

THE DIFFICULTY OF DIAGNOSIS

Don't be surprised if your pediatric rheumatologist puts more emphasis on examining your child and talking to you than looking at results from the lab.

Dr. James Jarvis, a 2003 TMA grantee, recently made a case for greater reliance on clinical skills and family history when diagnosing children. Dr. Jarvis is the chairman of the American Academy of Pediatrics rheumatology executive committee and a pediatric rheumatologist with the University of Oklahoma. His two-year grant from TMA allowed him to identify and reach out to juvenile myositis (JM) patients from Native American families in the northern Oklahoma plains, where certain extended families had multiple cases of JM.

Writing in the October, 2007 issue of *AAP News*, Dr. Jarvis reminded his colleagues that "children aren't just small adults," especially when it comes to diagnosing chronic autoimmune diseases. Jarvis told his fellow pediatricians that tests commonly used to identify adult forms of rheumatic disease may be misleading in children with juvenile forms of these diseases, including rheumatoid arthritis and dermatomyositis.

Despite the anxiety of worried parents and the pediatrician's wish for a swift, definitive diagnosis, diagnosis in juveniles has less support from laboratory results than diagnosis in adults, Jarvis writes. "While there is a reasonable desire for a simple 'test' that will tell us when to consider or exclude rheumatic disease as a catego-

ry in children, such a test simply doesn't exist."

"You've probably heard this dozens of times before," he writes: "This might be an autoimmune disease. Order an ANA and a rheumatoid factor." The rheumatoid factor, present in 50-80 percent of adults with rheumatic disease, is a valuable clue and has been used for years. But twenty years of experience with this approach has taught pediatric rheumatologists that it just doesn't work for children.

The evidence, he says, supports a more limited use of the laboratory by primary care doctors evaluating children with muscle complaints and suspected rheumatic disease. It turns out that most children with positive rheumatoid factor tests don't have a juvenile rheumatic disease. In fact, a study in the late 1990s showed that children who *did* have positive tests and also had a rheumatic disease were easily identified by physical examination. In other words, "the test did nothing to establish the diagnosis," Jarvis said.

Another test, the antinuclear antibody (ANA) test, is misleading in the opposite direction. Dr. Jarvis notes that these tests routinely are positive in healthy children, and that follow-up research shows that the healthy children with positive ANA tests are no more at risk for eventually developing rheumatic disease than other children. In fact, Jarvis writes, evidence demonstrates that the blood levels of ANA seen in children with diseases like juvenile rheumatoid arthritis and juve-

nile myositis so completely overlap those of healthy children as to "make a positive test useless in distinguishing a healthy child from one with one of these diseases."

What's the answer, then, for getting a correct diagnosis for a complex collection of symptoms? "Unfortunately, there's no easy answer," Jarvis says. The speed of the diagnosis, as well as the treatment of the disease, depends greatly on the experience and observation of the pediatrician. Parents working with doctors to establish a complete and accurate history of the patient, the patient's family and the disease onset, coupled with a thorough physical exam, are the most vital tools for both diagnosing and excluding chronic inflammatory diseases in children, Jarvis says. He said this means that the practitioner needs to be familiar with all the various clinical signs of rheumatic disease in children, including both typical and unusual signs and symptoms, the typical ages of children who commonly first show signs of each disease, and the childhood rheumatic diseases that might mimic the disease being considered.

"We are left," says Jarvis, "with what good pediatricians have always relied on: a good history, focused physical examination and broad knowledge base."

For further information

See Dr. Jarvis's TMA-funded research project at www.myositis.org under Research, TMA Grants & Fellowships.

Published by: TMA, Inc.

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Risks, benefits of pet ownership

If you have a pet, and your child has an autoimmune disease, it's mostly good news. Pets are considered positive therapy for people dealing with chronic illness, depression and hospital stays. There are wonderful physiological effects, like lowering blood pressure, and substantial emotional benefits from an animal's focused attention and unconditional acceptance. Animal-assisted therapy has become more widespread in recent years with more research behind its therapeutic benefits.

On the other hand, pets bring risks of infections, ranging in severity from minor skin irritations to rare but life-threatening illnesses. Specific infections include parasitic, fungal, bacterial, and viral. Parasitic infections are the most common, and these are typically transmitted through contact with animal feces. Toxoplasmosis generally occurs from direct contact with cat feces from changing the litter; cutaneous larva migrans from walking barefoot on contaminated soil. Fleas act as hosts for certain parasitic infections.

Most parasitic infections are asymptomatic in humans, though some can lead to itching, abdominal pain or mild flu-like symptoms. The possibility of severe disease is in vulnerable populations, such as very young children, the elderly and people who are immune-compromised, either from a disease or because they're taking medications that suppress their immune system.

Common bacterial infections include campylobacteriosis, causing gastroenteritis, and salmonellosis, potentially leading to severe disease, especially in children. Cat-scratch disease from exposure to cats with fleas carries an added risk of complications in immune-suppressed individuals. Some very rare exotic diseases that are usually asymptomatic or have mild flu-like symptoms pass from pet hamsters, guinea pigs and other rodents.

What does this mean for you, your child and your pet? Experts say prevention is essential, especially for those with compromised immune systems. Have your family take these common sense measures:

- Wash hands frequently, and especially after contact with pets or other animals
- Properly dispose of animal waste, including wearing gloves to change litter
- Schedule regular visits with your pet to the veterinarian
- Wash areas immediately after a pet bite or scratch

The bottom line: "The benefits of pet ownership, including positive effects on mental health, outweigh the potential risks of infectious disease," say the authors who reported their conclusions in the November 1, 2007, edition of the *American Family Physician*.



UNDERSTANDING SKIN SIGNS OF JM

The first sign of juvenile myositis is often skin redness or rash, though muscle weakness can become apparent before any skin signs appear. Both are difficult to treat, and JM research continues to examine the causes of skin rash and muscle weakness, the relationship between skin and muscle signs, and how to best treat both features of JM. This piece focuses on the skin signs associated with juvenile myositis.

Characteristic skin signs

“There are at least eight different potential manifestations on the skin,” said Dr. Amy Paller, Walter J. Hamlin Professor and Chair of Dermatology, Northwestern University’s Feinberg School of Medicine, and Attending Physician at Children’s Memorial Hospital. In terms of the appearance of the skin, she says, adults and children exhibit similar signs, including Gottron’s papules, heliotrope rash and malar rash.

Gottron’s papules. Gottron’s papules – raised, often scaly bumps found over the knuckles, elbows and knees – are the most common skin symptom reported at diagnosis as well as throughout the disease course. “Kaitlyn had what we now know to be Gottron’s papules,” said Stephanie, mother of a 4-year-old with JM. “They were misdiagnosed by a couple different pediatricians who chalked up the weird rash to eczema.” Her elbows and knees had been red and rough for some time and appeared to be childhood scrapes or dry skin. Only looking back after the JM diagnosis did they realize this seemingly ordinary rash was an early sign of something more.

Heliotrope rash. The heliotrope rash, so named because of its red-violet color like that of a heliotrope flower, appears around the eyes and is often puffy. “She had the bright pink eyelids,” said Jill, whose daughter has

JDM. “It looked like she had gotten into leftover 1980s eyeshadow!” This skin rash is fairly exclusive to myositis, making its appearance useful to confirm the JM diagnosis.

Malar rash. The red rash on Kaitlyn’s face was the first clear sign to her parents that something wasn’t quite right. “It looked like a butterfly lying on her nose,” Stephanie said. The malar rash is in fact identified by its butterfly shape, appearing as a red and sometimes blotchy rash across the cheeks and bridge of the nose. While the heliotrope rash is rarely seen in any condition other than myositis, the malar rash is noticed in other disorders, particularly lupus.

Although Stephanie had always made sure her daughter used sunscreen, her first instinct was to take extra care in covering this spot with plenty of sunscreen. The rash kept appearing, even after Kaitlyn spent a week indoors. After doctors ruled out lupus, Kaitlyn was diagnosed with juvenile dermatomyositis.

Periungual telangiectasia. These visible blood vessels, occurring around the fingernails, appear as bushy and distorted capillaries at the base of the fingernail. Capillaries around the fingernails are normally evenly spaced with small, uniform loops that reach the edge of the nail. In juvenile myositis, these small blood vessels are the main targets of inflammation and damage, often causing the irregular pattern and loss of visible capillaries.

Long-term skin concerns

The skin signs in children with myositis are more likely to resolve completely than those in adults, suggesting a good overall prognosis for children. For children with ongoing skin problems, dryness, itchiness and “poikiloderma” are concerns. Poikiloderma is a medical term that

refers to thin skin with visible small blood vessels (telangiectasias) and dark and light spots. “The itchiness and dryness of chronic JM,” Dr. Paller said, “can be very difficult to control.” Fortunately, not every child will encounter poikiloderma.

Looking at the capillaries at the base of the fingernails, noting both the formation and number of these small blood vessels, gives doctors an effective way to determine capillary involvement and to measure changes over time.

Some children with especially sensitive skin can’t use most moisturizers and other agents. Doctors often recommend moisturizers with anti-pruritics, or anti-itch ingredients. Anti-inflammatory medicines can also help, but non-steroidal agents are not effective in general.

Since the skin rash can be easily visible and last for a long time, children may lose confidence and self-esteem. In these cases, cover-ups with sunscreen help conceal the skin symptoms while providing the necessary sun protection.

Dealing with the itch

Anyone who has experienced poison ivy is familiar with the irritating, relentless and often debilitating itch. Like that of poison ivy, the rash that accompanies JM can interfere with a child’s school work, ability to sleep and overall mood.

It seems that the longer the disease has lasted, the worse the itch becomes. Since dryness contributes to the itch, doctors recommend using generous amounts of emollients, oils and creams. These formulas are more effective than lotions, which contain alcohol and can be drying in the long run. Some children find that oatmeal baths ease the annoying itch. Doxepin and other topical anti-pruritics and other

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Skin signs of JM

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topical anti-pruritics are sometimes useful for stubborn cases of itching skin. For severe itching, doctors may prescribe antihistamines. These make children sleepy and should be taken at night.

Often, a scalp itch is one of the most irritating symptoms, and doctors prescribe oil-based topical steroids, which are formulated well for scalp use. Fluocinolone acetonide is one example.

As a general rule, choose non-drying formulas for all soaps, laundry detergents and other agents that will touch your child's skin. Use formulas prepared especially for sensitive skin types, and avoid products with added fragrances and dyes.

See Outlook, page 7 for further discussion of moisturizers.

Calcinosis

Better therapy is needed for calcinosis, or often painful deposits of calcium found under the skin often at pressure points (for example, elbows and knees), Dr. Paller said. Calcium deposits can be hard lumps or sheet-like in appearance and can change shape over time. Doctors do not fully understand why some children develop calcinosis while other children do not, but they have found that children who have delayed or inadequate treatment are more likely to develop these deposits. Doctors also note that some children with calcinosis are more likely to have a form of a particular tumor necrosis factor gene.

Most doctors agree that it is important to control the JM inflammation as quickly as possible. Although there are several possible treatments, nothing is especially effective in getting rid of calcinosis that has already formed. Further complicating calcinosis is the potential for ulcerations at the sites of the deposits. In her experi-

ence, Dr. Paller notes that most people with long-standing or extremely painful calcinosis have surgery to remove the nodules.

Medical treatments

Doctors continue to debate whether systemic medicines, or those taken by mouth or injected that affect the body in general, are needed when the skin rash is the only sign. Some believe topical medicines – medicines applied directly to the skin – are sufficient to treat the skin when muscles are not involved. Richard Sontheimer, MD (see Outlook, page 6), prefers to treat the symptoms rather than exposing patients to the potential side effects of immunosuppressive therapy. Dr. Paller relies more heavily on systemic treatments, not finding topicals as effective in her own experience. She notes that most children who have the skin rash alone in the beginning progress to muscle involvement.

Topical steroid preparations are available but carry their own risks, especially thinning of the skin. Stronger topical medicines may help for severe skin rashes but are not recommended for long-term use.

Kaitlyn, who had skin issues but little to no muscle weakness, has responded well to her oral and intravenous treatments. She was able to taper her prednisone completely within a short time and now takes only weekly methotrexate to control the skin rash.

An ounce of prevention

“The importance of sun protection and avoidance cannot be overemphasized,” write Drs. Barrio, Callen and Paller in *Myositis and You* (see “Further reading”).

Dr. Paller stresses taking a complete approach to sun protection – stay out of the sun, wear sun-protective clothing and apply sunscreen regularly and liberally. Avoid tanning booths altogether: “You’d be sur-

prised at how little understanding there is about tanning booths and their risks” she said. Sun protection is not only important for skin health but also to prevent the return of the underlying disease.

“We are vigilant with sunscreen,” Stephanie said, “using L’Oreal with mexoryl each day at least 30 minutes before Kaitlyn goes outside.” They limit her to 30 minutes outside between the peak hours of 10 am and 4 pm, and she sports long-sleeved bathing suits and hats. In fact, her preschool teachers faithfully remind her to wear her hats, even if going out of doors only for 10 minutes. Lindsay (DM) also remains aware of the risks, noticing a connection between her own sun exposure and worsening skin rash.

Jill recommends the “no-rub” aerosol sunscreens. You may go through it more quickly, she says, but it is effective and causes less “trauma” putting it on. Like Stephanie, Jill is vigilant about using sunscreen year-round and reapplying it often. Be careful to apply all types of sunscreen evenly and in sufficient amounts, Dr. Paller said.

See “Winter skin care”, page 6 for more preventive and protective measures.

Further reading

Barrio VR, Callen JP, Paller AS. *Skin Rashes and Sun Protection (Chapter 16)*. From *Myositis and You: A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers*. Washington: The Myositis Association; pp. 217-225.

Sontheimer RD. *Skin Disease in Dermatomyositis – What Patients and Their Families Often Want to Know*. *Dermatology Online Journal* 8(1):6. See <http://dermatology.cdlib.org/DOJvol8num1/information/dermatomyositis/sontheimer.html>.



Finding – and sharing – hope

Those at TMA’s Annual Conference in Bellevue had a chance to see firsthand a painting Shelby Johnson contributed to the silent auction. Shelby, a 19-year-old from Tennessee, paints with bright colors and a generous spirit. She has also donated a number of paintings to the Make-A-Wish Foundation, raising money that helps grant the wishes of children with life-altering illnesses. Though she doesn’t see graphic art or a similar career in her future, she wants to continue drawing and teaching. Art is just one interest in Shelby’s full life. She’s a musician, a student, a teacher, a loving daughter and a loyal friend.

She’s also a juvenile dermatomyositis patient. Over the years, she says, she has come to realize just how much living with JM has shaped who she is: “Those experiences and what they have taught me are difficult to explain because it has to do with how I look at each day.”

Shelby was diagnosed at the age of 4 with JM, after going to a number of different doctors. She has been on prednisone for most of the 14 years since diagnosis, taking only a maintenance dose now, but she’s a veteran of the pharmacopeia of drugs physicians prescribe to alleviate muscle and skin problems of JM. She tried Plaquenil as a child, but had to stop because of eye problems. Methotrexate and cyclosporine came later in the disease course. She has also had monthly infusions of IVIG, the treatment that

finally effectively controlled her symptoms.

She is now just about symptom free but lives with some leftover muscle weakness, fatigue and joint pain. She’s also been touched by the long-term effects of prednisone. She’s not as tall as she might have been, she bruises easily, and she is still sensitive to the sun. Her doctor keeps track of her bone density, but it’s been okay so far, probably because she takes daily calcium supplements.

Since she was diagnosed at a relatively young age, she doesn’t remember feeling overly anxious or frustrated with the disease or the limitations it put on her activities. “My mom was so good at encouraging me to do things she knew I could do,” she said. For instance, her mom enrolled her in art classes and voice lessons early on.

Shelby is a triplet, which provided a daily contrast as she watched her same-age brother and sister do everything she couldn’t do. But her mother always worked hard, she says – even before her diagnosis – to teach all of the children (including an older brother) that they were each individuals with different talents. In fact, her mother had a brother with cerebral palsy and appreciates personally what it’s like to grow up being the sibling of a sick child.

“Mom worked hard to have special time with each of us,” Shelby said. “It sounds repetitive, but everything goes back to my mom. She is an extraordinary influence on us and an extraordinary mother.” This also affected her

brothers and sister, who all played important parts in supporting Shelby and each other.

What the future holds

Shelby has always enjoyed art and it’s still a very important part of her life. She now teaches art classes from her home, to students ranging from Kindergarteners to eighth graders. The ambitious college sophomore is also working for a double major in history and English. She plans to teach middle school after graduating, but her goals don’t end there. She dreams of working toward her master’s and eventually her doctoral degrees so she can teach at the college level.

Shelby says she’s learned a great deal from growing up with JM. She tries to focus on the good in her own life and does her best to bring that quality to the people around her. Even over the phone, her optimism and confidence are easily felt. “It’s definitely not an optimism that comes all at once,” she said. Her advice to parents: just be there for your children until they are able to find hope and confidence themselves: “I’m pretty sure they will” she says. “It just takes time.”



Winter skin care

Seasonal changes present a challenge for any skin type. Add in skin symptoms associated with juvenile myositis, and the problems are multiplied. Some tried-and-true tips from dermatologists and from people who have personal experience living with the often frustrating skin issues:

- Winter, Spring, Summer or Fall – remember sunscreen. The sun’s rays, as well as fluorescent lighting, are thought to exacerbate ongoing disease or possibly even initiate a flare in someone currently in remission.
- Go fragrance free, oil free and non-comedogenic. Be sure your soaps, moisturizers, make-up and anything else that touches your skin have no added perfumes or fragrances as these can irritate your already sensitive skin and lead to acne. Find formulas especially for sensitive skin.
- Use a humidifier in your home, especially in your bedroom. Heating systems can dry out the air, leaving your skin more vulnerable. Be sure to clean the humidifier regularly to avoid any impurities being pushed back into the air.
- Moisturize immediately after bathing, within a few minutes for it to work best. Opt for emollients or creams that are thicker and have less alcohol to dry out the skin. (These often feel thick and uncomfortable, so use these especially at night to provide a barrier to block in the moisture.)
- Avoid rough fabrics like wool that can directly irritate your skin. Instead, choose cotton and softer materials. Find other items that might act as irritants – fabric softeners, laundry detergents, etc.
- Layer clothing to prevent sweating that can be caused by wearing clothes that are too snug or too heavy. Sweating leads to skin irritation.

- Think from the inside out. Eating healthy fats, like omega-3 fatty acids found in many fish, can help your skin.

- Hydrate. Drink plenty of water so that you don’t become dehydrated, which can intensify the skin’s dryness.



Winter workouts: Is yoga for you?

It may seem like the hot new trend embraced by the most enlightened celebrities, but yoga has been around for more than 3,000 years. It had its start in India and is often called “India’s gift to the world.”

Yoga means “yoke” in the ancient language of Sanskrit. Its idea is to work with the mind, body, and spirit to increase vitality. It’s a different concept from our modern idea, where the physical, mental and spiritual are considered three distinct realms, with disciplines and doctors for each.

Although yoga includes exercise, the exercise is just one component. Disciplining your mind and body as well as connecting with your spirituality are the main goals of yoga. Before beginning a yoga class this winter, check with your doctor. You’ll also want to discuss your condition with your yoga teacher. She will show you how to do some of the poses in ways that won’t stress muscles that are weak from JM.

The physical exercises of yoga are called Hatha yoga, made up of a series of poses, called asanas. You will be led through a series of specific poses while controlling your breathing. Some types of yoga also involve meditation and chanting.

You may be bewildered by the choices in yoga classes, and the following information should help:

- Ashtanga yoga is a fast-paced yoga that builds flexibility, strength and focus. You’ll move quickly through a

set of poses while focused on breathing.

- Gentle yoga focuses on slow stretches, flexibility, and deep breathing.

- Kundalini yoga uses poses, deep breathing and other breathing techniques, chanting, and meditation.

- Iyengar yoga uses chairs, belts and other props to achieve the correct pose.

Yoga has a lot of benefits for someone with muscle weakness. It can improve flexibility, strength, balance, and stamina. In addition to the physical benefits, many people who practice yoga say that it lessens anxiety and improves concentration. Find a class at a fitness centers or YMCA, but be sure to talk to the teacher before you sign up to get some idea if it’s the right approach for you. Often, you can take or watch a sample class before signing up. Check whether the instructor is registered with the Yoga Alliance, a certification that requires at least 200 hours of training in yoga teaching. If you’re not sure you are ready, try a yoga video. Instructional websites, CD-ROMs, and books are helpful, but you will find you benefit from a real-life teacher and the class interaction.

Dress comfortably for your yoga class. You don’t need the glamorous spandex outfits that are sometimes seen at the health club. Snug-fitting shorts or tights and a T-shirt or tank top are best. No shoes are necessary, since yoga is practiced barefoot. Often, class members dress in layers so they are warm enough at the end, usually the time for guided deep relaxation.

Many people who practice yoga or take yoga classes like to use a “sticky mat,” a mat that gives them some cushioning and friction. Buy them in sporting goods stores or at the yoga class location.





JUST FOR ME

Fun facts and news for children affected by JM

Take care of your pets – and yourself

If you have a pet or have asked for one, your parents have probably told you that pets are a big responsibility. You have to look after them, but you also have to take care of yourself.

Animals can share germs and bacteria, but there are some things you can do to make sure you stay healthy and still have fun with your pets:

- Wash your hands after playing with or petting any animals – your own, a friend’s, and especially animals in a petting zoo. Don’t touch your hands to your face or mouth without washing them first.
- Be gentle with your pets and other animals to keep them from biting or scratching. Both bites and scrapes can spread germs to you.
- Don’t walk barefoot outside, especially if you have a pet that runs around in the yard. Cover your sandbox when you’re not using it.
- If you help with the cleaning, wear gloves when you change your cat’s litter box or wash a pet’s area. Even with gloves, be sure to wash your hands afterwards.

FUN PHRASES

Check out these animal-related phrases – what they mean and how they started:

Piggyback. This word might have started out as “pick a back,” with a child hearing it wrong and instead saying “piggyback” to mean riding on someone’s back.

Three dog night. When it’s especially cold outside, some people call it a “three dog night.” When cowboys used to sleep outside, their dogs would sleep with them to help keep them warm. On really cold nights, it took three dogs to do the job.

Let the cat out of the bag. Farmers used to take their chickens in large bags to sell at the market. Cats were cheaper so they would put cats in the bags instead of chickens. When people buying the bags thought they were being tricked, they would open the bags to find out. So to “let the cat out of the bag” grew to mean getting the truth out in the open.

Catty-corner. You might use this word when telling that a person’s house is “catty-corner” from yours, or on the opposite corner. It comes from catercorner, or diagonal.

Quick Tips

Remember to take care of your skin this winter!

Even though it doesn’t feel as hot as it did in the summer, the sun is still strong. Wear your sunscreen when you’re going outside, and show off your hats, too. Use moisturizers when you can, especially after you wash your hands or take a bath or shower. Dress in clothes that aren’t too tight or too hot, which can make you sweat and dry out your skin.

Fun for travel or at home

Are you traveling this holiday season? Whether you’ll spend a few hours on the road or just have some extra time at home, try these fun games.

■ **Going camping.** Gather some family and friends and go on a camping trip. The first person starts by saying “I’m going on a camping trip and I’m taking with me ...” The next person uses the last letter of whatever item the first person is taking to name an item they’ll be taking. For example, the first person says “I’m going on a camping trip and I’m taking with me some popcorn.” The next person must

choose an item that begins with the letter N. Keep going as long as you’d like.

■ **Grocery list.** In this game, the first person says “I’m going to the grocery store to pick up ...” The first item’s name must begin with the letter A. The next person must name the current grocery list (in this case the item starting with the letter A) and add an item starting with the letter B. Each person must name all of the items named before and then come up with another item starting with the next letter of the alphabet.

Have a great time!

Thank you!

Each year, individual members of TMA and others concerned about those who live with myositis organize golf tournaments, walks and other events to benefit The Myositis Association. In 2007, TMA was fortunate to have a number of very successful fundraising events. Listed below are some of the major events held in 2007. If you have interest in helping raise funds for TMA and to help those who live with myositis, call 1-800-821-7356, email [TMA @myositis.org](mailto:TMA@myositis.org), or create your own campaign online at www.myositis.org.

5th Annual TMA Golf Tournament
Sponsored by SOLEX

5th Annual Pedano/Berretone
Family Golf Tournament

Greendale 4th of July 5K Run/Walk

Baltimore Bridge Tournament

USC vs. ND Football Raffle

Steve Morris - Riding for those who can't
Sunset Cruise for Pops

Harris Teller Birthday Celebration

Gia's Wish for a Cure

Sue Boxrud's Grandma's Half-marathon

Peyton's Campaign Against Dermatomyositis



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