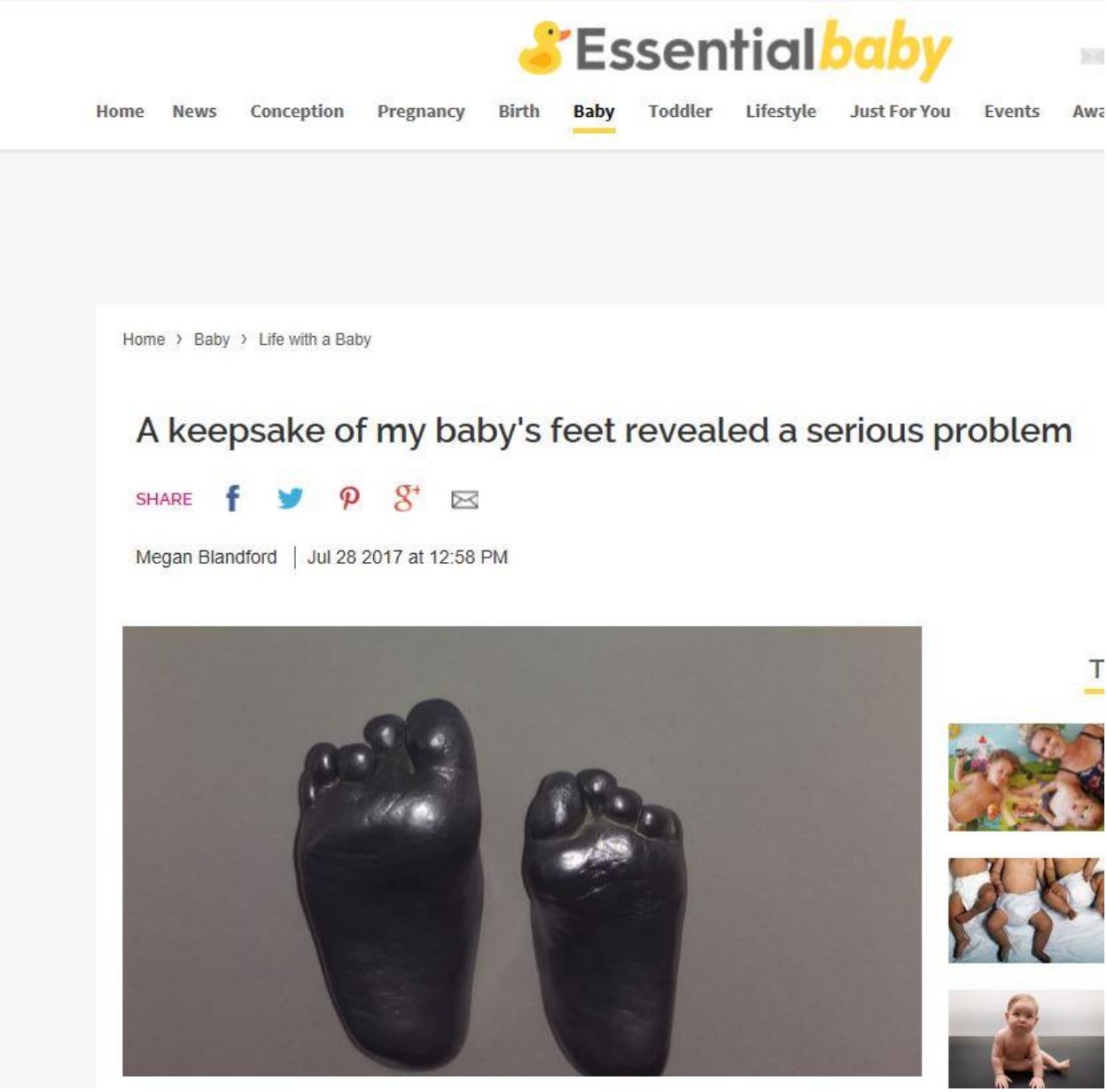

On 4 July, 2014, first time parents Naomi and her husband Michael welcomed the arrival of their daughter, Scarlett. Like many new parents, they wanted to commemorate the birth of their precious daughter and arranged for keepsake moulds to be made of her newborn hands and feet.

It was when they saw the completed moulds, they knew something wasn't right – Scarlett's feet was significantly different sizes. Coupled with her being underweight, Naomi took her daughter to hospital for a checkup. It became obvious that Scarlett's legs were also growing at different rates.

A series of blood tests was undertaken and, by five months, little Scarlett, was diagnosed with Russell Silver Syndrome (RSS). "We were in utter shock and disbelief," says Naomi. Doctors were able to reassure Naomi and Michael that RSS was not linked to death or cancer, it just meant that their daughter would be extremely small.

This came as a shock to Naomi and Michael, as there was no indication of a problem during the pregnancy. "Nobody knew," says Scarlett's mum, Naomi, "but if I'd known during the pregnancy, I could have been more aware and found out that I wasn't alone."

Babies with this rare condition have a low birth weight and often fail to grow and gain weight at the expected rate. Some, like Scarlett, experience asymmetric growth.

"She has body asymmetry: one side of her is large and the other side is short," Naomi explains. "Because of her different leg lengths, learning to walk took a long time (Scarlett reached this milestone at around two-and-a-half years old) and she was developmentally delayed for a while."

Dealing with the diagnosis, ongoing medical appointments and the condition itself was tough, and on top of that Naomi says it was a lonely experience at first.

"(RSS) is so rare, you feel like you're the only one and you don't have any support network," she says. "The doctors use such big words and medical jargon that you can't get your head around. You don't want to go to Google to find out, but sometimes that's the only thing you can do."

This turned around when she was able to connect with other parents going through similar things. "I found people through Facebook, and that's how I'm communicating with other families around Australia and America."

"Being able to speak to other families and find out what their children are going through has made it easier, and it's made me more aware of what Scarlett's future could contain."

A good cause

Friday, 4 August is Jeans for Genes Day and it's a cause that means a lot to Scarlett's mum, Naomi. The charity raises money for the Children's Medical Research Institute (CMRI) which helps to diagnose and treat the one in 20 children born with a birth defect or genetic disease, such as rare conditions like RSS.

"Through my home pastry chef business, I made over 700 cupcakes and raised over $2,000 for Jeans for Genes last year," says Naomi.

And this year, her efforts are going even bigger. "I'm running another cupcake fundraiser: I've already pre-sold 100 cupcakes, and businesses are jumping on board by taking fundraising forms and raising money in their workplaces on Jeans for Genes day", she says.

She does all of this for her daughter and other children like her. And the future is looking bright for Scarlett, who has recently turned three: "They're saying she should develop like the average child, just shorter (she's currently a whole head shorter than the average three-year-old), and we have the option for a heel raise or leg lengthening or shortening surgery," Naomi says. But until then, her cheerful and bright nature will undoubtedly flourish as she gets to experience new and exciting things.

http://www.essentialbaby.com.au/baby/life-with-a-baby/a-keepsake-of-my-babys-feet-revealed-a-serious-problem-20170726-gxivmq?cspt=1510183791|782af44af1355e230bec38603d115286#ixzz4xt05Y3Ov