THE OUTLOOK

The Myositis Association

FALL 2017
Quarterly Newsletter

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THE OUTLOOK

A quarterly publication of The Myositis Association

Cover Photo
Annual Conference Attendees
Photo courtesy of Brock Scott

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The mission of The Myositis Association is to:

- *Increase program support to the myositis patient and caregiver community*
- *Increase awareness of myositis throughout the general population with emphasis on the medical community*
- *Increase funding for TMA operations and myositis-related research*

Swallow Your Pride

That's right—it is time to swallow your pride and do what is best for you. This issue of *The OutLook* has articles on emotional well-being, being a caregiver while working, and when a feeding tube becomes your "new normal." All of these topics are things we would rather not have to think about. But, they are real and are important to deal with head on.

Myositis can be depressing. Myositis can cause patients to need the assistance of others. Myositis can require tube feeding. Each one of these outcomes is not pleasant to think about. Each requires an inner strength and will power to accept the reality of your condition. However, the sooner one accepts this reality, the better off you will be.

Denial and avoidance are common to us all. However, the disease is not going away and life goes on. Support of others is important—whether it be friends, relatives, or others who have the disease. You need to decide what works best for you and seek out the support you need. It can be professional counseling, or it can just be connecting with others to keep you engaged in life and the things you enjoy. TMA has support groups in many cities and recently started the Myo-Connect program to connect patients with others they can talk with online, by phone, or in person. However you do it, you need to find what keeps you active mentally and engaged emotionally.

Being a caregiver is a tremendous emotional, physical, and financial burden. It may prevent you from working, doing the things you enjoy doing with friends, or just being your "old self." If you are to remain a caregiver, you are not going to be your "old self." It is a "new normal" and it is up to you and the person you are caring for to find ways to manage the activities of daily living while still allowing you time to stay involved in the things that give you satisfaction and joy. Do not let the caregiving responsibilities make you depressed. If that is happening, it is important to seek help and comfort from friends or a professional counselor.

Everyone enjoys eating and the pleasure you get from the smells, taste, and atmosphere of enjoying a meal with others. For those needing a feeding tube—temporarily or long-term—it can be very discouraging to not be able to enjoy a meal as you did before the disease limited your ability to swallow. Unfortunately, there are few alternatives. You need nutrition. If other measures have failed to enable you to swallow, you need to consider how best to keep your body fed. You cannot risk choking or developing aspiration pneumonia without truly risking your life. A feeding tube can be discreet and managed in a way that you can be comfortable and still active socially. Your priority has to be your health.

Each of these topics is addressed in this issue, and I hope you will take the time to read and consider the important messages each contains. They are not pleasant or fun topics, but they are real. Better to consider and think about them now than wait until you are in a crisis and truly in danger.

TMA's 2017 Annual Patient Conference a huge success

by Linda Kobert

The reviews are in, and they tell us that TMA's Annual Patient Conference in San Diego in September was a huge success. Nearly 515 individuals participated in the four-day event, making it the largest ever gathering of myositis patients and those who care for them.

More than 50 speakers, many of them members of TMA's Medical Advisory Board, offered nearly 80 presentations on topics ranging from the basics of myositis disease to the latest research on IBM, and from what you should know about IVIg to what you should know about being a care partner.

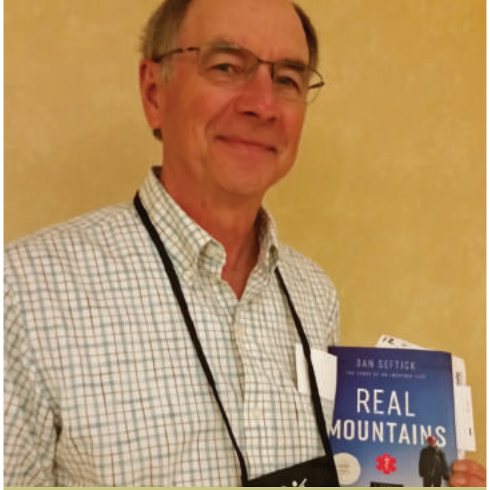
Below are some of the Conference moments.

Patients had the chance to try out the Dermoskeleton

Participants enjoyed the San Diego weather

Members traveled from South America

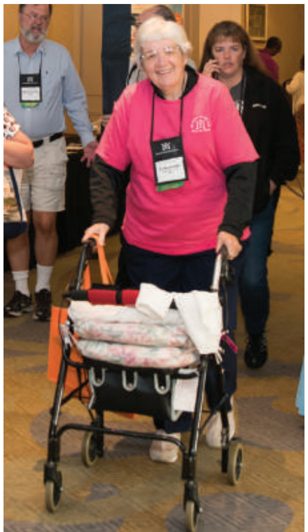
Participants shared their experiences with others who understand



Keynote speaker Dan Seftick spoke about how he transformed tragedy into inspiration

Feel Good Friday Night - free massage was a hit

Medical advisors respond to members' questions



Partcipants learn much from speakers

When tube feeding is your new normal

by Mariah Abercrombie

Having been diagnosed with polymyositis less than two years ago, I quickly learned that myositis can affect each person differently. Some people may, at some time or another, experience difficulty swallowing (dysphagia) and need to supplement their food intake using enteral feeding. This is a process that involves delivering nutrients directly into the stomach or intestines, usually through a tube. If enteral feeding becomes your new normal, it is important to understand everything you can about it.

Several types of tubes can be used for enteral feeding. If this process is expected to be needed for a short period of time, a nasogastric tube is usually placed through the nose and into the stomach or intestines. When enteral feeding is likely to be needed for the long term, a gastrostomy tube is usually inserted through the skin directly into the stomach or intestines.

Enteral nutrition can be given in the hospital or in the home. It can be delivered by gravity, by a small portable pump, or through a syringe. Pumps are small and lightweight, and many people infuse their feeds by carrying them in a backpack. I can carry my feeds in a small backpack, and most people are not even aware I am infusing. Most individuals can continue their daily activities, even when infusing their feeds.

Timing of feedings depends on your needs and lifestyle. Some people infuse the feeding slowly overnight through a drip or pump, while others do bolus feeds of smaller amounts using a syringe several times throughout the day. It's important to discuss your schedule and needs with your medical provider to find the best fit. It may take a few weeks to determine what works best for your body and lifestyle.

In preparing to administer your enteral feedings, it is important to stay organized. You will need a temperature-controlled storage space to store your supplies and a clean area to prepare your feedings. Most supplies do not need to be sterile, but it is important to keep things clean to prevent contamination.

If you use canned formula, prep time will be less and you will be able to store a week's worth of formula easily. You may also chose to blend real foods, using an industrial-strength blender; this mixture will need to be stored in a refrigerator. A ready-to-use blended food is available through Real Foods Blends (**http://www.realfoodblends.com/**). This is a good alternative if you want to infuse a real-food blend but don't want the time commitment of preparation.

If you chose to blend your own food, it's important to discuss this with your medical provider or nutrition specialist to make sure you receive all the calories and nutrients you need. Not all medical professionals are familiar with real-food blended feedings, so it is essential to locate a professional who is experienced with this process.

Before leaving the hospital after having the feeding tube placed, you will be given discharge instructions that explain all about the tube, how to care for it, and how to prepare and administer the feedings. It is important to make sure you understand how to care for the tube and complete your daily feedings prior to leaving the hospital. I also recommend requesting a home health visit by a nurse and/or dietician.

It is also a good idea to have a close friend or family member present for your discharge instructions, home health visits, and doctor appointments. It can be a great deal of information to retain, and having another person present can be helpful. You may even want to video record the visit on your phone.

You should ask what supplies you will need. In addition you will want to know the name of your formula/feeding supplement, amount per feeding, how many times a day you will be feeding, and the amount of water you will flush the tube with.

Caring for the tube may seem overwhelming initially, but with some practice it will simply become part of your daily routine. When the tube is first placed, you will likely be sore for about a week. This is normal. Keep the tube secure (you can tape it to your skin), and avoid tugging on it. Do not hesitate to consult your nurse or doctor if you have questions, especially in the beginning.

If a feeding tube is in your future, I can assure you there will be an adjustment period. But eventually you will probably be grateful for a tube that enables you to get the essential nutrition your body needs. I can promise you that the problems are rare and the feeding tube will become just another part of your myositis journey.

Mariah Abercrombie has lived with a rare gastrointestinal disorder since childhood, so she has been dependent on enteral nutrition for most of her life. She is a clinical social worker and a long-time member of the Oley Foundation, a non-profit support organization for those living with home intravenous nutrition and tube feeding.

> *Dr. Todd Levine talked about living with dysphagia and a feeding tube at the 2017 TMA Annual Patient Conference. See his presentation and many others at* ***https://www.youtube.com/user/MyositisAssociation/playlists***

How to be at your best despite the stress of chronic illness

Let's face it: dealing with a chronic disease like myositis, whether you are a patient or care partner, is hard. Not only is it physically challenging, but the toll chronic illness takes on our mental and emotional lives can be huge. It's hard to be cheerful and enthusiastic when your body aches and all you want to do is take a nap.

"Constant loss and decline is very hard to deal with," says psychologist Amy Wood. "My primary suggestion is that you recognize that your emotions around all this are normal. It's healthier to embrace your emotions than to fight them, so making room for all emotions—not just the enjoyable ones—is key."

Recognizing your emotions also means knowing where you find joy and comfort in your life. Reading an uplifting story, for example, can be therapeutic. Turning off the news on the car radio and plugging in some relaxing music can also relieve stress. And spending time with people who are happy and positive, especially those who understand and support you, can help you get past some of the emotional challenges you face.

Wood also suggests that you say no to anything that doesn't resonate with you…including all those "obligations" around the holidays. Do something you enjoy every day, even if it's just for one minute. And at the end of every day, list three things that went well that day and be grateful.

There is value, Wood says, in processing your emotions with a psychotherapist or by journaling about your experiences. Some people also find it therapeutic to make art. Spending time outdoors has even been shown to relieve stress and improve one's outlook.

"Stress and emotional issues have a big impact on our bodies," Wood says. The more stress you are under and the more unhealthy you are emotionally, the more likely you are to have physical health issues. And yes, people with chronic illness are more vulnerable to the physical symptoms of stress. This is why it's so important for myositis patients to reduce stress as much as possible and channel time and energy into extreme self-care."

Extreme self-care includes the physical as well as the emotional. Exercise, for example, can be just as healing for your mood as it is for your muscles. Eating healthy food, getting enough sleep, and doing things you love to do are all important for both your body and your emotions.

Getting enough sleep, however, can sometimes be a challenge, especially if you are taking prednisone. Exercise and diet can be important here, too. Sometimes mindfulness and meditation can also help. And it's important to develop good "sleep hygiene." This includes creating a regular bedtime routine and avoiding media stimulation and internet activity during the hour or so before you go to bed. Listening to soothing music or hypnotic CD's or sipping a relaxing herbal tea before bed can also help.

Coping with chronic disease or caregiving also requires getting support. "Make sure you connect with positive people, especially people who are in your position, so that you can support each other," Wood says. "Reaching out to fellow myositis patients through TMA is a good place to start."

If these suggestions don't work and your emotional distress starts to interfere with your life and work, that's the time to seek professional help. "It is better to seek professional help when you first notice emotional distress," Wood says. "Don't wait until it escalates into a crisis."

Amy Wood, PsyD, is a psychotherapist, professional life coach and mediator, motivational speaker, and author of the book Life Your Way. *Dr. Wood also has a close relative who has myositis.*

This article is based on a TMA Live Discussion hosted by Amy Wood in July. A transcript of this conversation can be found at ***http://www.myositis.org/your-myositis-community/live-discussions/569-how-to-be-at-your-best-despite-the-stress-of-chronic-illness***

With a little help from your friends

by Nancy Harber

Caregiver burnout is a real issue for all of us who care for someone with myositis. As the caregiver for my now-deceased husband Charlie, who had IBM, there were many times when I felt I couldn't possibly go through this for one more day.

Burnout starts when you realize how much your life will change because of this disease and how different that is from what you thought it would look like. As the individual you are caring for faces more challenges, you struggle to get more information, learn new ways to cope, and find others who can help you.

Care giving is not easy, make no mistake. Dealing with a difficult situation for a few days is very different from dealing with it for months or even a lifetime. Since this is the hand you have been dealt, here are a few suggestions to make it easier to play.

First get as much information as you can. Obviously the best source is a medical person familiar with myositis. But don't overlook the people you meet at a myositis support group or online on the TMA Community Forum. They are probably going through the same experiences, but if they've been at it longer, they have probably mastered a few more skills.

Next, be realistic about what you can and can't do, and set your priorities. After Charlie was diagnosed and later had to retire, I was still working full time as a nurse. Having two "full time" jobs was a bit much, and I knew I couldn't also take on the added roles of full-time housekeeper, cook, and yard man—though all of those things were needed. I set Charlie as my number one priority, and let some other things go. I found a man to help with the yard, for example. It was only one day a month, so I learned to live with high grass for a bit.

On my days off from my "salaried job," I cooked casseroles and large meals that I could freeze into smaller portions so we would have leftovers on the days I worked. I would also get really tired, so if Charlie was ready to go to bed early, I forgot about the laundry and went to bed too. The clothes got washed another day, often during our mealtime.

Probably the best advice I can offer is *lay off the guilt trip*! So the windows really need washing. Too bad!

And when people say, "You look so tired. Is there anything I can do?" *Do not* say, "I'm fine. Thanks for asking." Take your friends up on their offer, and ask them to pick up a quart of milk and loaf of bread for you the next time they go to the grocery.

Surprisingly, people really do want to help. They just don't know how. Don't let your pride add to your burnout and frustration. Your loved one with myositis needs you to stay as strong, healthy, and happy as possible. And you both need to enjoy every minute you have together. This journey is easier traveled together with openness and humor than alone with individual frustrations. You *can* do it… with a little help from your friends!

Nancy Harber's husband Charlie, who passed away several years ago, had IBM. As a registered nurse and informal consultant, Nancy shares the wisdom she gained as Charlie's long-time caregiver with patients and caregivers struggling with the challenges of myositis. While her experience was specifically with IBM, many of her solutions apply to other forms of myositis as well.

Applying for Social Security Disability benefits

by Deanna Power

Chronic inflammation and breakdown of muscle tissue that comes with myositis can lead to debilitating pain and fatigue, among other symptoms. Those with myositis can potentially qualify for Social Security Disability benefits, which can give you the financial resources you need.

Social Security programs available

People with disabilities of any age can potentially receive benefits through the Social Security Administration (SSA). The SSA has two disability programs:

- **Social Security Disability Insurance** (SSDI) provides support to adult disabled workers who have a sufficient work history and have paid Social Security taxes. So long as you've worked at least part-time throughout adulthood, you will likely qualify for SSDI benefits (**https://www.disabilitybenefitscenter.org/social-security-disability-insurance/how-to-qualify**).
- **Supplemental Security Income** (SSI) is the needs-based program that provides benefits to any person with a disability, regardless of age or work history, though applicants must meet income and financial asset requirements to qualify (**https://www.disabilitybenefitscenter.org/supplemental-security-income/how-to-qualify**).

Qualifying medically as an adult with myositis

The SSA maintains a listing of impairments in its Blue Book, which is a manual utilized in the review of disability applications. Myositis for adults appears in Section 14.05 (**https://www.ssa.gov/disability/professionals/bluebook/14.00-Immune-Adult.htm#14_05**).

This listing is specific to dermatomyositis and polymyositis and requires your medical records show your myositis causes at least one of the following:

- Severe impairment in your ability to walk or use your arms. This could include an inability to walk without a wheelchair or climb more than a couple of steps without use of a handrail.
- Difficulty swallowing with episodes of aspiration.
- Pronounced breathing issues associated with muscle weakness in your chest.
- Calcium accumulation in the skin, muscles, or soft tissues that affects the function of your intestines or joints.

There are multiple forms of myositis. Even if you have a type that doesn't appear in the Blue Book, like the orbital or inclusion body forms of myositis, you can still qualify under this listing, as long as your medical records match the level outlined in the requirements. The Blue Book was written for medical professionals, so you should discuss the listing with your doctor to get a better idea as to whether or not you'll qualify.

Children's disability benefits and medical eligibility

The SSA maintains separate Blue Book listings for children's disabilities, and the listing for dermatomyositis and polymyositis appears in Section 114.05 (**https://www.ssa.gov/disability/professionals/bluebook/114.00-Immune-Childhood.htm#114_05**).

Children can medically qualify by meeting or matching this listing, just like adults. The childhood myositis listing outlines the same medical qualifications as the adult listing. However, children can also qualify for benefits by having medical records that show any other manifestation of myositis, along with developmental delays or a failure to exhibit age-appropriate language skills, emotional responses, coordination, or to reach intellectual thresholds.

Household financial limitations are the number one reason why children are denied, not medical criteria. Your household income limits will vary depending on how many people are in your family. A single parent with one child could earn no more than $36,000 per year to qualify, while a family of five could earn about $50,000. You can view your family's unique income limit online (**https://www.ssa.gov/disabilityssi/**).

Applying for benefits with myositis

The application for SSDI can be completed online. Find your local office here: (**https://www.disabilitybenefitscenter.org/state-social-security-disability**). The SSI application however, requires an appointment with the local SSA branch. Schedule an appointment by calling 1-800-772-1213 or start your SSDI application online (**https://www.ssa.gov/disabilityssi/**).

Both applications ask for medical history and employment information for adults. For a school-age child, school evaluations and performance records are required. The SSI application requires financial records as well, such as bank statements, other benefits you may receive, and assets or real property you own.

Gather as many of your records as possible before beginning your application. You can learn more about the information required by reviewing the SSA's disability starter kits (**https://www.ssa.gov/disability/disability_starter_kits.htm**).

What to expect after you apply

After you submit your application, you should be prepared to wait at least three months for a decision, though many claims take longer. Children are more likely to medically qualify at this stage, but many adults receive a denial and have to request a second review and perhaps file an appeal.

This is because some can continue working with myositis and many cases of the condition can be effectively treated. If your myositis is severe enough to prevent you from working, though, you may have to appear at an appeals hearing to have your case examined more closely. If you're not sure if you qualify, ask yourself, "Can I earn at least $1,200 per month for the next year?" If your answer is "yes," you will not qualify for disability benefits. If not, you should pursue your case.

Returning to work while receiving SSD benefits

Receiving disability benefits doesn't mean you must remain disabled. If your myositis allows, you can return to work at some point, and the SSA has systems in place to help you test your ability to work without fear of losing your benefits. Learn more about work incentive programs through SSA publications like "Working While Disabled – How We Can Help" (**https://www.ssa.gov/pubs/EN-05-10095.pdf**).

*Deanna Power is the Director of Outreach for Disability Benefits Help, an independent organization that helps people of all ages receive the disability benefits they need. She can be contacted at **drp@ssd-help.org**.*

Disability-Benefits-Help.org *is an advertising service paid for by the lawyers and advocates whose names are provided in response to user requests. It is not an attorney referral service.*

Promising results for sIBM

TMA-funded researchers at Nationwide Children's Hospital in Columbus, Ohio recently reported on a study that may show promise for patients with sIBM. The clinical trial tested the effects of follistatin, a naturally occurring human protein that promotes muscle growth in mice.

In this trial of six male subjects, follistatin was delivered through a gene therapy process to weakened thigh muscles. Results were evaluated using a six-minute walk test before and up to six months after injection. The protocol also included an exercise regimen. Four of the six treated subjects showed increases in walking distance ranging from 58 to 153 meters, whereas two were minimally improved (5-23 m). Treatment effects included decreased fibrosis and improved regeneration.

While this is not a cure for sIBM, and more research is still needed to fully understand the effects of this treatment, including its safety, these findings show promise for follistatin gene therapy, at least for sIBM patients who are still able to walk.

http://www.myositis.org/storage/documents/IBM_Published_Research/Follistatin_gene_therapy_for_IBM_-_2017.pdf

IBM: Is it an inflammatory disease or am I just getting old?

In a recently published report, TMA Medical Advisors Dr. Andrew Mammen and Dr. Chris Weihl addressed the debate over whether sIBM should be categorized as an inflammatory disease, as are other forms of myositis, or as a degenerative disease of the muscles.

sIBM is a progressive disease that typically affects patients over the age of 50, with signs of both inflammation and degenerative processes in the muscles. Clinically, patients develop a characteristic pattern of weakness that affects the muscles of the forearms, fingers, and thighs. Muscle biopsy shows chronic muscle damage caused by both inflammation and protein inclusions (clumps of misfolded proteins).

In a presentation at TMA's recent Annual Patient Conference, Dr. Mammen explored the evidence supporting both of these disease-causing

Patients with active DM or PM needed

Bristol-Myers Squibb is currently recruiting adults with active dermatomyositis or polymyositis for a clinical trial. The goal is to evaluate the effectiveness and safety of a study drug, called abatacept, in combination with standard medicines in improving symptoms of active myositis. The effectiveness of this combination therapy will be compared to standard therapy for myositis.

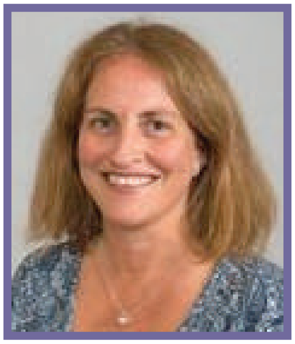
This clinical trial is underway and aims to enroll 150 patients over a three-year period. Multiple study sites are available throughout the US and abroad. Participants will first receive either abatacept, the study drug, or a placebo via a weekly injection under the skin for 24 weeks. Then, all study participants will receive abatacept for 28 weeks. More information on this clinical trial can be found at ***www.MyositisTrial.com****.*

mechanisms and how these ideas influence research and therapy. He concluded that future therapies should be designed to target both aspects of sIBM pathologies. You can watch a video of Dr. Mammen's talk (and many others) on TMA's YouTube channel (**https://www.youtube.com/user/MyositisAssociation/playlists**).

Research support for endurance exercise

The beneficial effects of endurance exercise in patients with polymyositis (PM) and dermatomyositis (DM) have been demonstrated for many years. In a recent clinical research report, scientists, including several TMA Medical Advisors, demonstrated what's happening on a molecular level when myositis patients exercise.

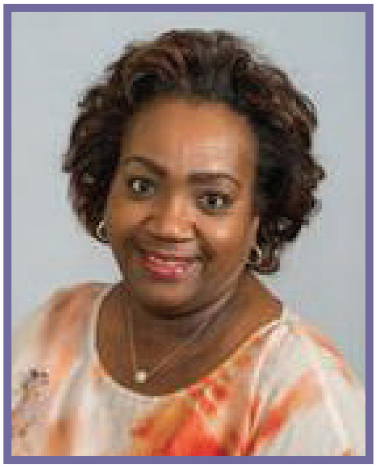
When compared with a control group of patients who did not exercise, patients in the exercise group showed reduced disease activity and reduced lactate levels in the blood (a measure of exercise intensity). Gene function related to capillary growth, glucose use by the muscles, protein production, intercellular remodeling, and muscle enlargement were increased in the exercise group, while gene function related to inflammation and certain stressors in the cells were decreased. The exercise group also showed a higher number of capillaries in follow-up biopsy samples.



TMA medical advisor Dr. Helene Alexanderson participated in this research

http://onlinelibrary.wiley.com/doi/10.1002/art.39624/full

LaDonna Johnson joins TMA staff



LaDonna Johnson is not new to TMA. Those who have attended the Annual Patient Conference over the past six years have interacted with her as she helped out with logistics and staffed the registration desk.

In September, LaDonna became a full-time member of the TMA staff, as Member Services Manager.

"I've always worked in community support or the healthcare field," LaDonna says. "I love helping people, especially those who can't help themselves. I'm looking forward to being able to work with members more."

LaDonna first became involved with TMA when she worked for another organization that shared office space with TMA. She got to know the TMA staff and wanted to know more about the disease and its treatment, so she offered to volunteer at the Annual Patient Conference.

In her new role, LaDonna will connect with members and others, providing resources and information about myositis and TMA programs and services. She will also work closely with TMA Support Group leaders, helping to enhance their efforts to support those living with myositis.

"LaDonna brings her warm and energetic personality to the position," says TMA Executive Director Bob Goldberg. "She is eager to help and brings enthusiasm and compassion to her role as Member Services Manager."

Leaving a Legacy

When one's days are over, they are remembered and not forgotten by family and those who knew them. You can be remembered by those close to you and an even larger "family" —those who follow you in having to live with myositis. Please consider including TMA as a beneficiary of your estate, a life insurance policy, or an IRA.

Your "myositis family" will appreciate you thinking of them, and they, too, will not forget you.

You can make a difference!

Thank you!

THE MYOSITIS ASSOCIATION

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Many thanks to all who made the 2017 Conference such a success!