

Meet Our Members: Katie and Bonnie Petit

Although Katie Petit has struggled with juvenile dermatomyositis for almost ten years – more than half her life – both she and her mother, Bonnie, try to focus on some of the positive things they've learned throughout this challenging experience.

For one thing, Bonnie said, it guided a change in her choice of profession. Bonnie's now an administrative assistant at HealthAlliance Hospital, a position she's held for six years. "After Katie was diagnosed, I took a job at the hospital to learn more," she said. She also took a medical terminology course to understand the pages of notes from the doctors managing Katie's disease.

Katie was 7 years old when she first developed a rash. As it became more prominent, her parents scheduled her for an appointment with a dermatologist to check out what they thought was a childhood case of eczema.

As luck would have it, the dermatologist had just diagnosed a child with JDM, and Katie's rash was all too familiar. The day they saw the doctor, the rash had just spread across her nose, Bonnie said. He referred them immediately to a hospital in Boston, where blood tests and an MRI confirmed the dermatologist's suspicions.

Katie took all kinds of medications: high-dose steroids, methotrexate and plaquenil; and she had extensive

physical therapy. Five years later, the family was relieved to see a break in the disease. "We thought it was a remission," Bonnie said. But the family's relief was short-lived. After eight weeks, Katie flared again. After another year-long course of steroids and methotrexate, she was no better. "We asked about IVIG and were told no, they would not do it unless she got 'much worse,'" Bonnie said.

Katie went to a special camp with other children with myositis and arthritis. Through some parents she met there, Bonnie found out where other children with JM were getting treatment and saw that they were responding to IVIG.

The family decided to have Katie change hospitals. Katie began going to The Floating Hospital for Children at Tufts Medical Center in Boston, where she received IVIG therapy for the next year.

In a few weeks the Petits, who hope Katie is now in remission, will find out what the exams and lab work reveal about her condition.

"We are very thankful for this camp she attended and meeting other families because she may not have gotten the chance at this other hospital, or this treatment," Bonnie said. "I would not have even known about it."

Katie remembers the early days of her illness: "The thing that scared me the most about being diagnosed with dermatomyositis was it being so rare,

and how there wasn't a lot of information on it," she said. "Not knowing what exactly is wrong with you or how to treat it is really kind of scary."

Katie believes that the support of her friends and family helped her a great deal. "Also going to camp with so many other kids with illnesses similar to mine helped me not to feel alone."

Katie said her friends were scared for her at first, but they were really supportive. Children who didn't know her were not so kind: "Some people made fun of me and called me names and stuff, but it was because they don't know me, and they were really immature about it, but that was when we were little. Now kids are a lot more mature about it."

Katie said her schools handled her situation really well, and everyone, from the nurses to the school cafeteria people to the principal and her teachers, were understanding about her needing extra help. "I'm thankful for that," she said.

"The camp really opened her eyes," Bonnie said. "On the days she felt like 'woe is me, I had an IV treatment,' she'd see a child who had daily injections that were very painful, or insulin pumps, or leg braces. She'd see kids who would fight their diseases for life, where she (at least we hope) has a shot at remission. Just seeing that there is always someone who has it worse out there made her

Continued on page 2.

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Katie and Bonnie, cont'd from cover

appreciate that she could be stronger than she ever thought she could be."

In the end, Bonnie believes, this happened for a reason. Both she and Katie found new goals. "It pushed me into a career in the medical field," she said. Katie, who learned a lot about

compassion through her own struggles and the children she saw at camp, now wants to work with animals.

Does your family have a story about how juvenile dermatomyositis affected your life? If so, email tma@myositis.org.



AskTheDoctor

What you should know about IVIG

Dr. Tahseen Mozaffar was featured in a live discussion about the use of IVIG in myositis treatment. Dr.

Mozaffar is a neurologist, an associate professor of neurology at the University of California School of Medicine, Irvine and he directs the neuromuscular program at the UCI School of Medicine. He is also the director of the UCI-MDA ALS and Neuromuscular Center. He is a member of TMA's medical advisory board. For the complete transcript, go to www.myositis.org.

My daughter had a relapse of her JDM in December. She underwent IVIG, with good results. She had a headache after infusion, but it went away with an increase in prednisone. For her second infusion, the IVIG type was changed and she had no problem at all. The 3rd IVIG infusion resulted in a migraine-like headache that did not go away till she was treated in the emergency room.

We followed all the recommendations of pre-treating with Benadryl and Tylenol. She drank a lot of water and the treatment went slowly. My question is, is this normal, because if she were to have to undergo treatment in the future we would like recommendations from you regarding dosage and length of treatment time. IVIG was a miracle in the length of her recovery time from this relapse.

Dr. Mozaffar: Migraines are not uncommon in IVIG therapy and

respond to premedication, slower rate of infusion and sometimes to migraine protective medications.

Which type of myositis is helped with IVIG?

Dr. Mozaffar: Dermatomyositis the most, then polymyositis. In my opinion, in few cases of early IBM, IVIG may have a role but not routinely in all cases of IBM.

What are the side effects of long-term IVIG therapy?

Dr. Mozaffar: Very little; there is risk of blood clots, and some kidney dysfunction, but overall very little long-term consequences.

My child has been on IVIG for two years, and recently started with a new provider. She now has headaches and fevers during the infusions. What would suddenly cause these symptoms?

Dr. Mozaffar: It sounds like your child may be getting too much IVIG. The symptoms of headaches and fevers are not unusual for IVIG infusions; they usually respond to slowing down the rate of infusion. Ask your doctor for a test to make sure that IVIG is not causing chemical meningitis, a rare complication.

Continued on page 5.

Build motor skills and relieve infusion anxiety

Respect the mess

What happens when your child plays in mud, works with clay, or builds sand castles on the beach? He's having fun -- which is important -- but he's also recovering and building fine motor skills in ways that are made possible by direct, repetitive contact with tactile materials. These materials (and others, like fingerpaints, Play-Doh and water) all have something in common: they're messy.

That's a good thing, says Gill Connell, author of "Moving Smart," an online child-oriented blog. In a June blog post, Connell says, "Movement is at the very core of how children develop intellectually, emotionally, socially, and of course, physically."

The post, entitled "Respect the Mess," shares some ideas of interest to all parents, but especially to those whose children need subtle encouragement to move those small muscles despite pain and weakness.

Connell, a child development specialist, says "messy play" is great for young minds discovering a hands-on world, and it develops strength and fine motor coordination in those curious little fingers. She writes:

"Now, most parents intuitively understand that kids come with a certain amount of mess and adopt a quiet tolerance towards it. But when you've

got the mop out taking care of your end of messy play for the third time today, it can be frustrating."

She goes on to list some of the kinds of materials to gather for messy play time:

- Wet, viscous - mud, slime, play-doh, clay, glue, fingerpaints, foam, snow in winter.
- Fun food - jellies, jams, peanut butter, jello, mashed potatoes.
- Bath time - bubbles, bath foam and gels.
- Dry, textured - sand, dirt, glitter, markers, crayons, dry baking materials like flour, sugar, grains, oats and other cereals.



Motor skills and creativity meet in "messy play" activities.

"These materials seem to have the ability to travel to places wholly unrelated to the designated play space and often show up weeks later despite the most vigorous and vigilant clean up,"

Connell writes. Despite this apparent drawback, she says she recommends whole-body messy play whenever possible:

"Think about the last time you had a blob of Play-Doh in your hands. Chances are you couldn't put it down -- squeezing it, shaping it, poking holes in it, pressing it through your fingers. The very nature of messy play is a call to action for the fingers, working the tiny muscles to build

strength, endurance, and coordinated movements."

When you allow your child to get extremely messy, there's a sense of freedom that gives children some relief from the everyday expectations of conformity and neatness, she adds.

Other important notes on messy play:

- Make sure your child helps clean up.
- Use bath time as a continuation of small-muscle exercise. Have plenty of bath foams, bubbles, sponges and containers on hand.
- Make a game of towel-drying, encouraging your child to stretch and bend to dry hair, toes, back and fingers.
- Follow up with lotion and hair-brushing, once again allowing your child to stretch and bend.

Find more on messy play and other child development issues at www.movesmart.blogspot.com.



Take some of the fear from infusion day

It's no secret that many children are terrified of needles. It's easy to understand why, since needles cause pain, a situation made even more complicated by the fact that a trusted adult is administering it. But if your child's fear of needles gets worse and worse over time, it makes the struggle to treat your child much more difficult.

Fear of needles in children can make IVIG treatment a battle, but there are some ingenious ways to minimize the discomfort. Most medical professionals and parents know that pain can be experienced as stronger or weaker depending on how intently the brain is focused on it. This is behind many theories of pain

Continued on page 5.

Current research of interest

New diagnosis vs. flares

An article, “Approaches for the treatment of new onset and flared juvenile dermatomyositis: An international multicenter PRINTO study,” in the June 17 issue of *Arthritis & Rheumatism* examined some of the differences between the two patient groups. Researchers found that new onset patients are more likely to improve significantly over 24 months than those with a JDM flare.

The study included 145 new-onset and 130 flared patients younger than 18 years. Disease activity and methods of treatment were observed at the beginning of the study, then at six, 12 and 24 months.

Patients were from four geographic areas: Latin America, North America, Eastern Europe and Western Europe. New onset children were given corticosteroid in higher doses and methotrexate when compared to flared JDM; the latter group was more likely to use cyclosporine. Patients from Latin and North America received pulses and higher dose of steroids when compared to Western and Eastern Europe. The use of methotrexate was similar in all four regions, while cyclosporine was more frequently used in Western Europe.

Clinicians observed that 57.9% of new onset and 36.4% of flared patients reached at least a satisfactory level of response at six months, which increased to 78.4% and 51.2 percent, respectively, at two years.



Itch and pain

No one who has had a chronic itch (or a child with one) would deny it. An itch that goes on and on, whether from medication or from the rash of juvenile dermatomyositis, is as dis-

ruptive and uncomfortable as chronic pain. Both interfere with sleep, cause frustration, take away our daily pleasure in life, and limit what we feel like doing.

This bit of knowledge has been confirmed by research. In a study published in the June edition of the *Archives of Dermatology*, researchers found that those who suffer from chronic itch (an itch that goes on longer than six weeks or so) have seen the same kind of diminishment in spirit and activity as those who suffer from chronic pain.

The *Archives of Dermatology* study says that chronic itch is actually a kind of pain, made no less serious by its location in the skin. Like those with chronic pain, those who suffer from chronic itch seem to battle with chronic depression.

At times it's unclear which comes first, the study suggests. People who are depressed or stressed somehow tolerate pain and itching less well than those who are not; but the endless, nagging experience of chronic pain or chronic itch seems to cause depression in many patients.

Like the perception of pain, the perception of itchiness changes immensely from one person to another, and both are very tricky to pin down. Both tend to elude treatment, and have plenty of emotional as well as physical components. The study found that there are other similarities between the two: a social support system matters greatly in how someone with chronic itch tolerates his or her symptoms.

In fact, both adults with chronic itch and those with chronic pain do worse when they're unmarried than when they have a life partner. One major difference between chronic pain

and chronic itch was found by the study, which was led by Dr. Seema P. Kini of Emory University. Kini said we know a great deal more about the physiology of pain than the physiology of itching. The diagnosis, treatment and impact of chronic pain have been extensively studied, but persistent itchiness has not been well investigated by researchers. The experience of both adults and children who fight the urge to scratch many minutes of their lives is poorly understood.

The study surveyed 137 patients at Emory University Medical Center in Atlanta who were being seen for chronic pain, and 73 who were visiting doctors there for itchiness. All were asked to rate the impact of their condition on their quality of life, how long they had been experiencing pain or itch, and to provide other information about themselves. Itchers reported devastating consequences in their quality of life, equal to those in pain. The study called for more support for the chronically itchy and more research into better treatments.



Rider honored by US public health service

Physician-scientist and researcher Capt. Lisa Rider, M.D., was named 2011 Physician Researcher of the Year by the Physicians Professional Advisory Committee of the United States Public Health Service. The advisory committee represents the nearly 900 medical officers in the more than 6,000-member Corps.

Rider, deputy chief of the NIEHS Environmental Autoimmunity Group, received her award June 21 at the annual meeting of the Public Health Service Officers Association in New Orleans. She was singled out for her

Continued on page 5.

Ask the Doctor, cont'd from page 2

Due to the high cost and many kinds of insurance not covering this treatment, is there any funding for IVIG treatment?

Dr. Mozaffar: No alternate funding for IVIG other than insurance-based.

What are the primary differences between the types of IVIG available?

Dr. Mozaffar: The difference is in how they are prepared, how they are purified, what the different salts and sugars are.

My son (seven years old) was diagnosed with juvenile dermatomyositis two years back, along with interstitial lung disease. Currently, he is on IVIG every four weeks, starting 1 1/2 years ago. His enzymes (AST and ALT) remained steadily in the 100s after they came down from the range of 500 - 600 with IVIG. He has been on Rituxan for the last six months, and enzymes are down to the 40s to 50s range. His initial frequency of IVIG of every three weeks has been changed to every four weeks for the last three months.

To my knowledge, the effect of IVIG comes down with time. We do not want him to go back to more frequent infusion of IVIG. Do you ever recommend giving higher than 2 gram/KG to maintain the same efficacy if needed rather than increasing frequency? How immunosuppressed is my son with Rituxan, since he is also on IVIG simultaneously? We appreciate your help very much.

Dr. Mozaffar: If the Rituxan worked, he may not need as frequent doses of IVIG as he did before, which is good. Rituxan is a pretty safe medication. We normally don't consider the kind of doses of IVIG that are used in rheumatology or neurology as immunosuppressive so it should not add to the immunosuppression from Rituxan.

Is there any way my doctor can get in touch with you for your opinion?

Dr. Mozaffar: My address is on the myositis webpage, www.myositis.org, under "Medical Advisory Board" and yes, your doctor can get in touch with me.



Practical Solutions, cont'd from page 3

control, from natural childbirth to meditation. If your mind is focusing on something else when a short-lived pain is experienced, it makes it much more bearable.

Young children with chronic conditions have many reasons to be afraid, since experience has shown they have little control over what's happening to their bodies. Sometimes, anticipating the pain of the needle that starts the infusion can be even worse than the procedure itself.

Experts sometimes recommend therapeutic play to make children feel more in control. Children sometimes benefit from pretending to start an infusion on a stuffed animal or doll, using equipment and supplies appropriate for their age. Older children may cope with the pain but dread infusion day because of boredom and isolation. A little bit of preparation and some specialty products may help.

■ **Try an over-the-counter numbing cream.** EMLA, a mixture of lidocaine and prilocaine, is available without a prescription and numbs the skin. Find it at www.astrazeneca.com. Eloquest Healthcare has a cream made from lidocaine that's intended to numb the skin of adults and children two years and older (www.eloquesthealthcre.com).

■ **Buzzy the Bee.** Buzzy is a portable, reusable plastic bee that

gives natural pain relief through cold and vibration. Designed for children older than four years, the bee vibrates and a specially-prepared ice pack fits underneath. A 2009 study found that Buzzy significantly decreased pain, especially in very anxious patients. Also available for kids are Bee-Stractor cards with age-specific questions that help distract them from medical procedures. Find Buzzy at www.buzzy4shots.com.

■ **IGlasses.** These virtual reality glasses are a high-resolution, head-mounted display weighing only 2.4 ounces. They feature a virtual image size of 80 inches as seen from five feet, with the capability of viewing 3-D formatted programming in true stereoscopic 3D, connecting to any standard video source (DVD, VCR, MP4). Find out more at www.iglassesstore.com.



Rider, cont'd from page 4

groundbreaking research in the area of juvenile dermatomyositis.

"[This award is] presented in recognition of her noteworthy basic and clinical research into juvenile dermatomyositis," read the citation on her plaque. "Her leadership in epidemiologic and clinical studies has contributed substantially to public health practice. Her career achievements are in the highest tradition of the United States Public Health Service."

Rider is one of the leading authorities on clinical presentations, pathogenesis, and treatment of idiopathic inflammatory myopathies, particularly the childhood forms of these diseases. She is an original member of TMA's medical advisory board.



Watch the summer drinks

Although everyone knows that pizza, ice cream and French fries are loaded with calories, most of us don't pay much attention to the amount of calories we take in with each cooling summer drink. Here are a few examples of how what you drink may very well affect your weight and blood sugar:

- An 8-ounce serving of Pepsi has 100 calories and 27 grams of sugar.
- A serving of Gatorade has 50 calories, and 14 grams of sugar.
- A cup of Red Bull energy drink has 106 calories, 26 from sugar.
- A cup of Tropicana orange juice has 112 calories, and 22.5 grams of sugar.

With medications and the hot sun causing you to be extra thirsty, it's easy to see how you could take in hundreds of calories in liquid form while barely being aware of it. Try alternating juice and soft drinks with lots of water or unsweetened tea.

Looking for a job? Know your rights

The summer issue of "I.G. Living" tells the alarming story of Tyler Sutton, a college student with excellent credentials about to graduate from a prestigious university. Sutton went on interview after interview, believing he was an excellent candidate, but he was hitting a wall. He wasn't getting any job offers, and he wasn't even being asked back for a second interview.

Concerned, he asked for an evaluation of his interview from one compa-

ny's recruiter, with little satisfaction. He began to look at the credentials of the people who were eventually hired and saw they had lower grade point averages than his, and fewer social accomplishments.

Sutton, who suffers from a rare disease, gradually came to suspect that his volunteer work with the charity serving people with his disease and online recognition of his success was actually working against him. Employers who do internet searches on potential hires would find out about his disease and fail to call him for a second interview.

Job discrimination because of illness is a complicated matter. Employers can discover your illness on social networking sites, but these very sites provide valuable information and support to people with rare diseases. Some patients use fictitious names and some only go to websites that require registration.

TMA often features both adults and young people in its quarterly newsletters, but these materials are only available with registration and do not appear in internet searches. In our materials, we always respect the rights of patients to remain anonymous when they are featured in a print article or online.

Rather than giving up involvement in support groups and online communities, educate yourself about the law and about how best to answer employment interview questions. As contributor Jennifer Kester points out in her I.G. Living article, the wrongdoing is on the part of the employer, not the person with the rare disease,

and there are laws to protect people with disabilities.

To find out your rights as you search for a job, read the full article at www.IGLiving.com.

Would assistive technology help you?

If you're headed to college or to the workforce and need some adaptations to be more effective, find out if you are eligible to receive them. Many students with temporarily weakened fingers or voices find voice recognition software and other high-tech assistive devices very important.

If you are presently receiving benefits from Medicaid, you may be eligible for some technical assistance devices that aren't specifically covered yet.

Medicaid, a health insurance program, pays for devices that are obviously medical. High-tech electronic devices are not so familiar. Aids like computers with voice output, or environmental control units may be more difficult to obtain, because they do not look like traditional "medical" equipment. However, if you need these kinds of devices to help restore or improve your functioning, there is a good argument that Medicaid should provide these devices. Medicaid should also pay for services (like instruction) to help you benefit from or use your device. To find out exactly what you are eligible for, contact your state's Medicaid office. Find contact information at <http://www.cms.gov>.

Have fun inside!

Although summer is a great time for swimming, baseball and all kinds of outdoor fun, you may have to stay inside more than you'd like because of your JM. You can have a good time indoors while also getting back some of your finger and hand strength by making things from clay.

You don't have to rush out and buy a bunch of clay from a craft supply store. Chances are the ingredients are right in your kitchen. You can make clay that's edible, rubbery or colorful; or one that hardens enough to paint by using one of these recipes:

Edible play dough

- 1/2 cup peanut butter
- 1/2 cup honey
- 1 cup powdered milk

Directions: Mix it up and mush it up with your hands until it's fairly smooth. Store in an airtight container and refrigerate.

Play dough

- 1 cup flour
- 1/2 cup salt
- 1/2 cup water

Directions: Mix well until it forms a ball. Knead and add food coloring. If too sticky, add some flour and if too dry add a small amount of water. Store in an airtight container in a cool place.

Play dough #2

- 1 cup flour

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- 1 cup warm water
- 2 teaspoons cream of tartar
- 1 teaspoon oil
- 1/4 cup salt
- Food coloring as desired

Directions: Mix all ingredients (add food coloring last). Stir over medium heat until smooth. Remove from pan, let cool slightly, and knead until blended and smooth. Store in a plastic bag or airtight container when cooled.



Options are endless with homemade clay!

Rubber dough

- 2 cups baking soda
- 1 1/2 cups water
- 1 cup cornstarch

Directions: Mix everything into a saucepan. Boil over medium heat until the mix is thick. Plop onto a plate, cool and play.

Keep it Clay

This mixture dries very hard, so it's good for making beads.

- 1 (1-pound) box baking soda

- 1 cup cornstarch
- 1 1/4 cups cold water
- Food coloring (Gel food coloring is best, or you can leave it uncolored and paint later)

Directions: Mix baking soda and cornstarch together, then add water. Cook and stir over low heat until it reaches the consistency of mashed potatoes. Remove the dough from the heat and cover with damp towel until it is cool enough to handle. Use for jewelry shaping or roll it out and cut with a cookie cutter to make decorations. Store in an airtight container.

Some ideas for clay creations:

- Use cookie cutters to cut shapes in the dough. Use a straw to make a hole at the top. Let dry, then string a ribbon through the hole and you'll have a Christmas tree ornament or other decoration.
- Roll the dough into ropes and make the letters of the alphabet or numbers.
- Make beads, string them on floss and let dry into a necklace.
- Make a collection of toy dishes.
- Make sculptures of your family.
- Make Noah's ark with animals.

Check out these great videos about working with clay on youtube:

www.youtube.com/watch?v=o7ReyLeGVk8

www.youtube.com/watch?v=qekGD9V74Qk&NR=1&feature=fvwp





THE MYOSITIS ASSOCIATION

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News&Announcements

Myositis information card

Are you tired of trying to explain myositis? TMA now has available a simple myositis “business card”. It contains your name and contact information and the back has a short understandable explanation of your form of myositis. It makes explaining the disease easier and gives people TMA’s website so they can find more information about myositis.

Help us create awareness of this disease and order your card today. You will receive 100 cards (personalized with your contact information) for just \$20. To order, go to www.theupsstorelocal.com/6134 and click on “Request Cards Here” or call 770-297-9944.

Combined Federal Campaign - Workplace Giving

Federal and military employees can support TMA through workplace giving by designating CFC# 11526.

CHECK OUT THE OUTLOOK

Take a few minutes to look through TMA's adult patient newsletter for items of interest to families with JM. In this issue:

- Fabio and his work with TMA
- More from Dr. Mozaffar on IVIG
- Alternatives for pain control
- Modern drugs improve outlook for chronic disease
- Monitoring multiple medications

JM COMPANION