

# Mom fights for answers on what's wrong with her son

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By Chico Harlan / Pittsburgh Post-Gazette

It is summer 2001, an evening, 9 p.m. A husband sleeps, tired from work. Two older children go to bed. The house on a wooded dead-end street in the McMurray area of Peters, falls quiet, but for the mother and youngest son, at least one of whom appears sick.

Drew is 2, almost 3. He says "mommy" and "daddy" and "milk," and often, when he points to an irritated patch of skin under his lips, "bugs." How strange, the mother thinks. She's already taken Drew to several Pittsburgh dermatologists and pediatricians, but nothing they've prescribed, for eczema, for atypical scabies, has stopped his itching. On this night, the mother bathes him, paying careful attention to his skin.

The boy snuggles into his mother's lap, dried off, quiet and agreeable. Mary Leitao rubs him with the prescribed scabies cream, making gentle circles with her hands. In the years that follow, the mother will think often about this moment, cursing it, re-examining it and pinpointing it as the start of everything. As Ms. Leitao rubs, something fiber-like emerges from the boy's skin, she'll later say. As a biologist, she's mesmerized. As a mother, she's horrified.

Ms. Leitao collects a sample of the strands from Drew's skin. They glide right off, like filaments from a dandelion. She places them onto slides, examining them under an \$8 RadioShack microscope. She's looked thousands of times into microscopes, fancier ones, first as a biology student at the University of Massachusetts-Boston, and later for five years as a medical researcher at two Boston hospitals. She's seen nothing like this before. She shakes her head and thinks, "These things cannot be coming out of my son's body."

The ambiguity soon rearranges her life. The resulting medical mission will come to obsess her and challenge her sanity, in large part because she's suddenly been planted opposite the mainstream medical community. The symptoms that Ms. Leitao now attributes to some 4,500 people nationwide are, by word of most dermatologists and psychiatrists, a part of delusional parasitosis, a psychiatric disorder. Victims complain of similar symptoms: crawling sensations and skin infestations. Those with delusional parasitosis insist such problems truly exist, and cycle from physician to physician, seeking validation, never finding it.

But then Mary Leitao sees something sprout from her boy's skin, and she sets out to find answers.

## Galvanizing force

"Fibers," she calls them at first. She hopes to find they're merely sweater strands, or a simple fungus.

But after months of studying, she finds something else, something variably red and black and blue that fluoresces under the proper light. Her first description: under magnification, the fibers appear ribbon-like and coenocytic, meaning without cell walls. Dozens of times, Ms. Leitao tries to prove herself wrong. People don't sprout fibers, logic tells her. She swabs Drew's irritations clean, ensuring them to be fiber-free, and covers them with a sterile, nonfibrous wrap. The fibers return.

Ms. Leitao uses a biology lab to continue her studies. She concludes that the medical system owes her some answers. Her husband, Edward, an internist with South Allegheny Internal Medicine in Bethel Park, tells her as much: Rely on medicine, he says. He, too, feels Drew has something unknown, and what good research doctor can resist a chance to crack away at an answer?

Ms. Leitao spends hours at home searching the Internet. She arrives at a message board, a scabies forum, where people nationwide share stories about crawling sensations and fibers. From the discussion board participants, Ms. Leitao hears that those symptoms often portend something far worse: a debilitating cognitive and neurological breakdown, appearing similar to chronic fatigue syndrome. An Internet user e-mails Ms. Leitao: If you are seeing these fibers with your son, you have a big problem.

First, Ms. Leitao accepts this notion, and then she fights for it. The stay-at-home mother, a graduate of Aliquippa High School, galvanizes an unknown subset of the country, a group united by its claims of crawling sensations and fibers.

Ms. Leitao creates a Web site ([Morgellons Research Foundation](#)) devoted to what she believes is a new disease, which she names Morgellons after an obscure 17th century French reference to black hairs. It is now March 29, 2004. She formally establishes the Morgellons Research Foundation, a nonprofit group headquartered in her home.

She's the executive director, meaning she must endure two recurring messages, both burdensome in their own ways. Those disputing the disease tell her she's crazy. Those convinced they're suffering from it tell her she's their last hope.

Daily, she spends four or five hours talking on the phone. She corresponds with a woman in Texas who once poured lighter fluid on her skin lesions, hoping to set fire to the insects inside her. She befriends a man in Virginia who'd gained 100 pounds and spent four years on his sofa, isolated from friends and family. And when a twentysomething dies of a painkiller overdose, ending his fight with Morgellons symptoms, Ms. Leitao calls the man's mother and tells her, "We are fighting a system that's so messed up."

In quieter moments, that self-assuredness threatens to buckle. Ms. Leitao's foundation inspires no medical uproar, no political support, no government action, perhaps for good reason.

Those registered as Morgellons sufferers swarm medical offices, reciting stories about the fibers, the fatigue, the joint swelling, the nights in which itching prevents sleep, the fatigue that drops them onto the couch for 30 hours straight, the hopelessness that prompts thoughts of suicide. The implausibility of such frenzied symptoms begets a common, simpler diagnosis.

"They suffer terribly, but it's psychiatric," said Dr. Dirk Elston, a dermatologist in the Geisinger Medical System in Danville, Montour County. "The fact that there's something online to cling to, it's a difficult obstacle for us."

"The moment you mention psychiatrists, these patients get extremely angry," said psychiatrist Alistair Munro, author of "Delusional Disorder."

"They say there's nothing wrong with their brain. They have all kinds of explanations."

Drew continues to see doctors, Ms. Leitao by his side. The fibers still sprout. The pair meets with UPMC dermatologist Douglas Kress, who diagnoses eczema. His prescribed medications fail to help. Ms. Leitao speaks with pediatrician Dr. Michael Frac, who describes himself as "pretty conservative, not a left-field-type of person."

The Bethel Park physician knows the medical skepticism about Morgellons, but he also knows history. He thinks of Polly Murray, who, decades before, had tried to convince the medical world that she was sick, not simply hypochondriacal. Her persistence pioneered Lyme disease.

"Maybe mainstream medicine has been dismissive of this, too," Dr. Frac said. "They haven't given this a fair shake." He acknowledges that most physicians lack the research power to find the causality of new diseases. He refers Ms. Leitao to Dr. Fred Heldrich, a Johns Hopkins pediatrician known for solving mystery cases.

Ms. Leitao continues to work from her home office. She eventually gathers seven advocates -- nurses and physicians -- into a medical advisory board, all volunteers, and she lists the supporters on her Web site.

The new voices widen Ms. Leitao's platform: Georgia-based pediatrician Dr. Greg Smith, who identifies himself as a Morgellons sufferer, writes to politicians with his story. Texas nurse Ginger Savely treats some 125 patients, telling them, as she prepares experimental treatments, "You're signing up as a lab rat." Dr. William Harvey, a former medical director of the lab contracted to work for NASA, observes 70 patients complaining of Morgellons and finds that all carry a bacteria called *Borrelia*, which, possibly, tampers with the entire immune system. He treats patients with antibiotics -- Rocephin or Zithromax -- and almost always, symptoms subside.

But the success, purely anecdotal, never helps Drew. His doctors refuse to prescribe powerful antibiotics without research that proves the need for them. On the advice of Dr. Frac, Drew and Ms. Leitao drive to Baltimore to visit the Hopkins expert, Dr. Heldrich. He forms his own conclusion about proper treatment of Morgellons.

"I found no evidence of [anything suspicious] in Andrew," Dr. Heldrich wrote to Dr. Frac after the visit. Then he added: "Ms. Leitao would benefit from a psychiatric evaluation and support, whether Andrew has Morgellons disease or not. I hope she will cease to use her son in further exploring this problem."

## **Rejection, widowhood**

Ms. Leitao endures the rejections and then, overnight, she must endure something more severe. It is July 27, 2004. Her husband, Edward, dies at 54 of cardiac arrhythmia. Her two older children, Jeremy and Samantha, both teenagers, now experience Morgellons symptoms, too, she says. They struggle to concentrate in school and miss dozens of class days. Her daughter takes ibuprofen every day for joint pain and quits the swim team. On days they do attend school, they return home and go straight to bed.

Over time, Ms. Leitao comes to think of herself as a machine engineered for one objective, denying grief because she can't afford it. Still, she recognizes the futility of a single-handed mission against the establishment. She needs help.

Dr. Randy Wymore finds her just in time. The Oklahoma State University assistant professor of pharmacology and physiology stumbles onto Ms. Leitao's Web site while surfing online. He's a

glutton for unknowns.

Dr. Wymore, a Unitarian, holds himself to no dogma.

"We don't claim to have all the answers," he said, "but let's try to help one another on the journey."

So he decides to help Ms. Leitao.

In the summer after her husband's death, Ms. Leitao moves her family to Myrtle Beach, S.C., a new start. At the same time, Dr. Wymore and his family drive from Tulsa, Okla., to California for a vacation. On the way, Dr. Wymore collects dozens of fiber samples: From clothing on Goodwill racks. From hotel drapes. From room corners upswept for 20 years. Though he maintains an open mind, he hypothesizes that Morgellons fibers come from an outside source, something easily explained.

Hundreds of Morgellons fibers arrive at his lab, sent from desperate patients, sent from nurses and doctors. As Dr. Wymore begins a comparison, his skepticism erodes. The fibers resemble one another, and yet they do not resemble hair or waste material or cellulose or any known textile substance.

The fibers, about the size of small eyebrow hairs, are not living organisms, Dr. Wymore decides. He teams with a Tulsa police department crime lab to sort through fiber samples, and though the lab owns a database of more than 800 fibers, these fibers match nothing.

By winter, Dr. Wymore asks Ms. Leitao to fly with her three children to Tulsa. Seven other Morgellons patients will meet there, too, for a one-day preliminary study. Two OSU physicians, Dr. Rhonda Casey and Dr. W. Stephen Eddy, examine the Leitao children's skin. Both doctors, within 45 seconds, encounter fibers lurking beneath unbroken skin. It is Feb. 23, 2006, the day Dr. Wymore and the doctors he's working with become certain of Morgellons' existence.

He plans the next steps, knowing he must gather funding and allies. One person will not figure this out, he decides. Dr. Wymore currently awaits spectroscopy results offering information about the physical and chemical components of the fibers.

"See, the people who don't want to discuss this, they just say, 'We don't grow red and blue fibers.' To a certain extent, it's a little bit of that Earth-is-flat mentality," Dr. Wymore said. "But how many people are open to self-change? [Morgellons] is almost as difficult to wrap your mind around as trying to convince someone to change religious views. Think about it: How often does that work?"

### **Waiting for answers**

It is June 2006. Drew now sleeps with his eyes half-open, a neurological abnormality that worries Ms. Leitao. Drew can't play baseball this season, because he sweats profusely in sunshine and sweat triggers his skin irritations. So instead, Ms. Leitao pitches to him in the yard.

Her older children show pronounced joint swelling. They struggle to concentrate and receive intermittent homebound instruction, available to students whose health limits school attendance.

Ms. Leitao gathers only a handful of donations for her foundation, and has yet to receive a grant. An anonymous blogger maintains an anti-Morgellons Web site rife with personal attacks. Some living with Morgellons become so discontented, they channel frustration toward the one person they can associate with the disease.

"People say, 'Mary, you need to take a break from this.' But it's not like I can forget about this now. I have a lot of friends with this, and they are all incredibly sick. Their neurological problems are getting worse. I've got to see this through. This is a mission. I don't know. ... I think it's fear-based behavior. It does appear to be a bit neurotic, unless you realize what is the driving force. The love of my children and the fear of an unknown disease.

"You know, maybe if enough baseball players get Morgellons, or enough politicians' children? I know, I sound like a crazy woman. ... But what does it take? What does it take?"

Dan Rutz joins an afternoon conference call with Ms. Leitao and her team. He's the spokesman for the Centers for Disease Control and Prevention. Ms. Leitao had written to him months before, asking for an investigation. "[F]or the past four years, ... I have been waking up to a horrifying nightmare," she wrote. Now, Mr. Rutz says, it will happen. The CDC will form a task force to investigate Morgellons. The group will need months to assess the disease's existence with case-control studies and lab work and, perhaps, a scientific fiber examination.

The CDC terms Morgellons a syndrome, fictitious until proven real.

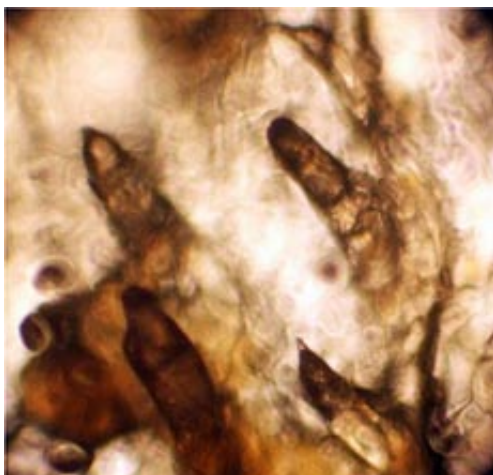
But Mr. Rutz, as the next month passes, allows for the possibility.

"The fact that people are suffering is real," he said. "We don't know if this can be explained under existing paradigms or if it is something new. But these people deserve more than to be blown off."

It is July 11. A 13-member CDC committee meets for the second time. The group includes infectious disease experts, parasitic disease experts, environmental health workers and, indeed, mental health specialists.

Ms. Leitao waits at home, one mile from the beach, knowing a CDC-issued answer could take months. She and Drew watch SpongeBob.

"At the end of the day," Ms. Leitao said, "the truth will stand alone."



**Microscopic view of a dry, membranous-like material formed over an open skin lesion of the type associated with what a small group of people call Morgellons disease.**



Click photo for larger image.

**Morgellons fibers isolated from a patient.**

**A microscopic view of**



Click photo for larger image.

**Mary Leitao, center, with her children: Samantha, Drew, and Jeremy.**

Click photo for larger image. Chico Harlan can be reached at [aharlan@post-gazette.com](mailto:aharlan@post-gazette.com) or 412-263-1227.

**A family photograph shows**

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