

# Fighting back

MEET EMILY SMITH AND ANDY MOY. YOUNG AND DETERMINED, THEY'RE TAKING CONTROL OF THEIR PSORIATIC ARTHRITIS.

By Heather Johnson Durocher

Emily Smith came home from school one day with this news for her mom: "I'm going to join the track team and pole vault."

That her teenage daughter wanted to get involved in a new sport wasn't surprising to Liz Smith—Emily enjoyed gymnastics as a child and was playing soccer at her high school—but the mother of six couldn't help wondering how wise it was, given Emily's psoriatic arthritis.

"But she said, 'I feel better,' so we talked to her doctor and he said, 'Let her do it, she's a smart kid,'" says Liz Smith, who lives with her family just outside of Washington D.C. "And she's having a ball. She doesn't always get to participate in every practice, but the coaches are fantastic, they're very supportive. And off she goes."

A confident, go-get-'em mentality is immediately evident when talking with Emily Smith. While the 17-year-old has dealt with psoriatic arthritis for years, she's not about to let it slow her down more than necessary.

"I try my hardest not to," she says. "I've encountered people where that is their thing in life, they are negative about everything, and I don't want to be that way."

As many as 7.5 million Americans have psoriasis, and of those people, up to 30 percent also develop psoriatic arthritis, which causes pain, stiffness and swelling in and around the joints.

## Biologics for kids?

Making the decision to try biologic drugs for children may not be easy for families because these types of treatments are not yet generally approved for use in young people under 18. Also, potential side effects include the risk of serious infections or malignancies because biologics affect the immune system. Still, doctors do prescribe them for children on a case-by-case basis.

As with any medication, it's important to weigh with a health care provider any potential benefits and possible risks of a using biologic drug. That's how the families of 10-year-old Andy Moy and 17-year-old Emily Smith, who both have psoriatic arthritis, handled their respective decisions.

"We had done so many other things, it was like, 'What's next'? And what was next was the biologic," says Andy's mother, Jaime Moy, of Waterford, Mich. "It was difficult but at same time it was all we had left to try. We didn't want to waste more time than we felt we had already lost."

Andy did experience rough side effects when he first tried a biologic. Since then, he's had more success with other biologics. Andy also takes medications for acid reflux, which his mother





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Few studies exist on how many children have psoriatic arthritis, which can appear at any age but most commonly appears between the ages of 30 and 50. Psoriatic arthritis comprises up to 15 percent of children of the cases of children with juvenile arthritis, says Dr. Marisa Klein-Gitelman, who heads the rheumatology division at Northwestern University in Chicago. And, according to Klein-Gitelman, about six of every 10,000 children have juvenile arthritis. The Arthritis Foundation describes juvenile arthritis as “any form of arthritis or arthritis-related condition that develops in children or teenagers who are less than 18 years of age.” >>>



Liz and Emily Smith

## Weighing benefits and risks

says is partly due to side effects from his psoriatic arthritis medication.

“We’re seeing great improvements now with [the biologic drug] Humira,” Jamie Moy says. “Andy likes gym class, he’s playing dodge ball, things he never would have done a few months ago.”

Liz Smith also is pleased with her family’s decision to try biologics for daughter Emily’s psoriatic arthritis.

“Quite honestly, putting Emily on biologics wasn’t a difficult decision for us,” says Liz Smith, who lives near Washington, D.C. “While we are always concerned about potential side effects of any medication, we also keep in mind that the side effects are just that—potential. Emily had been struggling for some time and needed a higher dose of methotrexate than her body could tolerate. Her quality of life was going downhill.”

The family trusted Dr. Harry Gewanter, Emily’s pediatric rheumatologist, when he suggested biologics.

“Soon after starting biologics—just before her 11th birthday—Emily told me that she had never known it was possible to feel so good. That was both a wonderful and a heartbreaking thing to hear.”

Dr. Gewanter is a proponent of using biologics to treat children who have psoriatic arthritis.

“Biologic medicines do a nice job for the vast majority of them,” says Gewanter, whose practice, Pediatric and Adolescent Health Partners, is in Richmond, Va.

“It’s just amazing,” he says, to see how well biologics can work for the kids he sees with psoriatic arthritis. “There are a lot of potential side effects, there are significant potential problems, but you have to weigh what are the potential problems with the potential benefits.”

Six years into using biologics to treat her daughter’s psoriatic arthritis, Liz Smith believes the benefits far outweigh any side effects.

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“We’ve been fortunate, as she’s not had any serious side effects,” she says. “For a while she did get more infections than she had in the past, but they never got out of control. As time has passed there have been fewer infections. We still wonder what the long-term effects of these medications might be, though it certainly appears that we don’t need to be concerned. But I’m a mom so I’m sure I’ll always worry.”

—Heather Johnson Durocher



A combination of drugs helps Andy Moy, 10, manage his psoriatic arthritis

### Diagnosed at 15

Psoriatic arthritis can be difficult to diagnose because there is no specific test for the disease. In Emily's case, she was first diagnosed as having juvenile arthritis as a toddler in 1994.

"She slipped and her ankle swelled up. It never healed," says Liz Smith. "Other things swelled and her pediatrician did a bone scan. We weren't completely shocked, yet you're still caught off-guard. We said, 'OK, it's just arthritis, it's not cancer, she'll get onto meds.'"

At age 15, when she discovered psoriasis on her face, Emily's diagnosis changed to psoriatic arthritis. She's managed her arthritis through the years with various medications—steroids, methotrexate and biologic drugs—and has switched when one no longer worked so well.

"There was a time when she was not able to get up and down the stairs independently," says Liz Smith, who acknowledged that "we've been through the wringer through the years.

"(Emily) still has some bad days, but nothing like we had in the past," her mother says. "She's older, she knows what's going on and what to expect. She doesn't try to hide it. She shares it."

### Finding the right drug

Ten-year-old Andy Moy of Waterford, Mich., was diagnosed with psoriatic arthritis when he was 5, after first dealing with scalp psoriasis.

His pediatrician thought the dry skin was likely ringworm and prescribed medication, says his mom, Jaime Moy. But when that didn't help, Jaime and her husband Nelson took their son to a dermatologist, who diagnosed Andy's skin dry skin as psoriasis.

As a preschooler, Andy endured a flare of guttate psoriasis that covered his body from head to toe with dry, scaly patches, Jamie Moy says.

"His gym teacher had called and talked to us. His motor skills were just not even close to being up to par with kids his age."

*As a preschooler, Andy endured a flare of guttate psoriasis that covered his body from head to toe.*

The family turned to University of Michigan rheumatologists, who prescribed methotrexate, a potent treatment with serious side effects. The Moys tried other treatments that worked better at managing his psoriasis and arthritis. Today, Andy takes a combination of drugs that includes twice-monthly injections of the biologic drug Humira.

### Making progress

Seeing the positive side of this disease can prove challenging, but both the Moy and Smith families say they are grateful for the strides they've made with their children's psoriatic arthritis.

"We're very thankful for the good days and try to get out and enjoy the world, and let him have fun on those days," Jaime Moy says.

"The good news is, I have a 17-year-old daughter who is wise beyond her years," Liz Smith says.

# Beyond meds

**Psoriatic arthritis doesn't have to keep you from doing the things you enjoy. Read on for tips for living well with this disease.**

- **Insert humor into your life whenever possible.** Emily Smith—whose diagnosis of juvenile arthritis when she was a young child turned into a psoriatic arthritis diagnosis when she was a teenager—says keeping things light has helped her deal with her health struggles. “When people ask me about my psoriasis, I tell them I have scales,” says Emily, 17, who lives near Washington D.C. “It’s the easiest way to explain it. I like to take a humorous approach to my health problems. It keeps your attitude more light.”
- **Maintain as active a lifestyle as possible.** Emily participated in gymnastics as a child. She went on to play soccer before most recently taking up pole vaulting on her high school’s track and field team after checking first with her doctor. Ten-year-old Andy Moy, whose psoriatic arthritis has been rather severe at times, enjoys playing outdoor sports. His family also likes going to theme parks, and they aren’t afraid to make use of wheelchairs for the tail-end of their time at these locations. “You want to make it memorable in a good way,” says mom Jaime Moy, of Waterford, Mich.
- **Become involved with organizations and support groups.** “I’ve been going to national arthritis conferences since I was 6,” Emily says. “I’ve been around a lot of supportive people so I have not let (psoriatic arthritis) bog me down too much.” Andy Moy and his parents have found support through such organizations as well as with fundraisers and awareness-building events held at Andy’s school and during arthritis and psoriasis walks.
- **Maintain close ties with your physician.** “Be an equal partner on the medical team,” Liz Smith, Emily’s mom, advises. As parents, encourage your children to listen to their bodies and be part of the process as well. “You get a much more cooperative patient when the patient is included in the decision-making.”
- **Keep things in perspective.** Along with finding humor, Dr. Harry L. Gewanter advocates remembering that each of us deals with something in our life. “Everybody’s got something. There ain’t nobody perfect,” says Gewanter, a pediatric rheumatologist who treats Emily Smith. “None of us gets to do everything we want. It’s how we handle things within our abilities.”

—Heather Johnson Durocher

Read about Heather Johnson Durocher’s own struggle with psoriasis on page 48.



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## About psoriatic arthritis

Though no one knows what causes psoriatic arthritis, researchers believe that genes, the immune system and environmental factors all play a role in the onset of the disease. Early recognition, diagnosis and treatment can help prevent or limit extensive joint damage that occurs in later stages of the disease.

## Want to know more? Check out these resources:

[www.psoriasis.org](http://www.psoriasis.org). Click on the “Learn” box, then click on “psoriatic arthritis.”

[www.arthritis.org](http://www.arthritis.org). Search for “psoriatic arthritis.”

[www.psoriasis.org/publications/booklets](http://www.psoriasis.org/publications/booklets). Read, download or order a copy of the National Psoriasis Foundation’s “Psoriatic Arthritis” booklet. Or call a Foundation health educator at 800.723.9166 to order a copy. ■