

INSIGHT

Conversations with Thought Leaders



**American
Autoimmune**
Related Diseases Association, Inc.

Welcome to **INSIGHT**, a series of conversations to bring new information and compelling perspectives on issues of critical importance to people with autoimmune diseases and stakeholders. Through interviews hosted by AARDA President & CEO Randall Rutta, **INSIGHT** contributes to our understanding of issues and ideas, best practices, and strategies for change in support of the autoimmune community and society.



*Mary McGowan,
Executive Director, TMA*

RANDY RUTTA:

Q. I am delighted to be talking with executive director of The Myositis Association, Mary McGowan, as part of our **INSIGHT** Series: Conversations with Thought Leaders on topics critically important to people with autoimmune disease, their families, and other stakeholders. Tell us about yourself, about TMA, The Myositis Association. What's your mission, and how does your organization raise awareness about myositis related diseases?

MARY MCGOWAN:

A. Thank you, Randy, for the opportunity. The **Myositis Association is the leading international nonprofit organization committed to the global community of people living with myositis, their care partners, family members, and the medical community. We provide patient education and support, advocacy, physician education, and research funding for myositis diseases. TMA has over 40 support groups nationwide. We host an annual patient conference for over 500 patients and care partners, and we've funded over \$7 million in innovative**

research grants. TMA also hosts numerous educational programs throughout the year using the expertise of our world-renowned medical advisory board consisting of 21 researchers in the fields of rheumatology, neurology, pulmonology, dermatology, and rehabilitation. TMA is located in Alexandria, Virginia.

RANDY RUTTA:

Q. That is so impressive. I've had the opportunity to listen to many of your webinars where you bring leading experts forward to answer questions, and make recommendations, interpret policies and practices that affect the lives of people

with myositis diseases and other conditions. TMA is a long-standing member of a group that AARDA is pleased to host, The National Coalition of Autoimmune Patient Groups. And in that context, you always contribute so much and create an opportunity for all of us learn together on how we can be effective advocates for people with all autoimmune diseases and conditions including myositis related diseases. What's unique about this particular patient group? What challenges do people with myositis related diseases face?

MARY MCGOWAN:

A. Myositis means muscle inflammation, and there are a number of myositis diseases. The conditions we support are rare autoimmune muscle degenerative conditions, and there are an extremely limited number of medications that have been approved by the FDA to treat myositis and only certain symptoms of dermatomyositis, polymyositis, and myositis associated with interstitial lung disease. Outside of these medications, all treatments are off label, which means they are difficult to receive insurance authorization for, are often denied by insurance, often require step therapy prior to approval, and when approved, they're very expensive for the patient. So, in the case of patients with inclusion body myositis, there are currently no FDA approved medications. The only therapy they have is

physical therapy that's available to the inclusion body myositis population. And, unfortunately, there's very little research funding being dedicated to these diseases.

For example, the most recent data we have is from 2013, and only \$8 per affected person of NIH research funding went to IBM research as compared to, if we look at ALS research funding, it was \$1,600 per affected person. So, there's a tremendous need for more research funding to be allocated to myositis diseases. And, so, that's really a unique challenge for this patient group.

RANDY RUTTA:

Q. Having more resources flow toward research and then the understanding of that research -- from bench to bedside, out into the community -- is so critically important. Are myositis diseases difficult to diagnose? And if that's the case, why?

MARY MCGOWAN:

A. Yes, myositis diseases are difficult to diagnose. It takes approximately three to five years for someone with a myositis disease to receive the correct diagnosis. For those living with dermatomyositis with lung disease, lost time to diagnosis often means irreparable damage to their lungs. And African Americans and other women of color have a particularly difficult time receiving the

correct diagnosis of dermatomyositis because physicians have been trained to see the telltale signs of DM rashing on Caucasian skin. Last year, TMA sponsored a successful women of color campaign that raised awareness of the specific challenges that they faced with diagnosis, resulting in over five million views in the traditional media and 11 articles published within 30 days. And this year, we're following up by creating a skin pantone of patients in flair to help doctors improve diagnoses for women of color, as this as a significant issue that we need to be addressing immediately.

RANDY RUTTA:

Q. We know that autoimmune diseases disproportionately affect women and in many cases, women of color, and so to have that kind of focus for TMA and the resources coming from your organization is critically important. We know, too, that this novel coronavirus, COVID-19, also has a disproportionate effect on people of color generally. How are you talking about that to people with myositis related diseases? What guidance have you been providing to your community?

MARY MCGOWAN:

A. COVID-19, of course, has had a dramatic impact on the entire planet, but poses significant higher risks for those living with an autoimmune disease and/or those with respiratory

issues. The TMA is a small, but mighty team of three full time staff and two part-time project-based consultants supporting, educating, and advocating for those living with myositis and their care partners globally. And upon hearing that this virus posed a greater potential risk to our already vulnerable population, our team sprang into action to immediately meet the needs of the myositis community.

Some of the COVID-19 initiatives that TMA has undertaken include transitioning our in-person support groups around the nation to Zoom technology, so these support groups are now open to all patients and care partners all over the globe. We immediately created a patient-facing [COVID-19 webpage](#) which we continue to populate with valuable and important information for patients living with myositis and their care partners and needs. This is where we post all of our advocacy sign on letters, videos, blogs, survey information, and numerous resources.

And in addition to that, TMA recognizes that our clinicians are on the frontline dealing with the challenges of COVID-19 every day. And so we created a [clinician-facing site](#) that includes information, registries, and resources from the FDA and CDC, as well as guidelines from medical societies like the American Academy of Rheumatology, and the Dermatology Association.

We also launched the International Myositis Journal Club during this time to continue the focus on myositis education, as many medical schools and residency and fellowship programs have either shut down or slowed down their education focus during on the COVID crisis. Through this program, TMA provides clinicians the opportunity to continue to stay up to date on myositis research with a monthly discussion. And as you mentioned earlier, we're continuing to conduct webinars with timely information on COVID, working with our organizational partners to bring the most valuable information to the forefront for those living with myositis.

And then one of my favorite things is a program we host called Feel Good Fridays which started during TMA's annual patient conference. During these challenging times, TMA decided to implement Feel Good Fridays virtual programs to help bring us together as a community. These programs are focused on meditation, laughter yoga, the power of positive thinking, poetry -- things that make people feel uplifted and feeling really terrific at the end of each week.

And then finally we have a [virtual summit](#) we're hosting in May, and we announced a new moderated session with a focus on COVID-19 to discuss how researchers and clinicians are coping

with myositis as part of our International Myositis Virtual Summit.

RANDY RUTTA:

Q. You bring such energy to everything that you do, and truly TMA is small but mighty. The impact that you have, for the reach that you have, through all the activities, one would think you have a staff of hundreds, but clearly you have such an engaged community working with you to raise awareness and bring resources forward, which is great.

TMA is a partner in our Let My Doctors Decide national campaign that, in addition to looking at the kinds of challenges people might face with COVID-19, is focused on the more routine barriers that people with myositis related conditions and others face just in trying to access insurance plan coverage for services and medicines that they need. As you know, the campaign is focused on raising awareness and driving reform to address those unwarranted utilization management practices that get between a patient and their physician and the medicines and care that they need. How do these restrictions impact the myositis community? What policy or regulatory reforms are needed to help improve the health and wellness?

MARY MCGOWAN:

A. As I mentioned earlier, patients who live with myositis don't have a lot of FDA approved drugs. So first and foremost, we need more funding for rare diseases like myositis. And secondly, access to off label medications is essential to our population. Fail first and step therapy programs create dangerous delays of access to medications, which are vital therapies in reducing flares and managing the complex system symptoms of these challenging conditions. TMA works closely with AARDA, on the Let My Doctors Decide project, which is an extraordinary initiative for those living with autoimmune diseases. It's vitally important to let the trained physicians manage the complex care of the patient, and we're so thankful to AARDA to be able to be partnering with you on this really important initiative.

RANDY RUTTA:

Q. It's our pleasure, and we so appreciate your contributions to our overall understanding of these issues that enhances our reach and effectiveness.

And, May is Myositis Awareness Month. Can you talk about what this heightened awareness means and how it helps your community? What kind of activities are planned?

MARY MCGOWAN:

A. We're so excited for this month, and our efforts actually kicked off a few weeks ago with the joint webinar with AARDA on isolation protocols, environmental challenges, and autoimmune diseases. This webinar was supported by Mallinckrodt pharmaceuticals and for those who are interested, a recording lives on [TMA's YouTube](#) and [webinar page](#) of our website.

And as you know, this webinar featured Dr. Aggarwal, who chairs TMAs Medical Advisory Board; Dr. Bauer Ventura from the University of Chicago; a patient living with DM, Felicia Brannon; and Virginia Ladd, former president and executive director of AARDA. We had 202 registrants, and since then we've had over 130 views of the webinar. It's an extraordinary resource, and I invite others to listen in.

We are excited about all the other activities this month including [TMA's International Myositis Virtual Summit](#), a virtual opportunity to help patients and care partners learn how to manage their myositis. This virtual summit allows participants to attend from their computers, from the comfort of their own homes. Participants will be able to view and engage in eight educational presentations and Q&As by the leading global myositis experts. We have 12 virtual exhibits with

industry leaders in myositis and virtual networking chat rooms and downloadable myositis resources.

And as I mentioned, we just added a bonus moderated session on COVID-19, and the participants will have an opportunity to access this content from the virtual summit for 30 days after the live event. In addition, we have an exciting tool that we've been developing, and will be distributing this new tool and tips through social media to improve the doctor and patient communication specifically for those living with myositis. This tool empowers patients with vital information about changes in symptoms, increased number of incidents, such as falls and other relevant physical changes that can better inform and help shape the discussion with their doctor.

This resource also includes tips for how to better communicate in the time of telemedicine. As we know, many doctor visits now are being done by telemedicine, and this is new, helpful resource. We also have a [webinar](#) scheduled to launch this doctor patient communication tool with Dr. Tom Lloyd, the research chair of TMA's medical advisory board. He has been instrumental in helping us develop this new tool, and on May 20th at 3:00 PM, he will host our webinar to help us launch the tool.

We're also really excited about TMA's first [Twitter chat](#) with Dr. Aggarwal, the chair of TMA's medical advisory board. This takes place on May 20th at noon, and it will focus on improving doctor patient communication and telemedicine -- what works, what doesn't. And, in late May, TMA will host another [webinar](#) on what we trends and opportunities that will benefit our population, as well as challenges. The discussion will include tips for how to better communicate with your doctor and how the clinic model might improve and challenges in billing and prescribing.

RANDY RUTTA:

Q. Telemedicine has really emerged as a way for people to stay in touch with their doctors and their health.

Having this TMA resource is going to be incredibly interesting and helpful in understanding what the unique considerations are for your population as they engage with their physicians through telehealth, what works, what could be improved because I think that will emerge as part of a new normal for how patients stay connected to their practitioners and to their health. Bravo to you for all that you're doing across the spectrum to help people with myositis related diseases and then also others that have chronic conditions who will learn from you, your patients, and physicians. Thank you.

MARY MCGOWAN:

A. Thank you, Randy, and AARDA and all of the partners that TMA works with. We are a small and mighty team doing a lot of work, but we can't do this work alone -- without our partnership with AARDA and others. We are so appreciative to everyone working collectively on autoimmune, rare diseases.

And then in terms of COVID and myositis, I want to encourage people to stay in contact with The Myositis Association and visit our [resource page](#) on [our website](#). We will continue to share our educational programmatic activities. For non-TMA members, we invite you to [join us](#). We use social media to reach the community at large, and I encourage everyone to visit [our website](#) because our primary goal is to support myositis community. A lot of the educational materials and programmatic activities are broad and can help the rare disease community. We hope others will participate in our discussions with global experts and others on many important topics.

RANDY RUTTA:

Q. Thank you so much for everything that you're doing. I know that you live every day in that spirit of collaboration and partnership. It is truly benefiting your own constituencies in the myositis community and anyone with a rare disease or who's in constant interaction with their

health and with the healthcare system. The work that you're doing is vitally important. Thank you and your colleagues who are doing such an amazing job to help us understand myositis related diseases and to engage in the resources that you offer.

MARY MCGOWAN:

A. Thank you, Randy, for your extraordinary work and for your incredible team that you have. We can't say enough about how grateful we are to be partnering with you and you are doing absolutely extraordinary work.



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