THE OUTLOOK

THE MYOSITIS ASSOCIATION

FALL 2020
Quarterly Newsletter

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THE OUTLOOK

A quarterly publication of The Myositis Association

Cover photo taken by Tricha Shivas Ladew of Topiary Gardens in Maryland

TMA's vision is a world without myositis

TMA's mission is to improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy

Published by:
THE MYOSITIS ASSOCIATION
2000 Duke Street, Suite 300
Alexandria, VA 22314
P: 800-821-7356
F: 703-548-9446
E: tma@myositis.org
W: www.myositis.org
Mary McGowan, *Executive Director*
Tricha Shivas, *Editor*

STAFF
Mary McGowan, *Executive Director*
Aisha Morrow, *Operations Manager*
Tricha Shivas, *Director of Development and Strategic Partnerships*
Khaleelah Cohen, *Consultant*
Dacia Williams, *Administrative Assistant (part time)*

CORPORATE ADVISORY COMMITTEE
Mallinckrodt Pharmaceuticals
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Dear Myositis Community,

It has been an honor and privilege to serve you as Executive Director of The Myositis Association for the past 2 years. As the leading international myositis association, working together, we have accomplished extraordinary things. This has been a time of exciting growth for TMA, with many new important initiatives launched, new relationships forged, and enhancements to our research program **resulting in a 40% increase in quality myositis research applications, and increased advocacy efforts resulting in better policies for those living with myositis**. I thank you for your engagement and support of these efforts.

TMA's visibility, reach and membership significantly increased **through education and awareness**. In working to increase TMA's footprint, I had the unique privilege to represent those living with myositis in over **35 national and international speaking engagements**, articles, podcasts, and interviews. To elevate TMA and our mission and messaging, I am proud to have been featured as a preeminent rare disease leader by numerous entities including AARDA, Global Genes, and NORD. TMA is also excited that through our nomination, Mr. Peter Frampton will be honored with the NORD Rare Impact Award next month at the NORD Rare Summit. TMA also was thrilled that through our nomination we were able to call attention to IMACS and myositis research through the Global Genes Rare Champion of Hope Award. In December 2019, TMA launched our **corporate video** raising awareness about TMA, our support services and myositis research which was viewed 1.4K times on YouTube, played on American Airlines flights for 2 months, and was featured in RokuTV and AppleTV.

In March 2019, we launched our successful and engaging educational **monthly webinar series**. **We have held over 16 webinars since its launch**. In September 2019, TMA held our **2nd largest Annual Patient Conference** in Bloomington, MN. Additionally, TMA has created numerous educational infographics including a services flyer, our educational flier on women of color and myositis, telemedicine tips and tricks, and a nutrition flier to help provide vital education to the myositis community. Our educational programming didn't skip a beat during **COVID-19**, in fact, we increased our educational awareness programs and initiatives and provided more support through videos, resources, and blogs. **My Myositis Tracker** was created and positioned to improve patient and physician communications. We even initiated *Feel Good Fridays* to try to offset some of the isolation and mental health challenges this pandemic brings.

One of the campaigns, I am most proud about is the hugely successful **Women of Color and Myositis National Campaign** resulting in over 5 million media impressions, a dozen articles, and numerous speaking engagements. It was an honor working with the Patient Advisory Council to raise awareness about those at highest risk for DM and PM. I'd like to thank the NIH for working with us to produce our **WOC infographic**.

Additionally, we are most proud of leading the trend with the great success of TMA's educational **Inaugural Myositis Virtual Summit** with 605 attendees representing 18 countries, planned back in October, well before COVID-19. And, we have been very excited to build off our learnings of this summit to an even more engaging and collaborative agenda and event for the first Virtual International Annual Patient Conference that is just weeks away. We were also thrilled when Mr. Peter Frampton agreed to produce a welcome video for this year's Annual Patient Conference. I encourage you to read **his memoir** highlighting his Final Tour and living with myositis.

TMA has made **major strides in our Advocacy efforts**, recently featured in the **Summer 2020 Outlook**. TMA proudly walked the Halls of Congress with patients and care partners during **Rare Disease Week**. In the past 2 years, **TMA joined 22 coalitions**, working together to speak up and advocate for those living with a chronic rare disease and through many sign-on letters. It was our honor to facilitate the **Patient Listening Session on IBM with the FDA**, a major step toward drug development.

Thank you to all of our corporate, hospital, and organizational partners. We are proud of the relationships we built, the work accomplished and the numerous collaborations including the **Myositis Hospital and Clinic Alliance, TMA's Visiting Professor Program, our Corporate Advisory Committee, the launch of *TMA's Myositis International Journal Club* and facilitating the IMACS Annual Meeting**.

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What Family Caregivers Can Teach Us about Resilience in the Time of COVID-19

By C. Grace Junea Whiting

Originally published on LinkedIn (republished here with permission).

C. Grace Junea Whiting *is the President and CEO, National Alliance for Caregiving and a member of Governing Board, International Alliance of Caregiving Organizations.*

The COVID-19 pandemic is changing the way we live. There's the Netflix binges, the sudden interest in learning how to bake bread, the decision to reconnect with those friends you haven't heard from since Facebook was cool. Before you Marie Kondo your closet, take a minute to notice something that's arrived on the doorsteps of nearly every person or community in the world. *Who cares for us when we get sick? And what happens if we're not available to care for our friends and family?*

In this new world, we're suddenly asking these questions together.

We're worried about an elder aunt staying in a facility who can no longer receive visitors. We're pacing the room because we can't visit our parents and, instead of staying put, they're out and about touching every item on the Costco shelf. We're carefully monitoring our children, siblings, or even spouses who have a chronic health condition that puts them at heightened risk—and wondering what will happen if we get the virus ourselves.

These "what if" questions are nothing new for the friend and family caregivers who wrestle with them on a day-to-day basis. And research indicates that we might have an opportunity to learn how to cope with a crisis from those already caring for someone day in and day out.

> *The people who have already weathered the strain of disease or disability may be able to show the rest of us the way.*

Can Caregiving Improve Our Outlook?

A 2013 Johns Hopkins-led study found in an analysis of 3,000 caregivers, the act of caring for a "chronically ill or disabled" family member provided an 18 percent survival advantage compared to non-caregivers. Over the six years of the study, this translated to a longer life expectancy, perhaps because caregivers find meaning and purpose in caring for another person. Study participants shared that they experienced enhanced self-esteem from the very act of caring for another person – and when that caregiving role was taken on willingly, the effect was amplified.

NAC research has likewise found that caregiving can have a positive impact. Our 2018 study of more than 1,400 caregivers of adults and children with rare diseases showed that 75% of rare caregivers have a "sense of loss" for what their life could have been without the disease. Yet this same group of caregivers reported overwhelmingly that caregiving has positive aspects including:

- Pride in understanding the condition (94%)
- Feeling valued as part of the care team (91%)
- Caregiving makes the caregiver feel closer to the person receiving care (85%)
- Caregiving gives the caregiver a sense of purpose (56%).

Likewise, our recent study on caregivers of people living with Crohn's disease or ulcerative colitis – a chronic condition that requires intermittent care – found similar positive effects. While less pronounced than the rare disease caregiving community, many still reported a positive impact in their lives due to caregiving:

- More than a third (34%) said caregiving had a positive impact on their family
- One in five (23%) said caregiving gave them a "sense of purpose in my life"

- More than half (51%) said they felt pride in improving their understanding of the underlying condition or disease
- More than half (52%) said they felt valued as part of the care recipient's health care team.

Can Caregivers Teach Us Resilience?

The idea that caring for another person – despite the demands of caregiving – can improve psychological well-being is nothing new. Yet the idea that we can learn from caregivers about how to be more resilient in the face of COVID-19 hasn't yet come to the forefront of international conversation.

One fascinating pilot study led by Dr. Frances Marcus Lewis at the University of Washington offers some food-for-thought. In a study of families where men were caring for women with ovarian cancer, Dr. Lewis and her colleagues examined depressed mood, anxiety, marital communication, and perceptions of spousal support. Women with ovarian cancer are often devastated by the diagnosis, and rates of depression are significantly elevated when compared to the population at large. Likewise, the people who care for women with ovarian cancer often experience greater-than-average anxiety and depression, affecting their ability to provide care.

The tremendous strain of disease on both people often means that families misunderstand each other.

The caregivers are often at a loss for why the person with cancer is saying things like, "I don't think I will survive this" or "We need to plan for me not being alive by this time next year." Likewise, the person with cancer is frustrated that the caregiver isn't listening to them or accepting the challenges they face. Families see the strain of disease as a barrier or deficiency in their relationship – clouded by the impact of this life-altering condition.

Using patient educators, caregivers participated in telephone training sessions in a program called "Taking Care of Her." The program included training with a nurse on:

1. how to provide interpersonal support to the person receiving care,
2. how to apply strategies to real-life situations in the home, and
3. how to help caregivers take care of themselves not just during the acute illness but through the long-term journey of disease and survival.

As the coaching progressed, caregivers began to learn that it wasn't their partner or marriage that was creating the strain – it was the burden of disease on the family unit.

Over the course of the intervention, caregivers also began to implement self-care. As Dr. Lewis described in her TEDtalk on the same body of research, effective self-care could involve as little as 15 minutes a day. Caregivers were encouraged to take "regular time out" for themselves and to identify supports from others in their life to help cope with cancer.

The end result?

Both the women living with cancer and the men who were caring for them felt that their ability to care for each other was improved. Women tended to rate the support they received more positively and both the men and women indicated that their communication with each other had improved. Assessment of depressed mood and anxiety for both also improved.

So, what does this mean for us in the time of COVID-19?

It means that when we look out at our communities and we see caregivers in our midst, we should think about asking them how best to cope with what's ahead. There are few people in our lives who better understand how to weather and survive the trauma of a life-altering disease or disability than the 44 million Americans who are doing this every day. For once, it's a moment to recognize that caregivers may have a road map to the challenges we will all face in the coming months.

For the latest news on public policy, advocacy, and events in the caregiving world, subscribe to This Week in Caregiving here.

Research Citations

Roth, D.L., Haley, W.E., Hovater, M., Perkins, V., Wadley, V.G. & Judd, S. (2013). Family caregiving and all-cause mortality: Findings from a population-based propensity-matched analysis. *American Journal of Epidemiology 178*(10), 1571–1578. **https://doi.org/10.1093/aje/kwt225**.

National Alliance for Caregiving in partnership with Global Genes. Research conducted by Greenwald & Associates. Rare Caregiving in America (February 2018), available at **www.caregiving.org/rare**.

Illustrations from C. Grace Whiting, President/CEO, National Alliance for Caregiving (2020), drawing on research from Lewis, F., Alzawad, Z., Griffith, K., Almulla, H., Wu, P., Chi, N., Zahlis, E. and Shands, M. (2017) Taking Care of Her: A Pilot Feasibility Study of Caregiver Intervention for Women with Advanced Stage Ovarian Cancer. Journal of Cancer Therapy, 8, 472-489. Doi: 10.4236/jct.2017.85041.

Corner Office Article - Continuation from Page 3

One of my greatest joys was to attend support group meetings nationwide and to work to **enhance our support services while elevating our Support Group Leaders** who are doing extraordinary work and are the boots on the ground. **Thank you all for your extraordinary leadership** and support of the myositis community. We are proud of the ways we have been able to enhance your leadership and support through the Support Group Leader Manual, the in-person training at the 2019 Annual Patient Conference, zoom trainings during COVID, and new grant-supported certification training currently under-development.

A huge thank you to the staff for working so hard to complete approximately **90% of the very ambitious strategic plan objectives for 2019 and 2020** and for their extraordinary work as a team. As of the 1st quarter of 2020, TMA is in the strongest financial position the organization has been in during in at least the last 4 years.

A very **special thank you to the Medical Advisory Board** who dedicate and volunteer their time and efforts to support TMA and the myositis community at large. It has been an honor working with these global experts who are the rock stars of patient care and research and their support has been overwhelming!

The undeniable results of the past 2 years have led to enhanced research, further awareness and reach, an elevated advocacy agenda, a more educated and supported community and closer outcomes to eradicating myositis disease. Thank you for your support and continued efforts to enhance the landscape of TMA, our important mission and our impact worldwide.

I will keep you in my thoughts as you continue in your myositis journey.

Coping with Anxiety in the Time of COVID-19

***Mike Matthews** is a retired teacher, counselor and mental health administrator with a mission of creating a healthy and cohesive community.*

Several friends have confided in me that they are struggling with negativity, anxiety, depression, anger, and sleeping problems. The coronavirus pandemic is universally throttling us with uncertainty, anxiety, and lack of control, so please understand that you are not alone, and these feelings can be expected in these extreme times.

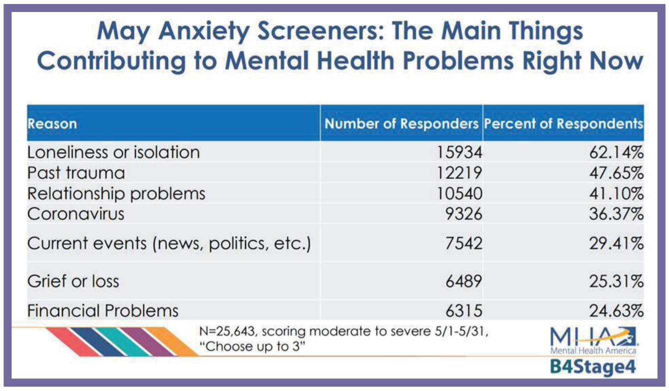
As always, we need to hold up and nurture our children in these frightening times as school-aged kids are finishing their school year at home and younger ones are often off their normal schedules. It is creating a challenging dynamic for families and it can be tempting to put children in front of the television to watch mind-numbing programs and ignore our children's needs as we try to cope ourselves. It is natural to try to protect children from the turmoil, but also important to engage them in age-appropriate conversations about the world they live in. As the saying goes, smooth seas produce poor sailors, children need to be able to navigate difficulties in life.

Children appreciate opportunities to contribute and feel connection to their community. An example is the Buttonwood Kids Bicycle Club who last weekend organized a well-attended food drive to benefit local food banks. In most cultures, childhood is about learning values, skills, and self-discipline. This is what makes kids feel their connection to the great scheme of life and creates a sense of responsibility to the common good. When we keep children unnaturally insulated and separated from the issues of their communities, they often feel lost and without necessary skills. The Buttonwood Kids Bicycle Club provides an example for us that we all can find ways to contribute.

We are all experiencing an unprecedented amount of stress, anxiety, and uncertainty during this pandemic, you are not alone. We can take care of ourselves by keeping healthy schedules and sleep habits, get some type of appropriate exercise, limit television viewing, be vigilant about social distancing and medically advised safety measures, and always seek appropriate professional help if needed. We can look for ways to help our most vulnerable citizens and be agents of positive change. Ultimately, the great challenges we face will cause us to grow stronger or become smaller people. The obstacles we are facing are not roadblocks, but temporary detours to ultimately the greatest national recovery we have ever known.

Loneliness and Isolation Main Contributors to Anxiety During Time of COVID-19

Mental Health America offers Mental Health Screenings through an online tool. 62% of respondents noted that loneliness and isolation are the largest contributor to their anxiety right now. The Myositis Association offers many different ways to help you find a community and stay connected even during these challenging times. Join a TMA Support Group and participate in virtual meetings, join TMA for online educational events and webinars, participate in virtual summits and conferences, sign up for TMA's Myo-Connect program and speak directly to someone living with your condition via phone or email. To learn more about these programs and how TMA can help send an email to **tma@myositis.org**. To learn more about Mental Health America's screening tools visit **here**.



May Anxiety Screeners: The Main Things Contributing to Mental Health Problems Right Now

Reason	Number of Responders	Percent of Respondents
Loneliness or isolation	15934	62.14%
Past trauma	12219	47.65%
Relationship problems	10540	41.10%
Coronavirus	9326	36.37%
Current events (news, politics, etc.)	7542	29.41%
Grief or loss	6489	25.31%
Financial Problems	6315	24.63%

N=25,643, scoring moderate to severe 5/1-5/31, "Choose up to 3"

How to Cope with Fear and Anxiety During COVID-19

It is safe to say that all of our lives have significantly changed over the last few months. It is important to acknowledge that these are uncertain and unsettling times. As you continue this challenge each and every day, The Myositis Association walks beside you.

Here are some vital tips to help you cope with fear and anxiety in these challenging times.

- **Stay informed** – Get the facts. TMA has created a **COVID-19 Resource Page** for people living with myositis. This page includes videos, webinars, blogs, and the latest resources relevant to the myositis community. TMA has also created a separate **COVID-19 page for clinicians** with training guides from the NIH and the CDC and other relevant resources.
- **Don't become oversaturated** – Step away from the news and social media. The constant loop of press briefings, headlines, and charts can make you more anxious, overwhelmed and raise your blood pressure.
- **Take care of your health** – Exercise and eat healthy. Being home-bound can make it more difficult to find the motivation to exercise. And with limited access to the grocery store and food in more limited supply, eating healthy is definitely more challenging. But small efforts can have big impacts. Even 20-30 minutes of brisk activity a day can have a big impact according to the American College of Sports Medicine. Even if you can't get out to fill your plate with fresh fruits and veggies, you can improve your diet by watching salt intake and drinking lots of water.

- **Look for the good** – Look for the good in the world. Even in challenging times there is a lot of good in the world. Read and share "**feel good stories**." Share good memories from the past. Watch comedy movies. TMA is hosting Feel Good Fridays as a way for our community to come together, relax and enjoy the good in the world together. Join us! For more information visit our website at **https://www.myositis.org/myositis-library/webinar/**
- **Be Glad** – Suzan Fishbein, TMA Support Group Leader and Social Worker at The Hospital for Special Surgery recommends that you try to be GLAD.

G think about one thing for which you are **grateful**; it can be small or large
L think about one thing you have **learned** today
A think about one thing you have **achieved** today
D think about one thing that has given you **delight**

- **Seek help if you need it** – If you are experiencing serious anxiety or mental distress or need assistance you may reach out for mental help from the CDC by calling: 1800-985-5990 or by texting TalkWithUs to 66746

How Exercise Improves Your Mental Health

By Erik Ensrud, MD

***Erik Ensrud, MD** has a joint appointment as associate professor in the department of neurology and the department of orthopedics and rehabilitation at the Oregon Health and Sciences University School of Medicine. His clinical practice focuses on rehabilitation and exercise-based treatment of neuromuscular disorders, physical medicine and rehabilitation, and electrodiagnostic medicine. Dr. Ensrud's research interests include exercise in neuromuscular diseases such as myositis, efficient and accurate physical examination of the neuromuscular system, use of orthotics for nerve and muscle disease, clinical trials for neuromuscular diseases, electromyography education, and neuromuscular disorders unique to service veterans. Dr. Ensrud is a member of TMA's Medical Advisory Board.*

Exercise is an activity often thought to be done primarily to increase various aspects of muscle-muscle strength or size, increased endurance, increased speed, or increased physical performance. In reality, for most of us those aspects of exercise are really quite secondary or of even limited importance.

Exercise is unique in that it is something that can often be done for free or minimal cost, yet it provides a wealth of benefits that go far beyond its effects on muscle. One of the very most important is its benefits on mental health, as mental health disorders are the leading cause of disability worldwide.

Many of us have heard of the benefits exercise can have on serious mood disorders such as clinical depression and anxiety disorders. Exercise is as effective as antidepressants in reducing symptoms of depression, and the use of the two combined has been shown to have a synergistic effect, often resulting in a better effect than either used alone. In our current stressful times, it can really help our mood to get some exercise!

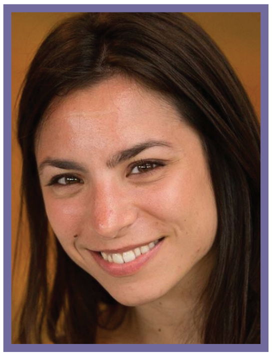
Regular exercise helps heart health, hypertension, asthma, arthritis, back pain, and reduces the risk of dementia.

Truly, if the effects of exercise were concentrated and delivered in a pill form, we would all consider it the world's miracle drug! Nothing works for everyone all the time, but so many of us can get real benefits from even mild exercise.

What is the science behind this? How does exercise really improve mood? Exercise increases your level of endorphins, which are chemicals in your brain that are natural mood lifters. Exercise helps by getting your sleep patterns back to normal. It's been proved that exercise improves blood flow to the brain and works to mediate the area of your brain, the hypothalamic-pituitary-adrenal (HPA) axis, that determines your reactivity to stress. This effect is passed on by the HPA axis to several other regions of the brain, including the limbic system, which controls motivation and mood; the amygdala, which generates fear in response to stress; and the hippocampus, which plays an important part in memory formation as well as in mood and motivation. Complex! Yikes. Well, that is your brain and everyone else's. In these ways and others, the effects of exercise spread throughout the brain to the many areas that affect mood and serve to elevate and stabilize your how you feel.

So, in a practical sense, how do you get going on exercise? How do we utilize it to help quickly boost our mood? Like, right now! If you're sitting, like most of us most of the time, and it is possible for you to stand with or without the use of your arms, try going from sit to stand several times. No need to rush it, just go from sit to stand multiple times. Breathe in on the way up, breathe out, and take a deep breath in when you stand. Going from sit to stand is a wonderful exercise that works nearly all of the muscles of your legs, including those that stabilize walking. If not is not possible to stand, move your arms as you can through the full range of motion you have. No need to hurry, just move the arms slowly and breathe slowly through the movement. Often moving slowly is more work for your muscles and improves the blood flow more than moving quickly. This is a principle behind the slow movement exercise called tai chi that so many enjoy and benefit from. No need to get changed, or go to a class, or get out of your home or office-you can exercise right now where you are! Your mood will really appreciate it.

Research Supporting Pets for Stress Reduction from the Human Animal Bond Research Institute (HABRI)



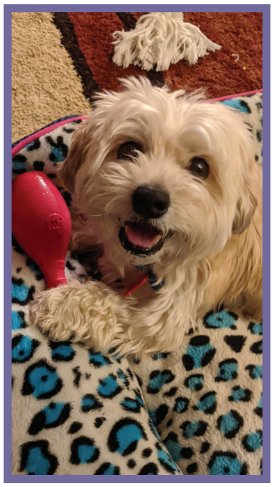
*As the Program Director for HABRI, **Lindsey Melfi** is responsible for managing the HABRI research grant program, which consists of a portfolio of 31 high-quality research projects investigating the health benefits of human-animal interaction. Lindsey also works to advance HABRI's media relations and public policy agendas to generate awareness of the science that demonstrates the positive roles that companion animals play in the integrated health of individuals, families and communities.*

It's well-documented that long-term, chronic stress can adversely impact mental and physical health. Less well-known, but also well-documented is the scientific research that suggests that the human-animal bond – or the mutually beneficial relationship between people and pets – can help alleviate stress for people of all ages and health conditions. Below is a brief summary of the research supporting the value of pets and human-animal interaction (HAI) for stress reduction.

Studies suggest pets can help buffer perceived stress and responses to stress through lowering heart rate and blood pressure. For example, in a study of pet-owning women, participants reported significantly lower levels of stress performing a stressful task in the presence of a dog compared to those in the presence of a friend. A similar study of children found that the presence of a pet was associated with lower cortisol response to stress, suggesting that pet dogs can provide socio-emotional benefits for children via stress buffering . After assessing the effects of a stressor on 240 couples who owned either a cat or dog, those with pets had significantly lower resting baseline heart rates and blood pressure compared to non-pet-owners. The study also found that reactivity to stress was lowest and recovery fastest in couples tested with their pet present.

Any hospital or doctor's visit can be stressful, and HAI has been shown to help reduce stress and improve outcomes. Results of a study examining children diagnosed with cancer indicated animal-assisted therapy (AAT) can contribute to improvement in pain and psychological parameters, including irritation, stress, anxiety, mental confusion, and tension in patients undergoing outpatient treatment. A study of children undergoing a simulated medical exam found that the presence of a dog lowered behavioral distress, suggesting that animals can decrease procedure-induced distress in children in a variety of health care settings.

One possible mechanism behind the power of pets to alleviate stress is their ability to increase oxytocin levels in the brain. HAI has been shown to influence hormones correlated with well-being, including oxytocin, a neuropeptide long known to promote maternal care in mammals. Oxytocin causes many physiological changes, including slowing heart rate and breathing, lowering blood pressure, inhibiting stress hormones, and creating a sense of calm.



Ask any pet owner and they'll agree, pets enrich our lives. While the pandemic continues to impact people's lives around the world, pets have become an important source of social support, physical activity and companionship, and the human-animal bond is stronger than ever. Sharing research supporting pets for better health is critical to helping more people benefit from the human-animal bond.

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The Power of Positivity

By Elisa Glass

***Elisa Glass** has been living with dermatomyositis since 2016. Prior to her diagnosis, Elisa was a professor, specializing in the field of Drug and Alcohol abuse. Elisa owned and operated MYTHS, LLC which focused on helping members in need, especially homeless.*

I was living a relatively simple life. I was at the height of my teaching career, running a small retail business and working out 4-5 times a week. Life was really good. Unbeknownst to me, I was about to embark into a new adventure.

In January of 2016, I was teaching during the winter session. This particular morning, I had awoken and was still very tired. During the class my legs began to hurt and I could not wait till class was over. This class was on a Thursday and by that Monday, I was in the emergency room, unable to move my arms and legs, rashes all over my body and in excruciating pain. This was the beginning of a 3-1/2 month stay at the hospital.

It took several days to be diagnosed. Dermatomyositis and a severe case of it. Then began the medications - so, many medications. Two weeks later, I had a severe flare and with it went my voice and my ability to swallow. I required a peg tube and it took two operations until it was correctly placed. My CK count was 39,000. The veins in my arms and legs began to collapse from all the IV's and blood draws. You could see the stress on the faces of the doctors who were in charge of my case. Things were not going very well.

It was explained to me that Dermatomyositis is a rare disease and without a cure, and no specific regiment for how best to treat someone with this condition. They did not know what would work and were surprised of my severe flare with all the medication I was on. They made it clear that my survival would be a miracle and told my husband to call the family to come and see me.

My mother arrived, then my sister. All four of my adult children came, one by one to see me. Then it clicked, I thought they were coming to say hello, but they were coming to say goodbye. Strangely enough, I began to laugh so hard that tears were rolling down my face. It was time to let everyone know my secret. I am a Warrior! This Soldier was now at war!!! I remembered thinking, these doctors will not and cannot convince me of my demise. I will show them! I will walk and talk again.

But first, I needed to build my arsenal. I requested a salt lamp in my room. Aromatherapy to be provided every day. Reiki from the trained nurses and meditation with the assigned neuro-psychologist. All of this was to be in conjunction with the traditional western medicine.

My plan was to stay positive and happy. I smiled a lot and never stopped giving the thumbs up. I visualized myself in the future being happy, healthy and strong warrior. A formidable enemy to Myositis and "He" knew it!! I continue this thought process till this day. Visualization is one of the tools I use to stay positive. My affirmation of "I Got This" is my daily mantra.

I changed my environment to accommodate my new needs and removed negative people from my space. I make sure I eat as healthy as possible and drink plenty of water. I had to learn to appreciate the new me and put restrictions on myself. I worked on how to self soothe in order to deal with the inconsistency of the disease. I played music to relax or try to dance.

And most of all I sought out support where I could share information, discuss my situation with people who understood, cry because I am still mourning who I was and what I was able to do. Thank you, to The Myositis Association for giving me such support. **Thank you, to all my fellow warriors for embracing me and allowing me to embrace you back.**

So, I leave you with my list of keys to my positivity: Meditation/Positive Visualizations, Aromatherapy, Reike, Music, Control your Environment, Self Soothe, Eat well, Drink Plenty of Water, Use Positive Affirmations, Stay Positive, Laugh, and Get Support.

Chronic Illness, Meditation and Mental Health

By Kimberly Joy Beam

Kim Beam Is a Licensed Clinical Social Worker practicing in Pennsylvania. She is also a qualified mindfulness instructor through UMass Medical School. Kim is a cancer survivor and the author of What Doctors Don't Tell You: One Woman's Journey Through Hodgkin's Lymphoma

In a discussion about chronic illness, its associated pain, and the role Mindfulness plays, it is necessary to go back to the beginning. Jon Kabat-Zinn was practicing meditation at the Insight Meditation Center in Barre, Massachusetts in the 1970s. As he sat, he received the "download" to bring meditation to the medical world where he worked, The University of Massachusetts' Medical Center. Shortly after, he contacted his colleagues saying, "Send me everyone you aren't able to help - the ones for whom medications are no longer working, the ones who have uncontrolled pain, the ones who are no longer responding to medicinal protocols." The research followed - those that practiced Mindfulness fared better.

Mindfulness was *created* for chronic illness.

So, what is Mindfulness? It is the practice of being present with what is present. But what does that really mean?

In truth, Mindfulness is best explained by practice. So, as you are reading this, find yourself seated (or standing if you are in your kitchen waiting for the pasta water to boil). Feel where your body makes connection with the chair, your feet with the floor, your back with the back of the chair. Find where you end and the rest of the world begins - your feet in your shoes (or slippers or socks), your legs in your pants, your arms in your shirt's sleeves. Feel yourself in relationship to your clothes and the world around you - this is called grounding yourself.

Once grounded, take a couple of deeper breaths in and out - notice where in your body you are feeling the air the most. Is it in your upper chest, your belly, your nose, the back of your throat?

Then bring the breath back to normal. Watch what is "normal" for you. Is it short and shallow? Is it deep and long? Is it somewhere in between? Does your normal breath hang out in your upper chest? Does it hang out in your belly? Do you feel anything when you try to "watch" your breath in your nostrils?

Your mind will wander and when it does bring it back to your breath. You will think about all sorts of things. Your thoughts will turn to the dishes in the sink, the water never boiling and your stomach growling for pasta, the never-ending to-do list, the fact that you still haven't made that phone call. If you are alive, your mind will wander. Noticing your mind has wandered is the practice. If you are alive, you are actively thinking. Active brains find watching the breath go in and out boring. Your brain will move onto more interesting topics. When you notice your brain has left the breath, celebrate the fact that you noticed your mind wandered and without judgement, without harsh words, come back to watching the breath.

I've heard so many people say that they cannot practice Mindfulness because they get too distracted and their brains wander. I always say, when you realize your mind has wandered, celebrate that you noticed - for that is Mindfulness. Then, come back to the breath. I've been in practice and for the whole session my brain attended somewhere else and not on my breath. I just celebrate the fact that I showed up to practice at all.

When you are ready to commit to trying practice, set a timer. Go for five or ten minutes to start. Try to use some soothing sounds at the end of the time if you can. More than I can count, I have set a timer and when the blaring "BEEP, BEEP, BEEP" at the end came, I flinched and made my pulse rate go way up.

Which brings me to the paradox of Mindfulness. Mindfulness can help some people come off blood pressure medications, and can help some people come off anti-anxiety medications. It can help some people manage their chronic pain and it can help some people control their diabetes. But that is the *side effect* of Mindfulness.

The main point of Mindfulness is the practice itself. When you start focusing on the side effects you are desiring, you lose sight of the practice. The practice is being present in the now, with your breath. Whatever goodness this brings into your life is the gravy (or marinara?) of mindfulness. The practice is the sitting and focusing on breath, and what is present in the body, the sounds that are going on all around - in short, the practice is what you take in with your senses.

Mindfulness is created through the commitment to showing up, getting the bum on the cushion, breathing the practice, and learning about one's self through the process.

The following are aids along the way.

Apps:

- Insight Timer – a mindfulness timer and it has many free guided meditations
- within the app. I basically spend all of my practice in this application.
- Calm
- Headspace

Other resources:

- EastCoast Mindfulness does the full MBSR online with tiered pricing.
- The Great Courses has a couple of different Introduction to Mindfulness programs.
- Your local universities may offer the 8-week Mindfulness-Based Stress Reduction (MBSR) course.
- There may be a couple of meditation centers in your area. A google search could help you find some near where you live.
- Visit SoundsTrue.com. There are a number of mindfulness programs, as well as many guided meditations on this website.

Animal Bond - Continuation from Page 10

The Human-Animal Bond Research Institute (HABRI)'s vision is for the human-animal bond to be universally embraced as an essential element of human wellness. Through advancing scientific research into the health benefits of pets, educating the public about the research, and advocating for policies that provide more people with access to pets, HABRI hopes to create a healthier, more pet-friendly society for all. For more information about HABRI, please visit **www.habri.org** or follow HABRI on **Facebook**, **Twitter**, **Instagram** or **LinkedIn**.

Citations

Allen, K. M., Blascovich, J., Tomaka, J., & Kelsey, R. M. (1991). Presence of human friends and pet dogs as moderators of autonomic responses to stress in women. Journal of personality and social psychology, 61(4), 582.

Kertes DA, Liu J, Hall NJ, Hadad NA, Wynne CDL, Bhatt SS. Effect of Pet Dogs on Children's Perceived Stress and Cortisol Stress Response. Soc Dev. 2017;26(2):382–401. doi:10.1111/sode.12203

Allen, K., Blascovich, J., & Mendes, W. B. (2002). Cardiovascular reactivity and the presence of pets, friends, and spouses: The truth about cats and dogs. Psychosomatic medicine, 64(5), 727-739.

Silva, N. B., & Osório, F. L. (2018). Impact of an animal-assisted therapy programme on physiological and psychosocial variables of paediatric oncology patients. PloS one, 13(4).

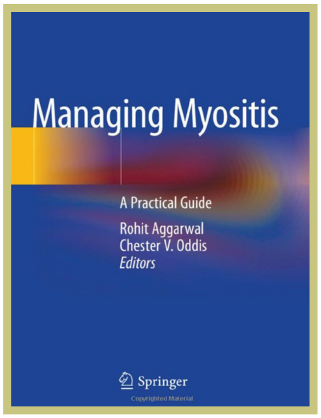
Hansen, K. M., Messinger, C. J., Baun, M. M., & Megel, M. (1999). Companion animals alleviating distress in children. Anthrozoös, 12(3), 142-148.

Beetz, Andrea, et al. "Psychosocial and psychophysiological effects of human-animal interactions: the possible role of oxytocin." Frontiers in psychology 3 (2012): 234.

Odendaal, J. S., & Meintjes, R. A. (2003). Neurophysiological correlates of affiliative behaviour between humans and dogs. The Veterinary Journal, 165(3), 296-301.

The Myositis Association's Inaugural International Myositis Virtual Summit

The Myositis Association's (TMA) 2020 Inaugural International Myositis Virtual Summit took place on May 8, 2020, from 8:00am ET - 8:00pm ET. This event was born from your feedback at the 2019 Annual Patient Conference. Through many conversations and in written evaluations we heard that a year was too long to wait for a large-scale myositis community activity. We also heard from many of you who said though you wished you could travel to the Annual Patient Conference each year; this is not always physically or financially possible. As a result, TMA began planning this virtual event last October as a way to better meet the community needs and offer an educational and community event to serve as a bridge between our in-person Annual Patient Conferences each year.



The theme for this conference was based on Dr. Rohit Aggarwal's, Chair of TMA's Medical Advisory Board, new book, **Managing Myositis: A Practical Guide**. This book, written for clinicians, is a guide in the day-to day management of patients with idiopathic inflammatory myopathies (IIM), with a particular emphasis on adult dermatomyositis (DM), polymyositis (PM), juvenile dermatomyositis (JDM), necrotizing myopathy and inclusion body myositis (IBM). The goal of the summit was to bring the content and experts from this book to the larger myositis community to invite meaningful dialogue on these topics amongst patients, care partners, clinicians, and industry partners.

Thank you to all of you for making this event a wild success. We had a total of 605 patients, care partners, industry partners, organizational partners, and medical partners registered for this unique Virtual Summit. There were 468 registered patients, 5 registered care partners, 18 registered non-profit partners, 24 medical partners and 90 industry partners. This summit included 9 sessions with 12 speakers, 12 exhibitors and representation from 18 countries from around the globe. Attendees thoroughly enjoyed the materials, platform, and exhibit hall. We had nearly 3,000 visitors to our exhibit booths and over 3,000 views of the session videos.

Evaluations revealed that 80% of attendees believed they learned something new by attending the summit, 80% believed the summit to be well-organized and informative, and 95% are interested in attending a future virtual event by TMA in the future.

Thank you again for helping us to make this virtual summit an enormous success, we couldn't have done without you or without the support of our incredible sponsors: Mallinckrodt Pharmaceuticals, Boehringer Ingelheim, Octapharma, Kezar Life Sciences, Ra Pharmaceuticals, Corbus Pharmaceuticals, Biotek ReMEDys, KabFusion, Optum, and NORD who made this summit possible. We work to make our community and partners proud of the educational programmatic initiatives that you support, and we hope you agree, that this was an extraordinary event.

A Weighty Matter

By Susan Honigstock

Susan Honigstock is a transplanted New Yorker living in Oregon. She retired from teaching young children to teach adults the wonderful game of Mah Jongg. Three sons, two daughters-in-law, and four grandchildren now make up her family which is scattered across the country. Susan was diagnosed with sIBM about seven years ago.

Since I am on a forced hiatus from Weight Watchers, I thought it would be a good idea to purchase a scale to keep me honest until I return to meetings. When I mentioned this to my son, he said that my daughter-in-law was also thinking about replacing an old scale. I thought, how easy it would be just to ask her to order the same scale she orders for herself.

Upon rethinking this idea, I knew it would not work. My needs as a senior citizen with sIBM forces me to face the reality of my scale expectations:

- I need a scale that weighs accurately.
- I need a scale that has a wide platform for stability.
- I need a scale that is not too high off the ground.
- I prefer a scale that is moderately priced (under $ 40.00).
- I need a scale that is light enough to safely pick up and is not made of tempered glass in case it drops from my fingers.

Since going to local stores is non-existent, I started my investigation on Amazon. When I had a few questions, I contacted the representatives of the companies. I found that most of the reviews were mixed and I read comments with a grain of salt. The following are a list of scales that seem to meet the above expectations.

Etecity: Stainless steel, digital, batteries included EB9388H.

Greater Goods: Silicone surround, but tempered glass. Scale has a cover included and other color covers are available at additional cost. Looked interesting.

Escali: Digital scale, US 200L, US 180 B. Batteries included.

Taylor: Stainless steel, 9-volt battery. Can also be found at Target and Walmart.

Famili: Hard plastic with small bumps on it. Wide base, non-slip. Batteries included.

Detecto: Stainless steel, CR 2032. Pricier than others, wide platform. Also available at Target and Bed Bath and Beyond. Batteries included.

I have done my due diligence and finally bought a scale. I have used it and it works well. My Famili scale seems to meet all my expectations. I encourage you to consider my recommendations and find a scale that works for you. I look forward to the challenge of my next obstacle.

THE MYOSITIS ASSOCIATION

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This year's Annual Patient Conference theme, *@Home*, unites us virtually from around the world during this unprecedented time of COVID-19. The Myositis Association is excited to bring you our first Virtual International Annual Patient Conference scheduled for September 11-13, 2020.

Fueled by direct feedback of thousands of attendees from previous conferences and TMA events, this robust 3-day Virtual Patient Conference is designed to inspire and empower you with interactive sessions to encourage collaboration, socialization and education.

This conference will move beyond a series of lectures and provides you unique platforms for collaboration, socialization, education, and FUN!

Collaboration. Interact with our myositis community from around the world, as we work together to learn about new research and advancements for myositis diseases.

Socialization. Reconnect with other myositis patients, care partners, experts and industry partners in one of our interactive chat rooms or social events. Gain new insights, engage in thoughtful dialogue, share your experiences, ask questions, support one another or just catch up and learn about tips and tricks others have discovered for coping with myositis.

Education. Join our virtual workshops facilitated by leading global experts to learn about the latest myositis research, mental health support, and disease specific recommendations and engage in Q&A sessions and discussions most relevant to your needs. Participate in moderated discussions on areas of interest and optimize all opportunities to connect with our global myositis experts in this virtual environment.

We're also going to have some fun! TMA is planning virtual social activities, so we'll have a few surprises leading to fun and probably more than a few laughs.

To learn more and to register, please visit **https://www.myositis.org/myositis-library/annual-patient-conference/**.