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THE  TIMES**Fatal insomnia: the couple searching for a cure**

Eric Minikel and Sonia Vallabh were married in 2009 Jason Grow

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## When Sonia Vallabh discovered that she had a deadly disease, her husband joined her in the search for a medical miracle

What if you watched your mother die one of the most horrible deaths imaginable, cowering in pain without a moment's rest? What if then you were told that death by sleeplessness was to be your fate too? What if the only way to find a cure to this tortuous and rare killing disease was to do it yourself? What if you had to give up everything to retrain at one of the most prestigious labs in the world? What if you had to race against a ticking clock to save your own life? What if the love of your life wanted to keep you alive so much he gave up all his dreams to help you? Meet Sonia and Eric, a love story like no other.

"We're in love," they say simply. "We've changed everything in our lives. Next, we want to change history."

There's something improbable about this story, so far-fetched that Hollywood would reject it out of hand. We have ticking bombs in the movies, but there is a ticking bomb inside Sonia Vallabh's brain. We have couples in blockbuster romances who defy the odds to stay together, but Eric Minikel knows that unless they can pull off a medical miracle his wife will succumb to a bizarre death by sleep deprivation while still in the prime of life. So Sonia and Eric embody what it is to be extraordinary. They are extraordinary in their terrible luck: the disease called fatal familial insomnia, where your brain disintegrates so fast it forgets how to sleep, is so rare that only 100 people in history are known to have had it. And they are extraordinary in their response to that terrible luck: to try to reverse it with a plan just as improbable.

And yet, when I speak to Sonia and Eric, a curious feeling comes over me. It's not pity, it's envy. This story isn't a quirk, a one-off so rare you can sleep sound in the knowledge it will never happen to you. It is in fact universal. We all have to face death. We all yearn to find meaning in life. The threat of Sonia's brain disease has given her mindfulness. The threat of never being able to sleep has awoken her from our big collective doze, as we sleepwalk through our lives.

But first, back to the start. Their story begins with a happy ever after. Sonia and Eric fell in love and had a glorious summer wedding in 2009 in the back garden of Sonia's parents' home. The wedding was her mother's project, and the last time the pair would see her well. Sonia and Eric were busy being members of the post-graduate academic elite, Sonia at Harvard

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Eric an urban planner trained by Massachusetts Institute of Technology. But Sonia says she never really fit well with the other Type-A Harvard lawyers: “I was hell-bent on having a good, normal, life with my husband. That was my mission.”

Yet life was not normal. Her mother began complaining of little things, forgetfulness, losing weight. There was a new restlessness to her that no doctor could diagnose. After all, at 51, she was too young for most likely illnesses. Anyway, they didn’t have the time: her descent was spiralling out of control. She forgot how to walk, eat, or talk to her family. Sonia lay in bed next to her mother but neither got any respite, she was agonised through the night. Soon her mother was hospitalised: bewildered, traumatised, and finally her brain almost completely attacked. Just before Christmas of 2010 the family took the decision to take her off life support.

Then came a cruel twist to Sonia’s bereavement. The autopsy was meant to bring relief. Instead it came with a diagnosis of what had killed her mother that was for Sonia an unspoken “you’re next”. It was “fatal familial insomnia”, a prion disease similar to CJD, the human form of mad cow disease, and called by one of its discoverers “the worst disease you can get”. Its average age of onset is 50, patients typically go without sleep for months and then die in pain within a year. It is incurable and untreatable.

Sonia had never heard of this outlandish illness, and suddenly her father was urging her to get a genetic test for it: there was a 50-50 chance she had inherited it from her mother.

“Telling Eric was the hardest thing I’ve ever had to do,” Sonia says. “To know that this terrible way to die could happen to us, to go through that was worse for him than for me.”

During the six-week wait for the test result, her mind continually flipped the death coin, over and over, until she could bear it no longer. As Eric said, “getting the news she was positive was less traumatic than hearing she was at risk. We didn’t necessarily feel much worse than before, and certainly in a few days we felt better.”

She was 29, and considered herself to have about 20 years left. For want of anything better to do, they went back to their lives in Boston as before. Two days later a friend came to visit, and said “science has answers for you”. They were grieving, and this struck them as insensitive: science had given them no hope. The memory stick full of the scientific literature on prion diseases he left for them was discarded on the coffee table.

Over time, however, his words wormed their way into their thoughts. At least they should become informed, even if there was no cure. As arts graduates, their collective scientific knowledge was “laughable”. Here, the city they were in, home to many of the most advanced medical science laboratories in the world, became their first piece of luck. So they began weekly science nights at their apartment where they would invite researchers they knew to get them up to speed on the jargon in the field of prion research. It wasn’t enough: before long Sonia was sitting in on every relevant class at MIT. By last spring she was impressive enough to give up being a lawyer and start a new job in stem cell research at Massachusetts General Hospital.

I ask how someone — even someone academically able — could switch paths so quickly, and she says that when she tells professors she has 20 years to cure herself, people find it pretty motivating. No one carrying a prion disease has worked in prion research before. Now the foremost experts in the field want to keep their colleague alive. This couple’s sense of urgency is so intense that I feel like I can’t even keep them talking for this interview too long.

“The irony is that before this happened I was all about sticking to 40-hour weeks, and now I’m the one getting the last train home after 10pm and so excited with what we’re doing.”

After a few months of this, Eric abandoned his beloved career and switched fields too, joining her in the laboratory, specialising in bioinformatics while retraining. Eric had loved his job, but “the momentum of it just felt so good”.

Some day, they would like kids, and if this happens they will use genetic testing to ensure Sonia does not pass on the disease. Right now, the work is all-consuming, and they both regard their second job as raising money for the charitable arm they set up, Prion Alliance, which has already funded its first study on a medical cure.

I brace myself for some difficult questions. Both Eric and Sonia, as you would expect, write powerfully. On his blog Eric said, “when in history has anyone had 20 whole years to dodge a bullet? As the pace of technology accelerates, the scythe of death seems to move slower in comparison”. They think they will cure Sonia, without a moment to waste. I try some pessimism against their optimism. What if 20 years isn’t enough? Does Sonia ever lie awake at night worrying, and then worrying as well that her sleepless worrying means the disease is taking hold?

“No,” she says quietly. “Not yet.”

Eric tells me that sometimes Sonia comes home from the lab with sore eyes from staring down the microscope all day. This was one of his mother-in-law’s first symptoms, and it makes him afraid.

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Share via “I do worry about it, about four or five times in the last two years, I’ve said, ‘Sonia, you’re scaring me’.”

Yet here’s the thing. They’re mostly not scared, because they are so happy. Living with the threat of a horrible death, and happy. Happier than ever. Blessed with purpose? Oh yes. They have married this mission, in sickness and in health, til death do them part. Eric declares on his blog that they count themselves among the “luckiest people to have lived. Mostly because we have each other . . . and a fiery hope that animates our every day.”

“None of us knows our fates,” writes Eric on his blog. “We only know the future is what we make of it.”

Sonia writes: “I submit that there remain important ways in which we can control, if not life’s random events, the stories that we tell with the lives that we build around those events, every day.”

I remind her that once her greatest ambition was to have a normal life with Eric. Can she achieve that too?

“Yes,” she says, and her voice almost sings with happiness. “I get to have lunch with him every day.”

Prion Alliance

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 **Brian Welsch**

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Dr Andrew Price

4 hours ago

Posting as the female Dr Price:

This is a touching story and they seem a lovely couple. Whilst I feel for them, the likelihood of finding a treatment or cure within 20 years is incredibly low. In addition, the cost of such research is not viable when considering the financial reward a company would receive from manufacturing a treatment. It's fantastic that their research is funded privately, but also lucky as I doubt they would receive funding from 'normal' sources.

This is far from my area of expertise, but I would suggest the couple need to find a more common disease with similar pathogenesis in order to attract large-sclae funding.

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Anish Lakhani

7 hours ago

A touching story. Wishing them both the very best in their endeavours

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Mrs Julia Pomeroy

13 hours ago

It seems odd to say that this is a lovely story but it is and the thing that makes it so is that those of us who are well, have a family, know where our next meal is coming from, have a safe job and every possession we could imagine, still find ourselves totally capable of whingeing and yet this couple who have every excuse to whinge do not. I trust this tells us all something about possessions, etc, not bringing happiness even having enough money does not, as this couple have proved and many of my Filipina and Egyptian friends have proved - they have nothing and yet are full of joy. My prayer is that they are successful in their endeavour and that their relationship will remain ever sweet.

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