THE OUTLOOK

THE MYOSITIS ASSOCIATION

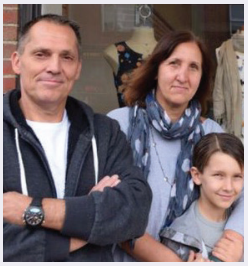
SUMMER 2020
Quarterly Newsletter

The Advocate

Table of Contents

THE OUTLOOK

A quarterly publication of The Myositis Association



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: TMA, Inc
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*

Advocacy Changes Lives!

Mary McGowan, Executive Director

Advocacy is one of those words that can mean many things to different people. But, in terms of advocacy for patients suffering from a rare disease like myositis, it means having your voice heard through an association representing the patients' interests or by individuals advocating for their own interests and those others who find themselves in a similar situation.

Advocacy includes individual advocacy (sharing and taking action utilizing your personal story), collaborative advocacy (working with other advocacy groups), Federal and state advocacy (engaging Capitol Hill, federal agencies and/or grassroots lobbying when Members of Congress are in their congressional district or state), raising awareness (hosting public events, speaking at conferences/events/fundraising) or seeking publicity (working with the media or usage of social media).

Each and every individual passionate about myositis can help advocate for important issues impacting those living with myositis and their care partners. Your participation in advocacy can help play a vital role in changing policies that meet the needs of those living with myositis, including the development and expansion of therapies for those living with myositis diseases, improvement of access to treatment options that are currently limited or restricted, and better support for those whose lives have been changed by living with this rare chronic disease.

Rare Disease Week (featured on pages 5 and 6) offers an extraordinary opportunity each year to advocate alongside other rare disease individuals on Capitol Hill. You will read how one TMA member decided to make a difference this year by coming to DC to share her personal story, to learn about the legislative process and to be a part of this extraordinary advocacy week.

What does it take for your story to have impact? Be sure to learn about the 4 tips provided by John Capecci, coach, consultant and writer, (on page 10) to ensure your stories have the power to move legislators from apathy to empathy to action.

TMA works with numerous other advocacy groups and coalitions. The National Organization for Rare Diseases (NORD) engages rare disease organizations collectively to speak up for those living with rare diseases and works to support us in these efforts. Be sure to read about our interview with Kristen Angell, Associate Director of Advocacy at NORD, (page 13) about individual advocacy strategies that you might find useful.

To effectively advocate for the interests of those with myositis, TMA works with Congress and federal agencies to make sure the voices of myositis patients are heard. You will learn more about this as you read about the first IBM Patient Listening Session we conducted at the FDA in March (on page 11).

In this issue of The Outlook, you will read stories of others who found their voice and path for advocacy. You will learn tips and tricks from experts on how you can become an advocate for the issues pertaining to myositis that you are most passionate about. You will learn how to shape your advocacy story, how you can engage in legislative advocacy at the state and local level, and how you can advocate through raising awareness.

Every time you raise awareness about myositis, every time you share your story, every time you help to raise funding for TMA's research and support programs, you are helping to advocate and draw attention to the need for more education and support for myositis patients and the pressing need for better treatments, therapies and a cure.

TMA is here to support you in your efforts to speak up, advocate and create awareness of myositis. Be sure to check out the sample advocacy letter (on page 12) we created to assist you as you advocate for change.

Thank you for all you do in your advocacy efforts to change lives!

TMA Advocates on Capitol Hill during Rare Disease Week 2020

Rare Disease Week

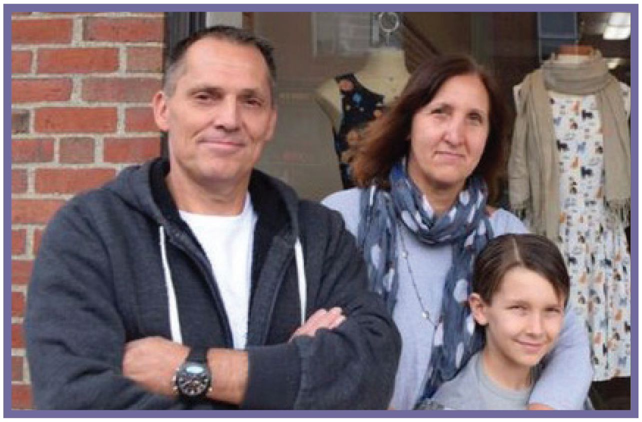
In February, The Myositis Association once again participated in Rare Disease Week. Rare Disease Week grew out of Global Rare Disease Day which takes place on the last day of February each year. Rare Disease Day is the official international awareness-raising campaign for rare diseases. This year is the 13th anniversary of the launch of Rare Disease Day which took place in 2008 by EURORIDIS-Rare Diseases Europe and its Council of National Alliances. The main objective of the campaign is to raise awareness amongst the general public and policy-makers about the over 7000 rare diseases impacting the over 30 million individuals across the United States.

This year's Rare Disease Week included an opportunity for patients and care partners to attend a public hearing at the Food and Drug Administration (FDA). On February 24, 2020, the FDA hosted a public hearing to highlight the challenges and needs of those in the rare community in rare disease development. TMA also participated for our second year, in Rare Disease Legislative Advocates (RDLA) Rare Disease Week on Capitol Hill, a program sponsored by The Every Life Foundation, where TMA patients and care partners were trained about the legislative process and then they had the opportunity to meet directly with their senators and representatives. TMA also attended NIH Rare Disease Day. TMA had an educational table at this event to help raise awareness about myositis and share our poster on our recent Women of Color and Myositis Campaign. Like last year, TMA had the unique opportunity to have a luncheon meeting with NIH researchers to get updates on the latest research and to tour the NIH Clinical Center.

Rare Disease Week offers TMA a unique opportunity to join together with others in the rare disease space to elevate the needs of those living with myositis. There is power in numbers and by uniting with others in the rare community to advocate for more research funding, improved drug development processes, and better access to treatments, TMA is able to increase interest of legislators, regulators, and the community at large and advocate for policies that meet the needs of those living with myositis.

Becoming an advocate for myself...

By Linda van der Does



Linda van der Does was diagnosed in 2019 with DM and the anti-MDA5 antibodies. She lives in Maine with son, Ries (9), and husband, Hans. She and her husband run four specialty retail stores selling women's clothing and accessories, named Toko.

When I saw the post on Facebook that TMA's partner, RDLA, was looking for advocates from my state of Maine, I was intrigued. I was not sure why I should go to Washington, DC to attend Rare Disease Week, what I could bring or take away, but after months of advocating for myself I felt drawn to go.

Even as I was on my way to DC, I still was not sure of what would come out of the trip, but little did I know it would be one of the most important steps in my fight with Dermatomyositis. I was diagnosed in October 2019 with DM and shortly after, it was found that I had the even more rare subset of the anti MDA5 antibodies. I began showing signs that something was going wrong with my health in June of last year. I am one of the lucky ones, most of us take an average of 3-5 years to diagnose. I was one of those like many, who was never ill, rarely took medication and was very active.

It did not take long after arriving in DC and checking in with the caucus that I realized as rare as our diseases are, we are not alone. I was about to meet 900 people who all felt at one time the way that I did. Scared, angry, alone and looking for answers. Our diseases all had different names, symptoms, prognosis but we were all the same. Others were there because their loved ones were diagnosed with a rare disease and others fighting for a cure. Regardless of the reason, we had a connection. I also had the pleasure of connecting with other myositis patients while advocating for rare disease issues as well.

For two days I listened. I listened to courageous stories, brave individuals, scientists, politicians, moms, dads, teenagers. Everyone in the room, even those without a microphone or standing on a podium had a story. Stories I could connect to, stories that made me both laugh and cry, stories that gave me hope. Everyone in the room had a voice. Every voice mattered.

Now knowing that I did have a purpose and a reason to be there, I was ready to take on the responsibility of meeting with my Senator and Congressmen. I am not political and never had a cause worth fighting for, so this was brand new ground for me. It was an experience I also will never forget. They were names I knew, faces that I recognized and when it was time to sit down they listened. I was so lucky to have a great group around me from Maine. Three different diseases, each fighting for our cause. We supported each other, we shared our stories and we made lifelong friends.

On the final day of the conference I had the opportunity to attend the NIH Rare Disease Day, thanks to The Myositis Association. Another of many experiences I am so grateful to have had during this trip. I had the privilege to have lunch with the leading world myositis researchers. During these two hours I was able to ask them questions related to my condition as well as about the latest research and new work being done in the field. This was followed by a tour of the NIH Myositis Clinical Center where I could see first-hand where and how the state of art research is taking place. The hard work and dedication to our disease was amazing to witness. Thank you to everyone who made that final day so special.

Time has quickly changed since leaving DC in late February. The whole world is now fighting a different disease. I am so grateful I had this opportunity. I will do it again. In the meantime I will continue to advocate not just for myself but also for others.

Rare Disease Week in Pictures

Rare Disease Advocates during Rare Disease Week 2020

TMA Advocates at Rare Disease Week 2020

Dr. Janet Maynard (FDA) and Mary McGowan (TMA) at FDA's Rare Disease Week Event

TMA Advocate meets with Senator Tim Kaine during Rare Disease Week

Rare Disease Week

Dr. Adam Schiffenbauer (NIH/TMA MAB member) meets with TMA members during NIH Rare disease day

TMA Advocate meets with Senator Collins during Rare Disease Week

TMA and Cure JM meet with NIH researchers at NIH Rare Disease Day

TMA Advocate Meets with Congressional Delegate During Rare Disease Week

Dr. Adam Schiffenbauer (NIH/TMA MAB member) gives a tour of the NIH Clinical Center

My Neighbor's Smoke

By E. Felicia Brannon

E. Felicia Brannon has been living with Dermatomyositis, Interstitial Lung Disease, and Pulmonary Arterial Hypertension since 2013. As the former Executive Director of Community and Local Government Relations for UCLA, she is a tireless advocate for those who have environmental exposures issues, like secondhand smoke in multiunit housing, as part of their Myositis journey.

I participated in Rare Disease Week on Capitol Hill, February 24-28, 2020. I had no idea what to expect, given this was my first time. My experience exceeded my expectations as a patient and government relations professional. Allow me to explain why.

On the first day, at the FDA, I felt compelled to ask about the impact secondhand smoke exposure on medication efficacy and patient recovery. The speaker's response gave me a real sense of exhilaration. I finally felt my question had not fallen on deaf ears.

You see, I started showing signs of dermatomyositis, intersitial lung disease, and pulmonary arterial hypertension in late 2013. My formal diagnosis came in 2015, after several months of tests, a severe health decline, and lung/muscle biopsies. Feeling a little better in 2016, I switched from a professional advocate to one for patients espousing the benefits of smoke-free multiunit housing policy to protect the health of nonsmokers.

After my initial six to 12-month treatment regimen ended in 2016, I noticed repeat flare-ups and bouts of pneumonia. I concluded there might be an underlying factor prolonging my recovery. Knowing **secondhand smoke** can cause respiratory and autoimmune diseases, I could only surmise my neighbor's smoke was the culprit. It found its way into my home through every imaginable orifice, even medicine cabinets, also depositing **thirdhand smoke** residue on walls, carpet, furniture, etc. My pulmonologist validated my conclusion. Additionally, prolonged treatment ended my 27-year career.

Furthermore, secondhand smoke made my home uninhabitable, exacerbating my symptoms, and irritating my lungs. Forced to seek refuge elsewhere, a respite to recover after three-days of IVIG treatment or to relieve muscle aches/weakness and fatigue were not options. Some of my escapes included the park and library. My heart goes out to anyone who finds themselves in a similar situation, unable to leave home due to the Coronavirus stay at home orders.

I began researching the issue, pulling information from the **US Surgeon General**—"No amount of secondhand smoke is safe, (2006)," **American Nonsmokers' Rights Foundation**, UCLA Center for Health Policy Research, **law reviews**, and public health departments. I also found smoke-free housing policies adopted by local governments. I analyzed studies published by medical journals, and the CDC—**41,000** lives are lost annually to secondhand smoke. Armed with these compelling facts, in concert with public health advocates, I mounted a campaign, meeting with local and state elected officials, championing for smoke-free housing policy.

Even still, despite all the evidence pointing towards the need for change, it was met with harsh criticism, and reasons why such a request would do more harm than good. Moreover, the proposed measure was seen as an invasion of one's right to privacy. Secondhand smoke is a consequence of urban living, like noise. Right?! The funny thing about noise; however, when it leaves the privacy of your home and becomes a nuisance, there are laws to resolve this matter expeditiously. No such law exists as it relates to secondhand smoke in multiunit housing.

To further iterate the need for such an approach, you may be aware **HUD** implemented a smokefree policy in 2018 stating the need to protect the health of their nonsmoking residents and staff. Around the same time, after losing a long-fought legal battle, the tobacco industry was required to issue **corrective statements** saying they misled the public about the dangers of smoking and secondhand smoke. A consequence of urban living or a nuisance that deserves policy change; I will let you decide.

The FDA's response on the first day of Rare Disease Week brings me back to my original thought regarding expectations. My experience showed me that the work of The Every Life Foundation, NIH researchers, and the receptiveness of The Myositis Association, policy change in this area is possible!

For more on Felicia's Story and to learn more about social isolation, environmental challenges, and autoimmune diseases please visit our **webinar page** on our website to watch our recent webinar on this topic.

TMA's Support of Myositis Community During COVID-19

COVID-19 has had a dramatic impact on the entire planet and poses significant higher risk for those living with an autoimmune disease and/or those with respiratory issues. The Myositis Association is a small but mighty team of 3 full-time staff and 2-part time project-based consultants, supporting, educating and advocating for those living with myositis and their care partners globally. 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. Below is a brief summary of the important COVID-19 initiatives that TMA has undertaken in order to support, advocate for, and to keep our international community of patients, care partners, providers, and researchers informed.

- **Support Groups:** All support group meetings are now open to all patients and care partners all over the globe through zoom technology. The calendar of these meetings can be found on TMA's website **here**.
- **TMA's Patient-Facing COVID – 19 Webpage:** The Myositis Association created a COVID-19 web page which we continue to populate with valuable and important information for patients living with myositis and their care partners. This website includes: Advocacy sign on letters, educational videos, blogs, survey information, and resources.
- **TMA's Clinician Website:** TMA recognizes that our clinicians are on the frontlines dealing with the challenges of COVID-19 every day. This clinician-facing site includes information on registries, training information from the FDA and CDC, and Guidelines from medical societies like the American Academy of Rheumatology and American Dermatology Association. TMA also launched the International Myositis Journal Club during this time to continue the focus on myositis education as many med schools and residency and fellowship programs have either shut down or slowed down to focus 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.
- **Webinars:** TMA has also conducted numerous webinars with timely information on COVID-related information. Working with our organizational partners to bring you the most valuable information been working with partners to bring timely and up-to date information to the myositis.
- **Feel Good Fridays:** During TMA's Annual Patient Conference, TMA hosts an event called Feel Good Friday Nights. During these challenging times, TMA decided to implement Feel Good Friday virtual programs to help bring us together as a community. These programs include programs focusing on medication, laughter yoga, the power of positive thinking, poetry, and more.
- **TMA's Virtual Summit:** TMA hosted a late-breaking moderated session with a focus on COVID-19, how researchers and clinicians are coping with myositis as part of our International Myositis Virtual Summit.

What Does it Take for Your Story to Have an Impact?

By John Capecci

Coach, consultant and writer, John Capecci, is cofounder of ***Living Proof Advocacy*** *and coauthor of Living Proof: Telling Your Story to Make a Difference. John presented a session on persuasion and story crafting at the 2019 TMA Annual Conference, helped create our corporate video and provided coaching to TMA advocates preparing to speak at the recent IBM FDA listening session. He is currently helping develop our support group training materials.*

As a person with myositis or a care partner, you possess one of the most powerful tools of legislative advocacy: stories from your lived experience.

Your stories have the power to move legislators from apathy to empathy to action. Your experiences ground policy in real life. They make abstract concepts such as "access to treatment" concrete and memorable. And they help legislators understand and relate in meaningful ways to what you and others experience.

But how can you ensure your stories have the impact you'd like, especially in the very brief time you'll likely have an elected official's attention?

By carefully crafting your stories to focus on your most important messages.

Here are four tips to help you do so:

1. **Start by introducing yourself and who you represent, then give the specific reason you are advocating for this issue.** The key here is to be specific. Myositis may be the reason you're speaking out, but why are you speaking *today*? To underscore the importance of getting access to treatments? To address the challenges presented by step therapy? Use your opening moments to home in on your reason and why legislators should listen to the experience you're about to share.
2. **Next, summarize your experience.** Giving the "big picture" quickly is often the most challenging step, especially when you know all the twists and turns, ups and downs of your journey. Still, try to give a one-sentence overview that provides context. "I was diagnosed with polymyositis in 2012, and today I …" "I've been living with IBM for five years, but it took eight years to be accurately diagnosed …"
3. **Then, zero in on one or two episodes from your experience that relate directly to your reason for speaking out today.** What moments will help legislators understand, see or feel how myositis impacts you? A turning point? A low point? A high point? An image that sticks with you? Some phrases that can help you identify and transition to these moments are "I'll never forget when…," "Two years ago, on a Tuesday…" Again, specificity is key, so use details to paint a picture of what you felt, saw, heard and thought.
4. **Conclude with impact.** To do so, connect your story directly to your goal or message and make a clear "ask," whether that's urging support of a bill or asking legislators to stay in touch and use you as a resource. For example: "My experience and the experience of dozens of others in your district underscores the importance of getting access to treatment. I urge you to …"

One final tip: When you follow up with a written thank-you (and always do!), remind the policymaker of your story: "Thank you for allowing me to share the story of my long journey from five misdiagnoses to the correct diagnosis."

With thoughtful crafting and care, your story truly will have an impact.

The Myositis Association Conducts a Patient Listening Session with the FDA

By Martha Arnold

Martha Arnold has spent her career working with pharmaceutical companies, both in marketing and in regulatory communications. This experience, which has given her insight into the drug development and approval process, is a perspective she hopes to bring to the TMA Board. Martha was diagnosed with IBM November 2014. She lives near Philadelphia with her husband, Mark. They have a grown son, Eric, who lives nearby.

TMA's IBM Patient Listening Session at FDA (missing Jim Matthews, TMA Board Chair)

Over the past several years, the Food and Drug Administration (FDA) has been expanding initiatives to bring patient and care partner input into the process of developing and approving treatments for rare diseases. One of those initiatives is the Patient Listening Session. They are misnamed – calling them "FDA Representatives Listening Sessions" would be far more accurate as it is the people who work at FDA who are doing the listening.

These are meetings where persons with rare diseases can "make it real" for the staff at FDA who are charged with reviewing, and eventually approving, treatments. During the session held on March 5, a group of 13 TMA members wove together our diverse experiences to provide a detailed perspective on the disease burden of Inclusion Body Myositis. We focused on our daily lives -- the symptoms that we experience and the challenges we face (physical, functional, emotional, social, financial) -- and our hopes for the future.

FDA appreciated hearing from us and agreed that they would incorporate these perspectives into their evaluation of potential treatments in the future. While all regulatory decisions require a balance of benefits and risks, FDA representatives reassured us of their willingness to approve products that provide benefit that we, as patients, would find <u>meaningful</u> with risks that are acceptable <u>to us</u>. Of note, they acknowledged that while a cure would be ideal, incremental improvement or even stability would be appropriate goals for IBM clinical development in the meantime.

We, in turn, are very thankful for the FDA's interest and willingness to meet with us. We all left feeling that the patient voice had been heard and that FDA staff would refer back to this meeting when making decisions about products to treat IBM in the future.

A formal summary of the meeting is available on the **<u>TMA website</u>**. And – special thanks to Mary McGowan and Tricha Shivas for their work in obtaining the invitation for TMA and to the persons with IBM and their care partners who participated.

Sample Advocacy Letter

Date

Name

Address

Dear Senator/Representative/Governor ______________________:

My name is ________________, and I am a __year old man/women living with ______(type of myositis). I was first diagnosed _______. I am writing to you today as a member of the myositis community because (Examples: myositis research is severely underfunded/ there is a shortage in x medication that I, and my fellow myositis warriors rely on for treatment of our myositis condition/ insurance companies are denying critical access to IVIG treatment for people living with my disease/ being asked to try a medication before I am able to enroll in treatment my doctor recommends for me is seriously harming my health).

I am a member of The Myositis Association, the leading international nonprofit organization committed to the global community of people living with myositis, their care partners, family members, and the medical community. TMA provides the over 75,000 people in the US diagnosed with myositis diseases with patient education and support, advocacy, physician education, and research funding.

This issue is very important to me because (1-2 relevant sentences of your story. See John Capecci's article above on how to craft your story).

It is also important to the entire community that you represent because (Examples: myositis and all autoimmune diseases are on the rise in the United States and it is essential that we have more research funding to better understand why and how to effectively treat these debilitating conditions/ without access the appropriate medication patients get sicker and health care costs rise exponentially)

I urge you to consider the following actions:

1. ___________________

2. ___________________

3. ___________________

Thank you for your time and consideration.

Sincerely,

Name

Email

Address

Phone

TMA's Interview with Kristen Angell, Associate Director of Advocacy, National Organization for Rare Disorders

If someone has never done anything in advocacy, what tips would you provide to help them get started?

Kristen: Remember your elected official works for you! You don't need a policy background to advocate for things you are passionate about. The most valuable tool you have is not your education or understanding of policy, but your own story. Sharing a well-crafted story can have more impact than any 20 professional lobbyist.

How do you recommend a beginner go about crafting their story to have such an impact?

Kristen: Start with why. Why are you telling this story? Do you want to see a certain legislation pass? Do you want your legislator to oppose this? Is this the time when your state or federal law makers are working on the budget? Do you want to be sure they consider myositis for more research funding? Do you want to make them aware of an issue that is impacting healthcare access? Before you craft your story, you need to know what the goal is and what the ask of your meeting will be. Your story should be narrowly focused on the specific issue you want to address, not all aspects of your disease or condition. Sit down, write a draft putting everything you want to say on paper and then edit. There are always opportunities to come back and speak with your legislators on another day but during each meeting you have limited time to get across your specific request or need. Focus your story around this.

How do I identify legislations that are relevant to my cause? How do I learn when is the right time and way to approach a legislator?

Kristen: The Myositis Association (TMA) is a member of NORD. As a member of TMA, you have access to NORD's resources to identify actions that are useful to you. One of the most useful resources NORD has is **Rare Action Network**. The Rare Action Network provides patients with tools, training and resources to become effective advocates for rare diseases through national and state based initiatives across the United States. Visit the Rare Action Network to sign up for alerts or to learn more.

I also recommend you start to build a relationship with your legislators and their staff in the local offices for state and federal representatives. They can direct you to bills and legislations relevant to your specific concerns. Once they get to know you better they will also start to keep you apprised of community meetings or times when your representative is speaking or working on committees or issues that might be of interest to you.

If this is still all a bit overwhelming for me and I am not quite ready to take all of this on right now, is there anything that I can do from the comfort of my home that will have an impact?

Kristen: Yes, join the Rare Action Network. We will send you action alerts with simple forms that require just 1-2 sentences and with the click of a button you can help raise the voice of all those living with rare diseases all over the US. Share and raise awareness on social media. NORD's motto is "Alone we are rare. Together we are Strong." Sharing TMA and NORD's messaging to raise awareness can have huge impact.

Any last words of advice?

Kristen: Don't be intimated by advocacy. Remember your representatives work for you. They are waiting to hear from you. Let your voice be heard.

Resources: How to meet with your legislator toolkit: **https://rareaction.org/resources-foradvocates/educational-tools/#1469117433179-ae723842-447f**

How to Write your Patient Story: **https://rareaction.org/wp-content/uploads/2016/09/nord-rantoolkit-2016-how-write-patient-story.pdf**

My Latest Accessibility Quest

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.

I had been thinking about adding some safety bars to my small stall shower. I was showering standing up and feeling it was time to have some more safety measures. After many back and forth calls, I set a day and time with my longstanding contractor Doug. He arrived with the appropriate tools to figure out the proper placement and do the work.

I asked Doug to place a shower chair in the shower first so that I could sit down on it and figure out where the bars should go. Sitting down on it was fine, but when I tried to get up using the seat and my arms for leverage, I couldn't do it. I was shaken and upset, but thankfully Doug was there to help me stand up.

No progress could be made regarding bars until I found a suitable chair. I spent the following week online and on the phone trying to secure a shower chair higher than 22 inches. I called Nova, Essential Medical, Moen, Amazon and others, getting more and more frustrated. I was even thinking of perhaps finding leg extensions for my shower chair. I finally called a local company (All In One Mobility). After explaining what I needed, the salesman said " you need to look for a hip chair". After that suggestion, my search became easier! I found two wonderful chair companies each offering a hip chair:

Apex Hip Chair from Platinum Health. Priced at $157.00. Height adjustable from 23 to27 inches. Easy to assemble and can be used anywhere in the house. Has a back rest and arm handles. Free Shipping. Eagle Health Chair#73231 priced at $134.00. Height adjustable from 25 to 29 inches. Easy to assemble, free shipping. Has a back rest and arm handles.

I quickly ordered one and have been feeling safe and secure while taking a shower. I would be remiss not to mention two products from Drive which are higher in height but are not meant for showering. The first is Drive Medical kitchen stool at $64.19. The legs can be adjusted and it has a back rest and arm handles. The other Drive product is called a Delux hip chair with padded seat which sells for $286.24 and looks like a higher armchair.

I hope my research will make it easier for other people with disabilities to find the chair for the shower or elsewhere in their homes.

THE MYOSITIS ASSOCIATION

2000 Duke Street, Suite 300
Alexandria, VA 22314

You can leave a legacy too!

Are you looking for a significant way to help TMA grow and flourish? Providing a bequest or legacy gift is a promise to provide support to TMA as we work toward our vision of a world without myositis.

Join the prestigious TMA Legacy Society, a special group of supporters who recognize the importance of keeping TMA's programs and services available for future generations. For more than 25 years, TMA has worked to enhance the lives of those living with myositis through the vital support of the Legacy Society and other individuals who have made special commitments to TMA through their wills and estate planning. Everything we have accomplished we have accomplished with the support of you, our donors.

We hope you will consider joining the Legacy Society and help TMA ensure we can continue to provide and expand much needed services to those challenged with myositis and continue to fund research in our search for a cure. Through your estate plan, you can pass on your cherished values to generations to come.

Become a member of the Legacy Society by doing any of the following:
- Name TMA as a beneficiary in your will or trust
- Name TMA as a beneficiary of your retirement plan, IRA or life insurance policy
- Make a gift to TMA through a charitable gift annuity or charitable remainder trust

In gratitude for your generous lasting gift to TMA and in support of our efforts, you will receive special recognition and benefits.

You can make a difference!

Thank you!

For more information about the legacy society, contact Tricha Shivas, Director of Development and Strategic Partnerships at ***tricha@myositis.org*** *or 703-553-2633.*