

Woman Feels Like She's 'Burning Alive' Because Of Rare Skin Condition Erythromelalgia

Barcroft Media

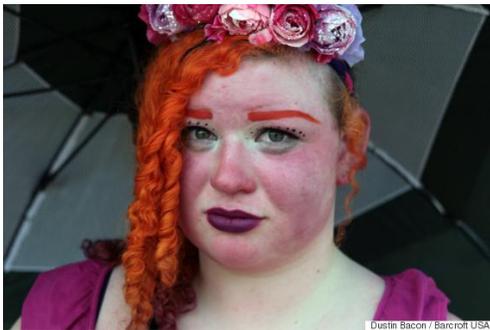
Posted: 29/12/2015 09:42 GMT Updated: 29/12/2015 10:59 GMT

A woman has been left housebound due to a rare genetic condition which makes her feel like she's burning alive.

Samara Rose Ingraffia, 25, suffers from erythromelalgia or 'Man on Fire syndrome', which leaves her feeling like she is experiencing constant second degree burns.

She also suffers from Raynaud's disease, an equally rare [health](#) condition that means her body reacts dramatically to the slightest drop in temperature.

Samara said: "I don't know what the worst part of this condition would be. It affects everything in my life. It's all-consuming and it's just maddening to be constantly burning alive – it's hell on earth."



Samara Rose Ingraffia

To lead anything like a normal life, Samara can only be exposed to a temperature of 17 degrees Celsius, as anything higher or lower will lead to pain and suffering.

Her father Brian is a former college professor who is also housebound with the same two conditions.

He said: "Knowing that my daughter has to go through even more pain than me is absolutely heartbreaking.

"Between the two of us we've tried every treatment that's been used for erythromelalgia but we have found absolutely nothing that helps.

"There is nothing that lessens the flare ups and absolutely nothing that can help lessen the pain."

Samara developed the condition aged nine but it took years to get a diagnosis after the family visited more than 100 doctors looking for help.

Traditional education soon became impossible for Samara because of the heat in the classrooms so she had to be homeschooled - leading her to become very isolated.

Samara said: "It's really hard to remember what my life was like before this.

"When I was a kid, before this started, I used to be outside all the time. I was born with black hair and then I was in the sun so much I had basically blonde hair when I was a toddler.

"I have definitely missed out on life a lot, it's so hard to imagine what normal life is like. It's been so long."

Her father Brian, 53, has had to conduct his own research into the condition. He said: "Whenever there's a slight increase in warmth the body massively overreacts and floods blood to the skin, the blood then gets stuck in the skin which leads to horrific nerve pain.

"Whenever someone with Raynaud's is exposed to cooler temperatures the blood withdraws from the skin, causing a sort of numb kind of burning.

"When I get into temperatures above 62/63 degrees Fahrenheit especially if I do any sort of movement it feels like I'm in an oven."

Samara's mother Ariella, 58, works in California to support the family but spends 10 days per month in Michigan looking after Samara and her father.

She said: "Samara can groom herself and clean herself but I have to do an awful lot for them both. All of their food has to be microwaved because they can't be near an oven.

"It's hard to think of them going through so much – I often get very upset just thinking about how much of her life she has missed out on."

The family has been desperately trying to find a cure for Samara and Brian, but to no avail.

Samara said: "I did get my hopes up when we were looking into stem cell therapy but it is insanely expensive costing around \$60,000.

"There's certainly no guarantee but it seems the most promising. But who has that kind of money? It really helps if you're rich when you're sick."