welcomes Chrissy and looks forward to her being able to be our guest at one of our meetings soon. The North Texas Support Group welcomes Chrissy Thornton to the Myositis family.

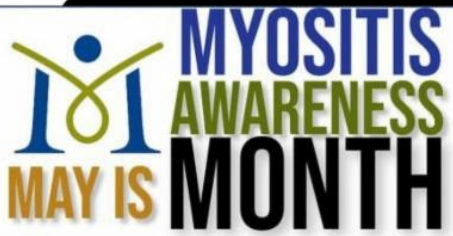


May 2021

May 1, 2021	Myositis Awareness Month Virtual Kick Off – 3:00pm EST
May 2, 2021	Video Spotlight – A Day In The Life (Myositis Awareness)
May 3, 2021	Physician’s Perspective featuring Dr. Lisa Christopher Stine
May 4, 2021	Virtual Exercise Session (Blood Flow Restriction w/ Brett Burton) 2:00pm – 3:30pm EST
May 5, 2021	Community Awareness Highlight – Vance Robinson Myositis First Pitch
May 6, 2021	Empowerment Clinic – Fundraising w/ Shevelle Montgomery (TMA) 6:00pm EST
May 7, 2021	Virtual MyoMovie Night (Back To The Future) 7:00pm EST
May 8, 2021	Special Release – Myositis Awareness Infograph
May 9, 2021	A Mother’s Day Highlight – Mothers & Myositis: Monica Pedano
May 10, 2021	A Patient’s Story – Dave Mochel
May 11, 2021	Virtual Nutrition Session (Better Choices w/ Kaniah Gunter) 2:00pm – 2:45pm EST
May 12, 2021	Community Awareness Highlight – Patrick & Kim Murray
May 13, 2021	Empowerment Clinic – Patient Advocacy w/ Michelle Vogel (CSI Pharmacy) 6:00pm EST
May 14, 2021	Virtual MyoMovie Night (The Greatest Showman) 7:00pm EST
May 15, 2021	TMA’s Fundraising Frenzy Family Trivia - 1:00pm EST Let’s Make A Deal - 3:00pm EST Painting With A Purpose - 6:00pm EST
May 16, 2021	MAM Social Media Takeover – Like, Comment, Share
May 17, 2021	A Patient’s Story – Michael Kerin (Myositis Mike)
May 18, 2021	Virtual Exercise Session (Chair Yoga w/ Adriene) 2pm – 2:45pm EST
May 19, 2021	Community Awareness Highlight – Marianne Moyer
May 20, 2021	Empowerment Clinic –Community Awareness w/ Chrissy Thornton (TMA) 6:00pm EST
May 21, 2021	Virtual MyoMovie Night (ET: The Extra-Terrestrial) 7:00pm EST
May 22, 2021	TMA’s Myositis Virtual Summit - 11:00am – 5:00pm EST
May 23, 2021	MAM Social Media Takeover – Like, Comment, Share
May 24, 2021	A Patient’s Story – Lisa Motley
May 25, 2021	Physician’s Perspective featuring Dr. Merrilee Needham
May 26, 2021	Community Awareness Highlight – Holly Jones
May 27, 2021	Empowerment Clinic – Volunteerism 6:00pm EST
May 28, 2021	Virtual MyoMovie Night (Jumanji 2) 7:00pm EST
May 29, 2021	MAM Social Media Takeover – Like, Comment, Share
May 30, 2021	MAM Social Media Takeover – Like, Comment, Share
May 31, 2021	TMA Staff Myositis Awareness Month Wrap Up Closing



The Myositis Association celebrates May as Myositis Awareness Month!



Take The Journey With Us!



SHARING YOUR PATIENT STORY

Patient stories offer valuable insights that go way beyond the statistics and the outcomes: they have the power to inspire, humanize, compel action, and challenge assumptions. Your experience deserves a seat at the table.



FUNDRAISING

Raising money builds support and momentum for our cause in the myositis community. Our organization depends on generous support to continue toward our mission of finding a cure – and to fund much needed myositis research.

Every dollar matters!



ADVOCATING FOR YOUR HEALTHCARE JOURNEY

Be your own advocate. Never be afraid to ask questions! It is your right to know about the benefits, side effects, and any disadvantages of recommended procedures and treatments. Understand how insurance works. Participate in trials. Maintain your own records. Know that you are entitled to other opinions.



CREATING COMMUNITY AWARENESS

It's time to activate! Host a community event, wear branded items and share marketing materials about myositis. Reach out to your networks, contact the media to share your story, use your social media to educate. **Be a billboard for myositis!**



VOLUNTEERISM

Volunteering can provide a healthy boost to your self-confidence, self-esteem, and life satisfaction. You are doing good for others and the community, which provides a natural sense of accomplishment. Your role as a **volunteer** can also give you a sense of pride and identity.



LEGISLATIVE INVOLVEMENT

Legislative advocacy is the most direct way to cause change in government policy. Whether through lobbying, contacting legislators by phone, letter, or email, sharing your views on issues, and compelling action on areas affecting our patients, your voice matters.



COVID-19 **SAFETY PLAN** FOR MEETINGS

Even though our stated meeting date is more than six months away, we will still practice good COVID-19 safety measures. Please note that we will have a meal that is pre-made, and individualized and not our normal sandwich and salad buffet, if we can work that out with our host venue. Just know that an alternative plan will be in place for several aspects of the meeting, including mask wearing, social distancing, and a larger space than what we've normally been accustomed. Our small group space will also be affected by these safety measures. **EVEN IF YOU ARE VACCINATED**, these safety measures will be in force. If you have other suggestions, concerns, questions, or ideas, please contact Don Parks with those. **YOUR SAFETY** and **CARE** are of utmost importance to us, and while we look forward to in-person meetings once again, virus trends and current conditions will be monitored and we will plan accordingly. Stay safe, each day! We will see you in November! DP

How Your Support Group Can Help YOU



Please remember that this is YOUR group, not "that" group. YOU belong. By virtue of this common disease and daily challenges, you are the reason we travel alongside each other sharing in these ways. We hope you will make every effort to attend the meetings and to stay in touch via email, phone, or snailmail, keeping us up to date on yourself. We not only desire to be a major help to you, but also to those who assist you as caregivers and supporters. We know firsthand that our caregivers are our lifeline. We hope that you find the meetings helpful as well as the newsletters and other support material. We encourage you to visit www.myositis.org often, the official website of The Myositis Association, for information, tips, and links that will hopefully make dealing with the disease an easier thing to do. Please send us suggestions, information, personal helps to share, or anything that might be good to include in the newsletter. This group exists to serve you. So, come and be a part! It will help you!

Don and Sandi Parks
(903) 926-4284 mobile

