

# THE OUTLOOK



THE MYOSITIS ASSOCIATION



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**SUMMER** 2015  
Quarterly Newsletter



**Bob Goldberg, Executive Director**

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**The mission of The Myositis Association is to:**

- *Provide support to myositis patients and their families*
  - *Provide connections between the Medical Advisory Board and the general medical and patient community*
  - *Increase funding to support myositis research*
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Dear reader,

You may have noticed a new look to this issue of *The Outlook*. We have freshened up the appearance of the publication and will be looking to share more research reports and true-life stories from those living with myositis. We hope you like the changes, and your comments are always welcome.

Speaking of true-life stories, our feature article shares the experience of a young child who despite the terrible trials and tribulations of juvenile dermatomyositis has developed into a robust, healthy athlete looking forward to competing with his peers on the baseball diamond. Joseph Berretone's story is one of inspiration and is a shining example of how perseverance and determination can help one get through the challenges of coping with a chronic disease like myositis.

Inside this issue, you will also find a report on an upcoming event TMA is holding along with the San Francisco Giants baseball team to honor their TV color commentator Mike Krukow. "Kruk," as he is known in the Bay area, is a local icon, especially among Giants fans. He publicly disclosed last year that he has been living with inclusion-body myositis but intends to continue broadcasting Giant games as long as he is able. He continues to travel with the team to all away games, rides the team bus, climbs into the announcer's booth, and delivers the colorful commentary for which he is famous. Kruk is assisted by his broadcasting partner Duane Kuiper. Kuiper has been there for Kruk throughout Kruk's battle with IBM and reminds us of how important it is for those with IBM to have someone nearby to assist when needed. More about the Giants event will be announced later this summer.

Another new feature in *The Outlook* is an article by Nancy Harber, a registered nurse, whose husband had IBM and died in 2006. Her article in this issue, and in future issues, will focus on the role of caregivers and how those living with IBM can make adjustments to allow them to continue to live full, enriching lives.

We hope you enjoy this issue and wish you a fun and safe summer.

Bob Goldberg  
Executive Director

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# There's a light at the end of the tunnel

*Young athlete goes from patient to player*



**It was a long journey, full of worry and heartbreak and amazing courage. Joseph Berretone III, diagnosed with juvenile dermatomyositis as a baby, earned his place last spring on the high school's junior varsity baseball team. "More than 25 kids tried out," said Monica Pedano, his mother, "and he was still in his freshman year, something almost unheard of at the school for a kid his size."**

Joseph was 18 months old when his parents noticed his skin was red. "We were outside a lot, so we thought it was sunburn," Pedano said. This went on for months and became much worse as they consulted doctor after doctor. They watched in horror as their son — a strong, active child — lost his ability to walk. "Just to see him try to bend over to pick something up was heartbreaking," she said. "He bent like a little old man, as though every bone was stiff and hurting."

Joseph was finally diagnosed with juvenile dermatomyositis at Children's Hospital in Philadelphia and treatment began. He spent the next eight years in and out of the hospital, trying many kinds of drugs, and dealing with the side effects of both the disease and the medications.

One of the side effects, particularly from the steroids, was a delay in growth and muscle development. "He was always the smallest, the sickest, the weakest," his mother said. Nevertheless, every year found Joseph playing three sports, soccer in the fall, basketball in the winter and baseball in the spring and summer, fitting it all in between IVIG infusions, trips to the hospital, and severe flares. He was determined. "No matter what, he was going to play sports," Pedano said. She made sure everyone understood the disease that Joseph was up against. "The coaches always recognized the heart in this kid," she says. "His challenges made him stronger and more determined."

Pedano has been surprised to learn that Joseph remembers none of the pain and uncertainty. In fact, she said, he remembers mostly that the hospital cafeteria prepared corn in a way she's been unable to duplicate at home. "Imagine that," she said. "He's sick, in pain, being admitted to the hospital for lifesaving treatment and now what he remembers is that he liked the food."

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***No matter what, he was going to play sports.***

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In 2008, Joseph was enrolled in the RIM (rituximab in myositis) trial, a large study that included children as well as adults. "That was it for him," she remembers. "At the end of his trial, his symptoms were finally in remission."

Still, she thought, Joseph would always have some residual problems. A huge, painful calcinosis (calcium deposits fairly common in children with myositis) was removed by surgery, and Joseph remained small. That is, until this past year when he grew a full 16 inches. When he began to work with weights, she could see that his muscles were developing just like any other teenager. "I honestly didn't believe that would ever happen," Pedano said. *(Continued on page 9)*

## **Pedano family myositis charity golf event**

For 12 consecutive years, the Pedano family has held an annual golf outing and charity auction to benefit The Myositis Association. The family has now raised nearly \$500,000 for TMA and the fight to find better treatments and a cure for juvenile myositis. To honor the family's efforts, TMA named a \$100,000 research award in 2012, The Pedano Family Juvenile Dermatomyositis Research Grant. This award was made to the Hospital for Sick Children in Toronto, Canada, to study the effects of creatine supplementation in children with myositis. This year's golf event will be held on July 17 at the Seaview Resort and Spa in Galloway, NJ.

**For more information about this year's event, go to [www.josephstmaevent.com](http://www.josephstmaevent.com).**

# Catch a plane, hop a train, enjoy Orlando

## *Travel to TMA's Annual Patient Conference and beyond*



Travelers with disabilities have more choices than ever before, but advance planning is still the key to a successful trip, says Rosenda Calloway, regional sales consultant for AAA Auto Club South. Calloway has more than 30 years experience in the travel industry and specializes in accessible travel.

Flying is certainly the fastest way to travel to Orlando but can seem intimidating if you depend on a wheelchair,

walker or scooter. If you're flying to Orlando for TMA's Annual Patient Conference September 10 to 13 — or anywhere else — Calloway has some advice for making sure you get the help you need.

### **Use larger airports**

If you live in a small town, drive to the largest airport near you, Calloway says. "You most likely have a comfortable and safe way to travel by car or van, so pick the largest airport and the most direct flight to Orlando, so you won't have to worry about whether your wheelchair or you makes the connection." Avoid small regional jets and turboprops, as they generally board through steep, narrow, self-contained stairs. The airline may promise help ascending and descending, but it will be tough for everyone.

### **Ask for "meet and greet" service**

This is offered by special travel agents either with an agency or with the airlines for a fixed fee, usually \$25. The agent will work with you on every detail of the journey. "Be very specific," Calloway says. "If you will need to be carried down the aisle, make sure you let the airline know.

### **Know your rights**

Travel expert Ed Perkins recently reviewed the rights of disabled travelers in an article for the Orlando Sentinel.

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**In most cases, airlines can't demand that someone else accompany you. If an airline decides you need an attendant, the airline must buy the ticket.**

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**Airlines must help you with boarding, deplaning, and making connections, including furnishing a ramp or lift if there's no level jetway.**

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**Airlines must accept your wheelchairs and scooters as checked baggage, without extra charge for any packaging they require.**

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**Airlines must allow you to take collapsible wheelchairs and other smaller devices on the plane as carry-ons.**

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**If an airplane of 60 or more seats has an accessible lavatory, it must have an onboard wheelchair. However, Perkins says, do not count on an accessible lavatory.**

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**Ask for assistance at least 48 hours before your flight for help getting you and your wheelchair through security. You're entitled to assistance even if you're not in a wheelchair.**

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**For more information, visit Access-Able ([www.access-able.com](http://www.access-able.com)), The Disabled Traveler ([www.disabledtravelers.com](http://www.disabledtravelers.com)) and Disabled World ([www.disabled-world.com/travel/airlines](http://www.disabled-world.com/travel/airlines)).**



## At the Orlando airport

Specific information about MCO will help you know how to navigate once you arrive. Here's what you can expect at the Orlando International Airport, courtesy of the Airport Authority:

- **Airport and vendor ground transportation include lifts.**
- **Skycaps (arranged with airline in advance and who work for tips) are available to assist passengers with check-in, carrying baggage, wheelchair assistance. More on skycaps: [www.travel-watch.com/skycaps.htm](http://www.travel-watch.com/skycaps.htm).**

## More helpful links

- **Wheelchair rental once you arrive in Orlando: [www.visitorlando.com](http://www.visitorlando.com).**
- **For maps of the airport and more detailed accessibility information, visit: [www.orlandoairports.net/ops/disabled.htm](http://www.orlandoairports.net/ops/disabled.htm).**

## Hop a train

Amtrak offers a 15 percent discount off the lowest fare, Calloway says, for people with disabilities and one companion, but make sure to make reservations well in advance, online at [www.amtrak.com](http://www.amtrak.com). Include the following needs:

- **How much room you'll need for your wheelchair or scooter in coach.**
- **If you want transfer seats with space to stow wheelchair.**
- **If you need accessible rooms in sleepers.**

## Paperwork

You must provide written documentation of your disability at the ticket counter and when boarding the train. Acceptable documentation includes:

- **Transit system ID card for persons with a disability.**
- **Membership card from a disability organization.**
- **Letter from a physician.**
- **Medicare card, if under 65.**
- **Veterans Administration disability ID.**
- **A copy of your disabled parking pass.**

Passengers booking an accessible bedroom must certify they require its features by signing a statement with the conductor. Register at least 14 days in advance: after that, accessible bedrooms are open to all passengers.

## Enjoy Orlando

Disabled travelers are familiar with this scenario: reserve an accessible room in advance, then arrive to find it is no longer available. That's usually because someone else with a disability has extended a stay — a situation that the hotel must also accommodate. To make your arrival go smoothly, Calloway recommends:

- **Check and double-check. Call well in advance and then a few days before arriving.**
- **Be specific. If you need a raised bed, specify how high. Say whether you need a roll-in shower or how high of a barrier you can negotiate. "Spell everything out," Calloway advises. "Don't presume."**

At the Annual Patient Conference site, the Caribe Royale, meeting rooms are accessible. Those needing a roll-in shower or an elevated bed in their sleeping room should specify that when making reservations. All rooms have refrigerators for those needing special food.

Orlando is a city that's extremely friendly to disabled travelers, Calloway says, especially at the theme parks. For details, visit [disneyworld.disney.com/faq/guests-with-disabilities](http://disneyworld.disney.com/faq/guests-with-disabilities).

If you'd like to be creative about an accessible place to stay — whether in Orlando or somewhere else — Calloway recommends "All Star Vacations," a service that offers fully equipped, accessible homes for as many as 14 guests. Reach All Star Vacations at 800-592-5568.

*Rosenda Calloway will speak on traveling with a disability at the 2015 Annual Patient Conference. ●*



# Do you suffer from profound fatigue?

## *Those with autoimmune disease identify major issue*

Fatigue described as “profound,” “debilitating,” and “preventing them from doing the simplest everyday tasks” is a major issue for autoimmune disease (AD) patients, affecting nearly every aspect of their lives, including emotional well-being and ability to work. These are the findings of a new online survey of autoimmune disease patients conducted by the American Autoimmune Related Diseases Association (AARDA). More details from the survey:

- **Almost all patients surveyed report they suffer from fatigue.**
- **About 90% say it is a “major issue” for them and 60% say it is “probably the most debilitating symptom of their disease.”**
- **More than two thirds say fatigue prevents them from doing the simplest everyday tasks.**
- **While nearly 90% report discussing fatigue with their doctor, 60% say no suggestions have been offered.**
- **More than 75% say fatigue has affected their ability to work; nearly 40% say they are in financial distress because of it; 20% say it has caused them to lose their jobs; while the same number report they have filed for disability as a result of their fatigue.**
- **Other results of fatigue reported are a sense of isolation, loss of self-esteem, anxiety and family tensions.**

*Do you suffer from fatigue? Do you have a strategy for coping?*  
Email [tma@myositis.org](mailto:tma@myositis.org).

## **Acthar for polymyositis and dermatomyositis**

Neurologist Todd Levine — past member of TMA's medical advisory board — presented some preliminary findings at a recent meeting of the American Academy of Neurology. Acthar, a hormone designed to release corticosteroids already present in the body, also acts through receptors in the immune system, muscle, and other tissues; and was approved years ago as a treatment for myositis.

In order to study patient profiles, correct doses, side effects, and efficacy of Acthar in PM and DM patients, a small registry was established for 25 adult DM and PM patients treated with Acthar who did not respond well to other treatments. A pathologist specializing in muscles reviewed the biopsy slides, and information was recorded at beginning of treatment and then at three, six, nine and 12 months. Nine of the patients had DM, and 16 had PM.

The median age was 58, with 15 patients being female and 10 being male. There was an average of 3.2 years since their diagnosis, and they had been treated with an average of 3.4 medications before Acthar was prescribed. Previously, 23 of the patients had been treated with corticosteroids and six patients remained on steroids during the trial.

All 25 patients were started on 80 units of Acthar twice a week. After responding, many patients were maintained on as little as 40 units of Acthar once a week. There were no serious adverse events. The most common adverse events were spikes in blood sugar and lower extremity swelling.

The study concluded that Acthar at 80 units twice a week seems to be well-tolerated in patients with dermatomyositis and polymyositis. The registry will continue to collect data and intends to enroll 100 patients and record 12 months of follow up and long-term results from the larger study.

## **Myositis working groups to examine patient-reported outcomes**

A group of myositis experts, including present and former TMA medical advisory board members, have formed two working groups designed to better incorporate some common patient concerns when measuring the success of treatment. Researchers found that patients commonly reported pain, fatigue and confusion as symptoms that particularly concerned them. Noting that present outcome measurements don't include these concerns, the group will determine the best way to expand patient input.

## **Partial MRI satisfactory in diagnosing myositis patients**

A group of researchers compared diagnostic success with whole versus partial-body magnetic resonance imaging (MRI) for confirming myositis. They concluded that, since no evidence of myositis had been found in the trunks of those studied, a partial MRI was sufficient for diagnosis and would save expense and time.

## **Antibody in IBM predicts more severe involvement**

A team of researchers in California and Missouri are identifying the role that autoantibodies play in anticipating disease progression in IBM. To do this, they examined 25 consecutive IBM patients and determined that 72 percent were positive for the NT5c1A antibody or seropositive. Among their findings:

- Females have higher odds of being seropositive.
- Participants with seropositive IBM took significantly longer to get up and stand.
- There were no significant differences between the two groups in terms of distance covered on a six minute walk.
- Seropositive participants were more likely to require assistive devices such as a walker or wheelchair for mobility.
- Participants with the NT5c1A antibody were significantly more likely to have symptoms of dysphagia.
- Facial weakness occurred in 50% of seropositive participants while it was only seen in 14% of seronegative participants.

Researchers concluded that even the small sample showed those positive to the NT5c1A antibody are likely to have greater motor and functional disability. ●

One of the first problems Charlie had was pulling shirts or sweaters on over his head—his arms wouldn't reach up. And the shirts with all of the little buttons down the front were a source of constant frustration as he tried to button them each morning. We soon learned that we needed a change from clothes that went over his head to those that opened in the front. Thanks to a western party we attended, for which we bought a new western shirt with snaps, we learned how to avoid button-up shirts. I also learned to sew strips of Velcro in those dress shirts with buttons, and to move the buttons from the inside lapel to the outside lapel. Thus, the shirt went on, the Velcro held it together, and the buttons looked like they had gone through the buttonholes. And most of the time, Charlie could manage the snaps on shirts.

Shoes and socks were another combination that needed to be changed. Charlie had always worn shoes with laces. That was an unnecessary expenditure of energy (his and mine) so he found good loafers with adequate support and switched to those. At this point, let me digress and strongly urge you to consider approaching your physician about a referral to an occupational therapist (OT). These are specially trained people, like physical therapists, but OTs focus on all of the ADLs. And the neat thing is they have the greatest bag of tricks to share with people who need to make adaptations to their life style. There are long-handled shoehorns, hooks to put into your socks and allow you to pull them on, splints for hands and wrists to improve function, and many more products we didn't know about. We only needed two visits to find what was out there, and life really did become easier.

On my own, I learned about dinnerware with fat hard rubber handles on the end of the knives, forks and spoons, to make them easier to handle. My kitchen cabinet of glasses took on a new look, with lots of plastic/acrylic, which is much lighter than glass. And we replaced smooth-sided glasses with large goblets with stems like wine glasses (again much easier for him to grasp). The other thing that helped him was to use a straw. Doing this allowed him to simply lean forward to sip and not have to pick up the glass at all.

Liquids were very important for Charlie, because he also had Sjogrens Syndrome, a condition resulting in dry eyes and dry mouth, and his was an extreme case! To add to his challenge, Charlie had fairly severe dysphagia (difficulty in swallowing.) For him, because of these two things, little sips of liquid during his meal were necessary.

Keep in mind what we have all learned: IBM affects people very differently and what works for one person may not work for another. I know several people who can't handle thin liquids and need to add a thickening agent to the liquid. And some say they have to eat all of the solid food first, then go to the liquid. I say — whatever works for you!

*Nancy Harber will be part of the caregiving program at the Annual Patient Conference in Orlando, September 10–13. ●*

## Partners in care solve problems

*Tips for accomplishing those ADLs by Nancy Harber*



*Nancy Harber, a registered nurse, was the long-time caregiver for Charlie Harber, an inclusion-body myositis patient. She serves as an informal consultant to patients and caregivers struggling with the challenges of myositis. Although her experience was specifically with IBM, many of her solutions will apply to other forms of myositis as well.*

ADLs, IBM: Sounds pretty crazy, doesn't it. Most of us know about IBM, but what in the world are ADLs? Believe it or not, all of you get involved with them every day.

These are the activities of daily living: dressing, bathing, eating, brushing teeth, combing hair, pulling on socks etc. These are all tasks we do every day of our lives and have since we were little. And generally we don't even think about them, we just do them. But with IBM and other forms of myositis, they can become a real challenge.

# Myositis: spread the word

By Charlia Sanchez,  
TMA Member Services Manager

Myositis Awareness Day is September 21! Awareness is crucial for everyone in the rare disease community, and the myositis community is no different. Since few people know about myositis, TMA relies on patients, their families and friends to spread the word about the disease and bring much-needed attention that has the potential to make a difference in the lives of all of those affected by myositis.

In the last year, supporters in our myositis community have found creative ways to spread awareness, working on special projects and fundraising efforts that support research, bringing us closer to a cure and helping those with myositis have better lives and find comfort in knowing they are not alone. You can join us!




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We can also send you wording for a myositis awareness proclamation for your city or state. Email [tma@myositis.org](mailto:tma@myositis.org) for sample letters that you can send to your elected officials. We also have ideas for news releases to send to your local media. Call TMA at 1-800-821-7356 for any publications or awareness materials such as this myositis ribbon magnet.

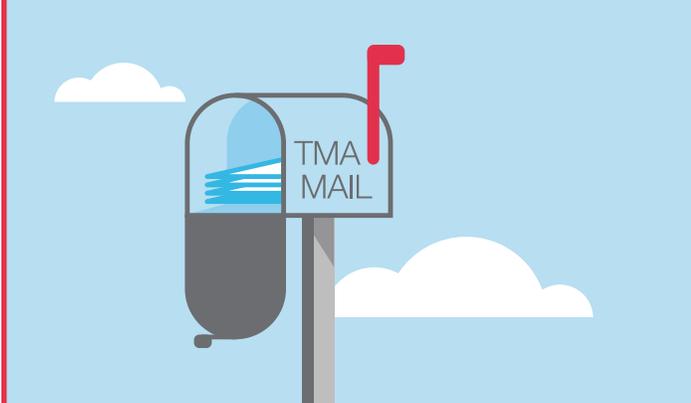
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Need inspiration? Below are some examples of creative awareness efforts and events from last year's Myositis Awareness Day, all planned by people like you! Please let us know your plans for spreading the word about myositis.

- **The Bolgers (Colorado) planned the 2<sup>nd</sup> Annual Picnic in the Park Myositis Awareness Event.**
- **Stanley Prather (NM, TX Northwest) set up an information table in Albuquerque at the New Mexico State Fair and did an interview for his local morning news station.**
- **Nancy Cannon (Carolinas) helped to get a proclamation passed recognizing Myositis Awareness Day in South Carolina.**
- **The New York City support group organized a myositis awareness event at the Hospital for Special Surgery.**
- **Let us know your plans! Email [tma@myositis.org](mailto:tma@myositis.org).**

International members please note KIT contacts:

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 UK | Irene Oakley | T: 023 8044 9708 (Mon-Fri 10-3, answers phone)  
 E: [msg@myositis.org.uk](mailto:msg@myositis.org.uk) | Australia: Anita Chalmers |  
 E: [geoffandanita6@bigpond.com](mailto:geoffandanita6@bigpond.com) ●



Dear editor,

I enjoyed reading Kathryn Nevard's comments in the recent issue about living with DM since I have it as well. I could definitely relate to much of what she has to say, and I feel very strongly that proper nutrition has played a major role in my road to recovery.

However, I would like to comment on her suggestion of seeing a nutritionist for "allergies," since I have been a practicing allergist for more than 25 years. Generally nutritionists, chiropractors, naturopaths and other non-physician providers order tests that use IgG testing, which does not diagnose true allergies but reveals what a patient has ingested in the past. These are expensive tests, often not covered by insurance, and, in my experience, almost always lead to the practitioner telling the patient to avoid wheat and dairy. In contrast, IgE testing is the immunologic method to detect true allergy.

As discussed during my nutrition talk at the TMA Annual Patient Conference for the past few years, there is some scientific data showing benefit for patients with PM and DM to avoid gluten. This is not referring to those patients who also have celiac disease (another autoimmune disorder), who must avoid gluten.

Celiac disease can be diagnosed with appropriate diagnostic testing. Unfortunately, there is no test to verify non-celiac gluten/wheat sensitivity. Gluten avoidance also doesn't seem to be as effective for those with IBM. That said, many people feel better when they don't consume wheat products, but testing will not help make that distinction.

I found relief from several symptoms by removing wheat from my own diet and would encourage those who want to try this to do the same, but encourage them to do it with the guidance of a registered dietician or appropriate dietary references.

**Renee Lantner**

*Dr. Lantner is an allergist and a member of TMA's Board of Directors. She will present a session on nutrition for inflammatory disease at TMA's Annual Patient Conference in Orlando, September 10-13. ●*



## San Francisco Giants to raise awareness of myositis

On September 20, the San Francisco Giants baseball team will hold a home plate ceremony before its game against the Arizona Diamondbacks to honor Giants TV commentator Mike Krukow, who has inclusion-body myositis. Krukow has been broadcasting for the Giants for more than two decades and has a huge following in the Bay area where many know "Kruk" as an icon in the community.

In addition to the ceremony before the game, the Giants will be featuring Kruk in their game-day magazine, which is available at AT&T Park during the entire month of September. There will be a community information booth at the stadium where myositis patients will be available to meet fans on September 20, answer questions about the disease, and provide TMA literature and awareness materials for fans to take home. This event occurs the day before National Myositis Awareness Day and will help draw public attention to myositis.

There will also be a fundraising component to the event that will enable fans to donate to TMA in honor of Kruk. The Giants and some TMA corporate supporters will also be providing funds to TMA as their contribution to the fight against myositis. More details about this event will be made available as we get closer to September 20.

## Myositis Dan retired

Myositis Dan, the horse named to bring public attention to myositis, has been retired from racing. "Dan" had a racing career of 10 races. He won three races, finished second twice, and was third three times. Dan earned about \$140,000 in purse money during a racing career that spanned almost exactly one year.

Airdrie Stud, the farm that owns Dan, determined that an injury Dan sustained last fall did not heal in a way that would allow Dan to resume his career on the racetrack. Dan will be retiring to a more leisurely life of grazing and being ridden

for pleasure. Airdrie informed TMA that they plan to put the word "myositis" in the name of another of their racehorses, which will be their fourth racehorse with the word "myositis" in its name. Although it may take some time before the next "myositis horse" is ready to race, we look forward to continuing to have a myositis racehorse bringing attention to our rare disease. Thank you, Airdrie Stud! ●

## Continued from page 3

Joseph has grown in ways other than size and strength, his mother said: "No one has more heart than he has. He's learned from everything, and so have we." She has some suggestions for parents who may feel alone or frightened:

- **Find support.** "When I found TMA, everything changed," Pedano said. She learned about the disease, joined her local support group and was a member of the TMA board of directors for five years.
- **Focus on what your child enjoys.** Researchers now know that children with myositis benefit greatly by remaining active. "If your child doesn't feel well, he's not going to play at something he doesn't like," she said. "Make sure to encourage the activities your child likes."
- **Remember children are resilient.** "It's much, much harder on the parents," Pedano said. "Joseph never dwelled on his illness."
- **Find creative ways to protect your child.** Joseph's skin had to be shielded from the sun, so he had an array of cool hats and shirts that covered him without making him feel too different.
- **Educate your community.** Pedano made sure every teacher, administrator and coach knew the details of Joseph's disease. That way, they understood why he became fatigued or short of breath and why he had to stay out of the sun. Friends and their parents learned about myositis, too. "That way, you're teaching as well as looking out for your child," Pedano said.
- **Stay positive.** "This went on for years, and sometimes it was pretty awful," Pedano said. "But remember there's always a light at the end of the tunnel." ●



Together we  
can help ensure  
Lisa's story has  
a beautiful outcome



Lisa—28 years old, IG infusion patient  
Photographer, favorite subject: her son

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#### ACCREDITATIONS



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