

From Russia with love

After Sarah Settelen's young daughter, Ellie, died, Sarah set out to help other special needs children in a Russian orphanage, as a legacy to Ellie. There, she met another little girl

Lots of children have a favourite story they like to hear again and again, and nine-year-old Natasha Settelen is no different. The one she loves is set in Russia, and begins with a small three-year-old girl playing alone in the dirt, in an orphanage.

One day, a British woman called Sarah arrives, goes to the young girl and scoops her up. Sitting on her lap, the child suddenly cups the woman's face in her hands, looks into her eyes and beams. How could Sarah not fall in love?

The poignancy of the tale is that it's Natasha's own. But it's only one chapter in the more complicated story which began with another little girl, Ellie. The journey that led to that faraway orphanage begins with her.

Ellie was Sarah and Peter Settelen's daughter, born in February 1996. By May, joy had turned to concern, Ellie couldn't hold her head up, and never made eye contact with her parents. She was distressed and cried a lot.

"She'd smile at noises, but never at us," says Sarah. Months of tests and visits to specialists followed. The couple were offered occasional glimmers of hope, only to have them brutally dashed. Ellie was blind. She probably wouldn't live

beyond 12 years. "Finally, when she was six months old, our paediatric consultant said, 'It's cerebral palsy.'"

Ellie was severely disabled and needed constant attention. "If I put her down for a moment, she'd cry — and crying made her sick. It might have taken me an hour to get 2oz of milk into her, and it would all come up. She had gastritis which caused her pain, and suffered constant epilepsy. But now and then she broke through and connected. She liked squeaky kisses and interesting sounds. She had a wonderful beaming smile."



'Ellie made me understand that even if a child can't speak or feed themselves, they have a lot to offer'

At the end of 1999, Ellie caught flu. Sarah recalls the millennium celebrations on TV, her daughter limp on her lap. Six days later, flu turned to pneumonia: Ellie was rushed to hospital and died on 5th January 2000.

"When she died, she didn't leave a gap in my life. She was my life," says Sarah.

At the beginning of Ellie's life, Sarah struggled with her feelings. "I loved her, but there was an aching grief that I didn't have the child I thought I'd have. After a couple of

years, I realised I'd stopped wishing things could be different, and accepted Ellie the way she was."

Before Ellie's death, Sarah read an article about a little girl living in a Russian orphanage. "She also had cerebral palsy, and lived in her cot. I remember thinking. It's hard with Ellie and fighting to get help, but at least she's surrounded by love"

Two years after Ellie died, the memory of the article still pricked at Sarah's consciousness and she and a friend, Iona, spent two months volunteering in a state-run baby home in Ryazan, about a three-hour drive south of Moscow, where 150 children aged under four lived. It was there that she met Natasha. Conditions at the home were stark. It reeked of stale milk and urine. Carers were told not to spend too much time with the children, who were never cuddled.

"One day, Iona and I had taken some children out. One little girl had soiled herself and when Iona changed her, she started screaming. When we got back

parents, but she didn't understand what it meant. She had to learn a new language, along with a million other things. She'd never even seen herself in a mirror. Her diet in the orphanage was cabbage soup, boiled mince, and vitamin tablets instead of fresh fruit or veg."

Once she was at home, in Middlesex, Natasha took time to adjust. "Everyone fell in love with her — she's so sunny — but going without love, affection and attention in her early life had a profound effect on her. Our first year was spent getting to know her, helping her understand we were going to be here for her."

Natasha is now nine, has been in Britain half her life, and attends mainstream school. "She doesn't let her cerebral palsy stop her," says Sarah. "She gets around using sticks, or a walker which she uses to play in her disabled football team. She keeps up with her class in reading and is fascinated by the world. She enjoys swimming, riding her three-wheel bike... and the colour pink. Sometimes I look at her and it shocks me to think she's not our flesh and blood."

But helping one child wasn't enough for Sarah. After Ellie's death, she had promised that her daughter's life would not have been in vain. Her experiences in Russia gave her a way to keep that promise, by improving the lives of special needs children in baby homes and orphanages throughout Russia, where disability carries huge stigma. During her life, Ellie had gained from a teaching system called portage, designed to help special needs children and their parents. Skills, such as walking, talking and holding, are taught in achievable steps. Not only does it help children develop, it also gives



them physical contact and one-to-one attention. Sarah has since introduced portage to Russia, and set up a charity, ThePromise, a charity which carries out that work in Russia. "With the help of Mollie White, the UK's leading expert on portage, I spent 18 months raising money to set up a training programme in the orphanage. The director was sceptical but agreed to a six-month trial, with the children given 30 minutes of concentrated attention every day. After two months, the director couldn't believe the progress made by children. We now have 30 workers who work in baby homes, orphanages for older special needs children, and who support families who care for their children at home.

'The work being done in Russia is making a real difference. I look on it as a legacy for Ellie. To show she's not forgotten.'

ThePromise

SARAH SAYS: 'Only ten per cent of children in Russian baby homes are orphans. Others are there because of family breakdown, parental alcoholism, or the stigma of disability. At around three, children undergo a brief assessment. Those who "pass" go to an orphanage where they get a modicum of education before ending up on the streets at 16. If they "fail" (as many do because they're institutionalised), healthy kids may fester in orphanages. When they leave, the majority end up on drugs, as prostitutes, or in prison. Ellie made me understand that even if a child can't speak or feed themselves, they still have a lot to offer. Their feelings are important. After just a year, the difference portage has made to these children is huge. Bedbound kids have more time out of their cots. Their carers see them differently, hold them, and know them all by name. The kids are smiling for the first time.'

* To donate to ThePromise, visit www.thepromise.org.uk or send a cheque, payable to ThePromise, to: ThePromise, 181 Jersey Road, Isleworth, Middlesex TW7 4QJ.

Sarah with her Russian adopted daughter, Natasha, who has cerebral palsy