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Spreading the Word

Seven-time Grand Slam champ Mats Wilander formed the MW Foundation as a way to help build awareness of Epidermolysis Bullosa, a connective tissue disorder that causes extremely fragile skin.

Finding a Cure

Mats Wilander helps lead the charge against what's described as The Worst Disease You've Never Heard Of

by **Andrew Friedman**

Mats Wilander's son, Erik, plays hockey, not tennis. He loves the sport that made his father a household name, but he can't play, at least not singles. The constant starting and stopping, and the friction they create inside his shoes, cause his feet to blister and bleed.

Erik was born in 1997 with a relatively mild form of Epidermolysis Bullosa, or EB, a genetic connective tissue disorder that causes extremely fragile skin that blisters and tears from minor friction or trauma. Those born with EB are sometimes called "Butterfly Children" because it's said that their skin is as fragile as the wings of a butterfly.

Wilander and his wife Sonya hadn't heard of EB. When they brought Erik, the third of four kids, home from the hospital after he was born, he developed blisters on his head. "I took him to a doctor and the first thing he asked was, 'Has he been near any hot items?' implying that I'd been burning him," Wilander recalls. He pauses, then adds, "The doctor didn't know."

The Wilanders connected with a Yale University physician who was familiar with EB and explained to them that the disease was inherited, enabling them to connect some dots in their family history. "We learned that the reason a few of Sonya's sisters couldn't walk more than a mile without getting

Wilander decided to make himself available as the "face" of DEBRA. "They were excited," he recalls. "They needed a high-profile case because it's hard getting funds." He began hosting an annual fundraising event comprising tennis, golf and a dinner at the Westchester Country Club in Rye, NY, in 1999.

"Without Mats, I'm not sure the organization would exist today," says Brett Kopelan, who became executive director of DEBRA of America in 2011. "To have him involved has been really advantageous."

Kopelan runs DEBRA from its New York offices and first learned about EB when his daughter was born in 2007 with what he says is a "particularly severe form of the disease." Kopelan did what too many of us do when faced with a medical mystery. "I went on Google," he says. "That was a bad idea. What I saw was grim. I thought, 'This is the worst disease I ever heard of.'"

Kopelan also came face to face with the harsh reality all EB parents must confront: There is no cure.

"My daughter is an incredibly young, smart little girl," Kopelan says. "I would like her to live into adulthood."

Kopelan says DEBRA has always provided great services, but it had fallen short in the fundraising department. A former marketer, he has been working to raise awareness and donations.



Generating Support The first official MW Foundation event took place this past August at the West Side Tennis Club, the fabled facility in Queens, NY.

blisters was not from lack of exercise," Wilander says. "My daughter also has it, but it came out only when she went to soccer camp and played for three hours a day."

Many EB patients live in a constant state of pain management, in the worst cases tending to a steady proliferation of wounds; many have such sensitive skin that friction with bed sheets causes them to wake up each morning with new wounds, requiring sheets to be gently peeled from their skin and wounds to be wrapped in expensive gauze bandages. The disease can also affect internal organs and bodily systems; more severe forms can result in disfigurement, disability and early death, sometimes in the first months of life; others before the age of 30.

Shortly after learning about EB, the Wilanders found out about DEBRA, or Dystrophic Epidermolysis Bullosa Research Association of America, founded in 1980, and part of an international network. The Wilanders' education continued.

"Insurance companies don't like paying for prevention," Wilander says. "They don't like paying for gauze bandages; they'd rather wait and pay for the skin grafts."



Children who are born with Epidermolysis Bullosa are sometimes called "Butterfly Children," because it's said that their skin is as fragile as the wings of a butterfly.

Wilander's own fundraising efforts have evolved in the past few years as well, with the development and success of Wilander on Wheels (WOW), his traveling tennis fantasy camp that he runs with business partner and co-instructor Cameron Lickle. The dynamic duo travels to individual clubs and other organizations and venues across the United States, offering clinics, meet-and-greets and exhibitions.

What began out of Wilander's more-than-gently-used Winnebago has evolved into a thriving business that keeps Wilander and Lickle on the road roughly a third of the year. The team has added a new, second RV to their "fleet," and developed relationships with 120 new clubs over the past year. Wilander and Lickle also host a traditional fantasy tennis camp at Zynergy Health Club and Spa in Idaho's Sun Valley a total of three weeks each year. The team recently released their first instructional e-book, *How to Be the Best Player You Can Be*, and has taken on such sponsors as Lacoste, whose clothes they wear at all times, and BuchuLife, a South African nutraceutical producer; samples are handed out to participants at every clinic.

Since starting WOW, Wilander and Lickle had been sending out periodic emails to raise awareness about EB and support

photographs with guests who paid \$250 each to attend, then treated the fans to an exhibition.

Just before the exhibition, Wilander spoke about EB, then Kopelan, dressed in tennis whites for the occasion, described how the disease attacks not just the patients, but also their families. "It attacks you emotionally and financially," he said, explaining that bandages alone can cost a family \$10,000 per month. (Last year, DEBRA allocated \$400,000 to helping families relieve this expense.) Wilander also presented Kopelan with a check for \$20,000 from the MW Foundation to DEBRA. The event was followed, in October, by a dinner and auction at the Museum of Modern Art in New York City.

"When I came on, we were raising about \$600,000 year; now we're in the \$1.3-million range," Kopelan says of such events, which he describes as "the lifeblood" of DEBRA. "Hopefully, it will be higher this year."

Those might not sound like huge numbers, but last year, DEBRA International, according to Kopelan, funded about \$4 million in research. The big challenge for DEBRA, he says, is that EB affects "only" about 20,000 people a year, not enough to register with many potential benefactors or corporate sponsors. To change that, he finds himself balancing the grim and



Helping Hands Former pros Jonas Björkman, Thomas Johansson and Karel Novacek were among those who attended the August MW Foundation event.

for DEBRA, but felt that the email was disappearing into the virtual ether. "We weren't feeling anything coming back from it," Lickle says. So, last winter, they formed the MW Foundation, and began making a sales pitch at the conclusion of each clinic, trying to pay WOW's success forward to DEBRA.

It seems to be working: By September, this grassroots effort, coupled with follow-up emails, had inspired, according to Lickle, approximately \$35,000 in donations. Most of those funds will go to DEBRA, and a small portion will likely go toward supporting wounded-warrior initiatives, a cause close to Lickle, who served in the U.S. Navy as a nuclear engineer.

On the first Wednesday of this year's US Open, Wilander and Lickle in conjunction with Kopelan, organized the first official MW Foundation event, an adaption of the former Westchester fundraiser, set at the West Side Tennis Club, the fabled facility in Queens, NY, situated amid Tudor-style homes in an enclave of Forest Hills. Wilander was joined by fellow former pros Jonas Björkman, Thomas Johansson and Karel Novacek. On the club's grass courts, the pros played, chatted and posed for

graphic nature of the disease (he recently introduced a DEBRA tag line, "the worst disease you've never heard of") and the inspirational nature of those who endure it. He hopes to see as many as 25,000 new donors in the next two years thanks to the coming online advertising campaign and other initiatives.

Kopelan is also guardedly optimistic about what the next few years will bring on the research front as strides are being made with protein replacement and gene therapy. "It could make EB like diabetes," he says. "You'd go to the hospital every four to six weeks and get an infusion. You'd still have the disorder, but it'd be controllable." A cream that promises greater wound relief has also been developed, with clinical trials set to begin in 2014.

"I feel an urgency because they're getting close to a cure," Wilander says. "You meet Brett and his daughter and realize they're fighting for their lives."

Wilander and Lickle are excited by their new foundation, but would also happily see it dissolved, under the right circumstances. "The goal," Lickle says, "is to find a cure. Then there would be no more need for it."

DAVID KENAS