

WILHELMINA'S STORY

Genetics and Silver Linings

Wilhelmina is a master at finding silver linings in dark clouds. And, as someone who's suffered from CFS for more than 20 years, and whose daughter was diagnosed with the disease as a teenager, Wilhelmina has had an abundance of stormy days.

In 1983 she was a mother of two and a graduate student at Howard University working on her doctorate in physics when she began to "feel suddenly very unwell. At first I thought it was exhaustion," she recalls.

It soon became clear it wasn't a simple case of exhaustion. She had been active, but now couldn't exercise. She would often find herself leaning against a wall, gasping for air, after a simple walk. She would get lost driving to places "I could have found in my sleep before," and would pull into parking lots and cry because she couldn't figure out where she was.

She couldn't think clearly, unable to comprehend papers she herself had written before her illness. She couldn't complete the work required for her Ford Foundation fellowship. She couldn't finish her doctorate. She couldn't teach physics anymore. "I loved it so much too," she says. "I thought physics was the most beautiful thing in the world, and I couldn't imagine anything else than teaching this lovely, lovely subject to young people."

Wilhelmina became clinically depressed. And now, looking back, she considers that a blessing. "I was lucky because my doctor treated the depression and it went away, leaving everything else," she says. Once her doctor realized the depression was gone, but her symptoms of pain, fatigue, sleep disorders and mental confusion remained, he was able to diagnose her chronic fatigue syndrome.

Wilhelmina credits her husband with holding things together. "I was very fortunate to be married to the kind of man who accepts what happens in life and deals with it the best he can. There were times I was bedridden for long periods of time and he would literally feed me. Whatever I needed him to do, he was there to do it."

In 1990 after Wilhelmina's son went off to college, her daughter Kamilah began showing signs of the illness. She'd always been active and athletic, a teen who loved to dance and run, and who was on the high school drill

team. Wilhelmina became concerned when her once-energetic daughter began collapsing on the couch after school and having difficulty reading.

Kamilah recalls that as an extremely difficult period in her life. "They thought I had dyslexia because I started to have trouble in school, switching letters," Kamilah recalls. "And I hit word blocks where you can't think of words for things."

For Wilhelmina and her husband, a professor at Clark Atlanta University, the symptoms were all too familiar. They worked with Kamilah's high school teachers to eliminate everything from her schedule she absolutely

didn't need to get her diploma, allowing her to conserve her energy for studies and some semblance of health. Her social life was reduced to maintaining one or two friendships.

"The first year Kamilah was sick I wasn't sure she was going to make it through high school," Wilhelmina says. Kamilah's doctor "was absolutely wonderful though, and I knew from my own experience how to deal with it." Instead of focusing on how awful it was for Kamilah to get CFS too, she found the silver lining, grateful that she knew how to help her daughter because she had been through it all herself.

After finishing high school, Kamilah went on to undergraduate and graduate studies at

Clark Atlanta, finishing summa cum laude. She now serves as director of customer relations, enrollment and training for Big Brothers Big Sisters of Metro Atlanta.

Kamilah and Wilhelmina, who have appeared on *Oprah* to discuss the illness, believe there is a genetic predisposition for developing CFS, like so many other diseases. "My son is fine," Wilhelmina says. "I think we were just unlucky. The genetics just hit."

"The more we think about it—and none of us is a doctor—we think my mother had symptoms of it when she was in high school," Kamilah says. "We really believe there's a genetic component."

An added concern is that the next generation might develop it. Kamilah and her husband have a young son, and every hope that he will go through life without CFS.

"It's a spirit-breaking illness. It's a heartbreaking illness," Wilhelmina says. "But it's not the worst illness in the world," she adds, again showing her glass-is-half-full attitude.

