



Elizabeth Allen keeps careful records of the many treatments she has undergone to relieve the symptoms of chronic fatigue syndrome.

The invisible disability

Research into chronic fatigue syndrome has a rocky past. Now scientists may finally be finding their footing.

BY AMY MAXMEN

ame a remedy, and chances are that Elizabeth Allen has tried it: acupuncture, antibiotics, antivirals, Chinese herbs, cognitive behavioural therapy and at least two dozen more. She hates dabbling in so many treatments, but does so because she longs for the healthy days of her past. The 34-year-old lawyer was a competitive swimmer at an Ivy-league university when she first fell ill with chronic fatigue syndrome, 14 years ago. Her meticulous records demonstrate that this elusive malady is much worse than ordinary exhaustion. "Last year, I went to 117 doctor appointments and I paid \$18,000 in out-of-pocket expenses," she says.

Dumbfounded that physicians knew so little about chronic fatigue syndrome — also known as myalgic encephalomyelitis or ME/CFS — Allen resolved several years ago to take part in any study that would have her. In 2017, she got her chance: she entered a study assessing how women with ME/CFS respond to synthetic hormones.

After decades of pleading, people with the condition have finally caught the attention of mainstream science — and dozens of